

FUTURE JOURNEYS

A TOOL FOR
PARENTS OF
CHILDREN
WITH SPECIAL
NEEDS TO
EXPAND THEIR
PERSPECTIVE
ON FUTURE
THINKING

MASTER THESIS

Future Journeys

A tool for parents of children with special needs to expand their perspective on future thinking

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In collaboration with: The Ontzorghuis



Ontzorghuis

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What a journey! A journey that wouldn't have been possible without the support and warmth I received!

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GLOSSARY

This section briefly describes the definitions of terms and abbreviations used within this thesis and potentially unfamiliar to the reader.

TERMS

Children with special needs: The term children with special needs (CSN) includes every child that presents physical disabilities, learning disabilities, chronic illness, Autism, ADHD, Anxiety, OCD, and Developmental Trauma

Future thinking: When we talk about future thinking in this report, we are referring to the action or process of proactively thinking about a short or long term future.

ABBREVIATIONS

SDT: Self Determination theory

CSN: Child/children with special needs

EXECUTIVE SUMMARY

“It’s a given that parenting is hard work. But when you’re raising a child with special needs, the level of care and stress is not just higher, it shifts the foundations of families and adds unimaginable complexities for everyone involved.” (Pinhorn, 2018, www.gottman.com)

This project is developed in collaboration with The Ontzorghuis, a Dutch organisation founded to support parents of children with special needs. This assignment aims to enhance the capabilities of the CSN parents’ community to fulfill their basic psychological needs, which are essential for psychological health and well-being (Decy & Ryan, 2008).

Inspired by the Capability approach (Alkire & Deneulin, 2009; Sen, 2004; Nussbaum, 2001) a qualitative study was conducted to evaluate the common capabilities that characterise the CSN parents’ community, as well as the individual practices or paths of success that parents come up with to deal with their challenging circumstances. The study consisted of initial desk research based on the social media expression of CSN parents and remote field research that involved 6 CSN parents who participated in a series of generative research exercises and interviews. An innovative approach for remote user research is presented. It is based on metaphorical visualization exercises that are able to engage a sensitive community with little time available into a conversation about intimate and relevant topics that are often difficult to share.

The findings collected from this research narrowed down the scope of this project into the topic of future thinking. Many parents experience

fear and anxiety when facing the big unknown that supposes having a life-long dependent child. Their capability to think about the future appears as a decisive factor in their wellbeing.

The proposed solution, Future Journeys tool, integrates the concept of Resourcefulness (Giaccardi & Nicenboim, 2018) into the context of future thinking. While the capabilities of this community are significantly reduced, the opposite may happen with their resourcefulness (ability to creatively adapt to challenges for which no commonly agreed solution was available). Future Journeys leverages the creative ways of approaching future thinking of some individuals to expand the perspective of relatable others who, although in similar circumstances, experience a negative relationship with the unknown future.

The proposed tool is presented with the shape of a mobile phone application that aims to provide CSN parents with a common language to reflect and share their perspectives about future thinking. The solution promotes self-reflection through an exercise of guided metaphorical thinking and completes the experience with social interactions where the users share their perspectives to inspire others. This solution enhances the basic psychological needs of CSN parents. The impact of the tool on its users’ wellbeing was evaluated taking into account Self Determination Theory’s three fundamental needs. Furthermore, the results provided valuable insight into the potential of the tool to expand the capabilities of the CSN parents’ community and helped to draw further recommendations for the future development of the tool.



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The first chapter of this graduation thesis aims to introduce this project's foundation and origin, presenting the Ontzorghuis, stakeholders of this project, and how the designer joins forces with them to help parents of children with special needs to improve their wellbeing. This is followed by an introduction of what is it to be a parent of a child with special needs, the project's scope and relevance, the three theoretical frameworks that will serve as the basis for the whole design process and the assignment's approach.



CSN PARENTS & THE PROJECT

“ A few weeks ago, I was helping my 14-year-old daughter get ready for her school’s production of The Lion King. I put her hair in a ponytail and made sure she packed her sandals for her costume. Then I ordered her three red roses in a presentation bouquet at the florist.

Watching Lizzy perform that night, with my husband and two sons beside me, my heart felt as if it might explode. It was exactly the type of proud parenting moment I’d always dreamed of – and even expected to have – ever since she was born. What I never expected was that she would be performing at a school for children with significant special needs.”

Kathy, a special needs mum www.seleni.org

1.1

THE DESIGNER & THE ONTZORGHUIS



The Designer: Maira Ribelles



Ontzorghuis founder: Marise Schot



Ontzorghuis co-founder: Astrid Bontenbal

In my opinion, every project is the people behind it, their values and motivations, that's why I'm going to start introducing myself and The Ontzorghuis. I am Maira, the graduate student doing this project. What sparks my inspiration is the very idealistic aim of making of this world a better one. I still believe, that we, as designers, have that power, if not to change it to at least contribute to a better future of society. One of the reasons why I chose to apply for this graduation opportunity was the strong aim of helping people, in this case, parents of children with special needs (CSN parents)•

This project is a collaboration between The Ontzorghuis and myself, so let's introduce them!

The Ontzorghuis was established by Marise Schot and Astrid Bontenbal in 2018. This organization aims to support CSN parents.

Marise's expertise lays in the Design for Happiness methodologies with a focus on healthcare design. Besides that, she is also the mother of a special needs child. Her designer mindset expands to her private daily life, bringing her a very special and helpful perspective. She has been applying different techniques on her own to solve and achieve challenges in her life•

Astrid is an expert on persuasive game design for mental well-being. She developed concepts to promote parental involvement and a healthy lifestyle. She addresses societal challenges in the field of health. Astrid is also a yoga instructor•



ONTZORGHUIS VISION AND DIRECTION

The Ontzorghuis helps CSN parents to connect, empathise, inspire, and help each other while learning new ways of overcoming their challenges. Ontzorghuis combines various activities to achieve this goal: They share parent's stories, provide information, create a feeling of community, offer online self-care-reflecting exercises, and offer (online and offline) parenting training. In addition to these activities, they are currently developing a cooperative housing community.



Het
Ontzorghuis

ONTZORGHUIS CURRENT ACTIVITIES

Ontzorghuis provides practical and emotional support for CSN families through an online (and in a near future, also offline) community. The focus is on the wellbeing of the CSN parents, supporting them in finding a healthy balance between their own needs and the needs of their children.

Marise and Astrid see a very big potential in the self-reflecting exercises, therefore, they keep working to improve and continue developing new online material for this section. On the other hand, Ontzorghuis is currently working on going beyond the digital services to offer “an oasis of peace, a place where families feel like they are in a big safety net”. In other words, a cooperative housing community, where parents can move in for long or short stays to enjoy 24/7 care support. In this cooperative, families can rely on the warmth of the rest of the community to find a balance between their own needs and their children's special needs.



1.2

WHAT AND HOW IS IT TO BE A CSN'S PARENT IN A NUTSHELL

“It’s a given that parenting is hard work. But when you’re raising a child with special needs, the level of care and stress is not just higher, it shifts the foundations of families and adds unimaginable complexities for everyone involved.”

Lisa, a special needs’ mum, www.gottman.com

The term children with special needs (CSN) includes every child that presents physical disabilities, learning disabilities, chronic illness, Autism, ADHD, Anxiety, OCD, and Developmental Trauma (www.gottman.com). Becoming a CSN parent means to go through a process, that each individual will experience in their particular way, a process that eventually might go through, insecurities, uncertainty, emotional-overload, stress, loss of meaning, resilience, acceptance and on finding creative ways to cope or manage challenging situations. Previous research conducted by The Ontzorghuis tells us that this challenging life limits the possibility to thrive of CSN parents, pushing them sometimes to go into “survival mode”. Some of the limiting aspects to consider are the pressure they go through from high ambitions, their CSN’s demands, having to manage their own personal and professional lives in between hospital admissions, doctor visits, diagnoses, medications, therapies, and other activities their children may require. This way of surviving is not always healthy for the parents since many times they end up taking medication rather than finding other ways to manage difficult situations.

1.3

SCOPE & RELEVANCE

This project aims to contribute to enhancing families of children with special needs' wellbeing by following a parents-centered approach. The project will be tackled with a design mindset involving user-centered research, creative, and analytical thinking.

This project places its inquiry at the intersection between these two aspects:

1. CSN's parents' common environmental circumstances: Paying attention to what makes their lives different from non-CSN parents. To do so, the research will draw from the Capability Approach, which will inspire a parent-centered research process to determine how having a CSN impacts parents' capabilities (opportunities to be and to do). The capability approach is a framework to analyse wellbeing which will be further explained on page 20 in the "Capability Approach" section.

2. CSN parents' particular strategies to manage their life: Paying attention to the practices and attitudes that have had a positive impact on fulfilling the basic psychological needs of different individuals, and thus, on their wellbeing.

The combination of these two focusses will guide the project towards a unique approach that will tackle a specific matter of relevance of this group.

THE GOAL

Taking into account Ontzorghuis's current focus and aim, this project will be addressed keeping in mind the next design goal:

To design an online tool that a community of CSN's parents can use to enhance their capabilities to fulfill their main intrinsic psychological needs (competence, autonomy, and relatedness), which are essential for psychological health and well-being (Decy & Ryan, 2017). The previously described goal is a path towards improving the subjective wellbeing of these parents while raising their children.

1.4 THEORETICAL FRAMEWORKS

INTRODUCTION

This project draws from two theoretical frameworks that try to define the nature of wellbeing: The Self-Determination Theory and the Capability approach. Each framework provides a different lens to analyse the perspectives and experiences of CSN parents as well as serving as inspiration during the design process by anchoring in the designer's mind the core concepts that the solution should tackle. Finally, these frameworks provide a theoretical background for the project's outcome and inspires the qualitative evaluation of the final proposal.

In addition to the two mentioned theories, this chapter also describes the concept of Resourcefulness and its connection to the capabilities of CSN parents. Both ideas proved to be very relevant when conceptualising the final solution as they play a significant role in what CSN parents have in common.



Figure 1 | image representing 3 psychological needs | Source: Unsplash

SELF DETERMINATION THEORY

Self-determination theory (SDT) is a psychological theory that tackles the motivation behind choices people make without external influence and interference (Ryan & Deci, 2017). According to SDT, there are three psychological needs that motivate the individual to initiate behavior and specify nutrients that are essential for psychological health and well-being of an individual. These needs are said to be universal, innate, and psychological and include the need for competence, autonomy, and relatedness (Deci & Ryan, 2017).

Parents of children with special needs can be considered a vulnerable group regarding the fulfillment of the three fundamental needs, which as Ryan and Deci explain, leads to diminished self-motivation, well-being, and mental health.

To analyse wellbeing, SDT focuses on the subjective and experiential fulfillment of the three basic psychological needs (De Haan, Hirai, and M. Ryan, 2015). On the other hand, the capability approach (which will be explained later in page 20), puts more emphasis on the influence of environmental affordances, the possibilities to be and to do what one values afforded by each individual's circumstances. Since all CSN parents experience a radical change in their environmental affordances when having a CSN, a capability-based analysis might provide richer insight on CSN parent's

uniqueness than focusing solely on the degree of satisfaction of their basic psychological needs. However, the experiential and subjective focus of SDT is useful to evaluate how the enhanced capabilities provided by the final solution translate into the satisfaction of fundamental needs and therefore into improving parents' wellbeing.

The three fundamental needs are defined as follows:

1 Autonomy: Desire to be causal agents of one's own life and act in harmony with one's integrated self (Deci and Vansteenkiste, 2004). In other words, being the cause of your own actions and feelings, being able to do things your own way. (Pieter Desmet, 2019)

2 Competence: Seek to control the outcome and experience mastery (White, 1959).

3 Relatedness: Will to interact, be connected to, and experience caring for others (Baumeister & Leray, 1995). This can also be referred to as the *need of belonging*. It's the need of being building or maintaining attachments, friendships, intimacy or sense of community. (Schot, Desmet, van Dijk, & Schoone-Harmsen, 2009)

CAPABILITY APPROACH

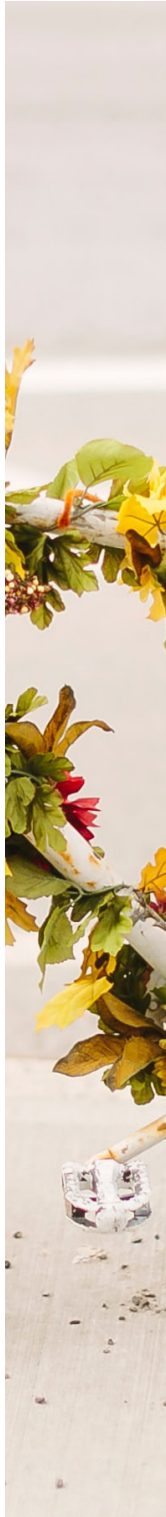
The Capability Approach is a theoretical framework that purports that wellbeing is a matter of what people are able to do and to be, and thus the kind of life they are effectively able to achieve (Wells, 2012). It analyses wellbeing in terms of functioning (the states of being and doing) and capability (the set of valuable functionings that a person has effective access to). Sen defines the capability of a person as the freedom she has to choose between different kinds of life that she or he has reason to value (Wells, 2012). This correlation between capabilities and freedom, particularly resonates with the project's target group, since, having a child with special needs drastically reduces the freedom to do and to be of the parents, and thus their capabilities.

Although the experience and circumstances of each CSN's parent might differ, they all experience a comparable change in their capabilities when having a child with special needs, which justifies this project's focus on the capabilities lost, left, or gained by these parents when trying to identify the target group's uniqueness.

HOW DOES THIS PROJECT MAKE USE OF CAPABILITY APPROACH?

Ilse Oosterlaken suggests the use of the capability approach as a design framework for social design, arguing that expanding human capabilities is in fact, the main goal of technological development (Oosterlaken, 2009). This thesis adopts Oosterlaken's premise as the design goal of the project, which, as mentioned before, is to expand the capabilities of CSN's parents through an online tool.

The framework is helpful for both the research and ideation phases of this assignment. During the research phase, the capability approach helped to understand the circumstances in which the parents live (beings) and the practices or strategies they apply in their lives (doings), giving particular importance to their opportunities to realise those beings and doings. Besides, During ideation, the framework helped to draw the boundaries of a coherent solution space as well as provided an inspiring lense to come up with solutions that leverage the capabilities of CSN's parents and their ability to build new functionings.



RESOURCEFULNESS

Giaccardi and Nicenboim explain the concept of Resourcefulness as a set of skills, objects, and values involved in dealing creatively with personal and situation-specific challenges for which no commonly agreed standard solution is available. (Giaccardi & Nicenboim, 2018).

Resources and resourcefulness are two different concepts. We can understand resources as objects, values, or ideas that have potential utility. On the other hand, resourcefulness takes place when a resource is used to overcome a specific challenge creatively (achieving a new utility for that specific resource).

The value of a resource depends upon individuals' ability to convert them into valuable functionalities (such as cycling), which depends, for example, on their personal physiology (such as health), social norms, and physical environment (such as road quality) (Wells, 2012). Resourcefulness involves the skills used to creatively convert resources into new/non commonly agreed utilities.

An example of a person being resourceful could be the first person who locked a bike into a street sign in memorial of a beloved one who died in a cycling accident. This person made use of the bicycle that was meant to transport people from one place to another, in a creative and resourceful way, to overcome a beloved persons' death. (see image 2 for an example of this kind of memorial act)

Chapter 6 explains in detail how the final concept leverages parents' resourcefulness to improve their wellbeing.



Figure 2 | Example of resourcefulness | Source: Unsplash

HOW DO CAPABILITY APPROACH & RESOURCEFULNESS COME TOGETHER

This section presents the connection between capabilities and resourcefulness (Figure 4), taking as inspiration the model proposed by Thomas Wells (see figure 3) that outlines the connection between the capability approach and the main alternative approaches focused on resources, and utility (Wells, 2012, <https://iep.utm.edu/sen-cap/>).

As mentioned before, the Capability approach purports that wellbeing is a matter of the valuable functionings that a person has access to. Two main elements take part in enabling those valuable functionings: The available resources that an individual has access to (objects or ideas with potential utility) and the abilities that a person has to transform those resources into something useful (Sen refers to this as personal utilization function). Depending on the circumstances and interpersonal differences of each individual (education, social norms, personal physiology), she or he would display different patterns (or abilities) of using resources.

Resourcefulness is defined as the ability to repurpose existing resources to achieve new utilities. In other words, the ability to develop new patterns of use (resourceful functionings) that provide a creative solution for a situation-specific personal problem. This definition implies two things:

1. A resourceful way of using objects or ideas results in a valuable functioning, since, by definition, they solve a challenge that the individual was facing and bring value to him/her.

2. Resourceful functionings have an improvisational (experimental) nature which makes them hard to define or predict before they have been performed for the first time.

These two aspects of resourceful functionings raise an interesting question: Does the capability set of an individual include the potential functionings he is not aware of? Or for more clarity: was it in the capability set of Newton to discover the law of gravity? Is it in the potential of any of us to engage in functionings that nobody has ever engaged with?

Although the answer to these questions could be affirmative, for the purpose of this thesis a distinction was made between resourceful functionings (truly potential functionings, infinite and non-existent until put into practice) and capability set (accessible valuable functionings that we can predict a priori).

The interesting part here is that when a person discovers a new resourceful functioning, this one becomes part of her capability set. This newborn practice can be shared with other individuals (as a knowledge resource) who, if gifted with the appropriate ability (interpersonal characteristics and circumstances) will integrate such practice into their capability set (if they consider it valuable, of course). People don't know what they can do until they are shown what is possible.

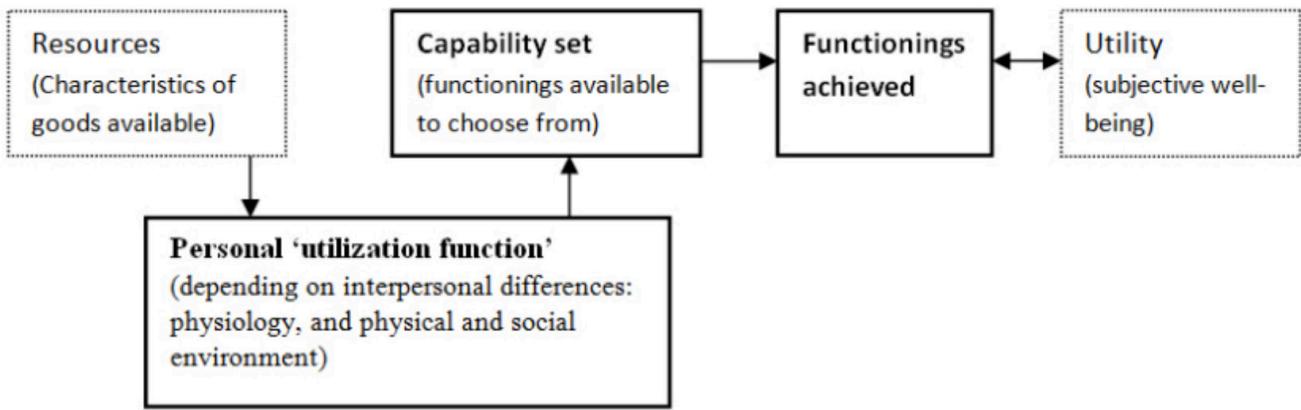


Figure 3 | Outline of the core relationships in the Capability Approach, Wells, 2009

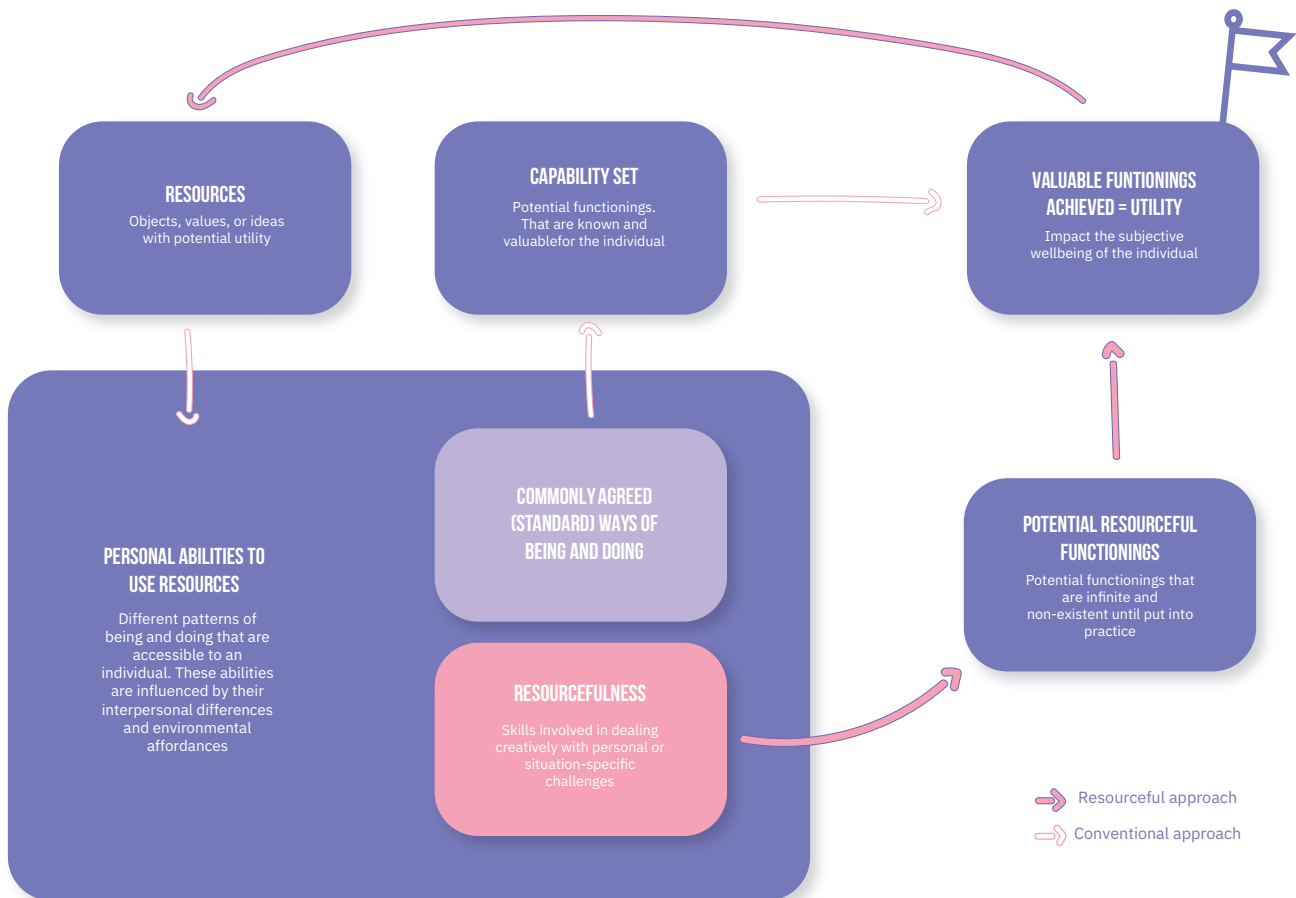


Figure 4 | Connection between capability approach and resourcefulness

1.5 APPROACH

This project is splitted into two phases, research, and a design phase, with a double diamond structure (Figure 5). Through a qualitative study inspired by the Capability Sensitive Design approach (Oosterlaken 2009, Grande 2013), the research tried to understand what makes CSN parents unique, exploring their functionings, capabilities, and perspectives about their own life. The research phase concluded by defining a strategic vision that helped to identify promising design directions in the next phase.

The design phase presented an iterative nature that was based on the findings obtained from testing. In this phase, a design direction was formed and the concept was defined and validated. To see more details about the distribution of the phases and sub-activities please see figure 5.

The research and design phases were subdivided, resulting in the four progressing stages detailed below:

Discover: This stage is based on acquiring a holistic understanding of the context through desk and field research. The desk research was centered on social media expression of these parents. On the other hand, the field research consisted of a qualitative study (conducted remotely) which focussed on empathising with the target group, through the collection of personal stories. This will allowed the designer to understand the users' perspective about their lives unveiling latent knowledge about what they can do, their strategies to cope, their values,

dreams, and concerns. This was done through interviews and research probes.

Define: In this stage, the information provided from the target group was analyzed and mapped out to create a strategic vision that defined CSN's parents' uniqueness. The strategic vision triggered a reflection on how the capabilities of these parents are limited, their relationship with the 3 fundamental needs, and how this affects their well-being. This understanding inspired several design directions which will steer the final design direction towards helping CSN parents to expand their perspective about future thinking while raising a lifelong dependent child.

Develop: This stage started with an ideation session on concepts to tackle parents' strategic vision. This direction afterward converged in a more specific direction: "Future thinking", narrowing the scope, and defining a specific concept, Future Journeys. Consecutively, the concept was tested iteratively aiming to its improvement in terms of comprehension and value.

Deliver: After analysing the insights acquired in the last round of iterations, the delivery stage consisted of presenting the final proposal, defining the evaluation method based on SDT's three fundamental needs. Research questions regarding the three fundamental needs were explored. The results of the evaluation were contrasted with the tool's aim of expanding parents' capabilities to think about the future and further recommendations were presented.

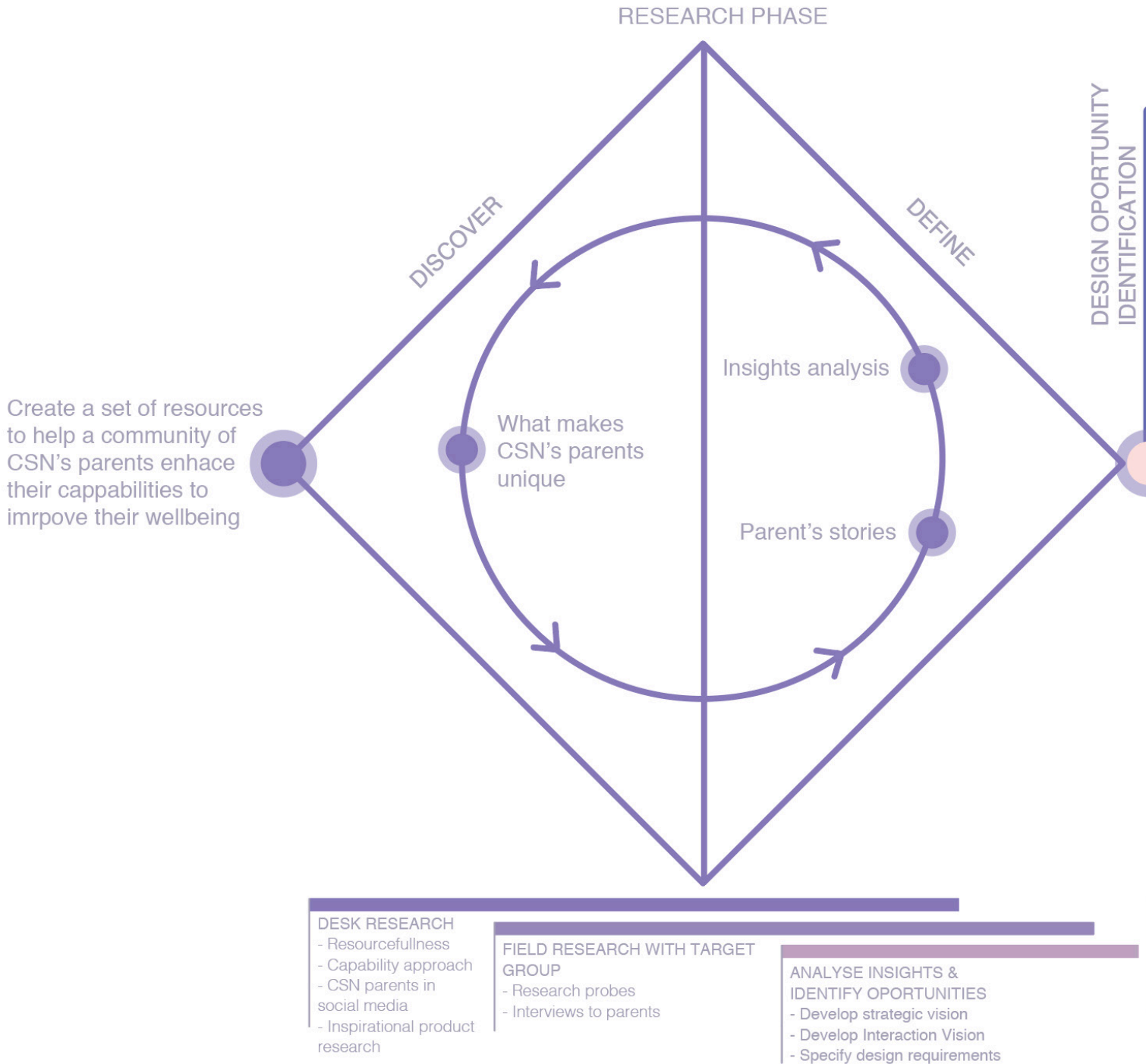
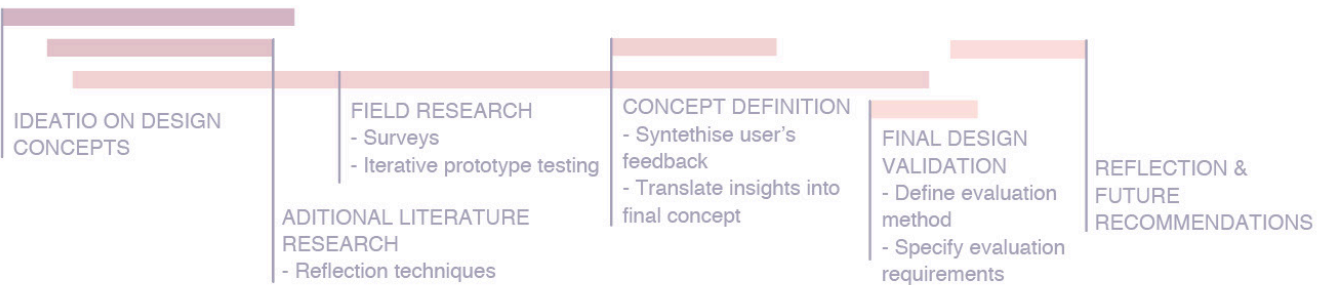


Figure 5 | Project's approach and structure, detailed visualization



2

This chapter presents the desk research conducted for this project and its results. The research aimed to get a first contact with the context of parents with special needs through social media. The main channels consulted were Facebook support groups and Youtube channels, sources that provided a base of knowledge to be able to afterwards start an informed field research.



CSN MUMS IN SOCIAL MEDIA

2.1 A WINDOW INTO CSN PARENTS' LIFE

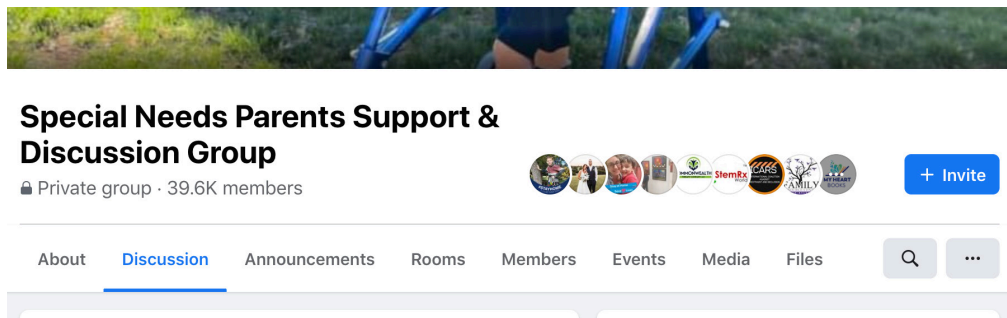


Figure 6 | Example of Facebook group for special needs parents support

Social support is recognised as an effective buffer against the stress and isolation faced by CSN families (Ainbinder et al., 1998). Another aspect to take into account is the uncertainty these parents experience since the path they are going through is very little explored and therefore there is very little guidance available. This makes it very hard to find answers anywhere else, according to one of interviewed CSN mums testimony:

“ I’m in quite as few Facebook groups actually! They come in really handy to know your child is doing the same as others as there is no instruction manual for kids with special needs.”

CSN parents, especially mums, use social media as a resource to connect with other CSN parents. The most commonly used platform is Facebook, they join groups for

parents’ support and discussion as the one illustrated in image 6.

On the other hand, many CSN mums use blogging as a way of self-expression, they share their daily lives and express struggles, concerns, and suggestions to inspire other CSN parents.

“ It’s been amazing how cathartic it is to write about my journey as a special needs parent and the bonus has been connecting with others. It gives me a sense of accomplishment to create something.”

Laurie McLean, blogger & special needs mum

The relationship between social media and CSN parents converts digital channels such as Facebook and Youtube in an open window to these parents’ lives. This is the reason why it composed the desk research of this project.



Figure 7 | Kate from “Finding Cooper’s voice” and Jaqig, from “The special life by Ale”, both CSN mums and bloggers

STUDY SETUP

As justified in the previous paragraphs, social media was considered as a very accessible and rich source of information. This research served as a sensitiser for the designer before getting in touch with CSN families (which constitute a sensitive group that doesn’t dispose of much time to invest in research participation). This phase of the project was parallel to the participants’ recruitment.

The main sources checked for this desk research were **social media portals** such as **Facebook** groups for parents’ support and **Youtube** channels. Two Youtube bloggers were selected, The first one: Kate, with her channel “Finding Cooper’s Voice” and the second one: Jaqig, with her channel “The Special Life By Ale” (see image 7). Both of them aim at inspiring other parents and sharing their perspectives about being a CSN mother.

DESK RESEARCH FOCUS

The desk research of this project aimed at understanding how parents express their thoughts, dreams, values, and needs in an online setup as well as what kind of information where they sharing/exchanging.

The main research question for this research study was:

What are CSN parents telling to other CSN parents?

As mentioned before, this served as a way of sensitizing the designer to have a solid background to conduct the field research.

2.2 SOCIAL MEDIA RESEARCH TAKEAWAYS

During this research, different testimonies were collected and clustered. The main cluster categories were: Dealing with self-blame, dealing with the unexpected, finding similar others, self-care, and, being grateful.

The following cards show the different categories with a relevant quote (collected from CSN mums in social media, their identity is not revealed to protect their privacy). The quotes are suggestions that mums gave to other mums. Next to each card, the respective insight is displayed with a sign of an eye. The insights served to be kept as takeaways to proceed with the field research of this project.

DEALING WITH THE UNEXPECTED



“ You are going through a journey that is unexpected, but there's beauty in the unexpected and you will find that

“ Things take longer... We need to keep in mind that we need to be a lot more patient with them and know that every single failure is part of the process for it that big win.



CSN mums know that uncertainty is very hard to deal with and try to encourage each other suggesting patience and positivity.

DEALING WITH SELF-BLAME



“ Don't blame yourself, this is no one's fault, this is just part of life.



Guilt or self-blame is a common feeling that mums experience when having a CSN child. Since they usually link the fact of things not working out as a personal failure within their role of being a mother.

FINDING SIMILAR OTHERS



“ I couldn't find the right help through the health sector I needed to form a squad, I needed people around me that could support and understand me. Support and communities, thta's what's gonna get you thorough.



CSN mums are aware that it's important to find people that understands you, to find a community that can support you.

REFLECTIONS

The insights shown in the previous section are subject to self-interpretation since the information was gathered from social media and there was no conversation with the subjects. However, this will serve as data to be contrasted with the insights collected in the field research.

The knowledge acquired in this stage will also serve as a good background for the designer to be able to communicate appropriately with the participants during the field research.

FINDING LITTLE MOMENTS OF JOY



“ *What I've been doing is giving myself a reward when she's napping or at night time, I will go on to social media.* ”

“ *I write. I use my phone to just write my thoughts down. I wait until the kids are sleep and just relax. Most times I'm so tired but I still stay up because it's my only alone time.* ”



CSN mums have very little time available and lots of responsibilities, however, through time they sometimes manage to treat themselves finding joy in little moments of the day.

BEING GRATEFUL



“ *Express your gratitude for every single little achievement. It's a good habit to keep, it makes you a more positive person and motivates you.* ”



Mums are able to appreciate small achievements and celebrate them and this has a positive impact in their lives.

3

The third chapter of this thesis presents the main two research questions and how the field research course of action adapted to CSN parents' constraints. The research was conducted remotely combining research probes based on metaphorical thinking and interviews. The probes served as actioners for the participants to share the invisible, their personal stories, needs, values, dreams, and concerns.



METAPHOR AS A RESEARCH TOOL

3.1 GETTING IN TOUCH WITH CSN PARENTS

THE ALWAYS POSTPONED MEETING

After recruiting the first family, I scheduled an informal interview to get to know their situation, availability, and degree of involvement. The plan was to introduce the project and make a pilot of a generative session (see figure 10) through an online tool (Mural) to test if this was a suitable way of collecting qualitative data. This appointment got postponed 3 times due to unexpected events that altered the plans, as the dad

explained (see quote from CSN dad, family 1).

After this meeting, it was very clear that the research would need to be adapted to their restricted schedule and time constraints. We agreed that it would be more suitable to receive individual and short assignments (research probes) for them to do whenever they could find some 10 free minutes of their time.

“Any kind of plans tend to always be altered in some way or another when young children are around & would seem to be doubled when you throw a disability in to mix”

CSN dad, family 1

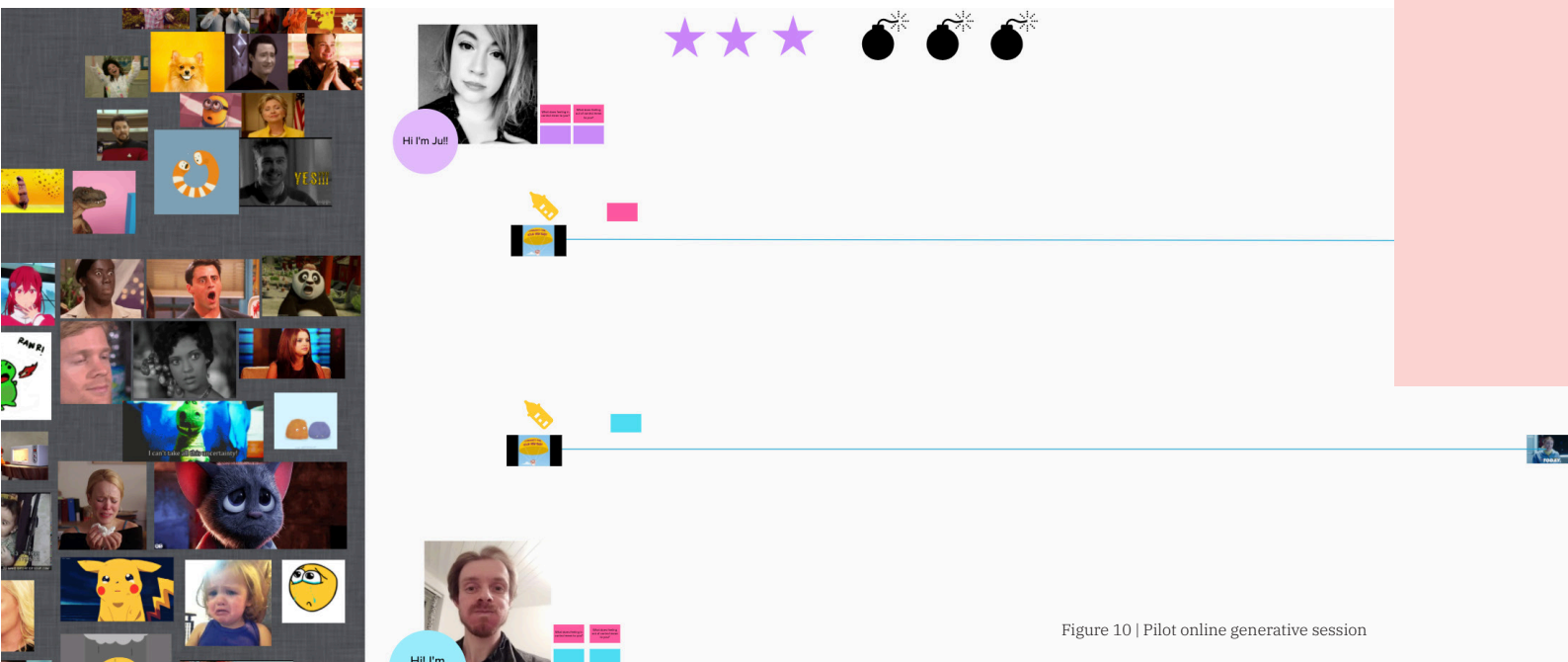


Figure 10 | Pilot online generative session

3.2 RESEARCHING PARENTS' STRATEGIES & CAPABILITIES

RESEARCH GOAL

The complexity of this assignment requires a deep understanding of CSN parents' lives, an understanding that just can come from their own perspectives, from stories that just they can tell.

Due to the open-ended nature of the qualitative research, the research probes and interviews' focuss evolved as the research advanced, slowly converging towards a more specific formulation as certain topics appeared to be more relevant for the project's global aim: Find opportunities to enhance CSN parents capabilities. However, two main research questions, inspired by the Capability Approach and Resourcefulness literature, drove the overall research:

RQ¹.

Which effective strategies parents engage with that have a positive impact on their basic psychological needs?

RQ².

What are the capabilities (opportunities and hindrances towards a quality life) that characterise the CSN parents' community?

While the second question converges into the target group's common circumstances and potential for wellbeing, the first question diverges into the stories of success and learnings of particular families. These stories although different from each other, are likely to be relatable and inspiring for others, as most CSN parents share similar circumstances and capabilities. The solution space of this project was defined with the answers to both questions, which consequently guided and inspired the ideation process.

In order to acquire answers to these questions, parents were activated to reflect on their personal perspectives about their lives. This was done through research probes that consisted of short exercises that didn't take more than 10 minutes.

3.3 RESEARCH PARTICIPANTS

PARTICIPANTS RECRUITMENT

The participants' recruitment was done through different Facebook groups for CSN parents' support. Several attempts were done for the call for participants; a flyer and a video were created to announce the need for participants and to let people know about the project (see figure 12), the flyer was designed trying to transmit trust with a professional tone of voice mentioning The Ontzorghuis. On the other hand, the video kept a more personal/student tone of voice to transmit transparency and personal involvement.

The group of participants that this study requires are parents with prior experience of caring for one child or more with special psychological or physical needs.



Image 11 | Call for participants video

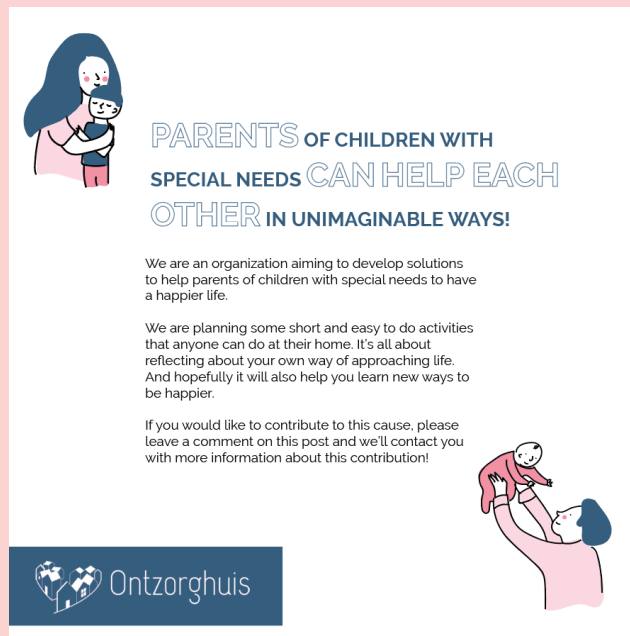


Figure 12 | Call for participants flyer

RESEARCH SAMPLE

Despite the difficulties for finding participants, five CSN mums and one dad were recruited to take part in the study. They provided a variety of profiles in terms of nationality (2 families from The UK, 2 from Spain, and 1 from The Netherlands), relationship status (divorced, married in new relationships, and single). On the other hand, their children display different care needs (Down syndrome, autism, chromosome 11 disorder and developmental delay). Also, the children's age is different and therefore these parents are in different life stages. A total of 2 fathers accepted to contribute to the study, the rest expressed their lack of availability for different reasons related to lack of time and interest.

3.4 PROCEDURE

COURSE OF ACTION

This research was carried in a remote/online setting due to the pandemic circumstances which didn't allow physical meetings.

As this project revolves around resourcefulness and individuals' capabilities, it was necessary to take an approach that allows the researcher to acquire a first-hand perspective of how parents manage their CSN parenting role. Therefore, the most suitable approach was a qualitative study.

The course of action consisted of assigning the participants with different short activities. Each posed a different level of abstraction driving the parents into a journey of self-dis-

covery and expression. This was done through different probes that encourage self-reflection and informal conversation through text and voice messages. All the information was registered and analysed dynamically, in a way that the insights of each interaction with the participants inspired the researcher to shape the next activity.

The different exercises are represented in the journey map detailed below (see figure 13). This chapter reports the filed research stages and activities in detail.

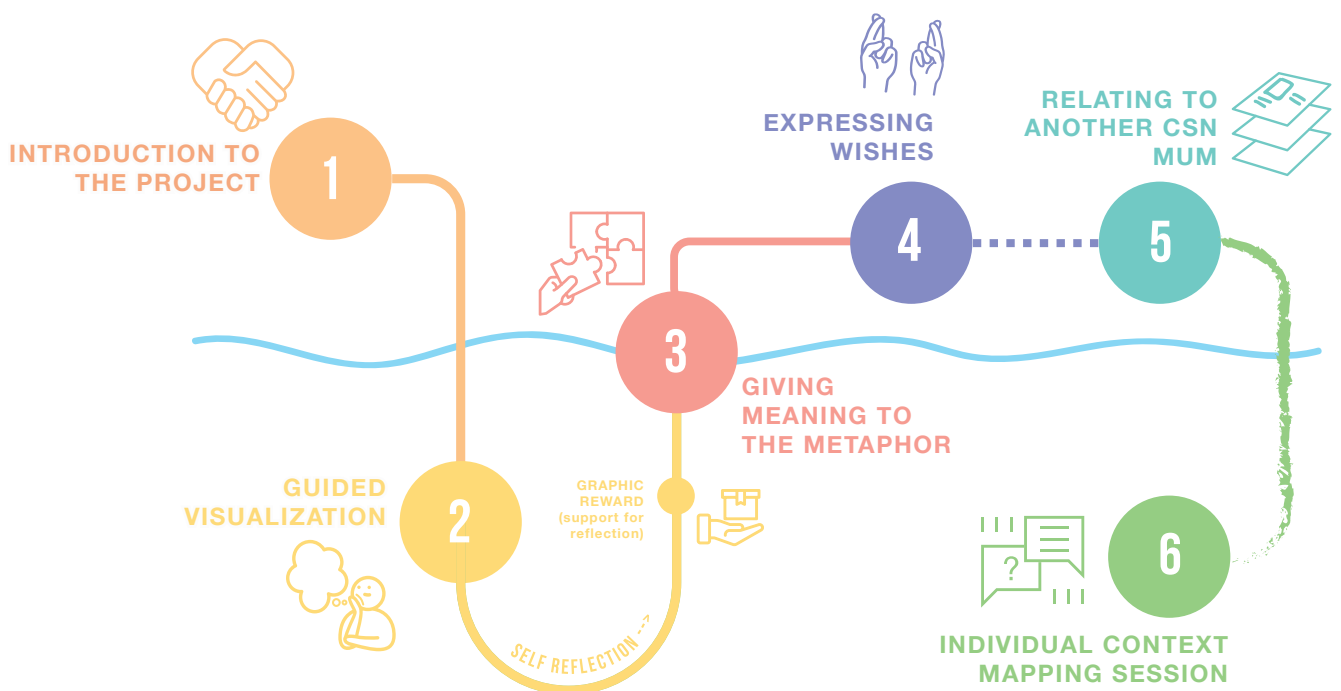


Figure 13 | Field Research journey 1



STEP 1: “INTRODUCTION TO THE PROJECT”

This first step of the field research journey consisted of thanking the participants for sharing their interest in participating and by introducing the project and answering any question they had. All participants completed a consent form where they were informed of the purposes of the study as well as about the anonymous usage of the data during and after the study.



STEP 2: “GUIDED VISUALIZATION”

After the first step, the participants were ready to start the first exercise which consisted of a guided visualisation of their lives. This activity worked as a communication vehicle to introduce their lives from their perspectives, that way they would express aspects they considered important in their experience of being a caregiver and parent of a CSN. It consisted of listening to a guided audio recording that brought the participants through an imaginative journey on a plane. The participants were free to imagine what would come to their mind, without any pressure of doing it right or wrong and without forcing the process. After doing the exercise they were asked to explain to the researcher what they visualised.

See the following pages (41-43) for details about the metaphor’s origin, script, and the possible interpretations or meaning of the different parts of the journey. Please note that all possible interpretations described are subjective and might differ between participants.

WHY A PLANE METAPHOR?

This section aims to explain how was this tool born and why was it designed.

The field research of this project had to adapt to these parents' time-availability constraints and to a remote setting. It was necessary to come up with creative ways to help them express their perspectives, values, dreams, and concerns. Therefore, this research tool was designed to help them imagine and share relevant aspects of their lives freely. It was also important that they would have an enjoyable time and that they would get something out of the activity such as new learnings about themselves.

The use of a metaphor seemed to fit very well the requirements mentioned in the previous paragraph. It was essential to find a suitable metaphor were these parents could imagine their lives and give meaning to their visualisation. Lives are in constant movement and change. A suitable metaphor would be a vehicle. Specially CSN parents' lives are in part very unpredictable and sometimes uncontrollable such as the weather conditions or the environment in which this vehicle moves.

The first research question of this project referred to the understanding of the target group's strategies to deal with such challenging lives. The term "strategies" can be defined as a path or plan of action designed to achieve an overall aim or goal. Therefore, the metaphor had to show a journey that takes a direction towards something.

In addition, the use of a vehicle seemed to fit very well with other aspects of these parents' lives, such as the very well needed energy to cope with difficulties.

Besides, The metaphor had to leave room for imagining the important individuals of these parent's lives such as their children, partner, family, friends, caregivers...

To identify capabilities (research question 2), the metaphor had to bring the option to the listener to imagine him or herself as the person controlling (or not controlling) the situation. Thus, this could bring them to express their wishes and concerns, in other words, their possibilities to be and to do what they value (their capabilities) and therefore to grasp knowledge about their subjective wellbeing situation.

Lastly, different vehicles were considered but the airplane was selected as it seemed to be the one that better seemed to fit this exercise purpose. Piloting a plane is an image that everyone has seen before which makes it easy to imagine. Moreover, most probably they have never experienced the situation of being a pilot, which could leave room to boost their imagination. Besides, being a pilot is positively seen by society, which could give them a feeling of pride and motivate them to imagine themselves in such a situation.

The following recording is a guided visualisation experience, it will take less than 5 minutes of your time.

You will go on a journey on a plane. This plane will represent your current life. I'll ask you different questions that will guide you through. If you can't answer any of these questions, don't worry, just visualise what comes to your mind.

Close your eyes and imagine your plane. Who's the pilot of this aircraft? Who controls it? Where are you sitting? How does that environment look like? Who else is on the plane? Take time now and think about the power of the plane... What generates the energy that makes it fly?

Where do you come from and most importantly, where is this plane going? Is there a destination?

Is your family on the plane? In case they are there... What are they doing? What's your mission on this journey? Is there someone that would help you out achieving this mission in case you need to do something else, for example, while you are sleeping, who would save your life in case something happens? Is this person there? How does the environment where you are flying look like? Now take a couple of seconds to picture that image in your mind and open your eyes when you are ready.

It was a pleasure to guide you through this journey. Now I would love to know what you visualised, the more details you give me the better! You can send me a text or voice message. Thank you!



WHO IS IN THE PLANE?

The people around the listener can be interpreted as the support this person receives or the person's beloved ones.

WHERE ARE YOU COMING FROM?

This question was created to invite the listener to refer to past experiences, to see how relevant is the past in this parent's lives.

This is an exercise to illustrate the invisible, to uncover latent knowledge about CSN parenting

WHO IS THE PILOT? IS THERE A CO-PILOT?

If the listener is the pilot of the plane, it might mean that he or she feels in charge of their own lives. This is not necessarily positive since sometimes this can also represent over-load of responsibilities.



WHERE ARE YOU GOING?

The direction can represent how people perceive their long and/or short term future. Perhaps some interesting events happening in their lives such as challenges they are currently overcoming or a future vision or goal they pursue.

WHAT'S THE POWER THAT MAKES THIS PLANE FLY?

The power or fuel of the plane might represent the energy that moves them and/or their motivations.

HOW DOES THE SKY LOOK LIKE?

The surroundings of the plane can represent the uncontrollable aspects of their lives as well as how they perceive their life and feelings.



STEP 3: “GIVING MEANING TO THE METAPHOR”

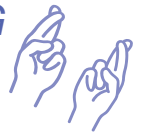


In this exercise the participants were asked to elaborate about the possible meaning of their visualizations decomposing each element of the plane journey.

To support them in this activity they were asked specific questions about the meaning of each key element of the story.

The participants were provided with a graphic representation of their visualizations to remind them about the different important elements they expressed (see image 10). This also served as a reward for their effort and to show compromise and gratitude from the designer’s side. These visuals were very handy for the designer to visualize the main insights and spark inspiration to keep analyzing the stories and comparing them to each other.

STEP 4: “EXPRESSING WISHES”



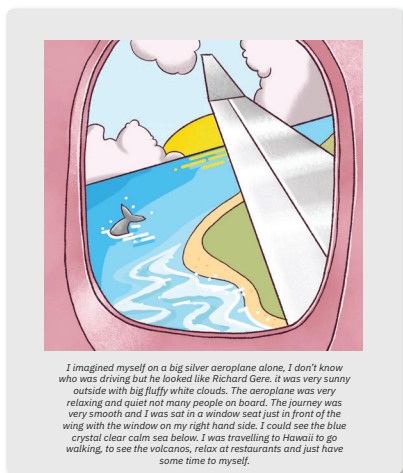
This stage was planned to unveil the wishes of the participants. In case they didn’t make it explicit in any of the previous conversations, they were asked to think of how would they improve the situation the story they visualized.

STEP 5: “RELATING TO ANOTHER CSN MUM”



The connection between steps 4 and 5, is represented in the journey map with a dashed line (see image 9), that’s because in this step the participants were asked to relate their own experience to a statement from another CSN mum’. The exercise was designed to prompt the participants to elaborate on topics of relevance that were not represented in their visualization as well as to see if the statements were common to the rest of the participants.

The material to support this exercise took the shape of cards where they were provided with a quote from another mum and the respective story of the metaphor see figure 14.



“
I just try to focus on the future and how it can only get easier in time and imagining what my children will be like when they’re older.”

Figure 14 | Example of card used in stage 5



STEP 6: "INDIVIDUAL SESSION ABOUT LEARNINGS"

Taking into account the time constraints of the CSN mums, resulted very difficult and inappropriate to carry this activity with the 5 research participants. However, fortunately, Marise, founder of The Ontzorghuis and collaborator of this project managed to arrange one hour of her time for this online individual session. The session was conducted in Miro (an online collaborative tool) and the session was audio-recorded.

The session aimed to answer the following questions: What is the most important knowledge a CSN mum develops through her experience? How did she reach that learning? And what ways of transmitting this knowledge does she consider effective?

The journey of the session was composed of 4 different exercises (see figure 15):

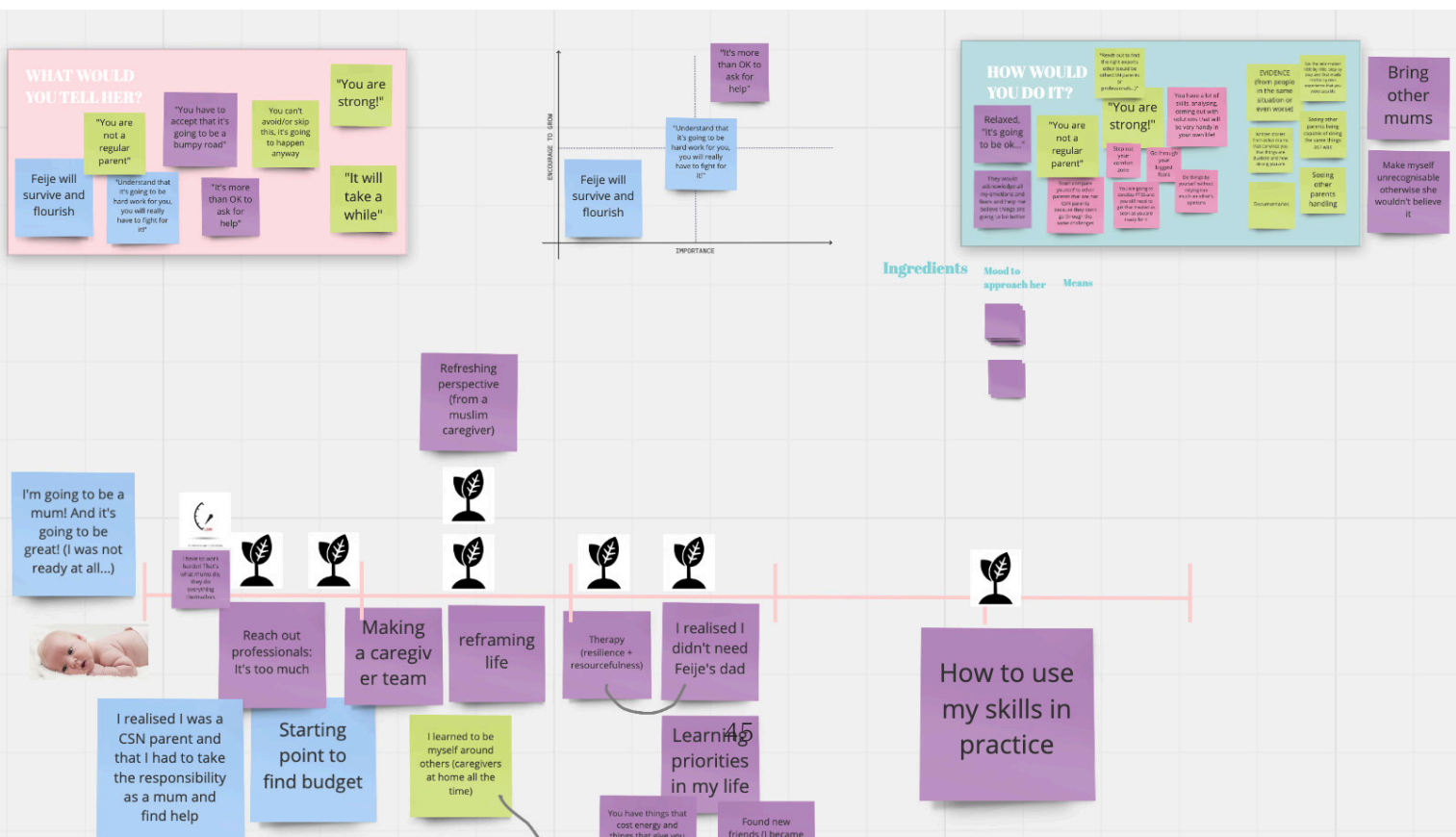
1 - The participant was asked the next question: What would you tell to yourself of 5 years ago when you just got a CSN?

2 - The second exercise consisted of moving those "self-messages" to a graphic with two axes, Importance (x), and encourage to grow (y).

3 - The third activity consisted of answering the question of: How would you tell all these important things to the Marise of the past without being able to appear and say "Hi, it's yourself from the future and this is what I have to say: ..." but instead ideate on ways that the Marise of the past would trust and understand.

4 - The last exercise provided the participant with a timeline with different icons that symbolized growth. The timeline was divided in 5 years which represented since her child was born until now. The activity consisted of identifying the different moments where she felt she grew the most, answer Why did that happen? and Where did this knowledge come from?

Figure 15 | Ideation session board



4

This chapter presents the results of the field research which are the stories generated provided by each parent, individual session main learnings, and the strategic vision of the target group, consisting of a definition of these parents' uniqueness. To finalise the chapter, a reflection on the guided visualization tool's main learnings is presented.

WHAT
MAKES CSN
PARENTS
UNIQUE?

4.1 FIELD RESEARCH ANALYSIS

Taking into account the qualitative and empirical nature of this study, the first analysis of the data was conducted on the go. This was done by downloading and analysing the data provided by each participant subsequently as the answers were arriving.

Since the participants were not answering at the same time, the analysis of each participant influenced the focus of the interview questions of the next one. The analysis of the data was done through the arrangement of relevant quotes, interpretation, and the conversion of those into insights.

This dynamic way of analysis aimed to increase the contextual understanding of the designer over two main aspects: What makes a CSN parent unique, and how to connect with parents in a way that maximizes the insight generation of each activity. Therefore, if between sessions an idea about how to improve the testing material sparkled, it made sense to include it in the next session as it would increase the chances of getting relevant information. This approach provided with richness of insights and allowed for the contrast of perspectives and strategies between participants.



Figure 16 | Ideation | Source: Unsplash

4.2 PLANE JOURNEYS, STORIES & VIEWS

The variety of CSN parents' profiles participating in this study was reflected in the results of the guided visualisation (first exercise of the field research). It revealed different strategies and personal perspectives towards their role as a CSN parent, providing rich stories on how each individual addresses their basic psychological needs (insight into the first research question of the study).

Working on those levels of abstraction brought a lot of depth to the conversation and helped the parents open up to the researcher expressing relevant aspects of their lives, wishes, and concerns.

The next pages show the different stories told by each parent next to a visualization of the key/ most important elements of their stories. The illustrations will be accompanied by explanations of the meaning the parents gave to each element visualized in the metaphor. The main insights taken from each participant are presented as bullet points and highlighted with an eye icon (see figure 17).

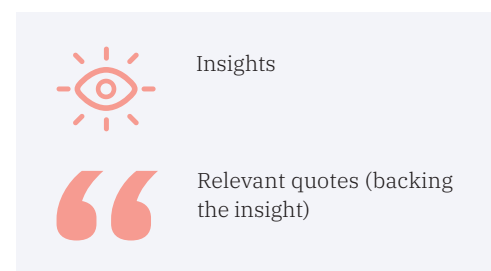


Figure 17 | Legend for insights and quotes

“THE AMAZED” - CSN DAD 1

non-main caregiver, partner of “The fighter” | 2 children in the autistic spectrum 4 and 5 years old

The plane that popped into my head was a little Cessna, so it has room upfront for myself & one more, being Ju, as I’d need a navigator (very symbolic), with seats in the back & windows all around. I don’t necessarily need to worry about the kids getting up & causing a distraction or a disturbance, as the views would be amazing & took me back to train & bus journeys we’d go on before getting the car, where they both loved looking at the hills & fields out of the windows & how they seemingly stretched on forever..., which would only be magnified from the plane, being so high up.

A regular, comfortable atmosphere is best, with normal clothes - keep everything comfortable, as even though we’re in a plane, high up in the sky, some sense of normality would help keep the kids grounded. There isn’t anyone with us, as even before lockdown came into effect, family members weren’t really on the scene, as they’re currently too busy with their own lives. We do see & speak to them on occasion, but not enough for them to be a part of the “scene” - it just didn’t stretch outside of our ‘little family’.

To be honest, there isn’t a destination. I imagined that we just get in & go..., then see where we end up.

“*I’ve just read my partner’s story, it’s so nice. Apparently we live two different lives!*”

CSN mum 1, the partner of this CSN dad (When she read his story)



Commonly, the main caregiver spends more time at home with the CSN, therefore there’s an imbalance between responsibility loads, which sometimes leads to a lack of understanding between the two caregivers.



Figure 18 | CSN dad 1 graphic representation of guided visualization

- 1 His partner (the mum) is the navigator, this means she has most of the responsibilities
- 2 The plane has no destination, this represents the enjoyment of the present moment and the lack of planning in this CSN dad's his life.

“THE FIGHTER” - CSN MUM 1

Main caregiver, partner of “The amazed” | 2 children in the autistic spectrum
4 and 5 years old

The plane flies on everlasting fuel because I forget/ can't find time to fill it up. I am the lead pilot, Kev's asleep, the plane has missiles attached to it because it keeps on getting attacked. We are flying really fast because we are trying to get to Caleb and Joshua who are waiting for us. It's an emergency and I feel panicked.

“ I normally read more on Facebook groups than I post, that's mainly because I don't have time and also because I'm very “I don't need anyone's help”

CSN mum 1

“ I wish that I could take the back seat sometimes. That I didn't shoulder a lot of the weight of decisions and responsibility. I wish I knew what our destination was and how life will pan out. I wish things were easier, I wish that I could enjoy the journey more.

CSN mum 1 (when she was asked what would she change to make this scene positive)



There's a strong wish for liberation of responsibility that comes from an overwhelmed main caregiver.



Figure 19 | CSN mum 1 graphic representation of guided visualiza-

- ① This CSN mum is (again) the navigator of the plane, she's stressed, fighting the attacks and driving fast. This represents the stress and big load of responsibilities in her daily life.
- ② His partner (the dad) is sleeping, this represents the fact of him not being present in her daily fight, but also the fact that he sleeps during the day due to his night shift job.
- ③ This mum leaves taking care of herself and resting in the background because she prioritises her CSN mum duties. This plane works with everlasting fuel because she feels she needs to keep going.
- ④ The plane is equipped with missiles to defend herself and fight for her children's rights and needs.
- ⑤ Some autistic behaviours are very deep and difficult to label, this makes the mum make an effort every day traveling to her CSN's world.

“THE DREAMER” - CSN MUM 2

Main caregiver | 3 children, one in the autistic spectrum, he's 7 years old

I imagined myself on a big silver aeroplane alone, I don't know who was driving but he looked like Richard Gere. it was very sunny outside with big fluffy white clouds. The aeroplane was very relaxing and quiet not many people on board. The journey was very smooth and I was sat in a window seat just in front of the wing with the window on my right hand side. I could see the blue crystal clear calm sea below. I had set off from Liverpool John Lennon airport and was travelling to Hawaii. I was travelling there to go walking, to see the volcanos, relax at restaurants and just have some time to myself.

“ I feel bad I couldn't visualise my husband or the children on the plane with me but I think it's because I can't remember the last time I did anything that was just for me.

CSN mum 2



There's a feeling of shame for wanting time on her own (not including the family).

“ I feel guilty about admitting I find it hard. I know some ladies who can't have children and would do anything to be in my situation so I feel I should be thankful.

CSN mum 2



She feels guilty of complaining about her difficult life because she feels she should be thankful.

“ I just try to focus on the future and how it can only get easier in time and imagining what my children will be like when they're older.

CSN mum 2



She uses a positive perspective of the future as a motivation to cope with the challenges of the present. This idealized perspective is an excuse to postpone her happiness.



Figure 20 | CSN mum 2 graphic representation of guided visualiza-

- ① She visualized herself traveling alone in the response of her need of spending time on her own and taking care of herself.
- ② To fulfill her self-care needs she visualized an idealized paradisiac landscape to enjoy on her own. The way she idealized the metaphor can be connected to the way she idealizes her future freedom.

“THE PASSENGER” - CSN MUM 3

Shared responsibility caregiver | 1 child with developmental delay, he's 19 years old

The plane is very messy, I'm sitting behind the pilot cabin (first seat line). I'm alone, I don't know where I come from and either where do I go. The only thing that takes my attention, is that there are a lot of objects around creating mess. I feel safe. I don't know how's the sky but I know is day time because there's light coming through the windows. from Liverpool John Lennon airport and was travelling to Hawaii. I was travelling there to go walking, to see the volcanos, relax at restaurants and just have some time to myself.

“ I'm afraid of taking the responsibility of making decisions, I overthink too much and feel very uncomfortable.

CSN mum 4



Decision making is a very big responsibility that generates fear, she feels more comfortable letting others take control.

“ I try to not think much about what will happen in the future, I try to calm down myself to avoid obsession and that feeling of fear that takes over when I think of what will happen to my son in the future.

CSN mum 4



The awareness about the lack of autonomy of a CSN in combination with thinking about the future evokes feelings of fear and anxiety.

“ We socialise usually with friends and family. I don't think I'm alone but I sometimes feel lonely because the obstacles you experience with a child with special needs, are family concerns, that just the parents can understand and tackle.

CSN mum 4



CSN Parents feel isolated even when having family and friends around because of the lack of understanding and perspective from the people outside the family unit.



Figure 21 | CSN mum 3 graphic representation of guided visualiza-

- 1** She travels alone as a passenger, she doesn't drive the plane because of her fear of decision making. Since she lets someone else drive, she's not aware of the destiny of the plane. This symbolizes the lack of future vision of the non-decision maker. She also trusts the driver, which reflects her "go with the flow" philosophy of delegating responsibilities.
- 2** There's a lot of untidiness around her, she feels a bit uncomfortable because of lack of personal space but she's not annoyed by the mess. This might symbolize the acceptance of her situation.
- 3** She can't see the outside view however she notices that there's light coming through the windows. In the same way, she learned to not pay too much attention to the path but still see it positively.

“THE STRATEGIST” - CSN MUM 4

Main caregiver | 1 child with chromosomal deletion, autism (corrected) heart defect and developmental delay, he's is 5 years old

I visualized a very bumpy big and heavy airplane that was ready for heavy tasks and I imagined I was the pilot and I was looking for other people to take over so they could be the co-pilot. I was the pilot because I was always in charge and I was navigating and deciding where to go to. I also imagined it like we were crossing heavy landscapes and covered paths.



I'm ready to think about the future of my child, but I always imagine it until he is 25, perhaps because until that age is normal that he still lives at home.

CSN mum 4



It's possible for CSN mums to see future thinking as something positive and useful, however, each mum sets her limit depending on what they are ready to think about.



Figure 22 | CSN mum 4 graphic representation of guided visualiza-

- 1 She's the pilot on a mission of trying to find people to take over and help out with her CSN's care. This can be interpreted as her arriving to the conclusion she can't do everything alone and from this awareness she's ready to ask for help and form a team that supports her.
- 2 The landscape is very bumpy and the paths are hard to see. This symbolizes the challenging life of a CSN mum and the big unknown the future represents.

“THE DETERMINED” - CSN MUM 5

Main caregiver | 1 child with Down syndrome, she's is 21 years old

My journey was to New York, I was with my two daughters, Tamara and Lorena. This was my 60 years old birthday gift. We were flying and we were getting some cocktails served, my daughters were taking care of me, constantly asking how was I doing, as well as the plane staff. It was a wonderful flight. I was very excited to travel to a new place where I've never been to. A very interesting thing that happened was that while we were flying we were seeing the sun rising. We were flying at the same time as time passed and we were going towards the light all the time. It felt amazing, even thinking of it right now gives me goosebumps.

“ *I have never been afraid of the future, I promised to myself since my child was born that she was never going to be a responsibility for anyone in the family.* ”

CSN mum 5



This CSN mum defined a very clear vision of the future of her child since the baby was born, which gave her direction and motivation to move towards her goal.

“ *I see the present very connected to the future, almost as they are the same thing. Everything I do now is constructing in a way what will happen in the future* ”

CSN mum 5



This CSN mum sees the future as something she can control by taking action in the present.



Figure 23 | CSN mum 5 graphic representation of guided visualiza-

- 1 The destiny of this journey was New York, an unexplored place with a different and interesting culture, this symbolises this mum's excitement for exploring the unknown.
- 2 They were traveling at the same time as the sun, which felt completely magic, the meaning of this is that when the three of them are together, things are always going to work out.
- 3 She was traveling with her two daughters, enjoying their company and attention.

4.3 GUIDED VISUALISATION LEARNINGS

IT'S ALL ABOUT THE CIRCUMSTANCES

The reader might be wondering if those stories represent specific kinds of profiles. The truth is that they shouldn't be considered fixed behaviors, it is more complex than that.

Human beings are resourceful, we adapt to circumstances and therefore when a specific kind of strategy doesn't work, we might try a new one. CSN parents are experts on developing new ways of functioning to adapt to their evolving challenges. When the research participants were asked to react to other parents' statements, they could identify themselves on different profiles, for example, one mum stated:

“ I've been the fighter before, but I realized this wasn't working for me, I realized I needed more people to help out so I changed my attitude into the strategist.”

CSN mum 4

The fact that they see themselves represented in multiple of the other's stories, is an indicator that many ways of managing are potential functionings for the rest. However, this doesn't mean that all of them are desirable. Not all strategies fit everybody's personality or circumstances; in other words, not all ways of functioning are accessible and valuable for the rest. For example, some people don't like decision making and need to share that responsibility. These personal preferences might not be altered despite being aware of other possibilities, and in the worst-case scenario, certain ways of functioning can be damaging for a person's wellbeing.

Two parameters were used to compare the stories, looking for what is common among this target group. On one hand, the short/long term perspective towards life management and on the other hand the degree of support that the CSN parent receives.

Some strategies are more future (long term) oriented such as The Strategist and The Dreamer while others are more present (short term) oriented like The Passenger, The Fighter. (See figure 25)

Some strategies are applied in different circumstances of support, for example, The Passenger, and The Amazed are strategies that can just exist when there's a supporting surrounding that allows them to enjoy the present moment while The Dreamer and The Fighter are developed in circumstances where there's no available support for them. In this correlation, we find The Strategist in a very "wanting to shift" position from not being supported to being supported. (See figure 25)

And additional correlation was found between the age of the child (experience of the CSN parent) and the acceptance of the role as a CSN parent and caregiver. This is not necessarily linear and might defer between parents (see figure 24). CSN parents also acknowledged their learnings about how to manage their CSN parenting life and expressed this as a learning curve (which could be comparable with the acceptance curve presented in image 24 (this aspect will be explored in more depth in the individual session, go to page 64 to see the results).

SUMMARY



The *Amazed, Fighter, Dreamer, Strategist, Passenger* and the *determined* are not fixed profiles, they might be considered **strategies or different ways of managing** CSN parenting. (different functionings as defined in the Capability Approach).



Personality plays an important role on CSN parent's current way of functioning.



There is a **path of acceptance** of CSN parenting role that increases over time and it's not necessarily linear.



CSN mums acknowledge having experienced a **learning curve** over time that helped them manage their CSN parenting life.



Some strategies can only exist when receiving support and others are just there when the parent doesn't receive **support**. This reflects how the environmental circumstances of each family conditions the capabilities of the parents.



While some strategies are **future-oriented**, others take place when the CSN parent has to deal with challenges of the present. For some, the focus on the **present** is forced by their circumstances and for others, it's a matter of choice since more supporting surroundings allow them to enjoy the present moment.

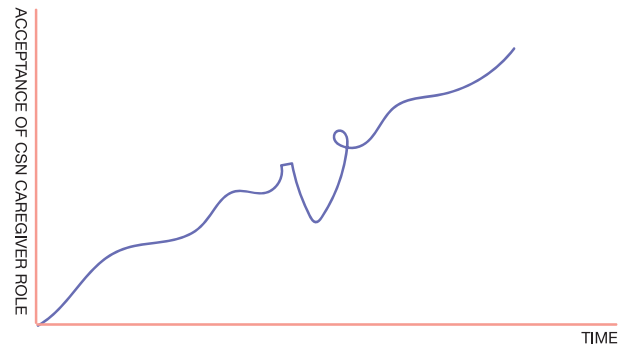


Figure 24 | Acceptance of care-giver role increasing over time

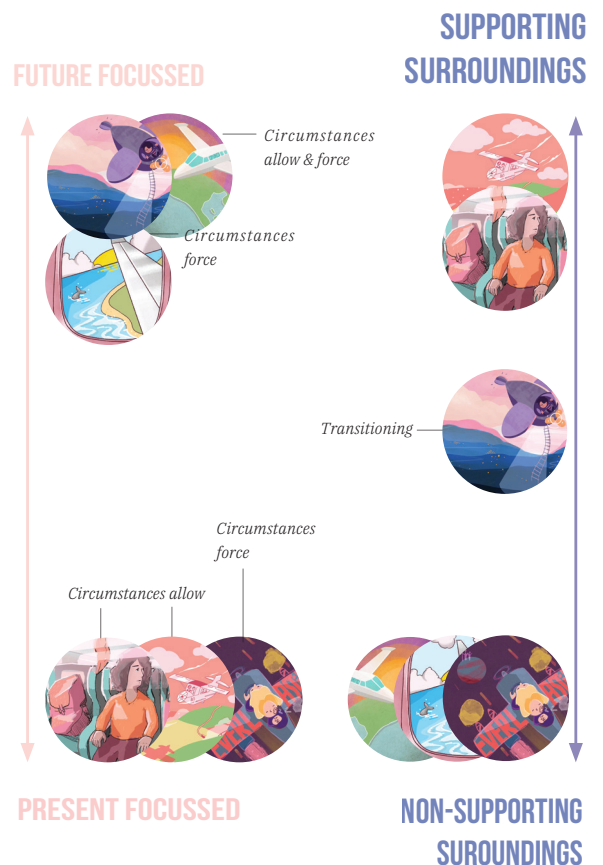


Figure 25 | Co-relations present/future and supporting/non-supporting surroundings

4.4 CSN PARENTING LEARNINGS

One of the main learnings acquired from the guided visualization exercise was that CSN parenting implies learning through time and finding your most suitable strategy depending on your personality, preferences, and situation.

This session was composed of four exercises intended to reach a deeper understanding of the learnings this mum went through, as well as what is the importance of those according to her and what ways does she think are best to transmit learning.

The following two pages aim to present the main learnings acquired from this session. The

following image shows the structure followed.

The results are presented in three different points that answer the three research questions proposed for this activity:

- 1: What are the most important learnings a CSN mum develops through experience?
- 2: How did she reach that learning? What are the most common learning/inspiring sources?
- 3: What ways of transmitting knowledge does she consider effective?

HEY THERE!

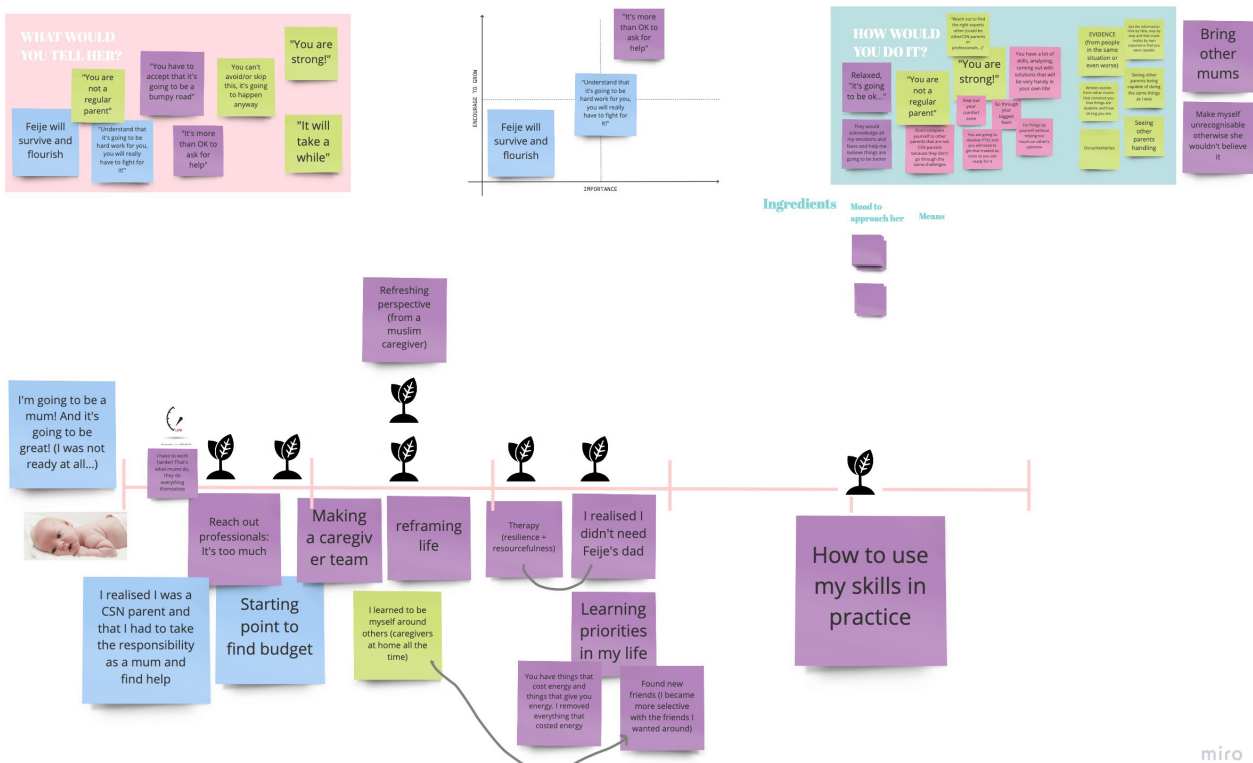



Figure 26 | Context mapping session with Marise as a CSN mum

1. IMPORTANT LEARNINGS FROM CSN PARENTING

 **IDENTITY SHIFT.** She shifted her way of perceiving herself from thinking she was a regular parent with a child with a heart defect to a CSN parent.


“ Finding out I was not a regular parent helped me start taking the responsibility of finding caregiving help

She explained the importance of this realization, of stopping to compare herself with other non-CSN parents and of accepting her role. She broke the idea of:

“ I have to work harder, that's what mums do, they do everything themselves


And adhered herself to a new one:

“ I have to take responsibility as a CSN mum and reach out for help if I don't know how to deal with stuff. I need a caregiving team to help out at home.


 **LEARNING TO PRIORITISE.** The high demands of her son pushed her to establish priorities in her life and that re-shaped her friendship circle.

“ 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.

2. SOURCES OF LEARNING & INSPIRATION


 **CSN PARENTS AS FRIENDS.** A friend of hers that is also a CSN father was very helpful giving her advice.

“ He knew that it was going to be a long road, so he gave me each time a little bit of information so I would be able to continue. He was trying to convince me that I could make it.


 **THE POWER OF A COMPLETELY DIFFERENT PERSPECTIVE.** One of the caregivers helping out to take care of her son told her about an Islamic belief that helped her see her situation from another perspective. The caregiver told her that in Islam, being a CSN paren 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.

“ I found this perspective very refreshing and inspirign and also helped me understand why she was also so involved and dedicated helping out

3. EFFECTIVE WAYS OF TRANSMITTING KNOWLEDGE

 **EVIDENCE, UNDERSTANDING & EMPATHY.** She described the Marise of 2015 as someone that needed evidence to believe in specific advice but also someone that would acknowledge her emotions and struggles.

“ If I had to give that advice to myself of 2015 (when just had a CSN baby), I would split myself up in different moms and then they would tell their story acknowledging all my emotions and fears but they would also help me believe that things are going to be better.

 **DOCUMENTARIES & READING CONTENT GENERATED BY OTHER CSN MUMS.** She described documentaries as inspiring sources of information that showed her how other CSN families were doing.

4.5 STRATEGIC VISION: PARENTS UNIQUENESS

This subchapter presents a strategic vision of the context, characterizing the common circumstances of being a CSN parent. The vision is an attempt to answer the second research question of the study: What are the capabilities that characterize the CSN parents' community? as well as to see express how their basic psychological needs are affected by their situation.

The vision is divided into 6 categories (see figure 27): Overload responsibilities, uncertainty, isolation, celebrating achievements, personal growth, and reframing life. The first three categories are considered the negative or more unfavorable side of the vision and the last three are considered the positive/favorable aspects.

The information presented in the six categories has been mainly gathered from the field research but has been also contrasted with the literature and desk research results. A validation session was carried out with The Ontzorghuis who provided their expert feedback helping to the completion and adjustment of the vision.

This vision will inspire and inform further steps of this project such as ideation and design. The following page provides a more detailed explanation of how these 6 categories connect to the capability approach, to SDT's fundamental needs as well as to the concept of resourcefulness.

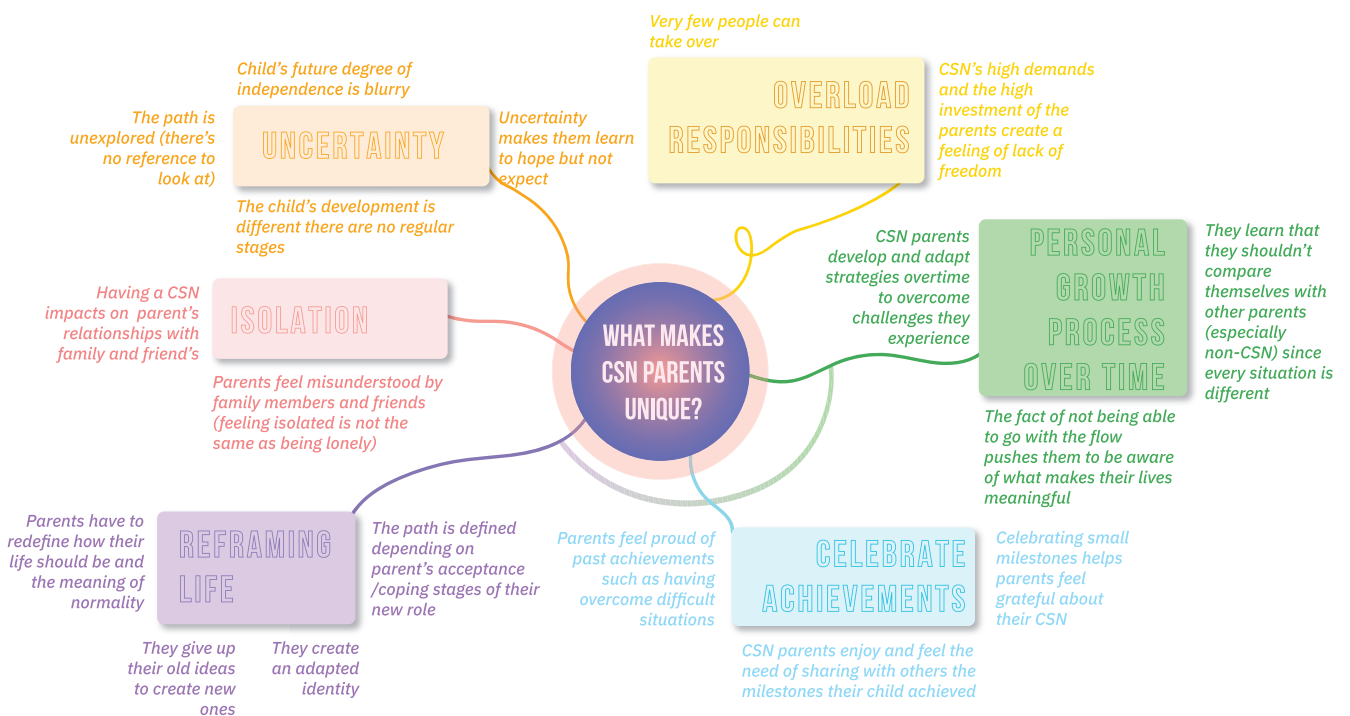


Figure 27 | Strategic vision

CSN PARENTS' UNIQUENESS & THE THREE THEORETICAL FRAMEWORKS

The following section explains the six categories that define CSN parents' uniqueness concerning the three fundamental needs of Self Determination Theory, resourcefulness, and capability approach.

CAPABILITY APPROACH

The following paragraphs will connect parent's uniqueness with the capability approach.

The three negative elements of these parents' strategic vision can be linked to their decrease in capabilities. For instance, the overload of responsibilities they experience affects directly their possibilities to achieve valuable functionings. The same thing happens if we look at the big unknown they face, the uncertainty of what will happen to their children in the future. Their CSN life-long dependency constrains their freedom to think about the future. Not to mention that many times they are not even capable to think about the future since this generates uncontrolled fear and anxiety.

Nussbaum describes the capability for affiliation as the ability 'to live with and toward others, to recognize and show concern for other human beings, and to engage in various forms of social interaction (Nussbaum 2001, p. 79). This is a very similar description to what we understand of relatedness in Self Determination Theory. The **isolation** these parents experience because of their CSN's intensive care demands in combination with the lack of understanding and empathy of friends and/or family results in a hindrance to their capability for affiliation impacting negatively their subjective wellbeing.

SELF DETERMINATION THEORY

RESOURCEFULNESS

An interesting reflection when comparing the concepts of resourcefulness and capabilities regarding to CSN parents is that while the capabilities of parents (freedom to be and do what they value) are most likely to be reduced by having a special needs child, the opposite may occur with their resourcefulness. The research conducted in this project illustrates how due to the continuous challenges and struggles these parents face, some of them become resilient and more prepared to overcome difficult situations. In other words, many CSN parents become more skillful than non-CSN parents in finding and adopting alternative ways of functioning.

CSN parents' **personal growth** is linked to their ability to resourcefully **reframe their life**. These two aspects of their uniqueness refer to their need for adaptation to their new role as well as the need of giving up old ideas of how life should look like and build new ones. Parents develop creative ways of managing their challenges and adapting (some to a bigger degree than others). Moreover, the fact of not being able to go with the flow pushes them to be aware of what is valuable for them, which is a first step towards improving their quality of life.

CSN parents feel proud of their past achievements such as having overcome difficult situations. In this way, they are often aware of their growing skills, which fosters the satisfaction of their needs for **competence and autonomy**. Moreover, the little achievements of their child teach them to value small milestones and practice gratitude more often. Sharing those achievements with the world, for instance, in social media is a common way of **celebrating**.

Most CSN parents usually experience an **overload** of responsibilities since their CSN's demands require specially trained care-givers. Because of this, it is very difficult to share their child's care with close family and friends. This is one of the main causes of a decrease in these parents' fundamental need for **autonomy** since the lack of freedom they experience doesn't allow them to feel as causal agents of their own lives.

As previously mentioned, for CSN parents is not easy to find time for strengthening relationships with friends and family. On the other hand, they also feel misunderstood by the rest of society, since it's not easy for non-CSN parents to empathise with their situation. The **isolation** they experience directly affects their fundamental need for **relatedness** since their circle of friends can be reduced.

4.6 GUIDED VISUALISATION TOOL LEARNINGS

IMAGINATION, GRAPHIC REPRESENTATION & REFLECTION POWERS

This section presents the value of the guided visualisation tool used in the qualitative research of this project. The tool served as an asset for further development of the solution of this assignment.

The guided visualization was combined with an interview that guided/facilitated the participants to interpret their visualization and provide rich qualitative insight on their life perspective.

This combination of activities generated rich stories that gave insight to defined the strategic vision of the target group. The aspects presented in the two following pink sections worked as takeaways and important considerations that directly influenced further design decisions.

MAIN TAKE AWAYS



It was an **engaging** activity that was considerably **new** for the target group.



The activity worked as a **communication vehicle** to establish a conversation about relevant aspects of these parents' lives.



It was a journey of **self-discovery** and **reflection** that unveiled latent knowledge of CSN parents. The visualization in combination with the interview worked effectively as a personal reflection and self-analysis tool. (Quote 3)



When the **stories** this tool generated were **shared** amongst the participants, some participants felt identified with others, which created a feeling of release and **relatedness** as the two quotes in the following page illustrate. (see quotes 1 and 2)



When the participants read other participants' stories and didn't feel identified with them, it triggered some **curiosity and willingness to establish a conversation** about it.



The symbolic meaning of the **airplane journey** was well adopted by the target group since it was **relatable** to their life journey and **specifically to their future vision**.

IMPORTANT CONSIDERATIONS



The guided visualisation was meant to represent the participants' vision about their lives. However, two of the participants visualised journeys that expressed their wishes (journeys to Hawaii and New York). The exercise worked to unveil the participants' lack of capabilities (lack of chances to do and to be what they value) but not to learn about their specific strategies (RQ1). Therefore, **to acquire the expected outcome and avoid results out of the research scope**, it might be good to **provide more clarity and guidance**.



The exercise left a lot of **freedom** of imagination, which brought some participants to visualize at a very abstract level. This made it **difficult** for them to **establish a connection** with their current/real situation. More guidance could contribute to a better and more autonomous experience of the exercise.



Again, because of the **freedom** of imagination the exercise provided, some participants experienced **negative feelings**, for instance, shame (see quote 1). Acknowledging that possibility in the guided visualisation recording could contribute to a more comfortable experience.

“I was ashamed I couldn't include my family on my fantasy of going on holiday but now that I know that another CSN mum had the same wish/fantasy, I feel better and I can even laugh about it!

Quote 1, CSN mum

“I can identify myself in these different stories specially in moments of my past.

Quote 2, CSN mum

“This exercise made me realise about my long term orientation, about how everything I do in the present is to achieve a specific goal in the future.

Quote 3, CSN mum

5

This chapter presents the ideation and definition of the Future Journeys tool. The different interactions that the tool suggests and the reasoning behind each of them are presented as well as this concept's connection with the capability approach and resourcefulness.



DESIGNING FUTURE JOURNEYS

5.1 FINDING COHERENCE & UNIQUENESS

IDEATION

The strategic vision and the outcomes of the research composed a very detailed and broad vision of CSN parent's situation. Therefore, it was necessary to narrow the scope down and define a specific direction for this graduation assignment.

An ideation session was organized with another interaction designer to come up with potential design ideas. The session was structured to ideate on different relevant how-tos for each characteristic of CSN parents' uniqueness (for more information on this process, please visit appendix C). Through a selection of inspiring how-tos, a concept was chosen and further defined taking into account the capability approach and resourcefulness theory and focussing on the topic of CSN parent's process of personal growth.

RE-FRAMING THE CONCEPT

This concept was evaluated considering two aspects: How coherent it was with the insights gained through the qualitative research with CSN parents and until which extent connected with the target group. These two aspects were especially important since it was essential for this project to provide a solution specifically designed for the target group. (for more information about this reflection please visit appendix D).

This process finally brought the concept to take shape and compose what was called "Future journeys", a tool to help parents expand their capabilities to think about the future while raising a life-long dependent child. The pink box on this page presents the two aspects that brought coherence and uniqueness to the focus of this project.

A COHERENT & UNIQUE CONCEPT

Looking back into the research and reflecting on the learnings acquired about the power of the guided visualisation exercise (presented in pages 70 and 71), it was considered to use again the power of metaphorical thinking since the exercise proved to be very valuable to help parents gain insight on latent knowledge about their life perspective as well as to reflect on topics that might be hard to reflect on.

On the other hand, looking back at the research also helped to narrow the topic of this project from personal growth (very broad and little specific to the target group) to a more specific one, future thinking management while having a life-long dependent child. This second topic proved to be a real concern for many CSN parents since all participants involved in the research expressed their concerns on the topic.

5.2 FUTURE JOURNEYS TOOL

WHAT?

Help CSN parents expand their capabilities to think about the future while raising a lifelong dependent child.

HOW?

Through a digital tool that:

- 1. Facilitates an understanding of what is the user's current strategy/perspective towards future thinking.*
- 2. Helps the user identify inspiring perspectives from other parents through the navigation of different statements created by the other CSN parents.*

WHY?

Many parents of children with special needs are sensitive to future thinking due to their children's lifelong dependency. Thinking about the future means for many of them to experience uncontrolled fear and anxiety.

On the other hand, the research of this project shows that different parents manage this in different ways. Therefore parents that have a more positive relationship with future thinking can be a source of inspiration for other parents who struggle and are open to new/resourceful ways of approaching this obstacle.

FLOW OF INTERACTIONS

Of Future journeys

The following two pages present the user flow of interactions with the proposed concept “Future Journeys”. This is a self-reflection & inspirational social tool that consists of a phone application that guides the user through 5 stages that transition from more introspective and self-reflective towards social interactions. In the introspective stages the user reflects and/or discovers her or his relationship with future thinking to be able to share it with others in the form of inspiring and relatable stories.



TOOL'S FEATURE

Guided visualization recording

Questionnaire

Badge generation

USER ACTIONS

Listen to the recording and visualize the different elements that compose the future perspective reflection exercise.

Reflect about the realistic meaning of the visualization.

Obtain badge and go through the animation/explanation of each element.

INTERACTION GOAL

Metaphorical reflection about personal perspective towards future thinking. Approach self-knowledge with curiosity through an engaging reflection

Strengthen knowledge about one's perspective on future thinking. Acquire deeper level of consciousness.

Self-identification and understanding of graphic representation.

SELF-REFLECTION

Figure 28 | Future journeys' flow of interactions



Question to post an inspiring statement

Create an inspiring statement for other members of the community answering a question related to one's perspective about future thinking.

Inspire other parents through self perspective



Statements exploration

Explore different statements from other CSN parents and mark as inspiring the ones that one would like to save.

Feel identified with others, get inspired and feel curious about other's perspectives.



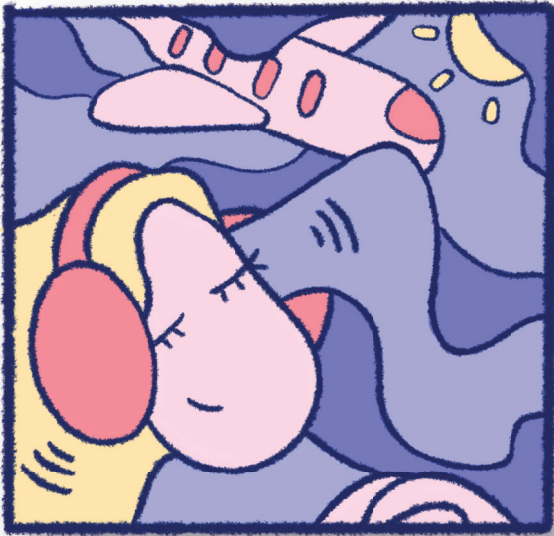
Profiles (second layer of information)

Explore the second layer of interaction, read more detailed stories, and see other parent's evolution through time.

Acquire deeper knowledge about similar others and their strategies/resources

SOCIAL

GUIDED VISUALIZATION EXERCISE



The first interaction the user experiences with the tool “Future journeys” is a reflection with the shape of a guided visualization exercise which consists of listening to an audio recording that will submerge the user into a metaphorical visualization that represents her/his relationship with future thinking. The overall goal of this exercise is to help the users reflect and/or discover their relationship with future thinking. It presents some similarities with the one used for the qualitative study of this thesis, however, it was adapted to the topic of future thinking and to the constraints of being incorporated into a phone application.

A JOURNEY TO REPRESENT ONES FUTURE THINKING RELATIONSHIP

After looking back at the main learnings acquired from the research visualization tool (see pages 70 and 71), it was decided to keep

the topic of the airplane. The reasoning for this is that the symbolic meaning of the journey was well adopted by the target group since it was relatable to their CSN parenting life journey and specifically to their future vision.

Therefore, the airplane metaphor research tool was adapted to this concept focus, this was done through the creation of a new script that would just refer to symbols of future thinking. That way, some parts of the metaphor were identified as useful since they proved to help parents think about the future during the qualitative research.

Another aspect to consider is that for this tool to work as intended, the visualization has to facilitate parents in a way that all of them reflect on the same aspects of future thinking and generate comparable and relatable responses. This is a challenging aspect since the reflection facilitation takes place through an automated system, a digital phone application. Therefore, the visualization had to be facilitated in a more guided way, already bringing the user into the reflection mindset of giving meaning to the different parts that are being visualized. Otherwise, based on the experience with the research tool, we would be running the risk of letting the users imagine completely different results in high levels of abstraction that might have been difficult to interpret afterward and would compromise the next interactions with the concept.

SUMMARY

- The overall goal of this exercise is to help the users reflect and/or discover and acknowledge their relationship with future thinking.
- The guided visualization of “Future Journeys” consists of an adaptation of the guided visualization research tool used in the qualitative study of this assignment
- A new and adapted script was created is based on the insights acquired from the use of the research visualization tool. Therefore a new script was created adapting the parts of the research tool that alluded to future thinking.
- For this tool to work as intended, the visualization has to facilitate parents in a way that all of them reflect on the same aspects of future thinking and generate comparable and relatable responses. To achieve that and in contrast with the research visualization tool, this guided visualization will present a more guided facilitation style towards creating a mindset of giving meaning to each element of the visualization.
- The questionnaire intends to help the users remember their visualization and reflect on the real meaning of their visualization. The answers to this questionnaire will provide the system with consistent information to afterward allow the users to feel identified and/or compare their perspectives with others.

QUESTIONNAIRE



The questionnaire is the following exercise to the guided visualization, it intends to help the user remember in a simple way the different elements visualised and connect them directly with their realistic respective meaning. That way the user acquires a deeper level of consciousness about one's relationship with future thinking.

This exercise also provides the system with common answers that will allow the users to relate and compare their perspectives about the future in further stages of their interaction with the concept.

BADGE GENERATION



Once the user completes the questionnaire, the app generates a personalised badge based on the answers the user introduced. Each element symbolises a different aspect of the visualisation and therefore defines each parent's current relationship with future thinking.

this element was an adaptation from the graphic representations that were sent to each participant during the research phase. The participants appreciated them and liked to see a representation of their visualizations, however, in the research this was a personalized outcome that was custom-made for each participant, which is something unfeasible in a digital automated product and also would not enhance the intended functionalities of the concept which are to easily allow the users to understand others situations at first glance. That said, the guided visualization and the badges were designed in a way that could give room for variety but at the same time be able to be compared with each other.

The feeling that this badge aims to transmit is the feeling of pride, of being such a pilot that has flown all this way in the journey of special needs

parenting.

The interaction with this element will consist of acquisition and a quick read through the different elements that compose the graphic.

MEANING OF EACH ELEMENT

The pilot - The pilot represents the parent, piloting the plane of future thinking, a plane that can just move forward, never backward, that's because it flies towards the future.

The sky - The background of the badge, the sky, intends to transmit the feelings that each parent experiments when dealing with future thinking.

The Asteroids - Those represent the obstacles some parents visualise while thinking about the future.

The weapons - The weapons will symbolise the fighting attitude some CSN parents present towards the future.

The direction - The direction is represented in the badge as a sign of determination, of having a goal or a mission towards the future. The visualisation guide also referred to the distinction between short or long term missions (this also composed one of the elements to be displayed in the profile of each parent).

The co-pilot - The co-pilot will show the support some parents have while raising their children. This aspect was considered important, even though is not directly related to future thinking, having a figure of support around can affect the overall relationship with future thinking.

SUMMARY

- The badge intends to provide a common language to allow CSN parents to identify their own and others' relationships with future thinking quickly and easily.
- The feeling that it intends to evoke through the shape of a pilot badge is the feeling of pride of having flown all this way in the journey of being a special needs parent
- Each element of the badge represents a different element from the visualization.
- The badge will work as the avatar image of each user in the app

QUESTION TO POST AN INSPIRING STATEMENT



This is the first interaction with the social aspect of “Future Journeys”, the app asks a question to prompt the user to write an inspiring statement about future thinking management for other parents to read. This statement will afterward be posted in a common feed where all CSN parents can access and see the badges in combination with the respective statements of each parent.

This part of the concept presents two challenges. On one hand, to give the right input to the users to activate them to share a rich and inspiring statement for others. And on the other hand, the challenge of extending this interaction in time, in the sense of keeping the user engaged with the generation of new inspiring content.

STATEMENTS EXPLORATION



This feature provides a feed where the users discover statements other parents have generated when answering the question to write an inspiring statement. The ideal interaction would consist of the reader establishing a relationship between the badges of each person (which graphically explains each user’s current relationship with future thinking) and the respective statement. The feed will provide all kinds of perspectives and statements. The users might feel in some cases identified, in disagreement, or even curious about a non very familiar perspective. Therefore, this interaction with the tool intends to generate a feeling of relatedness between CSN parents.

SUMMARY

- The App will provide users with a question to prompt them to generate a rich and inspiring statement about their own way of approaching future thinking.
- The statements generated through answering the previous question will be shared and displayed in a feed where all the users will go through to explore and get inspired by others' perspectives.
- The feed will provide the users with the option of expressing how do they relate to the other statements (for instance, by pressing a button that notifies the author about other parents getting inspired).
- The profile of each user will provide a second layer of information where people will be able to read more extended stories and more detailed information about each user (for instance, years of CSN parenting experience, the evolution of badges, etc).

PROFILE (SECOND LAYER OF INFORMATION)



The idea of including a second layer of information comes from the assumption that for the users will not be enough to simply read an inspiring statement, they might want to learn more about other parents stories (this proved to be true during the testing phase of this tool, which will be further explained in chapter 6. Testing the tool).

The profile will provide the users with personal information about each CSN parent. Displaying the last inspiring statement, the years of experience parenting a child with special needs as well as the evolution (since the perspective about one's future might change, and the users might do the guided visualization again in the future).

This part of the concept will be explored in more detail during the testing phase to see how to create a complete source of information that keeps inspiring CSN parents towards future thinking.

5.3

CAPABILITY APPROACH, RESOURCEFULNESS & FUTURE JOURNEYS

Before diving into how Capability and Resourcefulness inspired the concept of Future Journeys, let's bring back a couple of definitions presented in chapter 1.4

Resourcefulness: The ability to develop new patterns of use that provide a creative solution for a situation-specific challenge.

Resourceful Act (resourceful functioning): A pattern of use born from the creative adaptation of a resource to achieve a new utility.

Capability Set: Potential functionings that are known and valuable for the individual

Potential Resourceful Functionings: The set of potential valuable functionings that is still unknown to the individual. Since resourceful acts are improvised, this set of functionings is potentially infinite and non-existent until put into practice.

The concept of Future Journeys aims to leverage the resourceful acts that individual CSN parents' came up with, to expand the capability set of the rest of the CSN parents' online community. Particularly their capabilities to think about the future.

This idea is backed-up by the research of this project, which illustrates two key aspects of CSN parents: On one hand, the drop of capabilities they experience when they become CSN parents, which puts them in a relatable

and common ground regarding what they are effectively able to achieve. And on the other hand, the ability they develop to apply and adopt new ways of functioning is forced by the continuous challenges they experience when raising a child with special needs.

The initial introspective stages of Future Journeys intend to bring to the surface those resourceful acts that experienced CSN parents came up with. The fact that some parents have managed to acquire a valuable relationship with future thinking, proves their resourcefulness. They have achieved a new valuable functioning for which non-commonly agreed solution was available, repurposing the resources at hand for their unique circumstances. Therefore, valuable ways of thinking about the future can be considered resourceful functionings, and thus, the first aim of the tool is to help parents to acknowledge and define their perspective on this topic.

The second aim of Future Journeys is to encourage parents to share their way of thinking about the future. In this way, the resourceful acts of every single parent will become known by the rest of the community who, if gifted with comparable interpersonal skills and circumstances will automatically experience the expansion of their capability set.

Figure 29 illustrates this transition from individual resourceful functionings to an expanded collective capability set. The valuable perspectives on future thinking are shared as new resources of knowledge for the CSN parent's online community. However, it is

important to understand that for a resource to expand parent’s capabilities, they need to be able to perform the necessary patterns of use that extract utility from such a resource. Therefore, only the parents who have relatable circumstances (knowledge, social context, physiology, etc.) to the person who shared the statement will be able to embrace or repurpose this new pattern of thinking in their own life. In other words, by reading new but relatable perspectives on future thinking, CSN parents expand their capabilities to face this challenge.

The figure presented on this page shows the two available approaches to achieve new valuable ways of doing (Valuable functionings or utility)

Conventional approach: (Represented with white arrows) This approach consists of following the commonly agreed or standard way of being and doing to achieve utility (aiming towards a quality life). This path is not always available for CSN parents since conventional ways don’t provide a solution to their struggles.

Resourceful approach: (Represented with red arrows) This is the approach promoted by Future Journeys. It consists of using the available resources in a creative way to solve challenges for which non-commonly agreed solution is available. The last arrow shows how once the challenge is achieved the individual can share the knowledge with the rest of the community providing a new available resource.

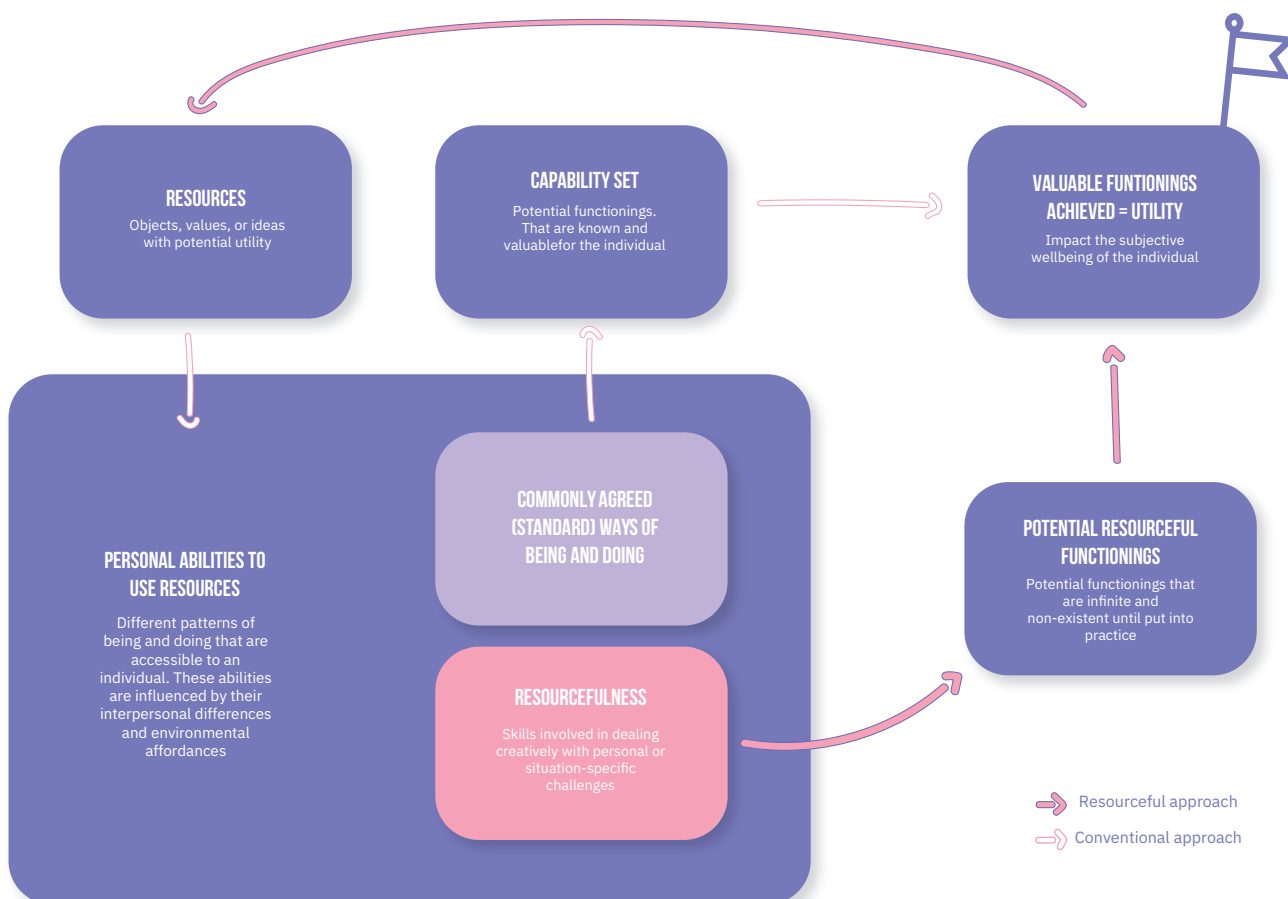


Figure 29 | Two available approaches to achieve new valuable functionings or utility

6

This chapter presents the test interactions carried out to improve the comprehension and value of the preliminary concept of Future journeys. A final list of improvements is defined to propose a more defined solution to be further validated in the next chapter of this project.



TESTING THE TOOL

6.1 TESTING THE VALUE & COMPREHENSION

ITERATIVE APPROACH

The testing phase of this thesis followed an iterative approach and was carried out in a remote setting, always trying to adapt to the time availability of the participants.

The test iterations were structured looking at each part of the tool's journey as well as at the overall concept and at how the different parts of the journey would influence each other. Some of the parts were tested individually and others consecutively depending on the iteration and research questions.

GOAL

The focus of these iterations lied on understanding how the target group would adopt the tool as well as on improving the concept regarding comprehension and value. Different research questions were formulated for each part of the tool and iteration. The questions were classified into the two categories mentioned before: One referring to the users' comprehension of the concept and a second one alluding to the value of the concept. The following sub-chapter (6.2 Test iterations) will show the different parts of the tool and how they were tackled in each iteration.

PROCEDURE

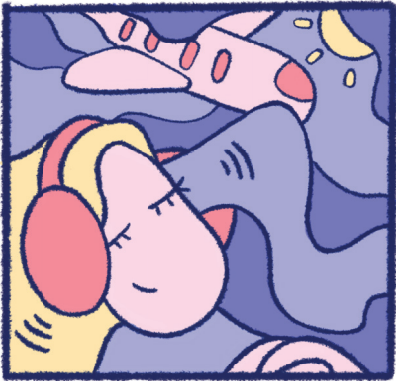
The tests were designed with a very short duration (of around 10 min each), depending on which part of the concept was being tested, the participants filled in a questionnaire, were interviewed through chat or either a phone call (depending on their availability and need of further explanation to acquire more insights to proceed with next iterations). The different parts of the tool were tested consecutively, they build upon each other.

THE PARTICIPANTS

Due to the difficulty to find participants and their availability constraints, this study combined two kinds of participants, CSN parents, and non-CSN parents. This second kind of participants tested parts of the concept that were referring to the understanding of the concept. The non-CSN parents took a more relevant part in earlier iterations, which helped to keep some of the CSN parent participants on hold for later iterations with a more developed concept without biasing them too early.

6.2 TEST ITERATIONS

1. GUIDED VISUALIZATION EXERCISE

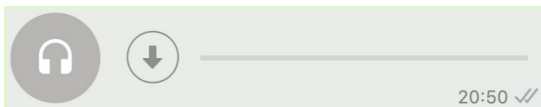


PARTICIPANTS

- per iteration*
- 2 CSN parents
 - 4 non-CSN parents

MATERIAL

- Guided visualization audio recording
- Type Form questionnaire



Iteration 1

This first iteration intended to understand if the adaptation of the research guided visualization tool was achieving the goal of helping CSN parents reflect about their relationship with future thinking.

All participants were sent an audio recording of the guided visualization and a questionnaire that combined the questions of the second stage of this tool and additional questions to see if the participant's answers were coherent with the actual relationship with future thinking.

After the participants sent the questionnaire answers, these were analyzed to see if there were any inconsistencies. Subsequently, a specific interview was prepared for each participant to complete the insights needed to proceed with the next test iteration.

RESEARCH QUESTIONS

Comprehension

- *Is the guided visualization easy to follow and to understand the meaning of each element?*
- *Does the new version of the guided visualization help participants reflect about their relationship with future thinking?*

Value

- *Is the visualization representative of the actual user's relationship with future thinking?*
- *Is the metaphor fitting the topic of future thinking while having a life-long dependent child?*
- *Do they find the activity engaging?*

RESEARCH QUESTIONS

Comprehension

- *Are the visualizations of the sky representative enough of the participants' actual emotions while thinking about the future?*
- *Does the new version of the guided visualization help participants reflect about their relationship with future thinking?*

Value

- *Are the emotions a nice added element to reflect on?*
- *How do people feel when their emotions are being represented in the sky of the badge?*

Iteration 2

The second iteration of this tool's part consisted of including a wider variety of emotions since the previous iteration just distinguished between positive and negative emotions, which also felt as good or bad situations. This contrast generated self-judgment amongst some of the participants, which didn't contribute to a nice experience.

Based on the research insights and on the participants' input from the previous iteration, the emotions that were considered representative of the experience of future thinking were: Fear and anxiety (represented by the wind), happiness (represented by the sun), sadness (cloudy), peace (silent night).

The participants were again sent a questionnaire after the test and interviewed to acquire the necessary information to answer the stated research questions. The questionnaire to test this iteration included two extra questions, one about the different emotions the guided visualization was proposing and another one about any other feeling that the user could have felt which was not described in the visualization question.

RESEARCH QUESTIONS

Comprehension

○ *Is the questionnaire understandable and easy to answer for the participants?*

Value

○ *How does it feel to answer a questionnaire after doing the visualization exercise?*

○ *Do the participants understand that the purpose of the questionnaire is to register their relationship with future thinking? Do they prioritise the truth about their perspective over the visualization in case of inconsistencies?*

2. QUESTIONNAIRE



PARTICIPANTS

per iteration

- 2 CSN parents
- 4 non-CSN parents

MATERIAL

- A type Form questionnaire

A screenshot of a TypeForm questionnaire. The form is titled "Let's visualise your future thinking!" and includes an introductory text: "This is a short survey that will guide you through the different questions of your visualisation." The form contains several questions with multiple-choice options. The first question asks for the user's name or nickname and the age of their child. The second question asks how long the user visualized a mission, with options: "Short term mission (to achieve soon)", "Long term mission (Far away in the future)", and "I didn't visualise a mission". The third question asks for the degree of difficulty of the mission, with options: "I found it impossible", "I found it very difficult", "I felt positive and thought I could achieve it", and "I didn't visualise a mission". A "Start journey" button is visible at the bottom of the form.

Figure 30 | A Type Form questionnaire sent to the participants (www.typeform.com)

Iteration 1

This part of the tool was tested consecutively and sent together with the guided visualisation exercise. It intended to test both:

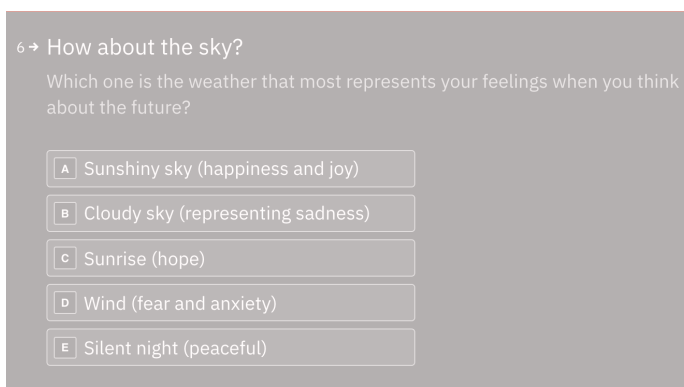
1. if answering a questionnaire after performing the guided visualisation was helping the participants easily remember their visualization.
2. If the guided visualization was working effectively (if the participants were visualizing their actual relationship with future thinking instead of just letting their imagination go free and visualise without giving sense),

The Type Form questionnaire included: - Questions directly addressing the guided visualisation (which is the original aim of this part of the tool) and some extra questions to identify potential inconsistencies.

Iteration 2

The main challenge encountered in this iteration was how to formulate the question referring to the weather conditions (which intended to represent the participants' emotions while thinking about the future) as well as how to formulate the respective multiple answers to this question. The main dilemma in this respect was to promote a representative answer to the actual feelings the participants experience when thinking about the future but still make reference to the metaphorical element (weather conditions) that they visualised. Giving too much emphasis on the metaphorical aspect could bring inconsistencies to the answers since there was a risk that the participants visualised something that was not representative of their reality.

In response to this reflection, the second iteration design attempt chose to refer to both elements equally (metaphorical and realistic). First, making a small reference about the sky, then providing a question that empathised on participant's feelings when thinking about the future and lastly, providing a combination of both (the weather and emotion) in the multiple-choice answers. Figure 31 illustrates the multiple answer question that was included in the questionnaire.



6 → How about the sky?

Which one is the weather that most represents your feelings when you think about the future?

- A Sunshiny sky (happiness and joy)
- B Cloudy sky (representing sadness)
- C Sunrise (hope)
- D Wind (fear and anxiety)
- E Silent night (peaceful)

Figure 31 | A Type Form questionnaire sent to the participants (www.typeform.com)

RESEARCH QUESTIONS

Comprehension

- *Do the participants understand the importance of providing a realistic answer (prioritising their reality over their visualization)?*

Value

- *How comfortable do people feel while sharing their identity in a system where they will also share personal stories?*

3. BADGE GENERATION



PARTICIPANTS

per iteration

- 2 CSN parents
- 4 non-CSN parents

MATERIAL

- Questionnaire

Iteration

The badge acquisition was tested once the participants sent the answered questionnaire of the first iteration of the guided visualization. See image 32 to see an example of the first graphic representations designed to be handed to the participants after answering the questionnaire. Please note that the badges' background at that moment just distinguished between positive and negative feelings (which was represented by the day and the night). The participants were sent these badges (without the explanations) were interviewed to see if they were able to identify the different elements they visualised.

RESEARCH QUESTIONS

Comprehension

- Can people understand properly the meaning of each graphic element?

Value

- How does it feel to acquire a graphic representation of one's relationship with future thinking?

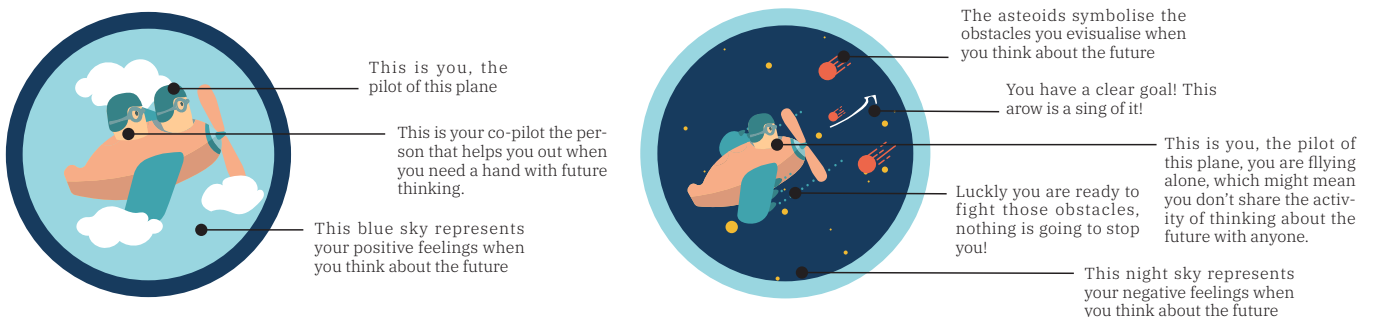


Figure 32 | The first design iteration of the badges and the meaning of each represented element

RESEARCH QUESTIONS

Comprehension

- *Are the new graphic representations of the visualization understandable?*

Value

- *How does it feel to go through an animation flow with explanations of the meaning of each element?*
- *How do people feel when their emotions are being represented in the sky of the badge?*

Iteration 2

The second iteration of the badges consisted of changing some graphic elements taking into account the participants' feedback of the 1st iteration as well as including the graphic representations of the emotions (different weather conditions).

The first iteration illustrated that the participants couldn't create a link with all the graphic elements of the badge straight away, therefore, an explanation was required. The prototype of the new badge acquisition with explanations was done through Figma, a digital prototyping tool that allowed the addition of some dynamism and small interactions where the participants could press next and keep adding elements and learning each meaning at their own pace.

The participants were interviewed while and after experiencing the prototype.

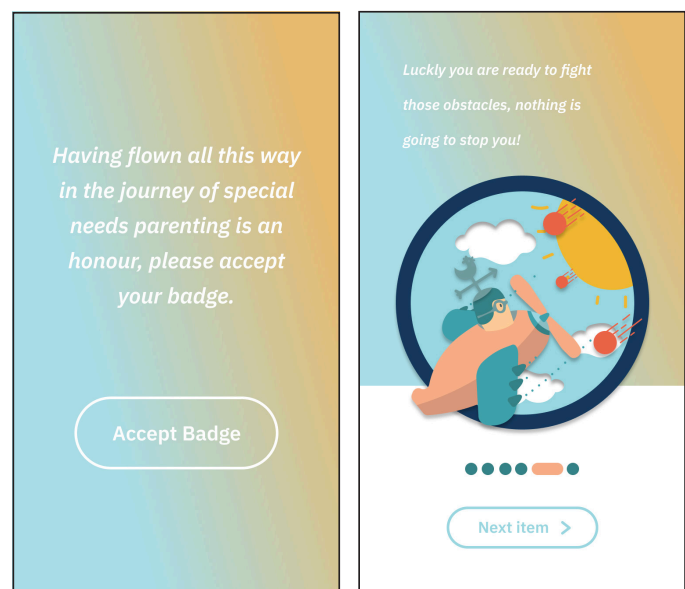


Figure 33 | Two screenshots of the digital prototype

RESEARCH QUESTIONS

Comprehension

- *Is the question understandable?*

Value

- *Is the question valid to prompt participants to generate inspiring content for other participants?*

4. POST AN INSPIRING STATEMENT



PARTICIPANTS

per iteration

- 2 CSN parents
- 4 non-CSN parents

MATERIAL

- Questionnaire



1 Now imagine yourself of the future would travel to the present and would ask you: "What do I need to remember to keep working for a positive future"? Please type your advice

Iteration 1

This test iteration consisted of providing the user with a question that would put the participant into the perspective of what is important to remember or to take into account when thinking about the future.

The question was added at the end of the prototype of the questionnaire (second part of the designed tool) to test if it was a valid question to generate inspiring content.



You just visualised a metaphor where you were the pilot of your plane, the plane that moves towards the future. As a pilot of such a plane, what do you think is the main skill you need to think more positively about the future?

Iteration 2

The first iteration of the question to generate inspiring content for other participants didn't generate positive results, most of the participants didn't understand it correctly. Consequently, this second iteration consisted of making the question easier to understand and more importantly, to connect it with the metaphor of the guided visualization.

RESEARCH QUESTIONS

Comprehension

- Is the question understandable?*

Value

- Is the second iteration-question a good trigger to generate an inspiring statement for other participants?*

RESEARCH QUESTIONS

Comprehension

○ *Are the new graphic representations of the visualization understandable?*

Value

- *How does it feel to go through an animation flow with explanations of the meaning of each element?*
- *How do people feel when their emotions are being represented in the sky of the badge?*

Iteration 3

The third iteration of the question to generate inspiring content was based on the second iteration outcome.

In the second iteration, the participants understood successfully the question, however, most of them responded in a very direct way and providing with a list of qualities to take into account when thinking about the future, which was not considered inspiring, since there wasn't any component of storytelling.

Interviewing the participants after the second iteration also gave enough feedback to state a hypothesis which stated the next: "providing with a clear explanation of the aim of the question, which is inspiring others, will motivate the users to create more inspiring content", so as a result, the question presented below was ideated and tested in this third iteration.



You just visualised a metaphor where you were the pilot of your plane, the plane that moves towards the future. but did you know that there are other pilots out there in similar and different situations, other parents of children with special needs... Write a statement to let them know how you approach future thinking, your words can be inspiring for others, so don't be afraid to share your thoughts!

RESEARCH QUESTIONS

Comprehension

- Do the participants establish a relationship between the badges and the statements?

Value

- Does reading other parent's statements expand the participants' perspective?
- How does it feel to interact with many statements at the same time?

6. STATEMENTS EXPLORATION



PARTICIPANTS

- per iteration
- 1 CSN parent
 - 1 non-CSN parents

MATERIAL

- Different statements with their avatars prototype

Iteration 1

This test iteration consisted of testing the interaction of the user with different statements related to their respective badges. The quotes generated from the previous tests by CSN mums were included in the list as well as additional quotes extracted from CSN parents' statements acquired in the online desk research.



Figure 34 | prototype of the exploring statements tool's feature

RESEARCH QUESTIONS

Comprehension

- Are the elements represented in the profile understandable (evolution, experience of the mother and current statement)?

Value

- How does it feel to have a second layer of information that others can visit?
- How does it feel to interact with many statements at the same time?

7. SECOND LAYER OF INFORMATION (Profiles)



PARTICIPANTS

per iteration

- 1 CSN mum

- 1 non CSN mum

MATERIAL

- Figma prototype

Iteration 1

This second layer of interaction was tested through a very quick graphic representation of the profile and was included in the digital prototype developed with Figma as the last screen the participant would visit after reading the statements. The participant was asked to talk out-loud when going through the profile and was interviewed afterward.

The design of this part of the tool was presented as a conversation starter to see what would CSN parents find relevant in the second layer of interaction.

Because of CSN parents participants' availability limitations, this prototype was tested with just one single CSN mum, however, this part of the concept is considered something to be studied and defined in further stages of this project.

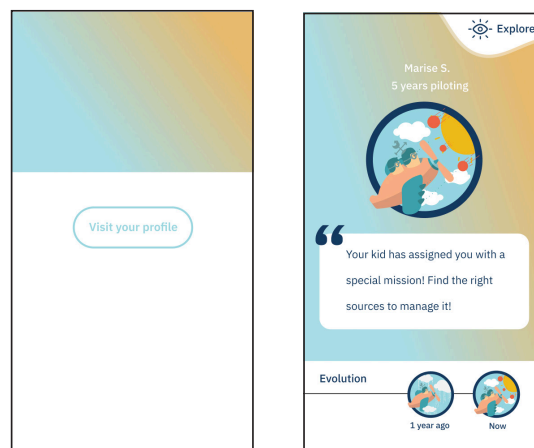


Figure 35 | prototype of second layer of interaction

6.3 IMPROVING FUTURE JOURNEYS

After analysing the feedback provided by the participants, several findings were taken into account to improve and define the final proposal to be further validated.

1. Guided visualisation



Giving very **clear guidance** during the visualisation exercise is important for the participants to understand the aim of the visualisation which is reflecting in a metaphorical way on their current perspective about future thinking.



Leaving enough time for the participants to reflect and imagine their journey is vital.



The **order of the feelings** (weather conditions) should be presented **from more specific** (fear and anxiety) to **more general** (happiness or peace) to avoid the participant to fall into the general and imprecise visualisation.

2. Questionnaire



The questionnaire has to **emphasise** on the importance of answering the questions **prioritising their reality over their visualisation**. This avoids inconsistencies between the auto-generated badge and their own perspective about future thinking.

3. Generate an inspiring statement



Short statements provide a glimpse of parents' variety of perspectives which generates curiosity and triggers them to visit the profiles to learn more in-depth about similar others.

4. Acquisition of badges



The **interactive storytelling** of the badge's presentation, is an engaging and fun way of providing them with an identity they feel related and proud of.

5. Statements exploration



The **contrast between badges help parents identify others** to learn from with relatable circumstances

6. Profiles



Providing **detailed stories of each element of the badge in the profiles** might be useful to **show parents that everyone is capable and resourceful to manage future thinking** in different and successful ways.



Adding a feature that allows parents to **react to others' badge stories** might **enhance parent's relatedness and sense of purpose**. The options to display (based on participant's feedback) could be: "I've been there", "I feel inspired" or "I love this story".

You are being attacked! This symbolizes the obstacles you visualize when you think about the future



7

This chapter presents the evaluation carried out to see the impact of future journeys on the users' wellbeing as well as their future engagement with the tool. The validation was based in SDT's three fundamental needs. To finalise,



FUTURE JOURNEYS' EVALUATION

7.1 THE EVALUATION PLAN

3 ASPECTS TO EVALUATE

This chapter focusses on the evaluation conducted to assess the following three different aspects:

- 1. The impact the tool has on CSN parents' wellbeing and their future engagement with the tool.** - This was done through interviews conducted after the participants experienced the tool. The questions were formulated taking into account the three fundamental needs presented in Self Determination Theory (autonomy, competence, and relatedness), which serve as a nutriment of individual wellbeing and foster an individual's motivation and engagement.
- 2. Whether the intended effect of Future Journeys tool was met or not and the reasons behind each finding.** - The desired effect of the tool focussed on the ability parents have to understand their perspective and share it with others, inspiring them, and expanding their capabilities to manage future thinking.
- 3. The usability and comprehension of the concept.** - The user test tried to recreate the experience to test the tool's flow of interactions in a phone Application and see if the tasks were completed successfully.

Since the concept is still in an initial stage, the evaluation aimed to understand how this project can be further improved to achieve its goal.

PROCEDURE

The final test to evaluate Future Journeys tool was designed to be conducted remotely and to adapt to the availability constraints this target group presents. It was very important to “dose” the number of tasks to not loose participants on the way since it was very easy for them to feel overwhelmed and skip the test or postpone it and eventually forget about it. This was done through the division of the concept into two parts:

1. The introspective/reflective part (To see the final script of the guided visualisation visit appendix K)
- 2: The social part

The first part was tested by sending the audio recording guided visualisation file together with the questionnaire (which asked about the different elements visualised referring to their relationship with future thinking). Once they completed the visualisation and the questionnaire, they were interviewed through email, WhatsApp, or Facebook messenger (depending on the participants' preference).

After completing the interview of the first part of the test, a customised digital prototype was designed for each participant to experience a flow of interactions that included the acquisition of their badge as well as the exploration through the different elements of the social part of the concept. (See appendix H to see the prototype structure and visit the link to experience the interaction).

The tasks the participants completed to validate the social part of the tool consisted of navigating through other parents' statements, profiles (the prototype provided them with a complete and validated profile with personal stories about each element of the badge of one of the CSN mums that participated in the study). In the last place, other social interactions were designed such as receiving a text message from another CSN mum that would comment about their statement and invite them to visit her profile).

After they freely experienced the digital prototype, they were sent the questions of the second interview together with a checklist of tasks they would have to get through before answering the questions. For a graphic representation of the process described, please see figure 36.

PARTICIPANTS

This evaluation required mothers and fathers of children with special needs. Eight participants were recruited, three dads, and five mums. Six of them never experienced before the tool of future Journeys, which brought a large number of non-biased perspectives to this study. Taking into account the past experience with testing with this target group, extra participants were recruited to compensate for delayed answers and dropouts.

DATA ANALYSIS

The participant's answers to both interviews were analysed through clustering the quotes in different topics that were relevant to each of the three fundamental needs, expansion of parents' capabilities and usability, and comprehension of the tool. This was useful to identify relevant data for each of the three aspects as well as to draw possible improvements for further development of the tool. (Appendix G).

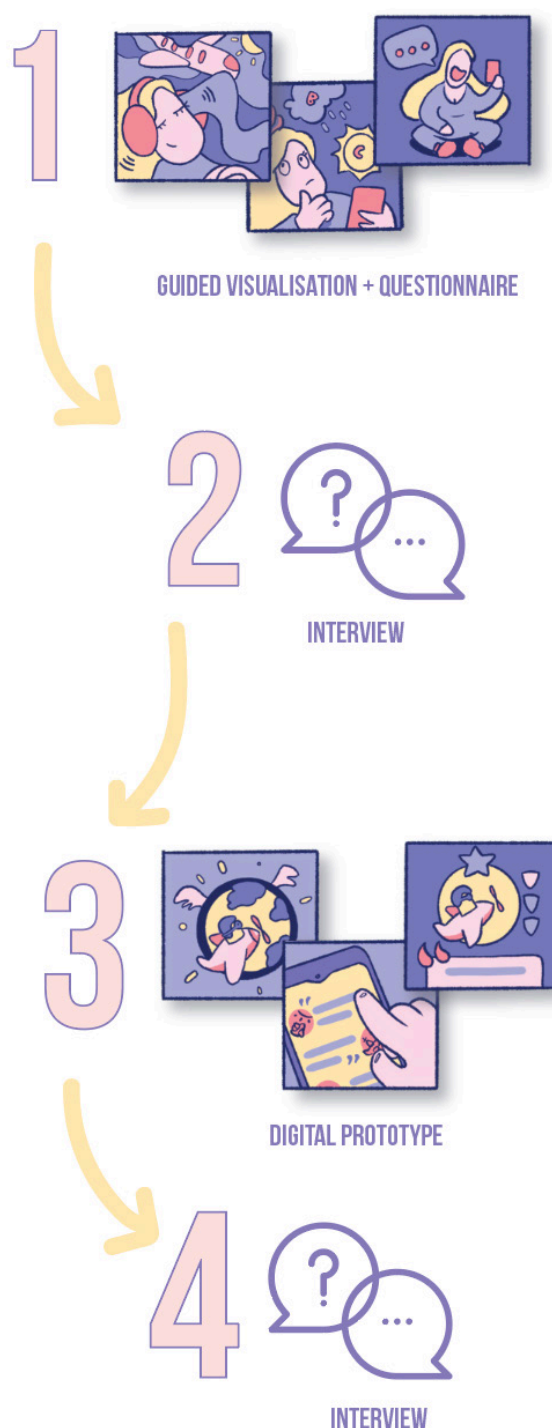


Figure 36 | Validation plan journey

7.2 TOOLS' IMPACT ON PARENTS' WELLBEING

RESEARCH QUESTIONS

Competence when reflecting & sharing a statement

- Does reflecting on one's experience of future thinking encourage a feeling of competence? If it does, how does it happen?
- Does helping other parents sharing one's experience encourage a feeling of competence? If it does, how does it happen?

COMPETENCE

The first four stages of the tool were tested in order to validate the enhancement of the need of competence and trying to understand how performing these tasks would enhance it, in other words, which were the "competence boosts". This was acquired through the interpretation of the different quotes obtained in the interviews and clustering them into categories. The main cluster categories referred to: Looking back at the past, the feeling of pride when people perform the act of helping others, and the feeling of competence parents experience when they realise they have a positive perspective towards the future comparing themselves with "less fortunate" parents.

The following cards show the different categories with a relevant quote. (To see the different clusters created in the analysis of this thesis' validation, please visit appendix X).

COMPETENCE BOOST



LOOKING BACK AT THE PAST LETS PARENTS APPRECIATE THEIR PROGRESS

☞
The metaphor made me think about the different perceptions I've had in the past of the future. I've got us so far, now my son has a fantastic special school place which was a big hurdle in itself. I feel like I can do anything now because I'm determined and confident.

COMPETENCE BOOST



WRITING AN INSPIRING STATEMENT MAKES PARENTS FEEL CONFIDENT AND PROUD THEY CAN HELP OTHERS THROUGH THEIR EXPERIENCE

☞
I feel like now I could help others so much... I literally could write a book of do's and don'ts based on my experiences.

COMPETENCE BOOST



CSN PARENTS FEEL COMPETENT WHEN THEY REALISE THEY HAVE A POSITIVE PERSPECTIVE TOWARDS THE FUTURE COMPARING THEMSELVES WITH "LESS FORTUNATE" PARENTS

☞
I am grateful that I'm in the position to be able to write something positive. I know a lot of parents of a child with "extras" don't have the energy to think positive thoughts.

RELATEDNESS (1st layer of information)

The feeling of relatedness was evaluated in all social interactions since there was a potential for it to be enhanced.

This page presents how the feeling of relatedness was fostered in the first layer of information (navigation through the statements in the social board).

The main “relatedness boosts” identified were: Seeing other’s statements and what they want to achieve, finding parents with similar journeys, and the curiosity the statements generate.

RESEARCH QUESTIONS

Relatedness when exploring others’ statements in the social board (1st layer of information)

- Does reading other parents’ statements encourage a feeling of relatedness? If it does, how does it happen?

RELATEDNESS BOOST

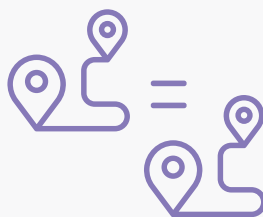


THE INSIGHTS GAINED THROUGH REFLECTION HELPED PARTICIPANTS FEEL EMPOWERED TO OVERCOME FUTURE CHALLENGES



Seeing others’ content leads one to appreciate what they’re going through & in part how they approach their own future. Looking up at the stars with someone can be much more thought provoking, than looking up at them on your own

RELATEDNESS BOOST



PARENTS FEEL MORE CAPABLE / AUTONOMOUS OF THINKING ABOUT SUCH A DIFFICULT TOPIC IF THEY ARE PROVIDED WITH A STRUCTURE



I felt like I wasn’t alone anymore and that others are on similar journeys so it somehow felt less daunting

RELATEDNESS BOOST



OTHER PARENTS’ EXPERIENCES AND ACHIEVEMENTS INSPIRE PARENTS TO TAKE ACTION AND SET NEW FUTURE GOALS



Scanning through people’s statements ultimately leads one to check out their profiles, as interesting/informative write ups leaves you wanting more...

RESEARCH QUESTIONS

Relatedness when reflecting & sharing a statement

○ Does learning about other's circumstances create a feeling of relatedness? If it does, how does it happen?

Relatedness over social interaction

○ How can the social part of the tool improve to better enhance a feeling of relatedness?

RELATEDNESS (2nd layer of information)

The feeling of relatedness was also tested in the second layer of information, which consisted of the exploration of profiles of the different parents and the navigation through the stories of each part of the badge (goals, strategy, feelings, support, and obstacles).

The main findings of this part of the study were that seeing other parents eager to give advice or the personal feeling of competence to give it increased the feelings of togetherness.

RELATEDNESS (overall social interaction)

Regarding the overall social aspect of this tool, some participants expressed it was important for them to perceive the people and statements were real and sincere. This will be further discussed in the "Further recommendations" section. Besides, two participants also mentioned their interest in meeting other parents in person and having group discussions about common topics of interest.

RELATEDNESS BOOST



SEEING PARENTS EAGERED TO GIVE ADVICE OR FEELING THE COMPETENCE TO GIVE IT, GIVES A FEELING OF TOGETHERNESS



Knowing that there are people going through similar situations, who are prepared to offer advice, or even just listen & help one another out shows that we are not alone in this.

RELATEDNESS BOOST



CSN PARENTS FIND IMPORTANT THAT THE SOCIAL PART OF THE TOOL LOOKS REAL AND SINCERE



Looks like everybody wants to make a positive statement. I think in reality you can't feel that yourself because you are too tired etc... I know a lot of parents are in very difficult situations. So the statements have to feel real and sincere.

RELATEDNESS BOOST



CSN PARENTS FIND VALUABLE PHYSICAL MEETINGS WITH OTHER CSN PARENTS



It would be nice if I could see them at a meeting/training!

AUTONOMY

The need for autonomy was studied after the participants experienced the whole tool of Future Journeys.

This part of the validation took as a starting point the next hypothesis: Increasing parents' knowledge on valuable ways of managing future thinking may result in them feeling more autonomous to choose between an increased amount of perspectives and therefore, expand their capabilities to think about the future.

The main categories of "autonomy boosts" can be found in the following cards.

RESEARCH QUESTIONS

Relatedness when exploring others' statements in the social board (1st layer of information)

- *Does an increased knowledge of available strategies create a feeling of autonomy?*

AUTONOMY BOOST



THE INSIGHTS GAINED THROUGH REFLECTION HELPED PARTICIPANTS FEEL EMPOWERED TO OVERCOME FUTURE CHALLENGES



It is good to realise that more obstacles will occur on my path and that I will also conquer them.

AUTONOMY BOOST

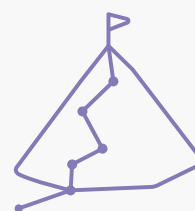


PARENTS FEEL MORE CAPABLE / AUTONOMOUS OF THINKING ABOUT SUCH A DIFFICULT TOPIC IF THEY ARE PROVIDED WITH A STRUCTURE



It helped me open my mind to approach other ways of thinking! It gives a structure for planning towards the future. Small, medium and long term goals. And the metaphor of the plane works to think of it more structured.

AUTONOMY BOOST



OTHER PARENTS' EXPERIENCES AND ACHIEVEMENTS INSPIRE PARENTS TO TAKE ACTION AND SET NEW FUTURE GOALS



The most valuable things I've learned through this tool and that I'll try to apply are: Planning towards the future, and giving some structure in it. And the concrete 'things' that Marly already did (regarding future housing, what to do when you die).

7.3 ENHANCING PARENTS CAPABILITIES

This section of the report aims to look closely at how parents expand their capabilities through the tool of Future Journeys. To do that, it is important to start from the beginning of the tool, from the introspective and reflective interactions, in which the main goal was to help parents acknowledge and define their perspective on the topic of future thinking. The following pink box shows the trigger identified that proved to help in achieving this goal.

NEW & STRUCTURED WAY OF THINKING

“I think about the future normally but I do it very ‘real’, not in a metaphor. And that helped me to look at it in a different way, and gave new insights. I guess it helped me to think of it in a new and structured way.”

CSN dad 1

The second aim of Future Journeys is to encourage parents to share their way of thinking about the future. In this way, the resourceful acts of every single parent will become known by the rest of the community who, if gifted with comparable interpersonal skills and circumstances will automatically experience the expansion of their capability set.

The pink box presented at the right shows the different triggers that allowed the design to achieve the previously stated goal. There is a close relation between how the tool tackles the need for autonomy and how it expands parent’s capabilities. Both are enhanced by increasing parents’ knowledge of valuable ways of managing future thinking.

NEW & RELATABLE PERSPECTIVES HELP CSN PARENTS ADOPT NEW PERSPECTIVES

“The statement that most inspired me was that one that talked about the future from that mum with a hopeful perspective. This way of thinking resonated so much with me, it was almost philosophical.”

CSN mum 2

“Sarah’s. It’s the most balanced response & is the closest to how I feel. It shows that whatever situation she may be in, it’s not the end of the world & if things do get a little tough along the way & beyond her control, she’s prepared to seek help.”

CSN dad 3

THOUGHT PROVOKING STATEMENTS IN RELATION WITH THE USERS BADGES PROVIDES PARENTS WITH NEW AND VALUABLE THINKING PATTERNS

“Using the App has drawn attention to & made me think about things more. I guess seeing profiles & statements from other people, as well as even just looking at the design of their badges, leads one to expand one’s thought processes”

CSN dad 2

7.4 USABILITY & COMPREHENSION OF THE TOOL

The usability and comprehension validation of Future journeys was studied in two parts, first through the questionnaire sent together with the visualisation recording (to check any inconsistencies or pitfalls) and secondly, a checklist of task performance that was sent after the participants freely experienced the prototype. They were asked to report any task of the list that they didn't perform previously as well as any confusing feature or interaction they experienced.

There weren't found any inconsistencies between the participants' visualisations and their real experience of thinking about the future. This might be because this aspect was already tackled and improved during the test iterations presented in the previous chapter of this report.

All participants reported having gone through all the tasks without any problem and they couldn't highlight any specific confusion. This part of the validation experienced some limitations since the designer couldn't observe the performance of the test but just ask the participants about their impressions.

7.5 LIMITATIONS & FURTHER RECOMMENDATIONS

BASED ON CSN PARENTS FEEDBACK

This section presents the different improvements the participants of this validation suggested when they perceived certain limitations. The following aspects and functions could be implemented for further development of the Future Journeys tool.

The main improvements mentioned referring to:

- **Adding more problem-related content and making the content feel real and not all positive.**

(See quotes CSN dad 2) This could be achieved by prompting the users specifically to share their struggles while thinking about the future. This could also encourage discussions and enrich the experience. Furthermore, real pictures of the users would make the tool feel more real and trustworthy, however, this would need to be further explored since it can rise certain privacy concerns and can distract and diminish the positive effect of the badges. See quote CSN mum 1.

- Two of the participants mentioned they value **personal meetings**. The tool could also provide the community with features to plan physical meetings and to facilitate those meetings for example sorting out participants by interests, situation, experience, or emotions they experience when thinking about the future. (See quote from CSN dad 1).

- The participants also brought to the table **privacy concerns** as well as contrasting opinions from other parents that can result in **criticism or harmful reactions**. Adding privacy controls or some sort of moderation could be a direction to tackle this concern. (See quote CSN mum 3)

☞ *Knowing people have the same problems helps a lot. I would like to find more problem related statements, it would feel more real and help me feel more connected to others*

CSN dad 2

☞ *Looks like everybody wants to make a positive statement but it does not have to be what I call a "instagram" statement. In reality you can't feel that yourself because you are too tired etc... I know a lot of parents are in very difficult situations. So the statements have to feel real and sincere.*

CSN dad 2

☞ *Photos of the other parents and children could be a good feature. Like a gallery where we can post achievements maybe? I think knowing we are all going through it together and when you see photos of other families it makes it more real and you know who you are talking to*

CSN mum 1

☞ *If the topic of the conversation is very personal, I would prefer real life contact, otherwise, digital contact (via an app) is fine!*

CSN dad 1

☞ *Privacy settings so you stay in control are important to me. Sometimes people can give "strange" reactions on social media and as a parent you want to get support and for example no criticism.*

CSN mum 3

VALIDATION OF THE CONCEPT'S IMPACT IN THE LONG TERM

Due to the time constraints of this project, it was only possible to evaluate on a short term basis Future Journeys' impact on CSN parents' well-being and their future engagement with the tool. However, for the validation of these two aspects, especially for the validation of how the concept enhances the need of autonomy, would be recommended to conduct a long-term study. It's important to pay special attention to the need of autonomy since the fulfillment of this one implies the fulfillment of the need of competence (first interactions with the tool) as well as the relatedness one (social part of the tool). The need of autonomy is also interesting to look at since its fulfillment also would mean the achievement of the goal of this tool, expanding parents' capabilities to think about the future.

Another interesting aspect to study on a long term basis is the questions to prompt inspiring statements, which would need to be altered over time and well studied to keep expanding users' capability set as well as maintaining their motivation over time.

FURTHER DEVELOPMENT OF STORY TELLING ABOUT DIFFERENT ELEMENTS OF THE BADGE

Throughout the first test iterations, the participants requested a second layer of interaction where they could learn more about the rest of the parents. This was developed and validated. However, due to time constraints, it was only possible to test the effect of looking at other's profiles and stories instead of having the users to complete their own profile. The stories shared of one of the experienced mothers proved to be useful, inspiring, and relatable to the rest of the participants. Due to these parents' lack of time some difficulties are predicted regarding the completion of this stories, therefore, further study is necessary.

A possible design direction to consider might be the exploration of slow storytelling, for instance, the App could prompt the user through notifications on different days. It could also recommend to read specific content of interest regarding one part of another parent's badge and ask to fill in the respective personal story after reading and getting inspired on the other parent's story.

HOW TO MOTIVATE EXPERIENCED PARENTS TO SHARE CONTENT

During the development of the Future Journeys concept, an assumption was made: “CSN experienced parents might be interested in helping non-experienced parents by sharing content” This assumption was based on some of the qualitative information collected during the research of this project, (for instance two mums explicitly said they would love to contribute to other parent’s guidance and inspiration) however, this would need to be further studied since the time constraints this parents experience could compromise the use of the tool. This study could be combined with the previously possible design direction of introducing slow storytelling into the concept.

WHO IS GOING TO BE THE MAIN USER OF FUTUR JOURNEYS?

The fathers of children with special needs that participated in this study showed more availability than the mothers, they answered in shorter periods of time and presented fewer drop-offs, in fact, any of the parents dropped the study, while three of the mothers were not able to continue participating.

An assumption to reason this fact could be that the fathers dispose of more free time than the mothers. This is an interesting observation and aspect to reflect about when developing further Future Journeys tool since it’s possible that the fathers are therefore more available to actively participate in the online discussions than the

mothers. It’s also interesting to reflect on how the fathers could acquaint the mothers of the value of the tool based on their first-hand experience.

REMOTE RESEARCH LIMITATIONS & ADVANTAGES

Performing remote research brought many advantages to this research, it allowed reaching a more culturally varied sample of participants. Using WhatsApp, Facebook and email allowed the study to adapt to the participants’ availability and time constraints and resulted comfortable for them. However, the remote setting also brought some limitations. Since most of the participants were not available for phone calls, the communication happened via text messages which might have affected the conversation in a way that the participants didn’t share everything they would have shared in a face to face conversation. The unavailability to not be able to meet the participants physically also affected the final validation of the concept since it was not possible to observe the participants’ performance while using Future Journeys prototype, this especially affected the insights regarding the usability of the social part of the tool.

7.6 FURTHER STEPS

Ontzorghuis is already planning a first attempt of applying the Future Journeys tool in the field. They are organising a retreat weekend for families with children with special needs where different workshop sessions will be organised for the families to share their ideas and resources and enrich their knowledge (See figure below for more information). Future journeys tool will be transformed into a workshop. This is a great opportunity to continue testing the idea to develop it further and finally see how it performs in a live setting.

Two crowdfunding campaigns will be launched

soon to collect funding for the retreat weekend and for Future Journeys further development and implementation. The showcase video of this project will be part of the material presented in these campaigns.

In addition, the project has been selected to be presented in Falling Walls Lab Delft Online Conference. The pitch that presents Future Journeys can be found on the following page.

Furthermore, this thesis will serve as background knowledge for future projects that are being developed in collaboration with The Ontzorghuis.



Deelnemers gezocht voor RETRAITEWEEKEND van 6-9 november 2020 voor MANTELOUDERS en hun KINDEREN

Ontzorghuis organiseert een eerste retraiteweekend voor 6 zorggezinnen. Het is een testweekend omdat we inzicht willen krijgen wat mantelouders tijdens een retraiteweekend nodig hebben om ontzorgd worden. Tijdens het weekend willen we een aantal sessies houden waarin we focussen op hoe je jezelf en je gezin kunt ontzorgen voor nu en in de toekomst. Daarnaast worden er ook een aantal ontspanningsmomenten zoals bv yoga of massages ingepland. Er is zorg aanwezig voor de kinderen zodat je mee kunt doen aan een sessie of ontspanningsmoment. Er is ook de mogelijkheid om je eigen zorgverleners meenemen. Het programma zal ontwikkeld worden op basis van de input van de deelnemende gezinnen.

Waar: Ronald McDonald vakantiehuis Kindervalei in Valkenburg

Wie: Voor zorgintensieve gezinnen (gezinnen met 1 of meerdere kinderen (tussen 0-18 jaar) met bovengebruikelijke zorg zoals een lichamelijke en/of verstandelijke beperking, chronische/progressieve ziekte en/of binnen het ASS.

Kosten: €105,00 voor huur appartement en €37,50 schoonmaakkosten

En: We vragen je twee keer om je mening. Een keer voor het weekend en een keer na het weekend. Dit zal ongeveer een uur duren.

Wil je er bij zijn? Stuur een mailtje naar info@ontzorghuis.nl

Wanneer er meer aanmeldingen dan plekken zijn, dan kunnen we je op de wachtlijst plaatsen voor een volgend weekend.



Figure 37 | retreat advertisement posted in social media to promote the event

PITCH TO PRESENT FUTURE JOURNEYS

My name is Maira and what sparks my inspiration is the very idealistic aim of making of this world a better one. I still believe that everyone has that power, if not to change it to at least contribute to a better future of society.

That's one of the reasons why I started working on this project...

I realised we have a lot to learn from parents of children with special needs. I'll tell you why... Humankind always learns from tough and extreme situations. When these people became parents of a child with special needs, found themselves in a situation where their world changed completely, where their expectations were not met and their dreams of how life should be were broken, where they had to re-invent themselves and their dreams to survive, adapt and thrive. An easy way to understand this mechanism is to go a few months back in time when the coronavirus situation started. Our world was upside down, everything stopped, we faced the uncertainty of not knowing what would happen in the future, some people lost their jobs, the world entered into an economic crisis, and even into an existential one.

The only difference between these two stories is that now our society is recovering and learning new ways of managing the situation but for many of these parents, the situation stays the same. Having a life long dependent child creates a huge unknown they will have to face the rest of their lives. Many of these parents can end up in very arduous situations, but fortunately, there are other ways of framing life. When the stipulated or

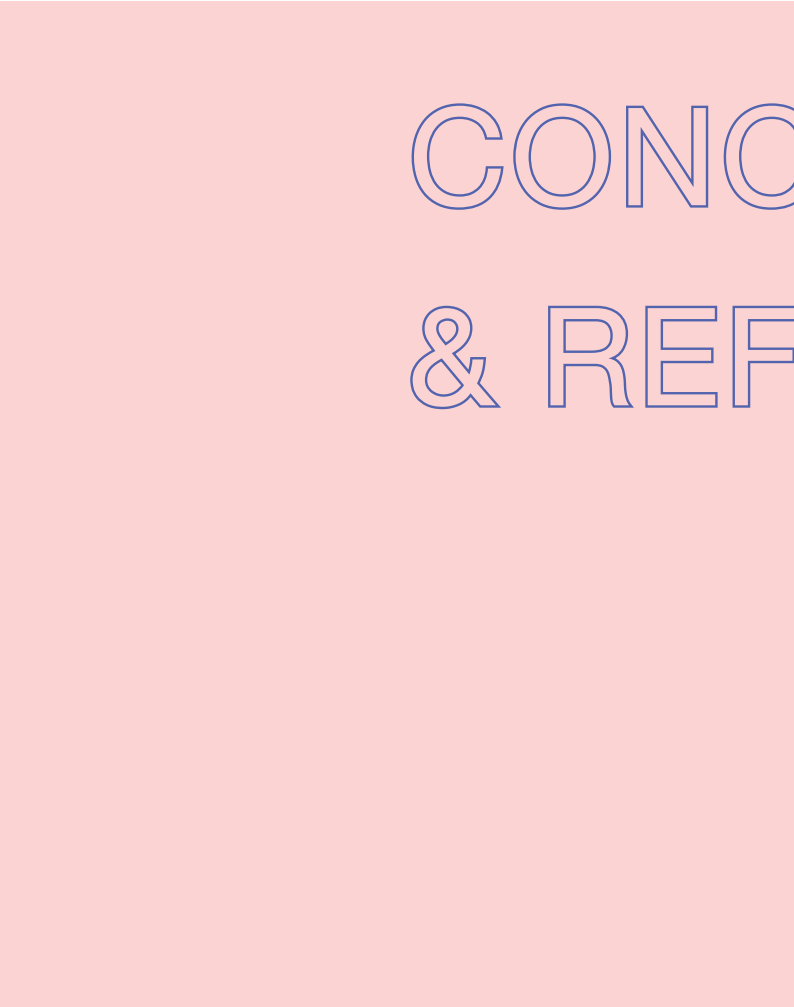
formally agreed way of approaching life doesn't work anymore, some of these parents find alternative and creative ways of managing things differently in order to adapt and live a fruitful life. You might be wondering... How can someone revert such a bad situation?

This is what future journeys, the tool I'm presenting aims for. This concept is a circular and tailor-made phone application that will allow these parents to first reflect and understand what's their strategy, what's their relationship with the big unknown future in order to afterward share it with the rest of the parents' community, that way, the whole community can benefit from a system of sharing and getting inspired by others' resourceful ideas, strategies and perspectives to all together fight the difficult challenge of thinking about the future while having a life long dependent child.

However my ambitions don't stop here, this solution is a scalable solution that can potentially help society re-invent in itself. So now I leave here some open questions for you to think about the potential of this circular social system where people share their resourcefulness to expand the capabilities of their community: How can society learn from this resourcefulness mechanisms? Would this be applicable to create a more inclusive world where small and currently marginal communities become equally understood and cared of?

Thank you.

8



CONCLUSION & REFLECTION

8.1 CONCLUSION

CSN parents use traditional Social Media applications such as Facebook or YouTube for both guiding and finding support from the CSN parents' community. While these platforms are helpful for many, they don't have an inherent purpose that addresses the needs of sensitive communities. Its open and generic design makes users fully responsible for the content displayed on them, instead of facilitating a more structured and guided conversation. The lack of tailor made solutions for CSN parents brought the opportunity to start this project, exploring the potential of a targeted digital tool to enhance the wellbeing of a sensitive and often forgotten community.

To explore the solution space for such tool, the project draws from the Capability approach, a psychological framework that inspired and focused the research on understanding what are the common opportunities and obstacles for CSN parents to achieve a quality life. Six differentiating aspects compose the shared experience of CSN parents: Overload of responsibilities, uncertainty towards the future, isolation, the importance of celebrating achievements, the need for reframing life, and the personal growth that all these aspects imply.

Beyond their common circumstances, the research also provided insight into the personal stories of the interviewed participants, showcasing an array of different perspectives and coping strategies. The concept of Resourcefulness is used to refer to their unique and valuable ways of functioning since all parents had to creatively adapt to a new life for which they were not prepared. To gather such sensitive and personal

information it was necessary to establish conversation and trust with extremely busy parents distributed around several European countries. In this regard, a metaphorical visualisation exercise proved to be a successful communication vehicle and promised interesting outcomes for remote qualitative user research with sensitive communities that have little spare time.

Integrating the concept of resourcefulness within the Capability Approach opened the design space to enhance the wellbeing of a target group with very limited capabilities. The idea this Thesis purports is that the creative strategies of managing life that different parents come up with can expand the capabilities of the whole CSN parents' community if those strategies are shared in a structured way and recognised by the people who are able to apply them.

While sharing perspectives is already an effective mechanism to encourage support and relatedness on other social media applications, the tool born from this graduation project, "Future Journeys" provides a distinctive approach that can be summarised in the following aspects:

Future thinking as the overarching theme:

The research of this project showcased the struggles CSN parents' experience while thinking about the future, and how their capability to do so is a decisive factor in their wellbeing. Therefore the focus of the proposed tool is to leverage the resourceful thinking patterns of successful parents to expand the perspectives of the community in regards to future thinking.

Self-reflection, through the use of metaphorical

visualisation: The tool encourages a process of self-discovery and analysis which helps to provide valuable insight for the user to be able to share it with others. The metaphorical elements give a structure to the thinking process and ground the conversation around relevant aspects of future thinking. Thanks to these visual elements parents can discuss and share perspectives about very abstract topics such as long or short term goals, strategies, obstacles, support, and feelings when thinking about the future.

Acknowledging different circumstances

within the CSN parents' community: The research conducted illustrated how each individual approached CSN parenting from different perspectives depending on their circumstances and interpersonal differences. Therefore, Future Journeys promotes the identification of relatable profiles to enhance the adaption of new, accessible, and valuable perspectives.

To conclude this project, an evaluation was conducted. The study focussed on Future Journeys' impact on CSN parents' wellbeing and their future engagement with the tool. Self Determination Theory was used as a theoretical framework to see how the three fundamental needs (competence, relatedness, and autonomy) were enhanced in the different parts of the flow of interaction and how specifically the need of autonomy connected with these parents' expansion of capabilities to think about the future.

8.2

PERSONAL REFLECTION

I see this project as an airplane journey... A journey I took with a clear mission to help parents of children with special needs improve their wellbeing, the airplane had very little controls but a lot of interesting and creative tools around that I was going to have to use in the specific moments of the flight that required it. I flew without a map, just trusting my power of intuition and adaptation through experimentation.

However, intuition and skills were sometimes not enough, the airplane flew through very foggy skies where I found myself with no power to find a direction to fulfill my very idealistic aim. But luckily I managed to set the plane back into sunshiny skies with very nice air strims that drove me back into the right specific path.

Now I look back to this journey and I realise how beautiful it has been and how much I have learned along the way. Thanks to the crew I had in part next to me and in part talking to me remotely. If I learned something in previous journeys, is that when you are traveling you should let yourself go with the flow, accept things as they come (sometimes you can't control everything), and get surprised, that way you will make the best out of it! That's exactly what I did with the current situation we are living, I tried to make the best out of the pandemic, a part of empathising with CSN parents and understanding what does it mean to be isolated from the rest of the world, I learned to use new remote research tools and invented new techniques that kept surprising me until the end. I'm very excited because this journey keeps going, we just achieved one small milestone! We improved the airplane controls and now we are ready to conquer the

next destiny, bringing Future Journeys tool to real together with The Ontzorghuis.

My greatest take away from this project is how I applied the concept of resourcefulness in different levels, not just to develop a solution but also in the way I researched using the powers of metaphorical thinking to unveil latent knowledge from these parents. It was very important for me to design a research that everyone could enjoy and that would facilitate the conversation between myself and these parents, who were part of a sensitive group of society and didn't dispose of much time to invest in boring research assignments. I also wanted them to take something out of the activities they were performing. This tool helped me get very close to them and the results kept surprising me until the extent that a tool that was designed to be used in the research of this project became an iteration of the final solution. Thanks to these interactions with the participants I managed to get a very close relationship with them, most of them started being strangers and ended up sharing stories that you would just tell your best friend.

This project also taught me to be specific framing a solution. As Pieter said, it's better to make a concept that these parents experience and say: "Hey! This has been designed for me" than a nice concept that can be used by many people but it stays generic and without a clear point.

I love reflecting and that might be one of the reasons why I ended up designing a reflection tool. I could keep reflecting on the great learnings this project has brought me, however, now its time to look forward, take the control of the plane and drive full of energy to the next destination!

9

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