Shifting perspectives

Applying systemic design to strategise long-term impact for parents of children with special needs

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Summary

This graduation project was in cooperation with Ontzorghuis, a Dutch charity that is focused on supporting the parents of children with special needs (CSN). It is crucial that CSN parents receive extra support, especially in the early stages when the child's diagnosis is still unclear. Parents of a CSN have extra responsibilities and care, which can easily overwhelm them and lead to burnout. In fact, 78% of CSN parents started working less after getting their child, and 60% ended up overworked and burned out (Okma, Naads, Vergeer & Berns, 2014). Their extra care can also lead to an escalation: if the parents' wellbeing is declined too much, the CSN has to be placed out of home. However, currently the Dutch care system is focused and structured around the child with special needs, not on the parents. Parents of special needs children are currently not seen as informal carers, giving them no right to extra support (Ross, 2020). This leaves the parents in a vulnerable position. The goal of this project is to use systemic design to develop a strategy for Ontzorghuis, to have a long-term impact on these parents.

After researching the context, several key actors in the system around CSN parents were identified: the national government, municipal councils, the care domain, charities and network. Ontzorghuis is part of the charity actor. For each of the actors, one or more interviews were conducted with someone working in this domain, 12 in total. The insights of the interviews were combined with those from literature research, to analyse the interactions between the actors. This forms the basis of the system map. The map consists of 25 points, representing the challenges actors have to face together, see figure 1 below.

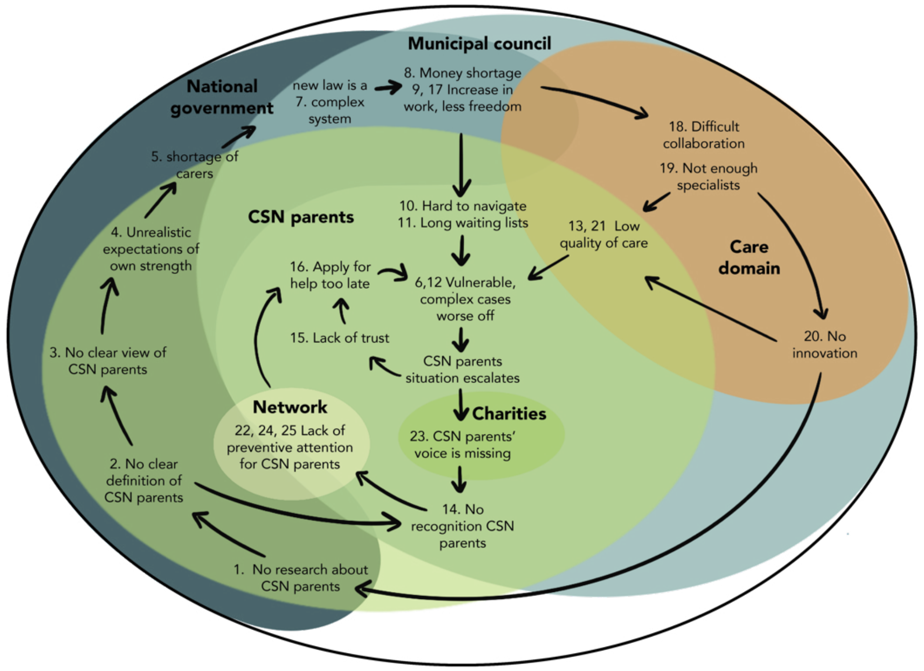


Fig 1: System map around CSN parents

This system map was then used to investigate the possibilities for systemic impact for CSN parents. Leverage points were identified, and used to map out future interventions. The insights were converted into an actionable strategy for Ontzorghuis.

The first step of the strategy is to make CSN parents visible within society. The graduation design therefore had the goal of helping actors reflect on their role in the system around CSN parents. Storytelling was chosen as the mechanism to convey the system, as "storytelling allows for thorough understanding of complex systems with limited time investment and without requiring expertise on systems design" (Talgorn & Hendriks, 2021, p. 50). Using storytelling also allowed room for the empathy needed for this vulnerable but inspiring target group. The end result is a children's book for any actors of the system, using a metaphor to tell the story of a CSN parent interacting with the system, and inviting readers to reflect.

Content

Reading guide

Chapter 1: Introduction
The first chapter starts off by introducing the charity I cooperated with: Ontzorghuis. I explain the project brief and the context of the project, and why there is currently a problem for CSN parents. Throughout this report I go deeper into this analysis, so the context is just a summary, to give an overview.

Chapter 2: Approach and Method
The second chapter is an explanation of my approach to the problem, and explaining some terms. Then follows an introduction to systemic design. Systemic design is inherently complex, so understanding the steps will help the reader understand the coming chapters. The methodology of my research briefly explains the combination of literature and interviews as sources for the system map.

Chapter 3: Introduction of the actors
In this chapter, the different actors around CSN parents are introduced. These are all the people surrounding CSN parents that have influence on the system. They are introduced and their role is explained, as well as their needs, drive and experiences. I also explain who I interviewed in more depth, and how they represent the different actors. Having a good understanding of the actors is necessary before reading the next chapter.

Chapter 4: Relations between actors
This chapter is by far the most complex. The relations between the different actors are explored, and what challenges they face together. Since it is based on many actors, there is a lot of detail and information in this chapter. The system map and sequence of 25 points between actors can help guide you through the explanations, and keep sight of that bigger picture. Each point explains the comparison of how the system was intended to be used, versus the reality. Since it is not a linear system, there is some overlap. For each actor pair, the relevant part of the system map is shown, which is added together at the end to form the whole system map.

Chapter 5: Strategy
Chapter 5 starts by analysing the system map, and drawing out the leverage points. This is part of the systemic design process. These points are then translated to a strategy for Ontzorghuis, which is explained in steps.

Chapter 6: Design statement
It is then explained how I translated the first step of the strategy into my design statement. First the mechanism of storytelling is explored in relation to systemic design. The choices are translated to a design requirements, user scenario and target group.

Chapter 7: Final design
This chapter I explain the concept and process of designing my final design. It starts off by explaining the metaphor. Then I show iterating of concepts, of which I choose one. The concept itself is explained, and the iterations towards the final design. It ends with an explanation how the final design, a children's book, fits the initial project brief and design statement.

Chapter 8: Evaluation
This chapter is a summary of feedback interviews I did on my final design, and its take-aways.

Chapter 9: Conclusion
This includes the discussion and recommendations for Ontzorghuis, and my personal reflection.

Project Introduction

1. Project introduction

Introduction of Ontzorghuis

This project is for Ontzorghuis, a charity initiative by Marise Schot. It is located in the Netherlands, and strives to support families who give informal care to their special needs child. Ontzorghuis is currently trying to gain the status of a foundation, and is in the start-up phase. Marise has gathered a team of experts to further develop Ontzorghuis.

Context

Ontzorghuis currently strives to relieve the burdens of parents taking care of their special needs kid(s). A child who needs extra care, is fully dependent on receiving care from their parents. The parents need to reinvent their lives and balance their time, in order to be able to constantly provide care for their kid. Therefore, it is of utmost importance that the parents themselves are taken care of too, and consciously work on balancing their lives to relieve some of the extra stress that comes from intensively taking care of their kid.

Families that have a child that requires extra care, are carrying a large burden. Not only do they need to provide informal care for their child, but their whole context changes and this can put a lot of stress on the parents and family. The current healthcare system focuses only on taking care of the child, whilst the parents are left alone to deal with all the changes in their context.
These changes include shifts in the family context, but also dealing with stakeholders involved which differ per situation. Many CSNs need extra trips to health experts and hospitals. Another sector they deal with is the social sector. Many parents also apply for government aid which gives them a budget to spend on extra care. Furthermore, their social and professional connections often change, as they rearrange their time, to give their child more priority, leading to a shift in their personal life.

Since the introduction of the new youth law in 2015, there has been a shortage of money and high workload at municipalities and the care domain. This manifests itself in long waiting times for CSN parents due to insufficient staff, among other things. Due to a lack of time and money, there is no innovation and the situation for CSN parents has not improved. Due to the complexity of the laws, uncertainty arises between parties about the division of financial responsibilities. This means the most vulnerable and complex cases of CSN parents are sent from one party to the other and their situation escalates. Due to their stressful situation, CSN parents have no space and energy to make their voices heard in society. This means that this target group of approximately 500,000 people (Okma et al, 2014) suffers in silence and is the victim of the complexity of our care state. If the position of CSN parents were to be recognised, the government would have to readjust their expectations in terms of capacity and the amount of help CSN parents receive. Just making the target group visible could prevent budget cuts in this sector in particular. This would create room for innovation and improvement of the long-term situation of CSN parents. These improvements together can be traced back to one goal: the position and recognition of CSN parents in society. Let's all ask the question: Who takes care of the caretaker?

Role of Ontzorghuis

Ontzorghuis is trying to alleviate the stress and help parents deal with these changes. Their long-term vision is to get society to take into account the needs and workings of the whole family, not just the special needs child. The family around the child greatly impacts their learning progress, so it benefits everyone to take care of the whole family.

Ontzorghuis has initiated a care community, where several of these extra care families would live together. They would share their government budgets, and have 24/7 care available, allowing families to receive care at the moment they most need it. Furthermore, the social aspect is important in the care community, as they will not only interact as families, but also with their surrounding local community, by providing public amenities (pool, playground or a café). Currently, the team of experts is developing plans to realise these communities, and are running tests like weekends to learn about the families.

Apart from that, Ontzorghuis is striving to become a platform for Dutch society, to reach more families who are caring for special needs children. They currently have a website, Ontzorghuis.nl, and are developing several tools and products that can help lift the burden for parents and caregivers. For example, one tool that was just developed by a DFI graduate, is based on reflection, and sharing stories. The idea is that these products could be sold to or used in health care.

My project for Ontzorghuis

The issue I tackle in this project, is how to approach the greater systemic change Ontzorghuis is trying to achieve. They have a clear goal to support CSN parents, and to put the focus of society to include CSN parents, but don't have a long-term strategy. To create the most impact, I suggested researching with the focus on systemic design. Currently, there are plans for a physical house, and the charity is in the start-up phase, but there are no concrete plans on how to grow into a care community for more families than just those living in the physical Ontzorghouses. The opportunities and optional directions are unclear, and there is no concrete future plan, just a dream of systemic change. This means the charity is currently developing individual projects, and working on a lot of different fronts to move forward. Apart from realising the Ontzorghouses, it is uncertain what they strive to achieve in the next 5 years. This is where I come in, and use my master SPD and focus on systemic design for this project statement:

"I will research, frame and visualise the bigger context of Ontzorghuis, in order to determine their opportunities to achieve their long-term goal of systemic change. I will build on their future vision and design strategic interventions to achieve systemic change, and design it in such a way that it is actionable for Ontzorghuis."

My graduation project researches how to achieve systemic change for special needs families in the health care and governmental sectors. I zoom out, and look at the bigger picture and all the stakeholders involved, and put Ontzorghuis and its ideals into context. I also zoom in, and research the stakeholders, and current practices and trends in the sectors that are part of this context. By diving into the different perspectives of the stakeholders, I can frame the system and gain a deeper understanding of the relations between them. This results in the deliverable of an actual visual representation of the bigger picture - a systems map.

This system map will include relations, tensions and leverage points, which is used to reveal the opportunities for Ontzorghuis to grow. By defining the future direction, and diving into these leverage points, I explore the possibility space. This leads to an advised strategic intervention model, mapping out a path of small steps that achieves the intended systemic change. The steps are developed in such a way that Ontzorghuis can actively start pursuing them. The idea is that the strategy can be translated into several design concepts, to be done by Ontzorghuis or other graduate students. During this graduation, I did not explore all of these intervention points, but chose one in further detail for my final design. My original project brief can be found in Appendix A.

Approach & Method

2. Approach & Method

To start, I will explain the basic decisions and terms that are relevant for this project. Secondly, I will dive into how I followed the systemic design process and what research methodology was used.

Approach

What is a system

Firstly, let me introduce the idea of a system. In usual design processes, designers work with a target group that is researched to determine opportunities for a successful design. In systemic design, the designer does not limit themselves to one target group, but looks at all groups that surround a certain problem or situation. The system boundaries are defined by the systemic designer or design team, after they have researched the context. In this project, I looked at the people surrounding CSN parents, both on a personal as well as a professional level. It was important to take such a wide viewpoint, as support for CSN parents can come from many different people. The figure 2 below shows the system for CSN parents:

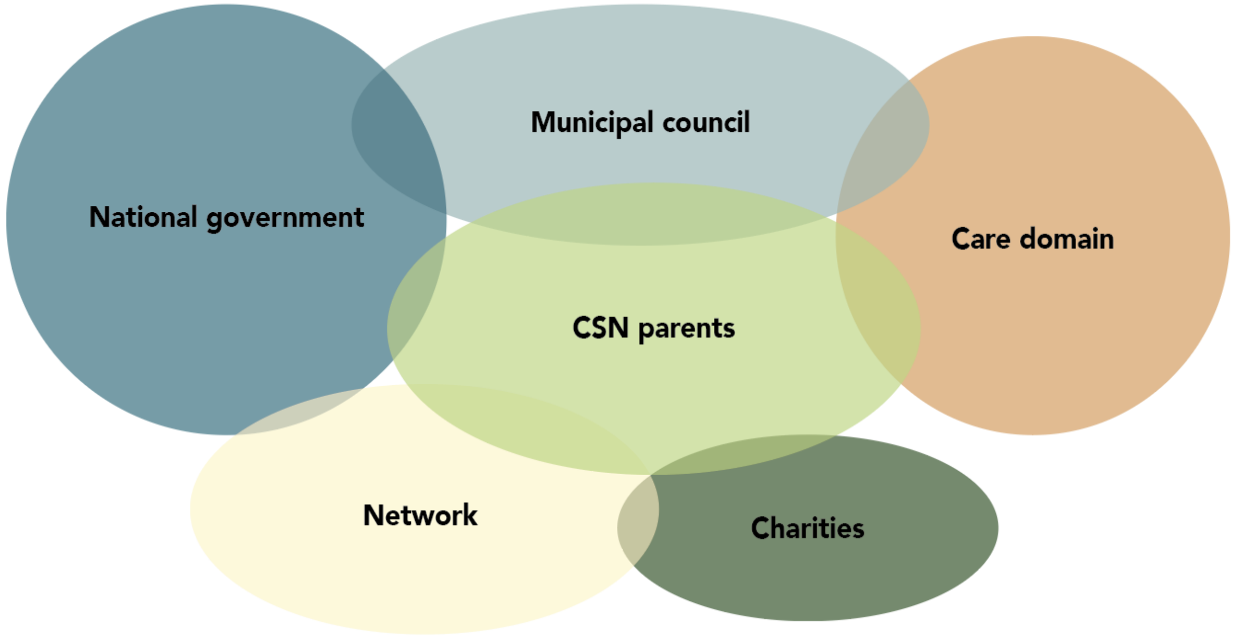


Figure 2: Actors in the system around CSN parents

What are actors

The people surrounding and interacting with CSN parents, or having influence on their situation, are all part of the system. These are divided into groups called actors. Dividing the actors is based on logical reasons, but is still subjective. The main reason for the division was to match the literature research, and the terms used there. The different actors are introduced in the next chapter.

Shifting perspectives

So, why is it important to understand the different perspectives of these actors? It seems more straightforward to just pick a target group and design for them. However, understanding the perspectives is crucial to understand the interaction between the different actors. To investigate the motives, reasoning and situation of the actors leads to understanding why the system is working the current way. So, for this project, I constantly shifted my perspective to a different lens of different actors. It allowed me to follow the problem, as it shifts from one actor to the next, and influences each other.

Important phrases

I already introduced some of these phrases but I will take some time to explain them to you carefully.

CSN parents: These are parents of Children of Special Needs, CSN for short. The more in depth introduction can be found in the next chapter.

Informal carers: Informal carers are any people that are taking care of someone close to them, voluntarily and without getting paid. There is always a relationship between them, so it could be family, a friend or a neighbour. Of course, in a relationship, it is normal for people to help each other out once in a while, but informal carers usually go beyond what is expected in their relationship. CSN parents fall under this category too, so they are part of the bigger group of informal carers. They give more care to their child, then parents usually do, this is explained further in the next chapter.

Jeugdwet: This just means youth law in Dutch. Its influence is explained further in the next chapters, but it is important to know its a nationwide law that makes national youth care the responsibility of municipal councils.

WLZ: stands for "Wet voor Langdurige Zorg", which is another national law that covers care for people with a handicap, as well as older people or people with mentally issues. It can be a source of budget for CSN parents, but the process can be quite complex.

CJG: In the Netherlands, when someone gets pregnant, they start visiting the "consultatiebureau". In short, it is a health care centre focused on children, where pregnant women and children are expected for routine checkups.

Respite care: Respite care is temporary institutional care for a person who needs care, providing relief for the informal caregiver. This has many forms, but for CSN parents, it is usually a fulltime care centre for their CSN, for a temporary time.

Systemic design

Since my goal is to design strategic interventions for a system, it is important to understand the process of systemic design. Systemic design first aims to gain a bigger picture of a certain situation or problem, and to fully understand it. This understanding may then lead to designing the possible solutions or desired future of this system. Namahn, a design Agency in Belgium, summarised the following steps to the process (Curatella, 2021):, see figure 3 below:

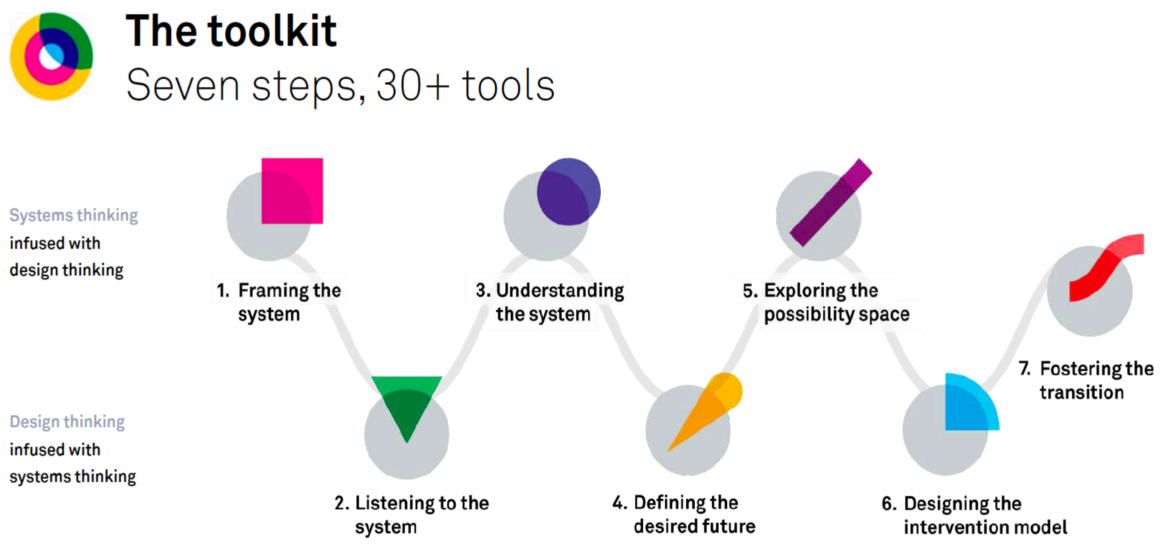


Figure 3: the systemic design process in 7 steps.

Here is a brief explanation of each step, and its place in my project.

1. **Framing the system:** First the system is framed by understanding the context, current practices and trends and by identifying stakeholders.
    1.1. *I framed the system by researching the system around CSN parents and interviewing many people active around them to understand their drive, needs and situation, and grouping them into actors.*
2. **Listening to the system:** Secondly, you listen to the system and analyse the interactions and relationships of stakeholders.
    2.1. *During the interviews, I often asked about the people they work together with, or people gave opinions about their situation. This allowed me to understand the relationships better.*
3. **Understanding the system:** it allows you to make a system map that visualises the structure and relationships, and use this to discover the leverage points.
    3.1. *To understand the mechanisms of the system, I made several iterations of a system map, and wrote down the relationships between actors. Visualising the system map helped identify leverage points.*
4. **Defining the desired future:** The next step is to define the desired future, and envision change and how it is made.
    4.1. *This step was done with focus on Ontzorghuis, they have a very clear vision of increasing support for CSN parents, which fits my system map.*
5. **Exploring the possibility space:** Focusing on this vision, you start exploring the possibility space and the options for intervention around the leverage points.
    5.1. *This step included a lot of brainstorming together with Ontzorghuis (Marise), and trying to grasp and formulate the core problem of the system.*
6. **Designing the intervention model:** Next you design the intervention model, this is a series of design concepts that are a strategy to make a systemic change together.
    6.1. *Understanding the core problem led to a strategy, and for my final design I started on the first design concept.*
7. **Fostering the transition:** means you make a roadmap to make sure the interventions can be done step by step, and keep pointing towards your desired future.
    7.1. *The strategy is formulated like a roadmap of steps, and the first step is the basis for my final design.*

The coming chapters show the results from steps 1-3, framing, listening to and understanding the system. It provides the reader with the insights of the complex system, including a system map to guide you. The system map shows 25 points, which are the challenges actors deal with together, and how they connect. They are explained in the chapter relations between actors. The rest of the systemic design steps are explored in the "strategy" chapter, which shows how the system map can be used to discover which points have the most leverage. These insights are then used to design for the future, and turn into an intervention model.

Method

Aim

In the chapter above, I explain the context of the research. The main problem is the current lack of support for CSN parents. I am using systemic design to dive into why the system is stagnant, and not supporting these parents, when the intention is to prevent any escalation. For the gathering of information, the first part of the project brief is the most important aim:

"I will research, frame and visualise the bigger context of Ontzorghuis, in order to determine their opportunities to achieve their long-term goal of systemic change."

Method

The method to research the bigger context, consists of two main parts: literature research and interviews. The first is literature research, sourcing documents and reports about CSN parents and the system around them. The main sources were charities and organisations informing about CSNs, informal carers or youth care, and governmental reports. There is very limited information available on CSNs specifically, so some parts of the report don't have a big diversity in sources. The information insights were gathered in Miro, which is a digital visual whiteboard tool that others can also look at. A lot of the information was visualised and clustered. It helped me to learn about the whole system, but also understand the different interactions between actors.

The second form of gathering information was personal interviews. It was still during covid, so I had less opportunity to see people face to face, and I did all my interviews digitally. I focused on Dutch society, so all my sources are Dutch and some are local to Delft and surroundings. This is an added benefit to Marise, as she is also based in this area, and is directly applicable to her work. Some interviewees were also contacts of Marise. All interviewees remain anonymous, for privacy reasons, but their consent to be interviewed and the information used for this project was given beforehand. After gathering one or several interviewees per actor, I had a total of 12 interviewees, an overview can be seen in table 1 below.

	Actor	Interviewee	Brief explanation
1	National government	Policy researcher	Does research Mantelzorg NL together with the government. Gathers information to make new policies, nationwide.
2	Municipal council	Council member	A member of the council, presenting the Christenunie in Delft.
3	Municipal council	Former team manager youth care	A former youth team manager in the Hague.
4	Municipal council	Member of social team: case manager	A case manager of youth care in Delft, seeing different CSN parents.
5	Care domain	Health insurance administrator	In the region of Delft, working at the DSW insurance company.
6	Care domain	Community nurse	Works for the CJG South-Holland west.
7	Care domain	Remedial educationalist	She has worked at several locations, currently in Amsterdam.
8	Care domain	Outpatient care provider	She has experience at a small company, based in Amersfoort.
9	Care domain	Regional manager of day care teams	Manages three different daycare centres (KDCs in Dutch) in the south Holland region.
10	Charities	Informal care consultant	Works in Delft, connecting different local organisations and volunteers.
11	Charities	PR coordinator of the Mantelzorg NL	Works nationwide to coordinate media attention.
12	Charities	Independent coach supports CSN parents	Works independently with many different clients, based from Amsterdam.

Table 1: List of people I interviewed, with explanation.

Each actor is represented by the interviewees, except for the actors of CSN parents and the network. In this report I merely give an overview of the situation of CSN parents that is relevant for the rest of the system. Though for this project I did not interview CSN parents initially, I read a lot of personal stories to gain empathy and respect for these parents. My main source was reports of Ontzorghuis's past graduates, as all three did extensive research on CSN parents, and their network. Maira en Suzanne had a special focus on CSN parents, and Irene on the personal network. They also developed tools, which I will explain very briefly in this section.

Maira designed a reflection tool called Future Journeys, which is meant to increase the confidence and reflection abilities of CSN parents. It also strengthens the relationships between other CSN parents. They can learn from each other as a community, and think more clearly about their future (Ribelles, 2020).

Irene's design Zachte Wacht encourages CSN parents to build their own network support plan, and to start preparing for the future. Through a positive ritual, it awakens ownership in a close personal group around the CSN family (Kingma, 2021).

Suzanne, the last graduate of Ontzorghuis, took a psychological approach to researching CSN parents, and dove deep into their minds. Her tool illustrates the effects of the extra responsibilities thrust into their laps, and what it does to their mental health (Lampe, 2021).

By using the insights of their reports, it allowed me more time to research the actors around them. For each actor, I talked for around an hour, and dove into several questions. The research question and supporting questions are seen below:

RQ: Who are they, what is their role in the system, their needs, drive and struggles?

Introduction
- Who are they, and what is their role?
- What are the basic things I need to know to understand their situation and perspectives?

Role in system
- How do they relate to CSN parents?

Needs and drive
- What is their main drive and motivation?
- What do they need in order to do their job well?

Perspective: positive and negative experiences
- What is going well in their situation?
- What are their main struggles and frustrations?
- What can be improved in their situation?

These are not just factual questions, but they explore a deeper, emotional level. I took extra time for people to explain their positive and negative experiences, and it allowed me to understand their perspective on the situation.

I asked for permission to record each interview, purely on the basis for me to be able to fully be present in the conversation, and not taking notes. I later listened to the conversation, transcribed some parts verbatim, and some parts I summarised, according to the questions above. Quotes in this report are translated from the Dutch verbatim interviews. More detailed summaries with some Dutch verbatim quotes can be found in Appendix B.

The different perspectives of the interviewees were summarised for each actor. I took the main frustrations, and also the main positive points and compared them to each other, to work out the main themes. This was done in several iterations, per actor, but already in a system map format to understand the interactions. This helped to make sense of the system map, with many iterations, combined with the literature research. I kept simplifying and summarising the map, until the iteration I present in this report. It is a complex story, but I invite you to explore the shifting perspectives with me in the next chapters, where I introduce the actors and then explain the system map relations.

System actors introduced

3. System actors introduced

The system around the CSN parents consists of many different actors. All of these actors influence each other and the situation of CSN parents. In order to understand the situation of the CSN parent, we need to dive deep into the world of each actor, and hear about their struggles and their situation. By understanding their perspective, we get a more honest and complete overview of how the current situation stays the way it is. It later allows us to use systemic design to understand the way the actors influence each other. Since Ontzorghuis is mainly focused on improving the lives of CSN parents, gaining this overview will provide useful insights for them. Ontzorghuis themselves are part of the "charity" actor. In this chapter I will introduce the main actors around CSN parents, and their perspectives. The chapter afterwards, will show the interplay between the actors and the challenges they face together.

This chapter will continue by introducing the different actors of the system, to help gain understanding of this actor, the variety of people in this actor and their situation. Below is an overview of the different actors:

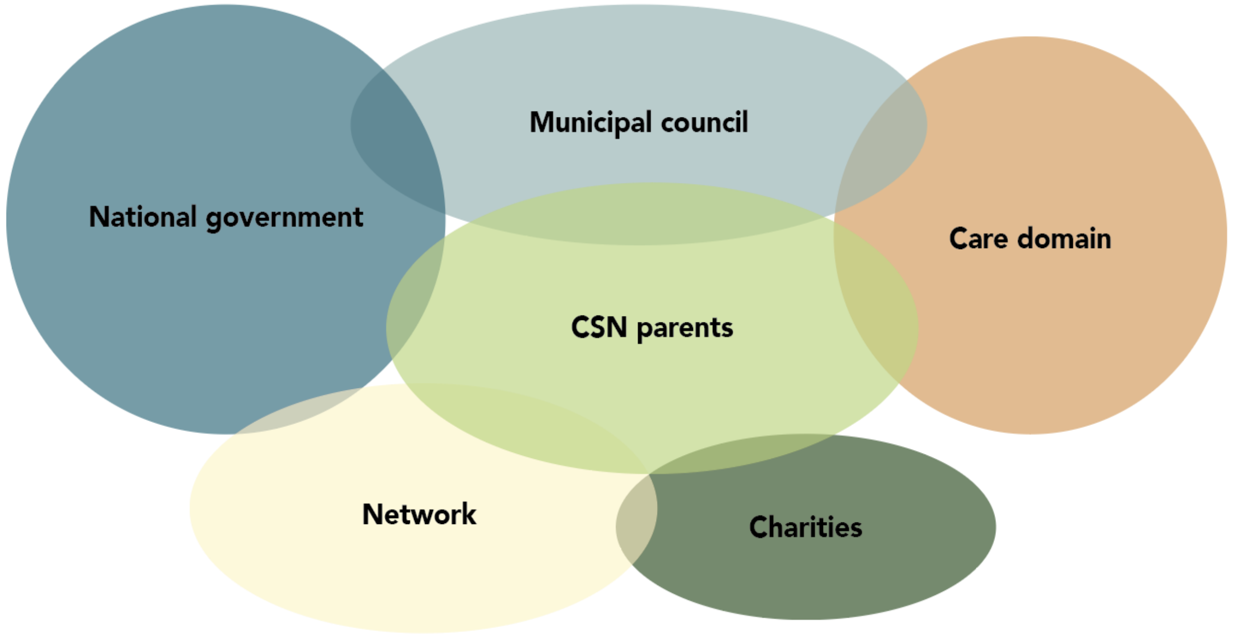


Figure 4: Overview of the different actors in the system around CSN parents.

Content

CSN parents

Network

National government

Municipal councils

Care domain

Charities

CSN Parents

Introduction

A CSN parent is a parent of a child with special needs. In Dutch it is 'mantelouder', which is a new term created by parents and Ontzorghuis themselves. It refers to 'mantelzorg', which is informal care, and 'ouder' meaning parent. CSN parents are parents with a caregiving task for their child(ren).

A parent who is the caregiver for his/her child may sound peculiar. The care you have for your child is quite self-evident. However, for some families the care is much greater than for a regular child. They deal with extra care tasks such as tube feeding, eating training, nebulizing, communicating with means such as pictograms or sign language. It also includes maintaining frequent contact with several doctors, therapists, specialised care centres, care providers, healthcare institutions and budget providers. Informal parent tasks are the tasks that a regular child would not need: extraordinary care. In the medical world, a care-intensive child is a child that needs 8 hours or more extra care per week in comparison to a non-intensive care child. This is difficult to recognize at first. You are a CSN parent if the child needs extra care for life (*Ontzorghuis*, n.d.).

CSN parents often become the case manager of their care-intensive child. They are the link between all parties involved, to ensure that their child receives the care it needs. CSN parents are their children's needs managers, the ones who guard their well-being and happiness. You become a CSN parent without preparation or training. CSN parents must stay strong and healthy in order to provide good care to their child (*Ontzorghuis*, n.d.). Parents of special needs children are currently not seen as informal carers, which makes it hard to defend their rights (Ross, 2020).

Role in system

What makes a child a special needs child? Even after months of research, this question is still met with a vague answer. The fact is, that there are many types of CSN children, and they are constantly growing and changing, and thus the care they need changes too. The definition of special care is a grey area, but care-intensive children are seen as those that need long-term care for an extra 8 hours or more per week. As children always need care at a young age, this is very hard to measure, and there is no concrete answer (Okma et al, 2014). Since the numbers are so uncertain, it is easy to underestimate the number of people belonging to this target group.

One of the main issues is that there are no concrete numbers on how many children with special needs there are. Specialised reports are speculative, and the numbers range wildly. An estimation is the target group consists of approximately 500,000 people (Okma et al, 2014). Needless to say, the group of their parents is large enough to deserve representation. Anyone who is pregnant could end up getting a CSN, so this group is just a natural part of society.

Needs and drive

After learning their baby needs extra care, parents are overwhelmed with new responsibilities. When the kids are that young, often the diagnosis is vague, ongoing or not complete, and the process of diagnosing can last several years. This means the situation of CSN parents can change quickly and it is hard for parents to estimate their future, as it is uncertain. They have to deal with a lot of new responsibilities, whilst having no time to accept their new situation. Diagnosis is often needed to get the right budget and youth care, so before that process is completed, parents are left to fend for themselves.

Most parents are stuck in survival mode, and isolate themselves, and this is not sustainable for them long-term. They have tunnel vision, and no time to get an overview and gather their thoughts. Since their burden is not acknowledged by others, it is usually not acknowledged by the parents themselves either (Kingma, 2021). Once they become aware of their poor self-care, they are usually lacking energy, and are in desperate need. Unless they become aware of this preventively, they are headed towards burnout (Okma et al, 2014). In fact, 78% of CSN parents started working less after getting their child, and 60% ended up overworked and burned out (Okma et al, 2014). The situation could also be worse: an escalation. An escalation is when the parents' wellbeing is so declined that the CSN has to be placed out of home for a short or longer term. It is a traumatic experience for both the parents and the CSN, and should be avoided at all costs. If they seek and receive help preventively, they can start to creatively solve their energy imbalance for the long-term (Lampe, 2021).

Perspective: positive and negative experiences

Maira was the first to graduate with Ontzorghuis, and she distinguished several types of CSN parents. Her graduation emphasises the differences between the situations, but also the reactions of parents. Parents react very differently, also depending on the expectations they had of their child (Ribelles, 2020). When parents have high expectations, they might go through a grieving period, where they mourn the loss of the life they had expected. Sometimes the special needs of children are discovered at a later age, which also can make it hard for parents to accept. It also depends on the location they live, and how they are treated there, as well as their network surrounding them. Parents that are already vulnerable before their CSN is born, can struggle more. The remedial educationalist mentioned she recognized these differences between the reactions of parents as well. She described some as being in the denial phase, refuting everything she said. Other CSN parents get angry: "*How dare you say my child is lagging behind!*". Some parents just ignore it all, and hope it goes away if they don't pay attention to it. Others choose to see where it goes, and those are easiest to work with, as they are willing to try everything.

Therefore, though they are all CSN parents, the situation can vary a lot, and also change for parents over the course of time. Parents are dealing with a stressful situation, and are not at their best, but at the same time are so resilient and hardworking, they deserve all the respect and support in the world.

Network

Introduction

The personal network of CSN parents includes family, friends, neighbours and other personal contacts, see figure 5. They can have a personal relationship with the CSN parents, but also be part of a bigger community. The network includes their employer and work colleagues, as well as sport team mates, or other organisations CSN parents are a part of. The role of personal networks is not always present, as there are also many families that don't have a (strong) network, a remedial educationalist explains. The network differs greatly per CSN parent, and can also depend on the cultural background; whether it is a taboo topic, and if people have managed to build up a network, and whether they are vulnerable themselves. However, many people participating in Dutch society can see themselves as part of some CSN parents' network.

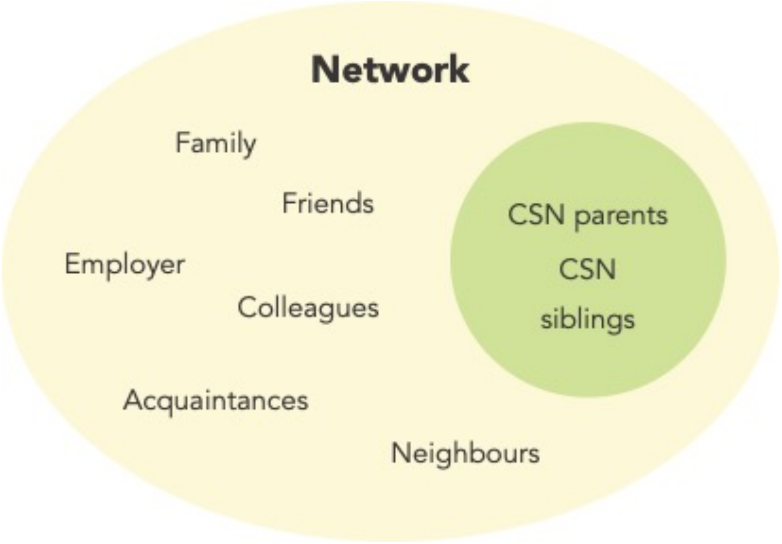


Figure 5: An overview of the network in relation to CSN parents.

Role in system

The third Ontzorghuis graduate, Irene, focused on the personal network, and I refer to many insights from her report. She explains that CSN parents need to redefine their family culture, as their responsibilities now include caring for their special needs child. They also need to find a balance of integrating their culture with the new CSN culture (Kingma, 2021). It is vital the family tries to keep in touch with their personal network, whilst also integrating into CSN culture for support.

The network often doesn't understand the extent of extra time it takes to care for a CSN. Since the parents are stuck in survival mode, they don't reflect, and can easily become overburdened. If the network is not keen on asking questions about the long term, the CSN parents can lose touch with them and become isolated. The PR volunteer coordinator of Mantelzorg NL mentioned the personal network needs to ask the difficult questions: "*start taking care of yourself, you aren't going to take care of your child like this your whole life, right?*". She emphasised the need for friends to wake CSN parents up, and find solutions "*So what are you going to do about it?*" If this doesn't happen, parents will become overburdened. So, the network can play a big role in preventing parents from becoming overworked.

Needs and drive

The network's main need is to maintain their former relationship with the CSN parent, and the way of interacting before. They either had some personal connection, or were involved in some activity together. The network often does not understand the situation of CSN parents. Since caring for their child takes so much time, CSN parents often lose touch with their contacts. This creates a distance between CSN parents and their personal network (Kingma, 2021). Their network might not understand what they are going through, why they keep cancelling plans, and they drift apart, isolating the CSN family.

Perspective: positive and negative experiences

The perspective of the network ranges wildly, as there are so many different people involved. All of them go through a change in how they see the family, and their relationship towards them. They can feel more distance or, if they are closer, go through the same process of changing their expectations.

Another part of the network who are often affected greatly are employers, as a large number of parents started working less (78%), and have even become overworked or ended up burned out (60%) (Okma et al, 2014). The employers and colleagues have to deal with the changing situation of the CSN parents.

National government

Introduction

The government of the Netherlands is structured in three different layers, as shown in figure 6. Firstly, what I call in this report the national government, which includes the house of representatives and the parliament. These are based in the Hague, and consist of ministers, representatives of voted parties. They ultimately decide and vote on the basic law structures in this country.

The second layer is the provinces, they have their own councils. They are not part of this research, as they do not have a big influence on the lives of CSN parents currently. The third layer are the municipal councils. These deal with local inhabitants, and also with CSN parents directly.

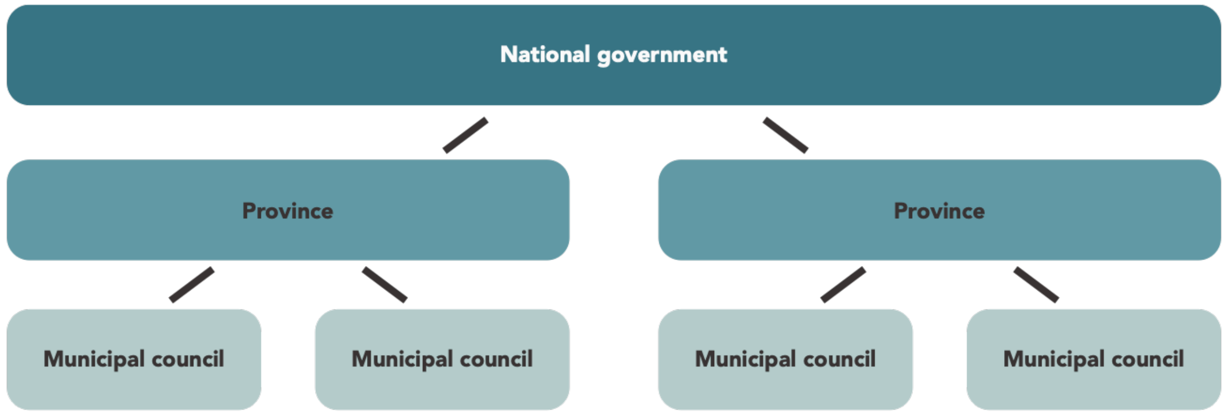


Figure 6: The structure of the government in the Netherlands.

Role in system

Following the second world war, the Netherlands strived towards making risks like sickness and unemployment a collective responsibility, instead of individuals. However, in more recent years an increasing number of people applied for care, and thus the costs have risen. The national government concluded the system was not sustainable long term.

A new ideology was decided upon, a change towards an "enabling state". This means the role of the government is no longer on providing for but on activating people. People would become independent with the right kind of support. The invocation of the citizen's own responsibility was the new goal: find out how much they can do on their "own strength" with their social network, before the government intervenes (Kromhout, Van Echtelt & Feijten, 2020). This also included people with a disability or condition: they should be encouraged to rely on themselves and participate in society as much as possible.

This means the role of the national government changed in 2015, from direct intervention to standby for help. This new law also changed the role of municipal councils, making them responsible for youth care. This changed the care to be based on a local level instead of national. From 2015 the new laws became reality, legally depicted as "the right of citizens to facilities has been replaced by a duty of municipalities to provide support" (*Staadsblad*, 2014, as cited in Kromhout et al, 2020, p. 29).

I interviewed a lady who researches informal caregivers, and gathers and bundles their signals, a policy researcher for the charity organisation Mantelzorg NL. The policy researcher explains:

> *"The idea behind the legislative system is: the municipality is closer to the citizen, and they have more insight into what the citizen needs, so they can provide customization, and therefore also be cheaper. Since it was all organised nationally, ... meant there was a lot of overhead, it was expensive, cumbersome and could not provide customisation. The idea is that the municipality can organise it in such a way that it can provide the care that is needed in the most favourable way, but for as little money as possible."*

Needs and drive

The main goal of the government is to make sure the care system is sustainable and effective. By structuring the system to be based on local municipal councils instead of nationally, the services offered would become more customised to local needs. The change in law meant boosting efficiency and effectiveness, as municipalities could react to the needs specific to their local area (Kromhout et al, 2020). The end goal was a "greater social participation, a more caring society" (Kromhout et al, 2020, p.101) and a system that is both less complex and financially sustainable (Kromhout et al, 2020). It would stimulate local organisations to work together, and provide better fitting care tailored to local needs. The goals were cheaper and better care, by means of providing early care to prevent more expensive specialistic care later on.

Apart from making sure the care system is effective, the national government is made of parties, each with their own agenda. One of the agendas was to make sure the system was financially viable. The national government therefore decided to already cut the budget before the system was launched, so as to have achieved the financially viable part of the plan.

The policy worker is part of this actor, as she provides data that can be used to make an effective plan. She gets great satisfaction providing useful data that can be used to lobby for the government.

Perspective: positive and negative experiences

It is complex to depict the experiences of the national government, as there are many different parties. I was also not able to directly interview people representing the national government, so my information is from someone who works for them. The national government also represents the ideology of the Netherlands as a whole. The most recent years have been greatly affected by the corona pandemic. The current ideology is one of a "meritocratic society: according to this philosophy life can be made, and failure and success depend on one's own merit, one's own choice and one's own responsibility" (Kromhout et al, 2020, p.17). The corona pandemic shows that life can't be predicted, contradicting this ideology. This emphasises the importance of the health care system, to take care of those who can't take care of themselves. It might mean the agenda will shift towards creating more space for healthcare, but similar parties are still in charge. More in the broader sense, the numbers from a report in 2019 show there hasn't been a large effect of the new system, as there is still an increasing trend of youths needing care since 2015 (*CBS StatLine*, 2020).

The policy worker explained her experience of working for the government. Informal care is hard to measure, and there are no standardised qualities, or research done proving effectiveness. The only research is done on very specific target groups. This means it is often the sector that undergoes budget cuts. Also, often the law has many gaps, leaving people confused on where to get help. However since *"no one feels ownership of the problem, the problem is there, everyone understands that, but no one feels ownership, so little progress can be made, and that is frustrating for our work."* Working for the national government is slow and tedious, and can be frustrating but also extremely rewarding when you make an impact.

Municipal councils

Introduction

Municipal councils are the government entity in direct contact with CSN parents. However, there is quite a variety of people within this actor. The main structure of municipal councils is: a local council, departments which then have teams. There are also other supporting parts of the organisation, but they are less relevant towards CSN parents. Below you can see an overview of the structure, and the people I interviewed in figure 7. Though their expertise on the situation of CSN parents differs a lot, there is a shared passion for the social domain throughout these interviews.

Structure of municipal councils		**People I interviewed**
Municipal council (Gemeenteraad)	-	**Municipal council member: part time**
Department youth care	-	**Former manager of youth care**
Social teams	-	**Social team member: Case manager**

Figure 7: Structure of municipal councils and corresponding interviews.

Role in system

As explained in the previous actor government, the role of municipalities changed in 2015 when they became the organisation that was responsible for all youth care. This means they are now responsible for caring for children with special needs, and by extension their families. The system has different laws and is very complex, and municipalities had to shift their way of working, as well as help the care domain shift too (Kromhout et al, 2020). In Holland, the municipal council is elected by the residents of the municipality. They represent the inhabitants of the region, and are associated with different political parties. The municipal council determines the policies, and checks whether they are being executed correctly by the municipality employees. I will briefly explain the role of the different people I interviewed:

The municipal council member explained it is her part time job, and she reviews many different topics and target groups. This means she is not an expert in one area, but has to read into each new case. The exact details of the responsibilities of the municipal council in the case of CSN parents was not clear to her, but she was eager to find out.

I interviewed a former manager of youth care who was in charge of leading 15 youth care teams right after the decentralisation. She was positioned between the municipal council and the social team professionals.

I also spoke to a social team member: a case manager in the youth care department. She is responsible for arranging the right care for 35-40 cases, and is in direct contact with a big variety of CSN parents, as well as parties for arranging this care.

Needs and drive

Even though the people I interviewed were at different levels of the municipal council they share the same need: to help those in need.

For the municipal council member this means she is driven to help those who can't reach out for help themselves, and immerses herself into stories of local citizens to lobby for them, she said:

> "*Giving a voice to people who don't make a fist - the complainers in our country know where to find you - what drives me is precisely the fact that there are people in our country who need help much more, who have much harder lives, who just don't have the time or energy, or feel defeated and therefore no longer fight for their own rights. I think you are in politics for that, to properly defend their interests.*"

She needs parents to reach out, and needs stories and examples to be able to defend them.

The former manager of the youth care department spoke of her passion for helping the kids, as well as the importance of supporting the family and network around them. Her needs were for the different teams and parties to work well together, to achieve their ultimate goal. She emphasised that almost everyone she worked with shared her passion for trying to help these families as fair as possible.

The case manager needs parents to be open and honest with her, so she can arrange the right type of care for them. Her goal is to help these families in such a way, they don't need her in the end.

Perspective: positive and negative experiences

The experiences differ per interviewee, but for all the tension was quite present in their depiction of their perspective. Their budget had been cut, more quality expected and as you can imagine, this caused high pressure for employees.

The member of the municipal council does it as a part time job, so she did not feel the tension as much as the other employees. She did explain it is hard to hear CSN parent's stories, and feel close to them when they are hard to reach as a target group.

The one most affected by the pressure was the former manager of the youth care department, as she was pressured from both sides: the council and the professionals in the teams. The municipal council was asking her to stay on budget which meant she had to decrease the freedom of care professionals. The intention was there, but the lack of resources really influenced their work, she says:

> "*We used to have an amazing team, who all were able to focus on the child and overcome their differences to work together. Because of increasing workload and administrative handling, and budget cuts, it put a strain on our relationship, and the team started having more tensions.*"

Personally, the pressure was too much for her, causing her to burn out: "*There was so much crazy pressure, and everyone knew better than the others, that I found myself between the professionals and those higher up the ranks, being pulled so much, in the end I couldn't make it.*"

For the case manager, the decentralisation gave her more time but also more responsibility and options. They do have a tight budget, so she is constantly trying to balance the care she can give with the budget available. It can be hard to make the right decision: "*You want to offer the right help, and you do what is needed, but you don't want to use help for something that is not needed.*"

Care domain

Introduction

The care domain has the most variety within itself as an actor. The actor care domain refers to all professionals that provide care for the special needs child. It includes all aspects of care: healthcare, budget and day care. Figure 8 below shows how each interviewee corresponds to the different areas of expertise. I spoke to an array of people in this field, and it is very diverse, so the experiences also range a lot. The care domain is often split into many parties, however, since they all have to deal with the same side of expectations and consequences within the system, they fall under one actor. Note that all CSN parents have a different care situation, so this is a generalisation to gain an overview. The main role, needs and experiences of the actor are shown in this section, but also examples for each of the interviewees are given.

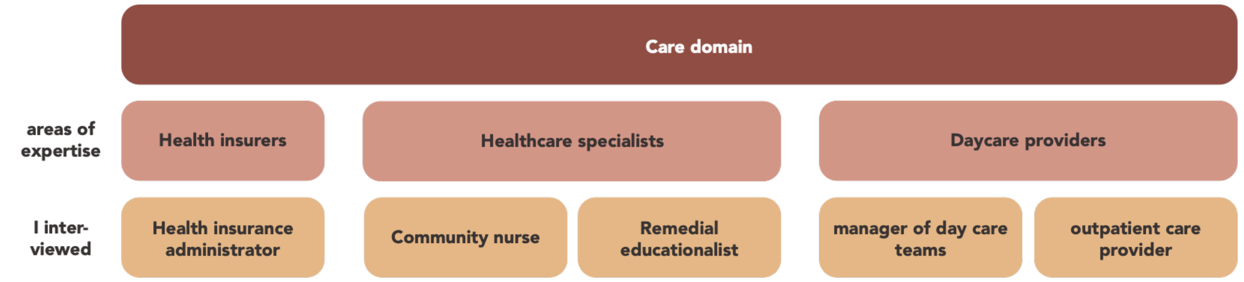
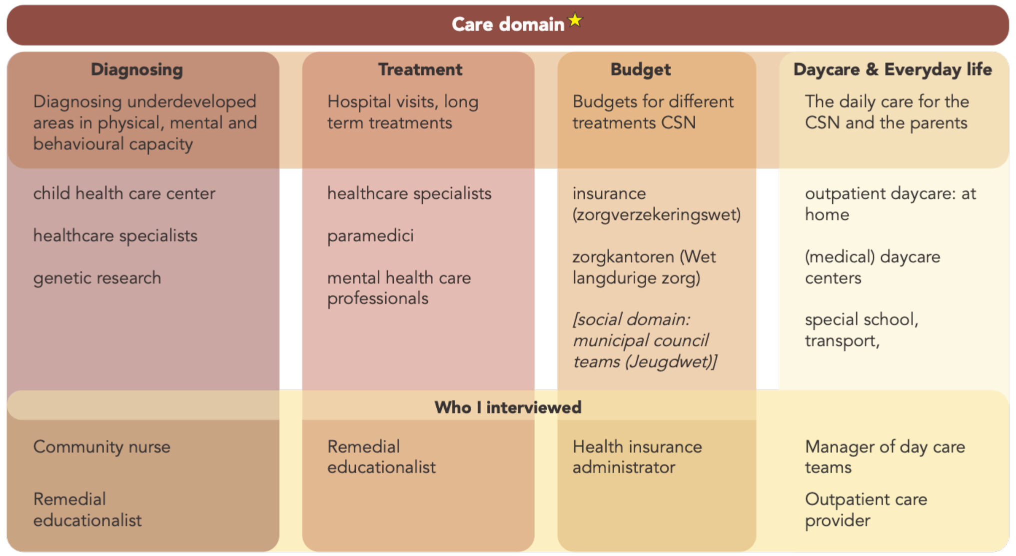


Figure 8: Areas that fall under the care domain.

Role in system

Below is a general overview of the system, as a visual figure 9. It is by no means a customer journey, but more an overview of where the people I interviewed fall under the care domain. Healthcare specialists provide a certain area of expertise on healthcare, from diagnosis to treatment. Examples are: physiology, genetic research, obstetrician, general practitioners, etc. Health insurers link the CSN to the health care budget they need. Day care providers take care of the child during the day, some in centres, some at home or providing transport. Some roles in the care domain overlap, giving both treatment and care during the day, for example.

The current role of the care domain in the system is to provide care for the CSN. This can take many forms, but they are always focused on the CSN. Almost always, the contacts are organised and taken care of by the CSN parents, so people in the care domain are in direct contact with the CSN parents. To give more insight, I will explain how each role fits together, and then the role of each person I interviewed.



Care domain ☆			
Diagnosing	**Treatment**	**Budget**	**Daycare & Everyday life**
Diagnosing underdeveloped areas in physical, mental and behavioural capacity	Hospital visits, long term treatments	Budgets for different treatments CSN	The daily care for the CSN and the parents
child health care center healthcare specialists genetic research	healthcare specialists paramedici mental health care professionals	insurance (zorgverzekeringswet) zorgkantoren (Wet langdurige zorg) *[social domain: municipal council teams (Jeugdwet)]*	outpatient daycare: at home (medical) daycare centers special school, transport,
Who I interviewed			
Community nurse Remedial educationalist	Remedial educationalist	Health insurance administrator	Manager of day care teams Outpatient care provider

☆ This figure is by no means complete, as every CSN has a different journey. It is just an overview of the actor "Care domain" to explain the variety of people who work in this domain.

Figure 9: Care domain overview in more detail.

Generally, a health care professional performs an assessment, judging how much and what type of care the CSN needs. This allows parents or carers to apply directly to health care providers themselves (*Zorginstituutnederland.nl*, 2021). The health insurance company then helps to set up the finances and contracts. They are the link between the insurance law, the CSN parent and the health care professionals. This budget is then used to pay both treatments and day care for the CSN.

Healthcare specialists

Health care specialists help the CSN in their area of expertise. The two specialists I spoke to were in close contact with the parents. They were very keen on making sure the parents were taken care of, but it is not always part of their role. The community nurse has a preventive role of making sure the special needs children are spotted as soon as possible and referring to the right specialists. She sees parents at set times. The remedial educationalist gives a diagnosis followed by treatment. She tries to engage the parents to help their child in the right way, and helps them find the next step.

Insurance

I spoke to a health insurance administrator who sees her job as an indirect healthcare supporter, as she helps clients find the best care. Her job has a big variety of tasks: from helping parents fill out forms, to checking procedures, as well as house visits and referrals. If she can't help them directly, she refers them to the right people: social teams or care professionals.

Day care

The outpatient care provider goes to visit families directly, and provides day care for the CSN at home. She helps the CSN to learn new skills, and practices with them. She operates alone but reports back to a team. There are also day care teams, which are groups of CSNs, in a physical location. They provide a day plan and also do special treatments. I spoke to a manager of day care teams, who used to work as a group supervisor, directly with the children. She manages the teams and makes sure they stay on target.

Needs and drive

The main need for care domain workers, apart from knowledge of their area of expertise, is to be able to deal with many different parents and CSNs. Each of them has a slightly different role towards CSN parents, but they share the same drive and needs.

Healthcare specialists

Healthcare specialists need to be able to deal with a big variety of parents, and also their different reactions to their stressful situation. They see parents from the start of their journey, the most stressful time. It is important for them to build trust with the parents, and to be able to guide them in the right direction.

The community nurse explains she is driven to keep doing the research to find a diagnosis, and to make sure the child gets help as soon as possible, preventively. What intrinsically motivates the remedial educationalist is her interest in the development of a child. She said she loves offering that first progress, development or insight in their whole life journey.

Insurance

Apart from knowing the ins and outs of health care law, the insurance administrator also has experience with a lot of different situations and parent reactions, and knows how to handle them. These conversations and house visits can be quite emotional, but her drive to help these people helps her deal with it. "*We try to speak to as many people as possible so that you can help them, because often people don't know where to go with their question.*"

Day care

Both the day care, as the outpatient care providers are in very close contact to both the parents and special needs children. Their work can be tiring, overwhelming, and emotionally draining, as well as extremely rewarding. Both the employees and managers need to find ways to balance this workload realistically, to manage expectations of the amount of care they can deliver. When is care good enough? Moments that provide feedback, an end point, or reflection are extra important for care providers. The manager needs enough time and a positive work environment to ensure she can provide the best care to her employees, and indirectly to the children. The outpatient care provider needs her team to help her tackle difficult situations and reflect.

Perspective: positive and negative experiences

All care domain workers struggle with the limits of the budget, each in their own position. Many would like to give more help towards CSN parents, but it is not always in their job description, or their ability to do so.

Healthcare specialists

Being a community nurse can be frustrating, as some parents need more help than she can provide. If she comes in contact with parents that are overburdened, she refers to local charities or organisations. "*It is important to monitor those closely, but we don't always have the time and budget for it.*"

The remedial educationalist also speaks of the budget problems, though it doesn't affect her job personally it does affect the CSNs she works with. CSNs are hard to handle, and the waiting lists are long., and she sees CSN parents struggling to take care of them and find the next step. Within her organisation, she tries to take initiative to help organise things, like the next spot at day care for CSN parents, but there is a limit to what she can do.

Insurance

The law became more complicated after 2015, leaving more work for insurance administrators. CSN parents are confused about where to find help and budget, and insurance administrators often have the additional role of pointing them in the right direction: "*We try to speak to as many people as possible so that you can help them, because people often don't know where to go with their question*".

Day care providers

The outpatient care provider is most proud of moments where she says goodbye to someone, because they learned enough to continue on independently. You can really see the change you made in someone's life: "*Before we come, there is often a lot of tension in the family*". She also values her feedback session with the team.

The manager is always trying to find balance between the effort and quality of care: "*The conversation I have a lot, is when is good, good enough?*" "*I also think that those girls honestly work really hard and give their heart and soul into supervising those children. But sometimes I also think: it needs to be done at some point, going on forever also doesn't make sense!*"

Charities

Introduction

A charity in this system is an organisation that is set up to help those in need. These do not need to be run by volunteers, but can have paid employees. Currently, CSN parents are not seen as informal carers so there are only a couple of charities who really focus on CSN parents. Most of them focus on CSN children, or informal carers generally. Charities can vary in size and be based nationally, or more locally. I interviewed three different sizes of charities: one on a national scale and one local organisation, and an independent worker. I interviewed the PR coordinator of a national charity for informal carers (Mantelzorg NL), a local informal care consultant, and an independent coach who also started her own local initiative.

Role in system

Charities have a big role in the lives of informal carers as they provide several types of support. Next to giving practical and emotional support, they also function as a signal towards the government. National charities research and monitor informal carers, and help people to tell their story publicly through media connections. Local charities have expertise in the area and are known to refer to each other and create communities. There can also be competition between charities, because they are often funded by the government. However, charities often work together, and support each other, so it depends on the situation.

I talked to the PR coordinator of the Mantelzorg NL team, who matches the stories of informal carers to media opportunities. Some of them are CSN parents. Her goal is to get attention from the government and organisations, to make sure change happens. She listens directly to many people, and hears many emotional stories.

The informal care consultant I interviewed works for an organisation that receives a budget from the local municipality. She refers informal carers (some of them CSN parents) to local care organisations and volunteers, and gives practical information as well as emotional support.

An independent coach supports CSN parents through conversations, both emotionally and practically. She aims for preventative and accessible support, at the earliest time in the process. She is focused on coaching CSN parents specifically.

Needs and drive

Charities are all about finding connections, and having time to understand the CSN parents or informal carers. Each of the interviewees explained their version of this need and drive.

The PR coordinator hears many emotional stories, and so she needs energy and focus to listen. She loves helping people, and igniting change in informal carer's lives and she has a lot of respect for the work. She is proud if someone gets to tell their story. She tries to understand as many perspectives as possible, reading people's stories on social media. It helps her empathise and keeps her from judging someone during conversations, by being curious about their experiences. She is striving for social change, that people start asking more after one another, and caring for each other in small everyday ways.

The informal care consultant needs time with her client. It is important to her, so she can listen well and help them improve their situation: "*Quality is very important to me, so I also make considerations, if possible, I keep it short, but if quality is compromised, I take more time.*" If she has enough time, she can understand the situation better and link them to the best local option.

The independent coach loves combining her personal experiences of being a CSN parent and researcher, and helping people find their way. Her main need is to be known, so people can find her, as her organisation is small.

Perspective: positive and negative experiences

The charity workers are all struggling to help CSN parents, as they are currently not visible. It means it is hard to get media attention, and hard to get parents to be referred to them, or get a budget to help them. They each explain how this affects their experiences.

The PR coordinator has learned to have empathy for many different people, and their perspectives. She empathised with the CSN parents, and many of her frustrations are shared with those of CSN parents, as she is a CSN parent herself. She needs CSN parents to become more visible, and to be seen in society. This could include new campaigns or platforms.

For the informal carer, especially the target group of CSN parents is hard to match to volunteers, since they need very specialised care. Sometimes this care can be taught by a medical professional, but many volunteers don't want the responsibility, it depends also on the qualities of the volunteer and their previous experiences. She is frustrated by more medical professionals not referring informal carers to her, and wants to be involved earlier on in the process, to prevent escalation.

The independent coach explained that budgeting is a big issue for her and her clients. Municipal councils have a lot of rules, and she cannot be paid by them, because she wants to be more flexible with her approach. It would be ideal if her work can be compensated by the municipal council, so all parents can afford it. This is largely due to the fact that municipal councils don't recognise CSN parents as informal carers and needing help: "*I would love for parents to feel a little more supported, and not have to figure everything out for themselves.*"

Relations between actors

4. Relations between actors

Introduction relations

Having just been introduced to the actors, this chapter continues by exploring the system in which they relate to each other. The ways actors are connected is complex. The main problem is found at the CSN parents: their situation is escalating in a vicious cycle. How this situation came to be, is explored in 25 points. A system map is used as a visual to guide the reader through the 25 points, seen below in figure 10. Following these points, the problem shifts between actors, and how it affects their situation and the relation between them. The points are explored between two actors at a time, showing the challenges that this pair has to face.

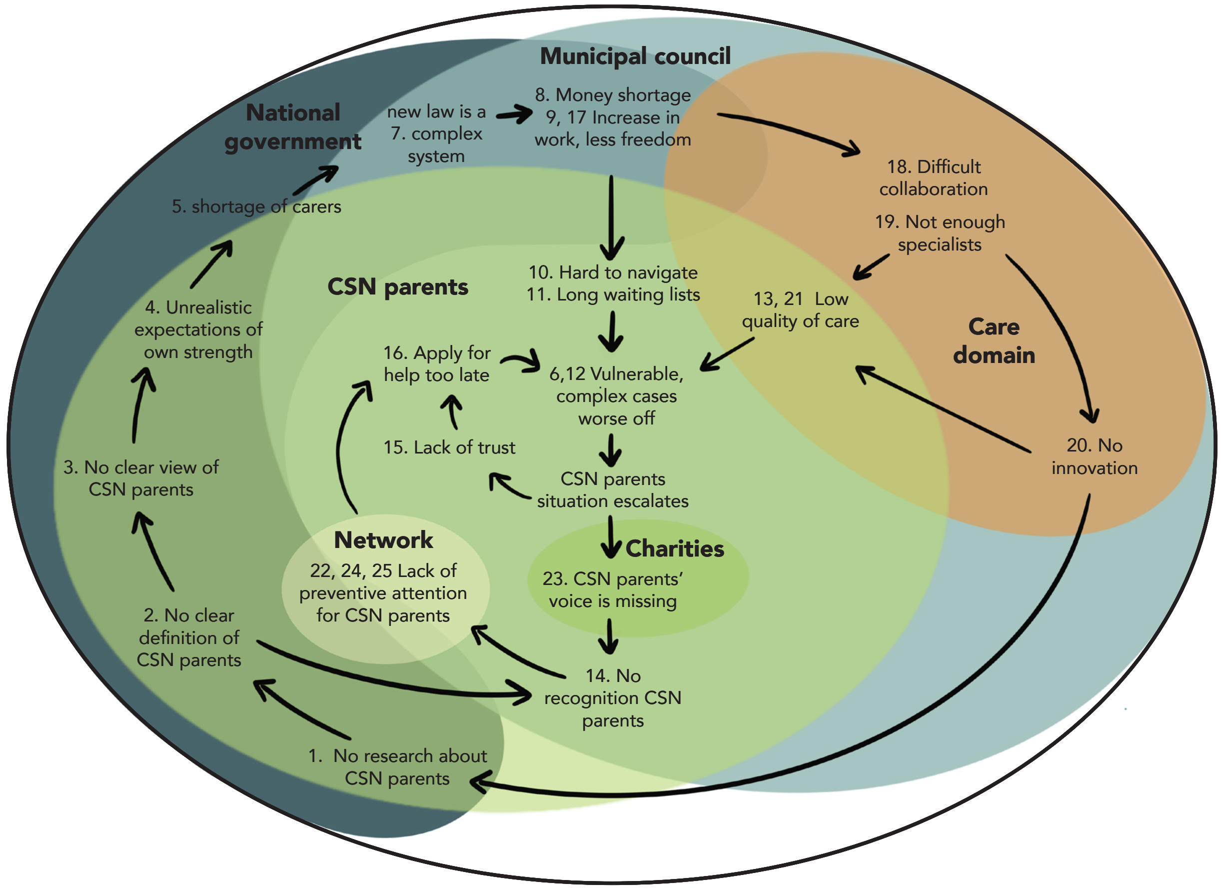


Figure 10: Map showing the system around CSN parents.

It is important to look at the relations between the actors, as most of the challenges arise when they deal with the other actors in the system. It is when their two (or more) perspectives collide and don't match that most of the challenges in the system arise. In order to fully understand how these challenges came to be, I looked at them between the two actors most involved. The relations are a simplified version of the real world around CSN parents, which give an opportunity to maintain overview and still look at the details. This simplifies the system enough to understand the dynamics and perspectives of the two actors around one point. It provides both sides of the story, and shows how the tensions came to be, and how it influences their relationship. Adding the points together to the system map at the end, shows the full complexity in the system. This can sometimes be seen when there is a third actor involved, who is not part of the actor pair explored, and there is a lot of overlap. It is just the structure I personally used to discover the perspectives of the actors whilst looking at points, without getting overwhelmed.

This chapter contains a lot of information, as it explains the details of the challenges that arise in the system. The choice to explain the system in depth, is to give the reader the chance to fully grasp the dynamics between the actors. Some points are complex in itself, deal with nuances or unclear factors, or are hard to believe since they seem contradictory. The contradiction stems from the mismatch of the intentions of the points in the system, versus the reality. As explained in the introduction of the actors, the national government set a new law structure. By centring the system around municipal councils the services offered would become more efficient, increase social participation, be less complex and financially sustainable. These goals were split into smaller "process goals", intended as improvements to the current care system.

This chapter compares the "intentions" of these process goals, versus the reality, and how it affects the system. The intentions are explored within the actor pair affected most directly by the point. For example, if the intention was better collaboration between domains, the point will be explored in the relation between the municipal council and the care domain. Since it's a complex system, there will be some overlap, as sometimes more than one actor pair is dealing with the same themes. You can see this in the system map, the numbers are listed at the same point.

Content

National government - CSN parents

Introduction

The national government is the entity that created the new law and structure of the system. Though most problems in the system lead back to this law and system structure, in this chapter the most direct points that effect CSN parents are explored.

Firstly, let's take an overall look at the relationship, as seen in figure 11. Whilst making the new law, the national government does not have a good overview of CSN parents in the Netherlands. Since there is no research on CSN parents (pt. 1), there is no definition of them (pt. 2) and no overview (pt. 3). It makes the governments' expectations of CSN parents unrealistic (pt. 4). This leads to a multitude of problems, for example a shortage of carers (pt. 5), and this is passed through the system. This eventually leads to vulnerable CSN parents being worse off (pt. 6), and continuing this vicious cycle. CSN parents that are in a bad situation, don't have energy to alert the government, and this leaves no feedback loop for change.

National government & CSN parents

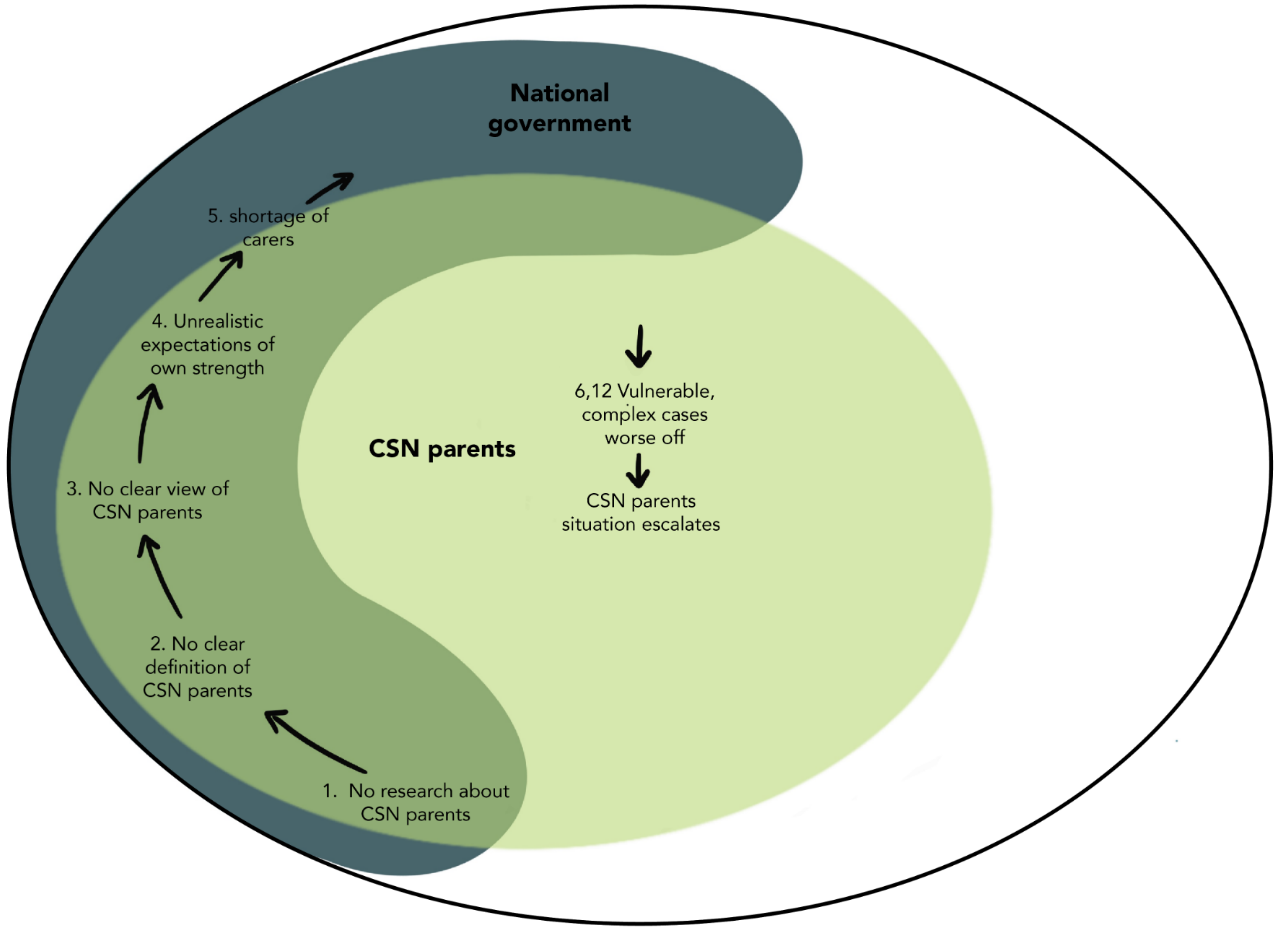


Figure 11: Relation of the national government & CSN parents

However, the intention of the national government behind this system is for it to be financially sustainable. This includes the new notion of encouraging citizens to be more independent and to take care of each other. Encouraging independence means making more preventive measures, and light, easy care available to help people overcome and tackle problems themselves. Taking care of each other is about encouraging citizens to look within their community to help. This all sounds like a good plan to help CSN parents as well, so this is why the intentions are not negative at all. It just doesn't seem to work in reality with no feedback loop, which is explored in this chapter.

To summarise the relation between the national government and CSN parents, basically there is not a conscious relationship between them. CSN parents live with the consequences of the decisions of the national government. There is no energy left for a feedback loop, so they stay off the radar of the national government. Even though they affect each other greatly, they don't seem to have a relationship.

Intention: Promoting preventive care to play into own strength

The current government is striving towards a meritocratic society, where your success depends on your work, and is your responsibility. The ideology that people should look to their own strength first, was the core focus of the new laws. It promotes preventive care and focuses on people finding their own strength and support from their social network.

1. Reality: No research about CSN parents

There is not a lot of research being done about the target group CSN parents, especially by the government. This means there is a lack of data, as "*informal care is hard to measure, and there are no standardised qualities, or research done proving effectiveness. The only research is done on very specific target groups.*" (Policy researcher). This means, there is some data available for specific CSNs, for example Down Syndrome or a certain medical disease. However, there is no national data of all the children with special needs, and their parents. Combining that with a system under pressure, there is no funding for researching CSN parents.

2. Reality: No clear definition of CSN parents

This leaves CSN parents in a predicament, as they are not recognized as informal carers, and therefore they currently don't receive preventive care (Ross, 2020). Since the system is set up around preventive care, this sets them up for failure. The researcher I interviewed emphasised this: "*If society would understand that parents already do the maximum care to their ability, and the amount of care they need to give is overwhelming, they would also focus more on preventive care" (Independent coach and researcher)*. As discussed in the introduction of CSN parents, there is no clear definition of when someone is a CSN parent. It is therefore hard to recognize them. There are loads of types of children with special needs, and since there is not a clear definition for them, there also is not one applicable for the parents. The scarce data currently available is of informal carers who have applied for care at municipal councils or other organisations. This means, there could be a big part of the picture missing, and it is unclear whether the government has reached its whole target group (Kromhout et al, 2020).

3. Reality: No clear view on CSN parents

This leads to the main reality: there is no clear picture of CSN parents and there is no feedback loop in which to change this. This starts by understanding, and gaining an overview of the target group. Currently, "*the government underestimates the care for disabled children, and doesn't have a*

good overview of the population of parents" (Regional manager of day care teams). The target group the national government is quite unknown, and therefore hard to keep track of. It is no wonder then, that the expectations of this target group do not match the reality.
Another area that lacks overview is the effect of making municipal councils responsible. Municipal councils have very different situations as their residents, size, opportunities and resources all differ. Research should focus on gaining a national overview, and understanding the difference between regions (Kromhout et al, 2020). This would ensure the new system works for CSN parents in the Netherlands. To summarise: in reality, the understanding and overview of this group by the national government is lacking.

Intention: Increasing people's "own strength"

The ideology of the new law was to build up people's confidence in their 'own strength'. Informal care and volunteering initiatives should be stimulated, and "where possible, applicants should be asked to use their own capacity and support of their social network before receiving formal help." (Kromhout et al, 2020, p. 107). The focus is on the self-solving abilities of the youth and parents. For CSN parents, it means the government expects more self-solving abilities, and to take initiative to ask their network for help. (The actor network is part of this point; however, the main point is about expectations the national government has of CSN parents.)

4. Reality: Unrealistic expectations of own strength

The term 'own strength' refers to the "possibilities for the client to draw on their own capacity or network"(Kromhout et al, 2020, p.107). This means the amount of own strength differs greatly per CSN parent. Some people have limited 'own capacity', as they are dealing with their own psychic issues. People may only have a small social network or none at all, or don't want intimate care from their network. Own strength can also be more personal, dealing with shame for example. Some people don't want their relationship to become dependent, becoming a burden. This idea that asking for help is a burden is grounded in reality, as only 20% of Dutch citizens think long-term help should be given by the informal network (Kromhout et al, 2020). This means "appealing to one's own strength and network is not always possible" (Kromhout et al, 2020, p.11).

Currently, the expectations of the government are not realistic. The expectations may be skewed because municipal councils don't ask about people's own strength and network. Only 50% of clients were asked about their social network plan (Kromhout et al, 2020). The family plan is talked about even less, only a third of the clients were asked (Kromhout et al, 2020). Since the own strength of people is largely based on their physical, mental and social situation, this is important information that is missing, leading to unrealistic expectations. Real life families are complicated, as an interviewee explained: *"I think the government underestimates the care for disabled children, and don't have a good overview of the population of parents. People are from different backgrounds; the language is a barrier"* (Regional manager of day care teams).

When the term "own strength" is used to deny people the support they need, it can discourage citizens, and lead to mistrust. Sometimes, the 'own strength' reasoning is focused on for too long, and the situation escalates. This puts CSN parents in a vulnerable position, as the expectations of the national government are too high. The main starting point to improve is "a rethink about realistic goals for citizens, society and the system" (Kromhout et al, 2020, p.110).

EXAMPLE: How focus on "own strength" withholds CSN parents of respite care
Since CSN parents are usually not recognized as caregivers, they don't receive any support. The expectations of CSN parents' strength is high. This means,"heavily burdened parents of children with behavioural problems are not eligible for support in the form of babysitting, because both municipalities and insurers see this as a regular obligation to bring up a child." (Ross, 2020, p. 25). The policy maker I spoke to explained this contradiction: "The process is a little different for parents with a disabled child. On the one hand you immediately know it is different for them, on the other hand it is also part of having children that you take care of them" (policy researcher). As more emphasis is given to "own strength", less money became available for respite care like babysitting. It is especially alarming that CSN parents are not recognized as caregivers, as it also makes it extra hard for them to receive respite care. Respite care could be used as a preventive measure against escalation, and allow parents to continue caring for their child long-term.

5. Reality: Shortage of carers

The number of informal carers did not increase, as was the intention. Currently, a third of Dutch citizens are voluntarily caring for someone, and the "number of potential informal carers will moreover decline in the future." (Kromhout et al, 2020, p. 109). This is because people's networks are smaller, but also because more people are working jobs. The fact that both parents work also puts more pressure on families (Kromhout et al, 2020). Undeniably, "*the number of kids that need help is increasing, and sometimes in horrible situations, where families are at the brink of collapse.*" (Regional manager of day care teams) This leads to overburdened carers, since they are not getting the support they need, with less network to support them. Especially CSN parents have less help, as "*the target group of CSN parents is hard to match to volunteers, since they need very specialised care. Sometimes this care can be taught by a medical professional, but many volunteers don't want the responsibility.*"(Informal care consultant) Therefore, the expectation of "own strength" of CSN parents and the network of CSN parents is too high, and there is a shortage of carers.

Intention: Preventive care can save money

Another intention of the youth law is to focus on preventive care, as this would make the system more financially viable. The "early help can prevent problems from getting worse at a later stage (prevention)" (Bröcking, 2016, as cited in Kromhout et al, 2020, p. 35). The national government expected to see a shift in people's needs, from heavier to lighter care.

6. Reality: Vulnerable, complex cases worse off

This paragraph explores the effect on CSN parents of the focus on preventive care. This new preventive method does not seem to work for the most vulnerable cases. Usually, it is more complicated cases, where "the expertise for these complex cases is lacking and light assistance is provided for too long, thus situations escalate" (Kromhout et al, 2020, p. 78). The fact is, the new preventive method is costing more money, as well as not helping the most vulnerable. The municipal council member explains "*We keep putting more money in, but it doesn't have the effect that more children can receive care, due to a multitude of factors. Often the initial help is too light, and the situation worsens.*" She means, the money that is being invested in preventive care is not reaching these vulnerable cases. The parents are not receiving enough care, and are becoming overburdened. This interplay leaves CSN parents vulnerable.

National government - Municipal councils

Introduction

Let's look at how the national government relates to the municipal council overall. Firstly, the municipal council is a form of government, the local branches. So, they relate directly to the national government. The national government wants to ensure the financial sustainability of the care system, in order for it to work long term. The new structure gives this responsibility to the municipal councils. So, the municipal council is the one making those goals reality. The national government has high expectations of the new law: it should be more efficient and better quality. However, the new law structure is really complex and hard to adapt to (pt 7). Secondly, the expectations of the government meant the budget was cut beforehand, leading to shortages in money (pt 8). This added work pressure for the municipal council (pt 9). Since the quality also needed to be increased, the government wanted to monitor the municipal councils to ensure this. However, this decreased the freedom of professionals (pt 9). You can see this interplay in the figure 12 below.

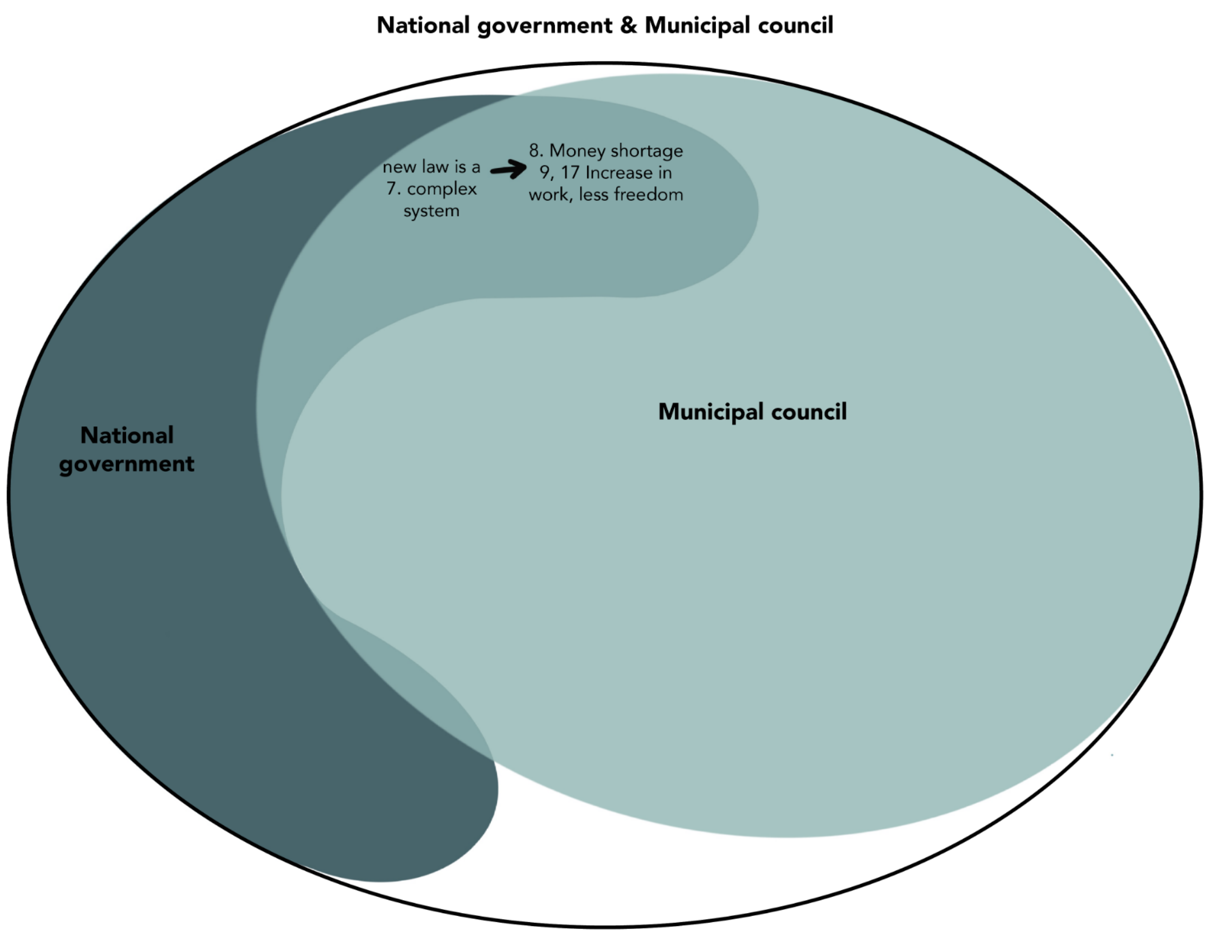


Figure 12: Relation between national government and municipal council

The national government has high ideals and the municipal council works towards those ideals on a local level. However, the unrealistic expectations of what the new law structure would provide beforehand, has left the municipal councils in a tight position. Their budget has been cut, and the quality and efficiency are expected to be higher. This leaves municipal councils very stressed as they are missing resources and money to deliver the quality, whilst still being monitored. It means they cannot do their job correctly, or adapt easily to unforeseen situations. There is a lot of variety in how this plays out locally, and how municipal councils deal with it. There is a feedback loop, but it is slow and bureaucratic. The national government did not equip municipal councils with the right resources to adopt this new law structure, and had too high expectations. However, since they are both representing the same government, the relationship is still strong.

Intention: clear system

The second intention of the new law structure was to have a system that is both less complex and financially sustainable (Kromhout et al, 2020). The goal was to have a system under 1 level of organisation (Kromhout et al, 2020), to make it easier to navigate the system. The complexity of the system includes the administration and monitoring, financial agreements and greatly affects the parties involved.

7. Reality: Complex system

In reality, "The overall system of social services is just as complex as before the decentralisation. There is still a myriad of different actors, schemes and provisions in which citizens, professionals and employers can easily lose their way" (Kromhout et al, 2020, p. 109). This is largely due to the formulations in the laws. Many expectations of the new youth law were "formulated in terms that are open to various interpretations. This gives municipalities the space to further flesh out the policy themselves, but it can also lead to ambiguity and confusion" (Kromhout et al, 2020, p. 34).

This means, in reality there are overlapping areas in the complex system of laws. So, the "*problems arise when people don't fit into one of the laws or processes*" (policy researcher). It is not always clear from which law a situation should be financed, and this causes problems in cooperation between the different sectors (Ross, 2020). The tension was also mentioned in by the regional manager of day care centres: "*There is tension between WLZ and Jeugdwet. The WLZ is becoming more critical when accepting kids, and the municipalities (Jeugdwet) want kids to get WLZ faster, because it will save them money.*" Another example is "*respite care, where it is unclear where the budget should come from: city councils, health insurers, or social support law. Respite care has therefore shifted to helping people who are overburdened, instead of its intended use of prevention*"(policy researcher). As you can see, the law is still complex, and this can put a strain on municipalities.

Intention: Offer better and cheaper care

Another process goal was to offer cheaper and better care. This was attempted by focusing on preventive care, more locally. A large part of this strategy involved focusing on 'own strength" and prioritising preventive care (Kromhout et al, 2020). The expectation was thus a shift from heavy to lighter care. Besides preventive care, the municipal council would be able to provide customised care that better fit the locals. Municipal councils are closer to the citizens, thereby "giving them greater scope to tailor services to the needs of their communities" (Kromhout et al, 2020, p.101). Since this would be cheaper, the budget available was cut beforehand. The budget cuts were deemed crucial for a better functioning and more sustainable financial system.

8. Reality: Money shortage

The intention of better care was somewhat reached, as generally people are positive about the quality of care, as about 70% of parents said their needs were met (Kromhout et al, 2020).

However, the intention of cheaper care by focusing on preventive care did not become a reality, as there is no evidence of a change from intensive to non-intensive help for either social support or youth care services (Kromhout et al, 2020). This means the expected shift from heavy to light care did not become reality. It is still unclear whether preventive care can potentially lower the amount of intensive care needed in the long term, as in some cases intensive care is essential. "*The CSN needs more specialised and more expensive care, for a longer period of time, which strains the municipal council's budget*" (Member of social team: case manager). On top of this, the number of youth applying for care has steadily increased since 2015 (*CBS*, 2020, as cited in Kromhout et al, 2020, p. 24). So, the amount of people using support has increased and there is no clear shift to preventive and cheaper care.

Since the budget was cut beforehand, the new system was implemented with a budget shortage, in case of the CSN parents. A municipality is focused on preventive care, and is "*obligated to give free, light help to all families. But this means some parents, who could have paid for a small course to help their child, now receive it for free, whilst this money is desperately needed to support those kids that need more specialised care." (municipal council member).* There are no definite numbers yet, but the reality is "local authorities are now reporting structural funding shortages "(Kromhout et al, 2020, p. 109).

Intention: more policy freedom

A further intention of the new system is to give municipalities freedom to make their own policies, as it would enable them to tailor services more closely to people's needs (Kromhout et al, 2020, p. 106). Next to customisation, the freedom of policy making would make the municipal councils more efficient. Additionally, the policies would give freedom to professionals to indicate the care needed, and give room for experimentation and innovation.

9. Reality: Increase in work, less freedom

In reality, the municipal councils found themselves in the paradox of more freedom versus an increase in monitoring. After the decentralisation, "*the government also saw the downside of letting municipal councils decide, and the shortages in the social domain*" (policy researcher). The councils were given more freedom to shape their policy, but also had to deal with "standards applied to local authorities with regard to duty of care and protecting the rights of residents." (Kromhout et al, 2020, p.106). This means professionals were made to follow certain procedures, so the quality could still be ensured.Even though the freedom of professionals seemed to be constrained by the bureaucracy and "the need for professionals to render account for their actions" (Kromhout et al, 2020, p.106). In other words, professionals dealt with the tension between the procedures and customising care. The increase in bureaucracy, added to the shortage in budget, meant an increase in work pressure.

Municipal councils - CSN parents

The relationship between municipal council and CSN parents is complex. Municipal councils are responsible for offering care for youth including special needs children, and also preventive care for local citizens. However, as we explored in the last part, municipal councils are dealing with high work pressure and low budgets. This unfortunately leads to a lack in preventive outreach, and it's hard for CSN parents to navigate their way towards help (pt 10). It also leads to long waiting lists (pt 11). Due to the high work pressure, municipal councils buy their care bundles before researching the local needs, and aren't always aware of the options. This leads to the wrong care being given to CSN parents (pt 13). Since some CSN parents are not being helped quickly or effectively, this worsens their situations (pt 12).

This deeply affects the relationship between municipal councils and CSN parents, see figure 13. It leads to a lack of trust towards municipal council workers (pt 15), preventing CSN parents from applying for help. This leads back into the vulnerable cases having their situation worsened (pt 12). The new law gives CSN parent a weaker legal position. The inexperience of many municipal councils has led to there not being any recognition of CSN parents, and they have a hard time keeping track of this group (pt 14).

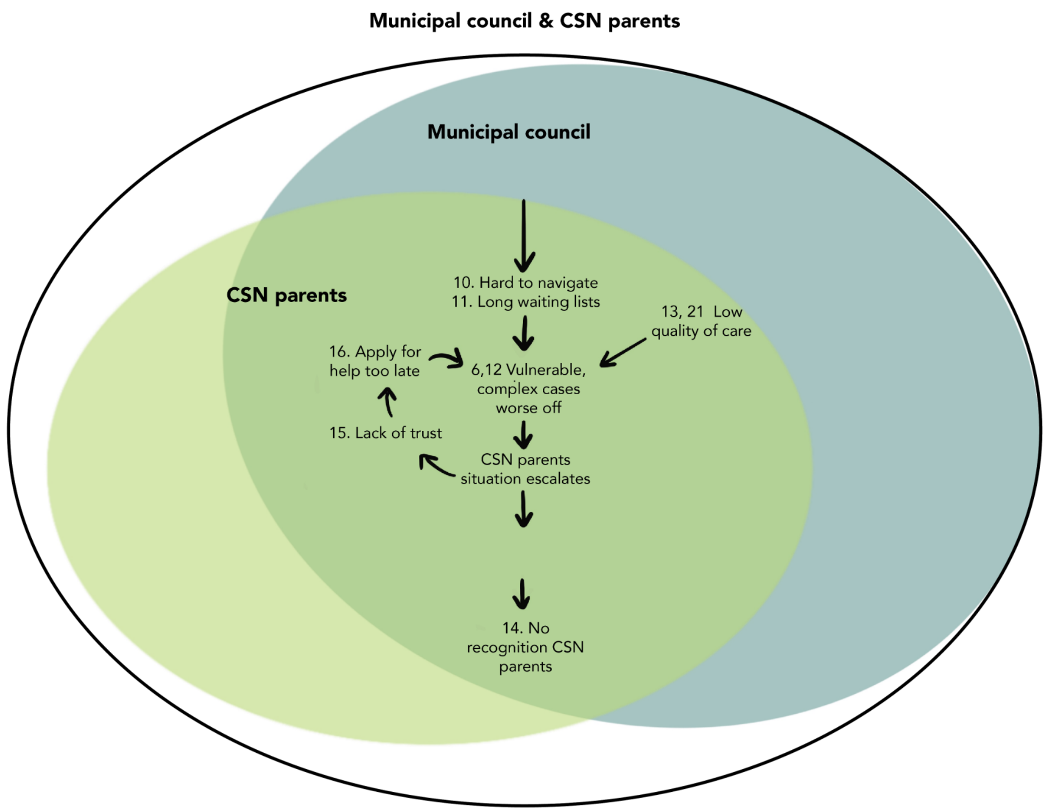


Figure 13: Relation between municipal council and CSN parents.

So, the relationship between municipal councils and CSN parents is complex. The municipal council is doing all they can with the lack of resources, money and time. They want to help everyone in a fair way, and are torn between giving the best help and being strict on what they can offer. Due to the nature of their situation, CSN parents often wait too long to apply, and don't always trust municipal councils with all their information. This leads to many miscommunications, and worsened situations for both actors, though their intentions are honourable on both sides. They are both under extreme stress, and it shows in their relationship. The details of these challenges are explored in this chapter.

Intention: Easy access to services

The expectation was that decentralisation allowed for preventive care, which would in theory lead to a cheaper care system. In order to provide preventive care for their communities, "local authorities organised low-threshold access to services through (community) social care teams". (Kromhout et al, 2020, p. 102). This would allow more people to be reached easily. The focus in municipal councils was to see a client in the means of 1 family, 1 plan and 1 director. This means around a child, they look at the family situation, and make a plan with all involved parties, which is communicated via a contact point. This stimulates parties to work together, to create cohesion for the child they are helping. The combination of easily accessed services, a clear plan and a supporter for informal clients would help people receive preventive customised care in an easy way.

10. Reality: Hard to navigate

Many municipal councils organised easily accessible services through social care teams, however their preventive outreach is not developed adequately (Kromhout et al, 2020). This might be because the options for support from the city council are not well known amongst the public. Municipal councils are aware of this: "*most CSN parents probably don't know they can apply for help at the municipality*" (municipal council member). There is not 1 contact point to go to, and people often don't know where to ask for the help they need (Kromhout et al, 2020). It is often the CSN parents that arrange the communication between these workers, and only half of the parents think they work well together (Kromhout et al, 2020). This can lead to an extra burden for the parents, and take up a lot of time, so "*It would be good for people to have 1 contact person, who can help them navigate where to get care*" (Health insurance administrator).

Intention: Provide quality youth care

The decentralisation was expected to result in better quality care. The municipalities have the responsibility to provide care for the youth. The goal is to have every youth grow up healthy and safely, and grow towards as much independence and participation in society as is possible for them. Since the care is organised locally, the new customisation meant "solutions to problems would be found more in liaison with the client and their informal carer or client support worker" (Kromhout et al, 2020, p. 107). This would improve the quality of care given.

11. Reality: Long waiting lists

In reality, the higher work pressure and budget cuts lead to long waiting lists. There are many registrations and it is hard to know who has priority. Municipal councils are under pressure, since they only have a limited budget and time available. A former team manager youth care said: "*Pressure from above telling us to work through our waiting lists, and take on extra people made everybody stressed, as we didn't get any extra time.*" Preventive help is not given on time, due to these long waiting times, and vulnerable cases often have to wait too long for the right care. So "the long waiting lists are a cause of concern"(Kromhout et al, 2020, p.107). Finding the right care on time "*is a source of worry for a lot of parents, because when you have a spot, there is still a half year or longer waiting list, and their child is just sitting at home in the meantime*" (Remedial Educationalist). This was known throughout the social domain, all people I talked to mentioned long waiting times, and stressed the need for preventive care. It puts a stress on both the municipal workers, as on the CSN parents themselves, and puts a stress on their relationship.

Intention: Integrated working for complex cases

It is more effective to help the family of a youth if other problem areas were investigated too. These problems often interlink, so an integrated approach covering several areas is quite complex: "*Informal care is very diverse, the spectrum is large and many problems overlap with other areas of life. This makes it more complex to solve*" (policy worker).

The new local structure was expected to make this integration easier. Since these areas are all the responsibility of the municipal council, this would make an integrated approach easier for people with problems in several areas (Kromhout et al, 2020). The municipal councils have different departments, which can easily confer and figure out the best approach.

12. Reality: Vulnerable, complex cases worse off

Currently, due to the lack of expertise municipal councils are unable to provide this integrated support, and complex cases are worse off. Providing this integrated support was new for the municipal councils after the decentralisation, and about half struggle with this (Kromhout et al, 2020). This is most likely since only 10% of municipal councils have a team for multi-faceted cases which specialises in this (Kromhout et al, 2020). Another barrier to working together is more on the financial side. Since each domain has a specific budget, the cases that overlap become unclear from which budget the case should be funded. It would help many complex cases if more municipal councils felt capable to handle domain overlapping cases, as when "*there just needs to be more clarity in different areas, as that is often quite a rollercoaster for parents*" (Remedial Educationalist)

13. Reality: Low quality of care

The expectation was better quality care, but in reality, there is a mismatch between the care made available, and the care needed. Municipal councils buy their care bundles before researching the local needs, and aren't always aware of the options (Kromhout et al, 2020). Municipal councils buy the packages of care beforehand, and afterwards starts trying to match this with clients. Care providers estimated only about half the care provided fits the needs of the client (Kromhout et al, 2020). It is often also very frustrating for the municipal council workers: "*But I am also frustrated, because often I don't manage to find a good place that everyone supports and agrees the child will be happy in*" (Member of social team: case manager*)* There are some new initiatives, but they don't conduct research on the needs of the caregivers (Ross, 2020).

Better investigation at the point of communication with the clients would help find the right care right away. Municipal councils can improve by listening to the needs of local citizens before making deals, and " *listening to people's individual stories and needs. This means, they recognize the person, and don't focus on the money, and take the responsibility to get to the whole story*" (PR coordinator Mantelzorg NL).

Intention: Legal position informal carer changed

The new law meant "citizens' right to services has been replaced by a duty of municipalities to provide support." (*Staadsblad*, 2014, as cited in Kromhout et al, 2020, p. 29). This gives citizens a weaker legal position, as it depends on the municipal councils to decide what care they need, giving them the power. The citizens can ask for neutral support person: "In order to guarantee the legal position of citizens, they are entitled to (free) independent client support"(*Staadsblad*, 2014, as cited in Kromhout et al, 2020, p. 29). Independent client supporters are there to help navigate informal carers through the process of finding the right help. In fact, "*Independent client supporters are a good idea, and really help families who are overburdened*" (Former team manager youth care).

14. Reality: No recognition CSN parents

In reality, a general respect for any informal carer is lacking. An informal carer is officially a cooperation partner of municipal councils, as they provide a service, caring is voluntary and deserves respect. However, "Informal carers felt that in those conversations there was often no attention for the help and support they offered"(Kromhout et al, 2020, p. 75). Many informal carers don't recognize themselves as such, or know their rights. A CSN parent is a type of informal carer that is not even recognised, so they have it worse.

In reality, the municipal councils have a hard time keeping track of this target group, they are often in the background. The group chairman of a party said "*I think the municipality does not have a good overview of all CSN parents in Delft, and doesn't know their needs."*(municipal council member*)*. Finances play a huge part in this as "*many city councils don't have enough money to support informal carers, and family care support is under pressure."* (policy researcher*)*. Even though supporting informal carers are technically part of the responsibility of municipal councils, the fact is that "*if the informal carer collapses, it doesn't cost the city council anything, it actually shifts the financial responsibility to the social support law."* (policy researcher*)*. This means if they would invest in informal carers, the money it saves also wouldn't benefit the municipal councils. Therefore, the position of informal carers in the legal system is weak.

In 40-50% of conversations between municipal councils and informal carers, it was not discussed how much support was needed. The independent client supporter is supposed to be a neutral party that helps parents navigate the system, but it is widely unknown. Two thirds of parents applying for youth law had not heard of this option (Kromhout et al, 2020). This applies directly to CSN parents, who are an unrecognised part of this group.

15. Reality: Lack of trust

The reality is, that many informal carers have experiences of explaining their needs, and them not being respected or met. Many informal carers experience a loss of trust in municipalities (Ministerie van Volksgezondheid, Welzijn en Sport, 2019, as cited in Kromhout et al, 2020, p. 91), which makes their situation harder to fix. Informal carers like CSN parents need to feel safe, otherwise they become calculating. They then tend to ask too much, to make sure their needs are covered if their situation changes for the worse over a longer period (Breman-Gijzen et al. 2018). On the other hand, the municipal council workers responsible see following a strict procedure as the best method to ensure they dont go over budget. This means, they are positioning themselves against the CSN parent, doing access control instead of thinking along with them. CSN parents waiting for the right care are losing hope, motivation and faith in the municipalities (Ministerie van Volksgezondheid, Welzijn en Sport, 2019, as cited in Kromhout et al, 2020, p. 91). This makes the relationship between municipal council and CSN parents a precarious one, as each is trying to only look out for themselves, instead of working together. It is hard to win this trust back, but it is necessary. The case manager explained: "*I need willingness to enter a work-relationship together, sometimes parents are held back by previous experiences, developed trust issues and are scared to share.*"

16. Reality: Apply for help too late

This loss of trust also prevents parents from asking for help, thinking they won't receive it and would rather save their energy. Many CSN parents had to deal with disappointments, and overall there is a "signal a loss of hope, motivation and confidence of parents in the youth care" (Ministerie van Volksgezondheid, Welzijn en Sport, 2019, as cited in Kromhout et al, 2020, p. 91). This means many are not open, or even "*Many parents will deny needing help*"(Remedial Educationalist). It can be a shameful, or hard topic to open up about. "*The informal carer can also initiate this conversation, but not all informal carers have that ability. Especially the more vulnerable ones easily overburden themselves.*" (Informal care consultant) This causes CSN parents to take on too much burden and to wait asking for help until it is too late, resulting in escalation.

Municipal councils - Care domain

The relationship of the municipal council with the care domain is mainly one of collaboration. These are two parties who are often working together to provide care for the local citizens. The care domain ranges from insurance, to hospital workers and care providers, so there is always someone involved. However, they also share challenges, as shown in figure 14 below. The work pressure and budget shortage experienced by the municipal council is passed to the care domain (pt 17). Though collaboration is happening, it is often difficult, as the tensions put a strain on their relationship (pt 18).

Since the care is now given on a local level, there are not enough specialists to provide insight for complex cases (pt 19). Smaller municipal councils don't have a budget for specialists, but that doesn't mean the cases don't exist in these regions. It constricts specialists from doing their work, leading to a worse quality of care eventually. The lack of budget shared by these two actors also means there is little to no room for innovation (pt 20), leaving them stuck in the same positions.

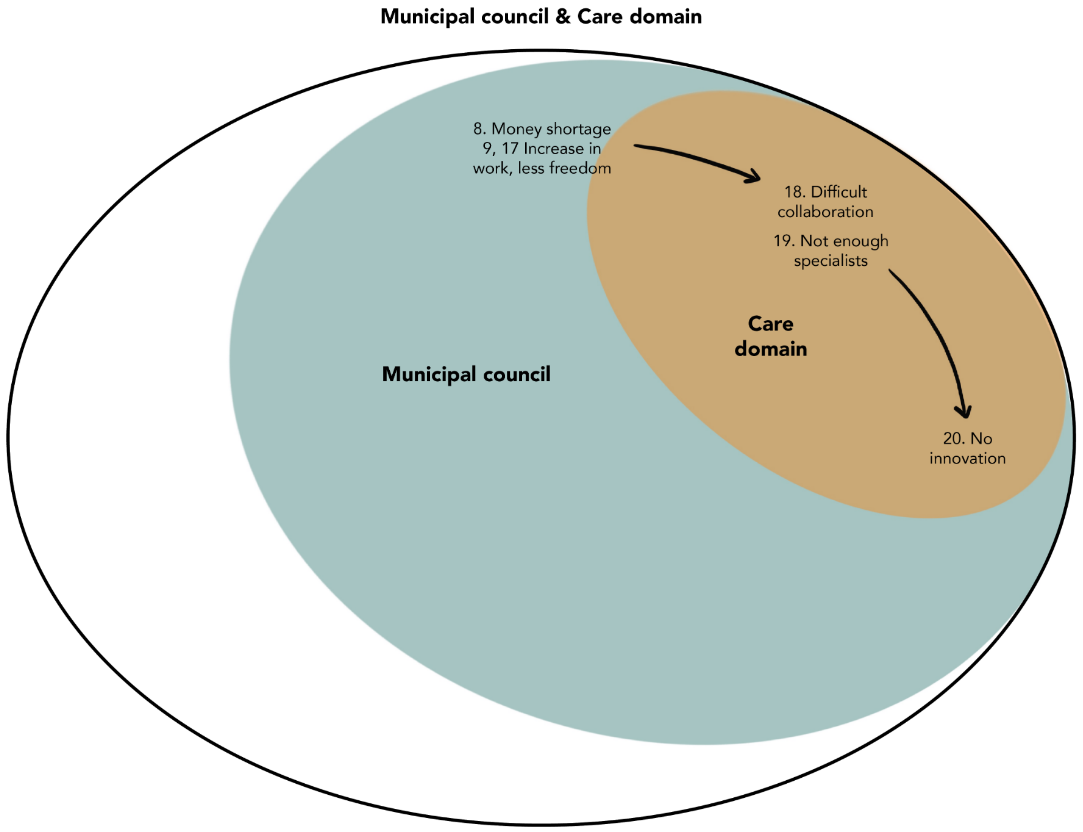


Figure 14: Relation municipal councils and care domain.

The relationship of municipal councils and the care domain is therefore one of shared stress, passing their problems from one to the other. When they are stressed, this means they are often defensive, and don't trust each other's expertise. They need time and space to give each other feedback, reflect and improve their collaboration.

Intention: Regional based care: freedom of policies

The new youth law in 2015, made the care more regionally based, instead of national. This would provide the opportunity for more customizable care, to cater to the needs of the inhabitants of that region. Municipal councils can customise care, by making their own policies, allowing for regional differences in policy making. "*The idea is that the municipality can organise it in such a way that it can provide the care that is needed most, but for as little money as possible.*" (Policy researcher). The care domain would benefit equally, allowing the relationship between municipal council and care domain to advance.

17. Reality: Increase in work, less freedom

The effect of the decentralisation on freedom has been discussed in the relation between the national government and municipal councils. However, it also had its effect on the relationship between municipal councils and the care domain.

Freedom seems to have increased, but is hindered by the bureaucracy required by the youth law (Kromhout et al, 2020). Bureaucracy means professionals are held accountable and monitored. Municipal councils have more administrative tasks, due to an increase in different types of contracts (Kromhout et al, 2020). Not only the municipalities, but also the care domain had an increase in administrative burdens. A nurse explained: "*The government gives us many rules and processes to follow, which can be very frustrating.*" (Community nurse). They are obligated to work with a lot more parties than before, and deal with several municipalities, each of which has its own policy. This leads to more regulatory pressure (Kromhout et al, 2020).

The increase in administration makes it harder to collaborate, like health insurers only having time for contacts with larger cities, and often not conferring with the smaller cities: "*There are more one on one meetings with municipalities, and for us it's frustrating, because we have to deal with a lot of them, and they all have their own policies.*" (Regional manager day care centers). Likewise, both GPs and indication offices are all less approachable, due to the increase in work (Kromhout et al, 2020). This does not benefit the collaboration between parties, as established by a manager who worked with both parties: "*We used to have an amazing team, who all were able to focus on the child and overcome their differences to work together. Because of increasing workload and administrative handling, and budget cuts, it put a strain on our relationship, and the team started having more tensions*" (Former team manager youth care).

Intention: Better collaboration between parties

Another intention of the new youth law structure was to facilitate better collaboration between municipalities and other parties. The youth law gives municipalities the responsibility to coordinate the different care services, as they buy the youth care at healthcare institutions and independent care professionals, and work together with education institutions and welfare organisations. The government report states "Giving local authorities responsibility for implementation would, it was believed, make it easier for them and other stakeholders to work with each other" (Kromhout et al, 2020, p.105). It also allows room for easy feedback and innovation since all parties work together.

18. Reality: Difficult collaboration

In reality, there is a two-sided effect: on the one hand, there was an increase in collaboration. For example, there was an 84% increase in collaborations with general practitioners, and a 73% increase with health care specialists (Friele et al., 2018, as cited in Kromhout et al, 2020, p. 55).

This is very important, as most people come to the municipalities' social team via another organisation. Most youth care, for example, is referred by a general practitioner.

On the other hand, the collaboration is more difficult, due to the number of parties and lack of cohesion. Municipalities have a hard time integrating the different care domains: half of them are struggling. This half says it's hard to work with the other domains due to 'financial barriers' (Kromhout et al, 2020). This can be because the policy and implementation of the youth law is the least specified in comparison with the other laws. There are a lot of grey areas between the new laws, which don't clearly define who is responsible for what, especially in terms of financing (Kromhout et al, 2020).

Parties have their own goals and methods, different finance structures, professional ethics codes and target groups which makes collaboration more difficult. Language and culture can cause misunderstanding between professionals, leading to a lack of trust in each other's expertise and plan. "The lack of trust in each other's expertise particularly affects the cooperation between local teams and specialist providers" (Friele et al. 2018, p. 66). This often leads to views that clash, as it isn't always clear what the best course of action is, given the complex situations: *"Sometimes working together with other organisations is frustrating, as the communication is off, many issues overlap, and the communication is not clear what everyone is working on."* (Remedial Educationalist).

Only about half of the city councils have an overarching social team (Kromhout et al, 2020). Even within the social teams, professionals still represent their own organisation and own interests. There is sometimes competition between parties (Kromhout et al, 2020).

Privacy rules further prevent smooth collaboration and slow down the process. It is hard to find "the right balance between the need to share data between professionals on the one hand and protect the privacy of citizens on the other." (Kromhout et al, 2020, p. 105). The privacy laws don't allow organisations to share data, and they have to ask permission, which takes time. "*The privacy law is hard to work with. Many families get help from several organisations, and we cannot view each other's work. It is up to the parents to be open about it, and it happens that crucial information is missing from my files.*" (Remedial Educationalist).

So, though collaboration has increased, it is more difficult than before. Local differences and having to work with a big variety of parties, has made it hard to collaborate and develop trust. Furthermore, it can even increase competition between parties. Privacy laws are not helping the collaboration advance either.

19. Reality: Not enough specialists

In reality, the new collaboration indirectly leads to less specialists available. Another downside of the decentralisation is that specialist care is still needed, but on a local, smaller scale it becomes unaffordable. Maintaining a regional specialist’s team is too expensive for most city councils, and only about 22% have youth specialists (Kromhout et al, 2020). Due to this lack of specialists, there is not enough knowledge available. The "right expertise for these more complex cases is lacking and light help is provided for too long, causing situations to escalate" (Kromhout et al, 2020, p. 78). It is often the most complex, vulnerable cases that need specialists. The remedial educationalist I spoke to affirmed this; "*Since the whole specialist help has been cut so much, you just have fewer groups, which is good on the one hand, on the other hand there are just children who really don't make it within the existing forms. And so, there are waiting lists for those, and those are often the most vulnerable children, who then sit at home, for example*" (Remedial Educationalist).

20. Reality: No innovation

An increase in collaboration of the new law was with the goal in mind to allow room for innovation. However, in reality, there is "no clear evidence of innovation in care provision in the first years after its introduction" (Kromhout et al, 2020, p. 106). The budget cuts and short-term contracts are limiting the opportunities for innovation (Kromhout et al, 2020). This means, preventive care has not been developed. Innovations in youth care actually miss the investments of care providers (Kromhout et al, 2020). Innovation seems like the only solution to solve the problems encountered in the care domain and municipal councils. This requires a renewed focus on the client, and mostly "transformational leadership" that can find the room to make changes (Yperen & Hageraats, 2018, as cited in Kromhout et al, 2020, p. 73).

Care domain - CSN parents

The care domain and CSN parents have a very direct relationship. They are often in contact, as the care domain takes care of the special needs child. Since the budget has been cut for the care domain as well, unfortunately the care is now of lesser quality (pt 21), see figure 15. It is something both the CSN parents and the care domain struggle with, as the care domain workers have high expectations of the care they can give. The care domain is very professional, and knows how to help the child. They don't have much time to check on the CSN parents, as it is not their responsibility, their first priority is the child. Therefore, the care domain and CSN parents don't often have the chance to discuss if the situation is going well, and to reflect together. However, the care domain has high expectations of CSN parents, eg. organising the care, but also learning to continue the specialised care of their child at home. The insight into the lives of CSN parents, and the pressure they are often under is therefore lacking in this relationship, and preventive care is not given for the parents (pt 22). This puts a strain on the relationship, and can lead to a lack of trust.

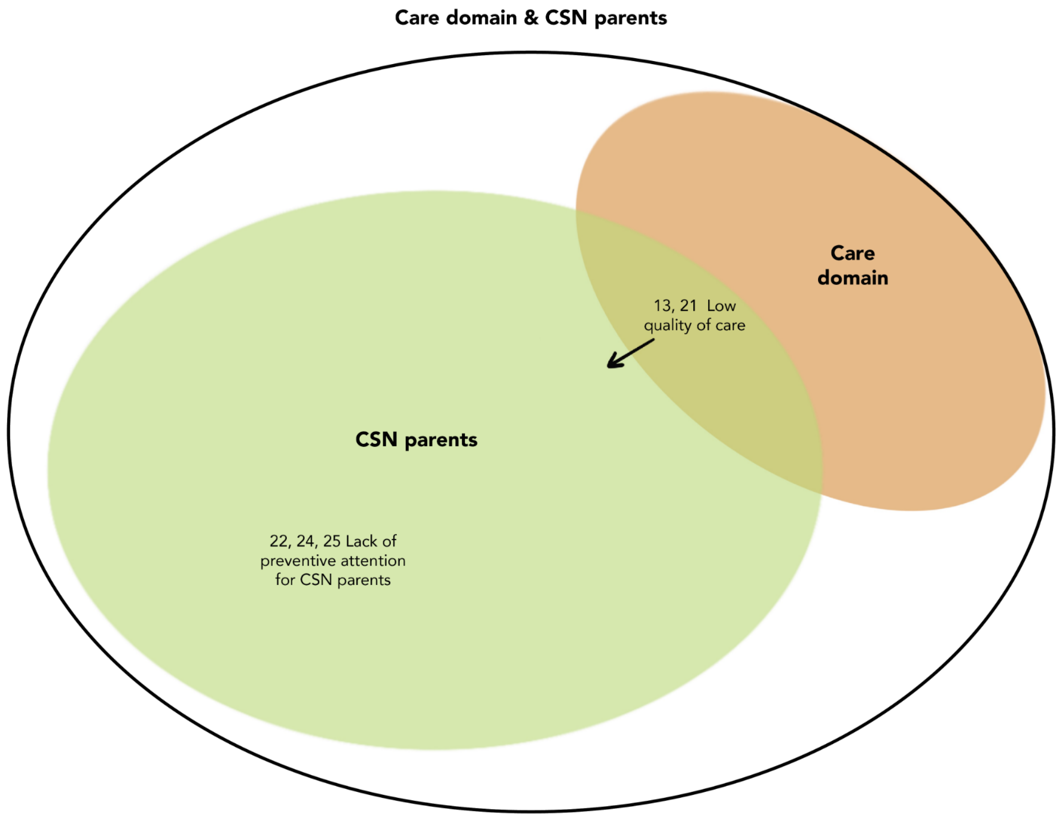


Figure 15: Relation care domain and CSN parents.

Intention: Decentralisation increases quality care

The decentralisation of care meant that the care was now organised locally. This would allow for better customization, leading to better quality care.

21. Reality: Low quality of care

In reality, since the decentralisation, the quality of care has worsened. This is a paradoxical effect, as the decentralisation was meant to make care more focused locally, but the effect is that local help has weakened (Ross, 2020). Similarly, "the experts signal a decrease in quality of care due to the low rates." (Ross, 2020, p. 25). As explained earlier, the lack of quality of care is caused by the budget cuts, which is due to the government's decisions. However, it does put a strain on the relationship between the carers and CSN parents, as carers cannot give the quality of care they strive for, and parents are left to deal with the lack.

Intention: Preventive care

As explained in previous parts of this chapter, one of the intentions of the youth law is to focus on preventive care. Preventive care would save money in the long run, by making sure the care stays as light as possible. Preventive care is currently focused on the client, in the case of CSN parents this is their special needs child. The parents of the child are also urged to be more actively involved in the process: "*If you look at the past few years, the trend in healthcare is that you want parents to be much more active in the treatment. You want to give them a much bigger role in the treatment.*" (Remedial Educationalist)

22. Reality: Lack of preventive attention for CSN parents

In reality, the intention to include parents more in the treatment has been fulfilled. Many care workers are focused on actively involving the parent: "*I personally think it is important to be close to the family, so you have to make sure you invest in the working relationship with the parent*" (Remedial Educationalist). However, what has been overlooked in the plan are the long-term situations of the parents. The current preventive care is focused largely around the CSN, to make sure the care stays as light as possible for the child. However, the parents are forgotten, as they, in most cases, also need preventive care in order for them to maintain their informal care over a long period of time. They are seen "at best as a derivative of the person he/she cares for" (Ross, 2020, p. 7).

It is crucial to support the CSN parents as they are a direct and biggest influence on their child's life. The consequences of not giving preventive care to CSN parents are that they eventually become overburdened. The decentralisation tried to save money by relying heavily on 'own strength' of CSN parents, and "*Respite care has therefore shifted to helping people who are overburdened, instead of its intended use of prevention*" (policy researcher). Instead of helping parents manage their responsibility, asking for preventive care has become a taboo, so "*asking for help is hard, and people don't realise how much they need it, or are embarrassed*" (Former team manager youth care).

Preventive care for CSN parents includes monitoring how they are doing, and supporting them in practical things. The social workers should use their expert position to help parents navigate the care domain, for example: refer them to local options for support like an independent client supporter, or other organisations, or a specific professional instead of a general direction. (Breman-Gijzen et al. 2018). When problems arise between parties about finances or methods, the care domain currently lets CSN parents figure it out. However, it is more efficient to solve it amongst themselves, openly share details with the new care provider, and think of an emergency plan together (Breman-Gijzen et al. 2018). Many doctors and medical professionals "*are scared to go outside of their expertise zone. They stay very safe in their comments, whereas it helps when doctors are open, and tell you the different scenarios and help manage expectations, or come with solutions* *themselves."*(PR coordinator Mantelzorg NL). Another mentioned "*Professionals should have more empathy for CSN parents"* (Independent coach), indicating the current lack.

Currently, some of the workers in the care domain are becoming aware of this problem, but are held back by the existing structure. For example, for respite care, "Waiting lists and administrative procedures are major obstacles. Not only the carer, but also the involved healthcare providers face this." (Ross, 2020, p. 7). Most workers in the care domain run into their limits at some point, as they *"try to support and hear parents as best as possible, but we can't always solve it either"* (Remedial Educationalist). It is therefore a topic that needs attention to improve the relationship between care professionals and CSN parents.

Charities - CSN parents

The big national charities are focused on helping CSNs and helping informal carers. There are some charities that give temporary relief for CSN parents and CSN families, for example those providing holidays, or respite weekends. These are very few small local initiatives focused on helping CSN parents in the long term. The relationship between charities and CSN parents is therefore a positive one, but it does not have a big impact on the system and situations. The bigger, national charities don't have CSN parents on their radar as a specific group, and therefore don't often act as a spokesperson for this target group. They would advocate more generally for informal carers, but since the CSN parent situation is unique, they don't always benefit. The relationship could become more powerful, and help CSN parents' voices be heard in society as they are currently missing (pt 23), see figure 16.

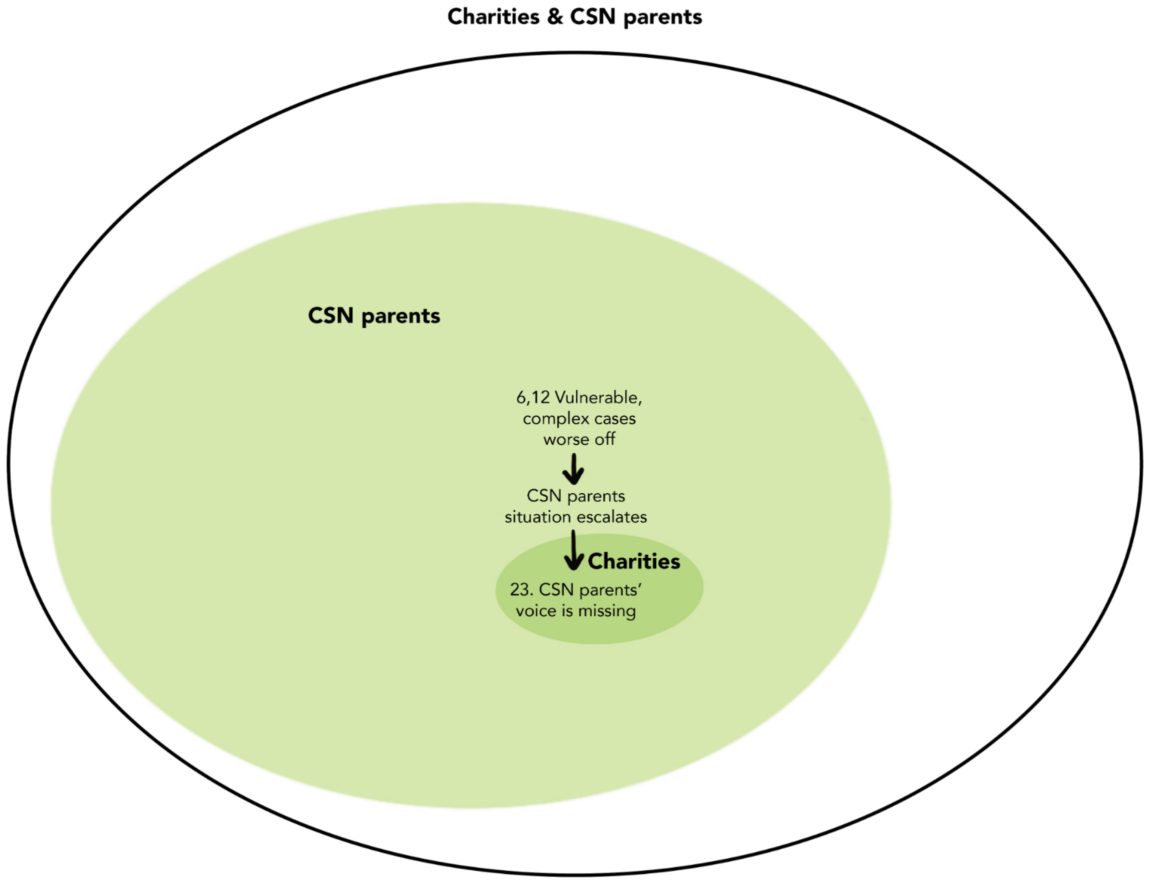


Figure 16: Relation between charities and CSN parents.

The changing role of charities

The structure change from national to local meant that charities had to change the way they operate. They now have to work together with municipal councils, and getting national data is more complicated. Their sources of income changed as well: now municipal councils can give them some budget, but there is also still some money available from the national government. This leads to some competition between charities.

Before the centralisation, charities played a big role in researching and spreading information, between informal carers and the national government. It is important they keep playing this role, since charities could be an objective party that researches the national data of informal carers. By providing a platform for informal carers, "*Their goal is to get attention from the government and organisations, to make sure change happens.*" (PR coordinator Mantelzorg NL) They can help "*informal carers to show their struggles, ambitions and needs, and encourage them to share their stories.*" (PR coordinator Mantelzorg NL).

23. Reality: CSN parents' voice is missing

However, since the structure has changed to more local, charities are also needed to mend the gaps between the city councils and care domain. One tension they could help relieve is to help local organisations collaborate and stimulate innovation.

Taking respite care as an example, one problem is that "municipalities and policymakers are insufficiently aware of the possibilities of respite care for the informal caregiver" (Ross, 2020, p.7). Actors are not communicating well with each other. Municipal councils are not aware of the possibilities, the care domain is kept in the dark, and the lack of self-recognition means informal carers don't seek out their options. Charities are in contact with all three actors, and though they often don't have the power to change, they are the messengers between the actors. Charities like "MantelzorgNL can play an important role in transferring the mission and good examples of solutions for the effective use of respite care" (Ross, 2020, p. 10). Generally, charities are needed locally, and nationally, to help the actors communicate better, since CSN parents are currently mostly unable to voice their own concerns.

Network - CSN parents

The relationship between the network and CSN parents is complex, because it's slowly changing. Since (or just before) the birth of the CSN, the CSN parents are dealing with a situation which the network doesn't understand. Since their child needs special care, it often isolates the CSN parents, and they are consumed with caring. It means they are less present in their network, and the relationship with them changes. Shame, guilt or the need to be independent often keeps CSN parents from asking for help themselves. Often, when the network sees the CSN parents being overburdened, there is a willingness to help. However, since they don't fully understand them, they often don't offer the right type of help. The network does not recognise what is needed for CSN parents to prevent them from burning out (pt 24), and often reaches out too late, see figure 17. The network and CSN parents grow apart, and this isolates them even more.

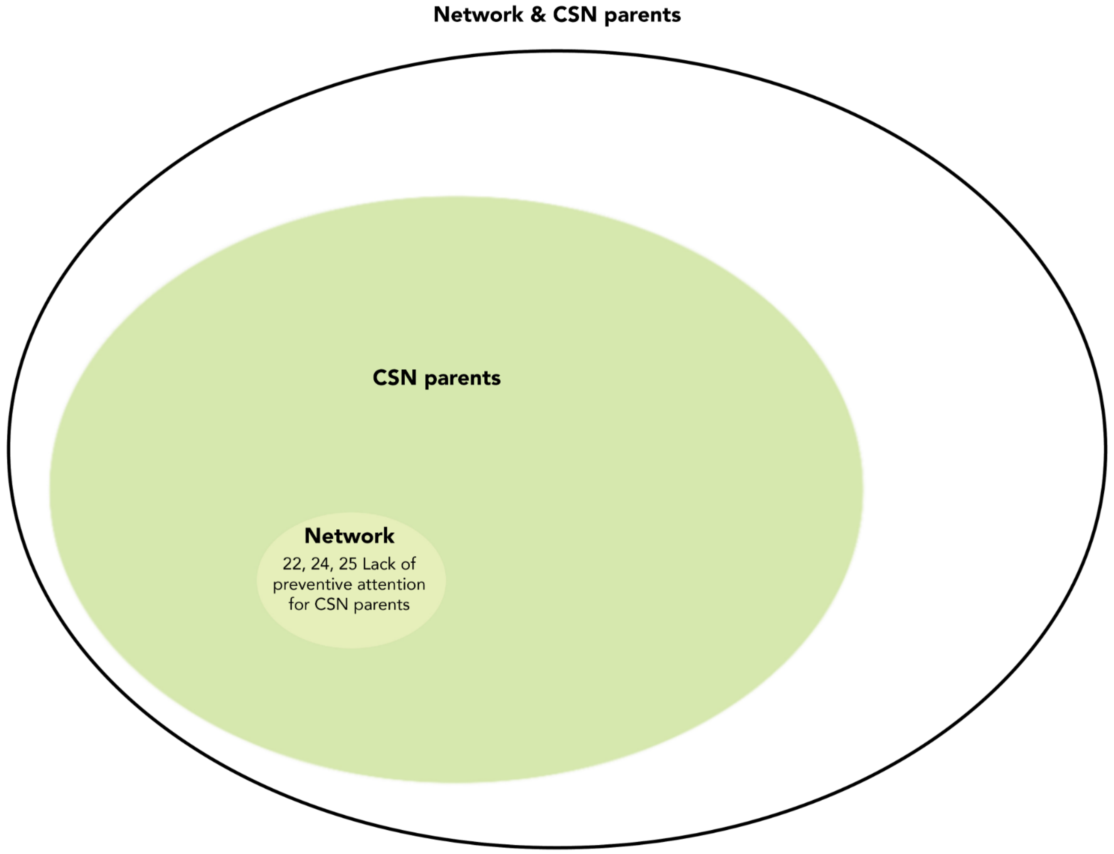


Figure 17: Relation of the network and CSN parents.

24. Reality: Lack of preventive attention for CSN parents

Currently, there is a lack of support from the network towards CSN parents, because they focus too much on the child. Many people in the network assume they would have to care directly for the child. However, "it is important to make a distinction between the child, for which specific and professional care continues to be required, and the temporary relief of parents and brothers and sisters for which the social network support can be used "(Okma et al, 2014, p. 31). The network doesn't need to learn to take care of a special needs child, but they can also support the parents, by relieving them of some of their other responsibilities: "*It would help many informal carers to ask their network what they would like to contribute, even if it's something like making some phone calls for them.*" (Informal care consultant). By asking people what they would like to contribute, or letting people offer the kind of support they do best, the network can also support CSN parents.

This kind of support can even be mental support, and helping CSN parents think more of the long-term. This is crucial for parents that are stuck in survival mode: "*You need people that break through informal carer's walls, and ask the difficult questions: you should take care of yourself, you are not going to take care of your child for the rest of your life, are you?*" (PR coordinator Mantelzorg NL). CSN parents need to be confronted with the fact that their long-term planning is not sustainable. This is the kind of preventive support that is best given by close friends, family and people you trust, and it is imperative for CSN parents that the relationship between the network and CSN parents stays strong.

National government - Network

The national government decides the laws and structures of most of society, in which the network of CSN parents is also a part. It also works the other way: since the Netherlands is a democracy, the society votes for the members of the national government. They influence each other, and together form the fabric of Dutch society, in which the network of CSN parents have a part.

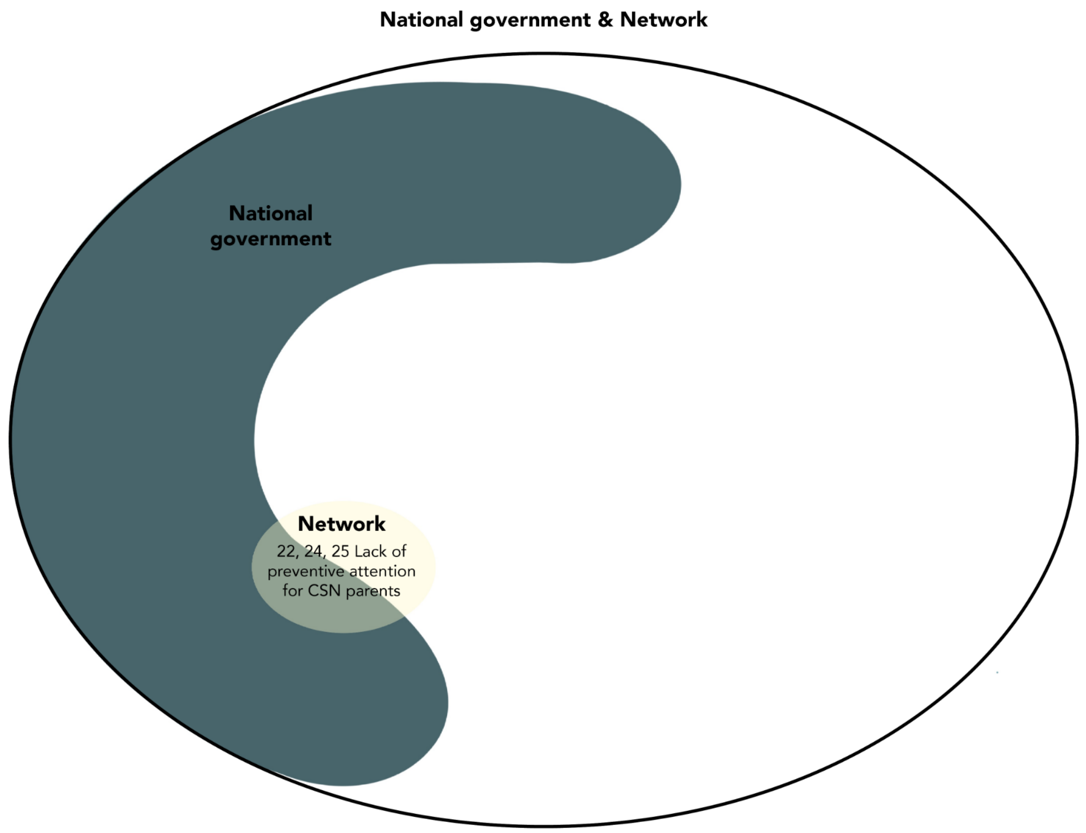


Figure 18: The relation between the national government and network.

The current (voted on) ideology is contradictory, as people are encouraged to work more, but also to be more available for helping their community. An example of such a law structure is that employers are not encouraged to give preventive care to CSN parents, though it could lead to the prevention of burnout, and more productivity. This is an example of how current society is structured so it does not allow much preventive attention for CSN parents (pt 25), see figure 18.

Intention: Equal earning chances

The ideology of the government is that everybody is encouraged to work and be productive. Additionally, there is a general desire to provide better support for their informal carers (Ross, 2020). Informal carers, especially CSN parents, are seen to have made the choice to stay at home and parent (Ross, 2020).

25. Reality: Lack of preventive attention for CSN parents

Since there is no exception made for CSN parents, and there is no clear definition, it is hard for employers to give preventive care for them. Currently, laws for CSN parents are the same as any other parent, and they could be changed to be more lenient and prevent burnout. Employers currently don't know how to support informal carers, and could be trained to know the local options for help (Breman-Gijzen et al. 2018). It comes down to the definitions and incentives given by the national government that also determine how the workplace sees it. Currently, "*if you can't work because your child is sick ... the taxes are in favour of couples who both work. That is not fair, since it was not a choice not to work, but a necessity to care for your child. This is a national process, not something we can influence locally.*" (Municipal council member).

Parents often don't have a choice but to stay home to take care of their CSN. Many CSN parents try to do both, and work next to taking care of their CSN. However, this is not manageable long-term and many have to stop working due to burnout (Okma et al, 2014). This causes problems for both the parent and the employer that could have been easily prevented.

This means the national government is currently not helping employers to support CSN parents. It is hard for employers to recognize the situation, arrange care and there is no incentive. By improving this, an "*employer can spot an employee who is struggling with their schedule, and the government can incentivize them to help their employee and support them.*" (Municipal council member). By providing information and incentives, the national government would improve the "employment" part of the network that can support informal carers. This would also immensely help the informal carers, as "*CSN parents should get the opportunity to keep working, and keep that part of their life the same, otherwise they end up in a negative flow of just caring.*" (PR coordinator Mantelzorg NL).

System map

Below, figure 19, is the final system map of the system surrounding CSN parents. It shows the steps 1-25, and their overlap. It is all the actor pair relations added together in one visual, showing the interplay between them and how they are all connected.

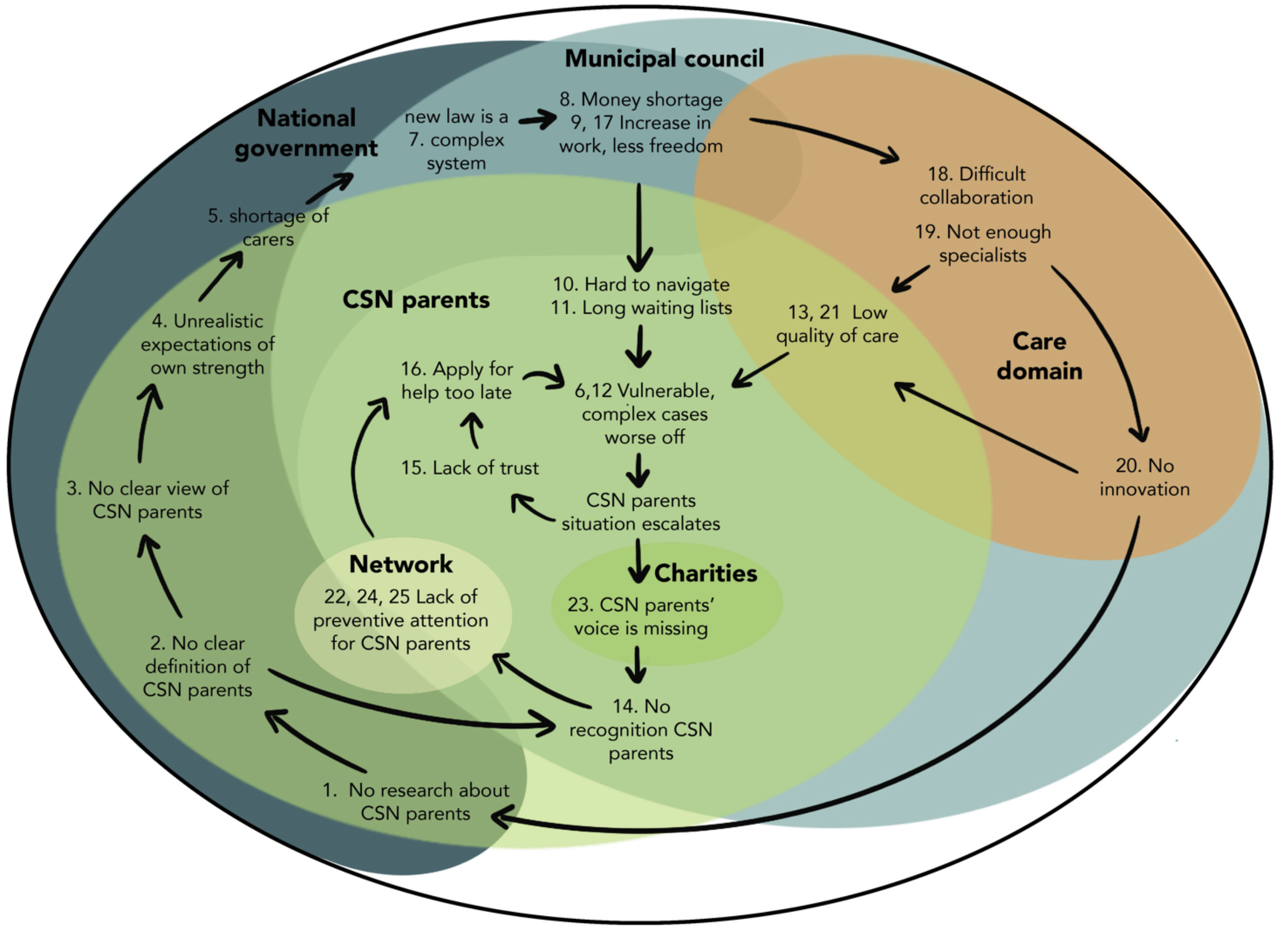


Figure 19: Final system map showing the relations between actors, including all 25 points.

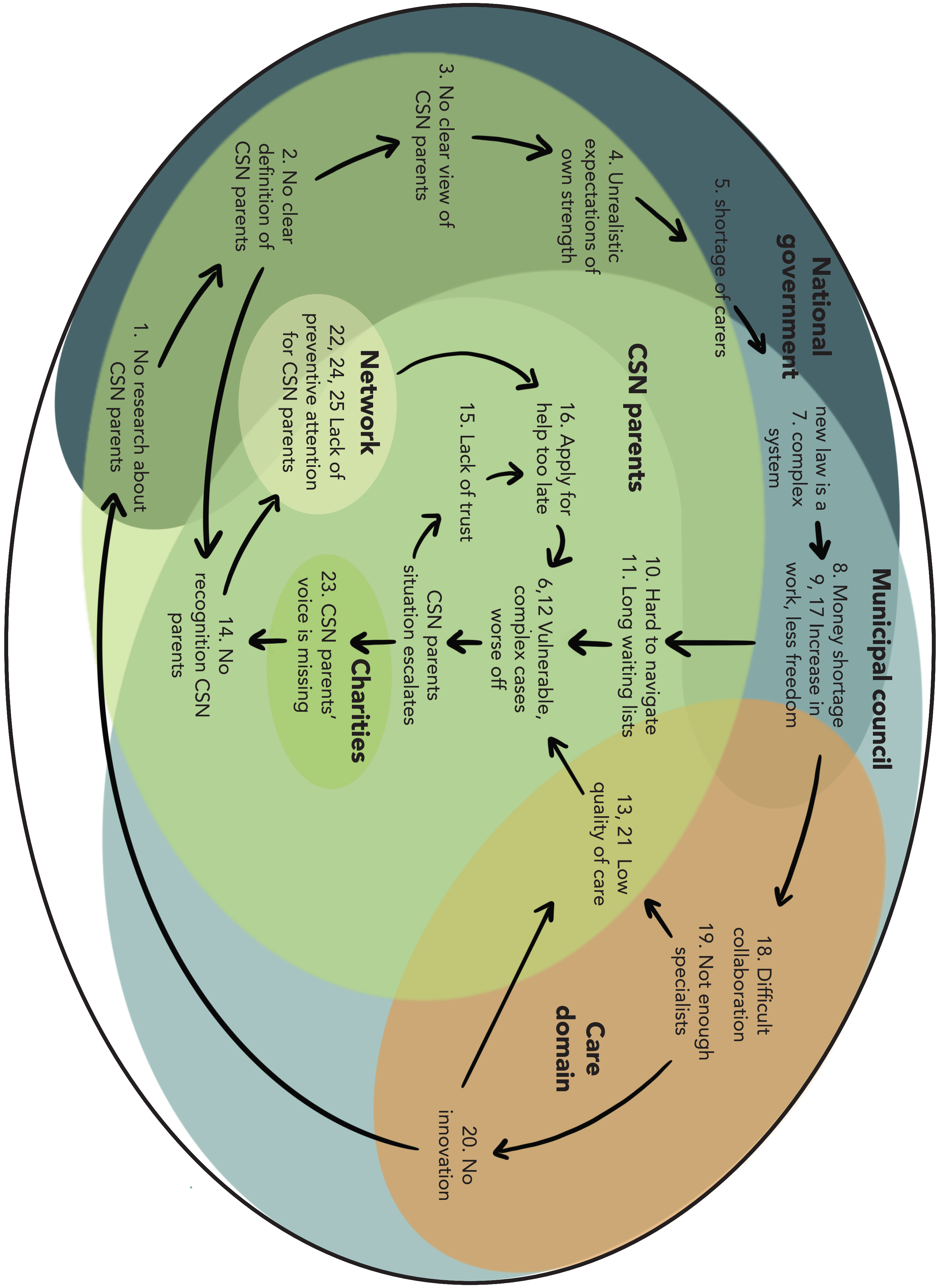


Figure 19: Final system map showing the relations between actors, including all 25 points.

Strategy for Ontzorghuis

5. Strategy for Ontzorghuis

Introduction

In this chapter, the conclusions from the systemic design research are translated into a strategy for Ontzorghuis. To start, let's take a look at my initial aim for my graduation:

I will research, frame and visualize the bigger context of Ontzorghuis, in order to determine their opportunities to achieve their long-term goal of systemic change. I will build on their future vision and design strategic interventions to achieve systemic change, and design it in such a way, that it is actionable for Ontzorghuis.

In the previous chapters I explained the findings of my research, and framed it in a system map. Using this map gives many opportunities for interventions. The next chapters are therefore dedicated more towards building a future vision for Ontzorghuis, and the interventions towards systemic change. I use the steps of systemic design introduced in the methodology chapter. In this chapter, I wrote down the steps so it follows a logical manner of explanation. In real life, this was not a linear process, and these steps were done at the same time.

Leverage points from system map

In order to translate the system map into a strategy, let me recap the systemic design process. The previous chapter shows the result of steps 1-2 which are **framing the system**, and **listening to the system**. It also shows part of step 3, which is **understanding the system**, as you explore the previous chapter with the system map (Curatella, 2021). The conclusions from the system map are also part of step 3, as it is used to discover the leverage points.

Leverage points are areas on the system map that can be used to achieve change. The change is always a chainreaction: since the system is interconnected, changing one thing will affect the others. Leverage points were researched by Donella H. Meadows, and they vary greatly in abstraction level. The more concrete points include parameters and numbers, stocks and flows, things you can measure. In the middle are things like structure of information flows and rules of a system such as punishments and incentives. The more abstract points are the goals of the system, mindset and paradigms (Meadows, 2012).

So, looking at my system map, you can see it is a summary of the relations between actors. Real life is more complex, but the basic structure of the system is visualised in this map. All actors influence each other, and you could put an intervention that would change the system at some level at any point. However, the key to systemic change is finding the points that has the most impact, the most leverage, and digging a little further there (Meadows, 2012).

The system map can be visualised in many different ways. I chose to follow the relations between the actors, and show how the problem shifts from one actor pair to the next. In the centre you find the CSN parents, whose situation is escalating, and experiencing the core problem. The map shows a variety of points that range in abstraction. Some points like money shortage can be measured, and are very straightforward. Points like difficult collaboration are a bit more abstract, but seem more like a consequence of earlier problems, then the core. If you solve a point earlier in the system, like less work pressure, this point would resolve as well. The points to achieve systemic change are those that will cause a chain reaction in the system: if you tackle these, many will be alleviated consequentially.

In this system, you can see the core problem in the middle: vulnerable cases worse off. The core problem is that CSN parents are suffering. There are basically two loops leading into it: firstly, they apply for help too late. Secondly, there are long waiting lists. These are pretty straightforward, and easy to understand. If you follow these loops backwards, they become more abstract. Together with Marise, I explored the impact each point would have.

- For example, if you have people applying too late, you need to make them apply earlier by making them aware. This means more preventive attention for CSN parents. But how do you reach these CSN parents when you don't know who they are?

- Same goes for the idea of money shortage: in order to increase money, the government needs to change their expectations. The government would need to get a new, clearer view of CSN parents. However, there is currently no definition of CSN parents, meaning they are impossible to recognise as a group.

- In fact, since there is no clear definition of CSN parents, parents can hardly recognize themselves. How can actors help prevent CSN parents from escalating if they do not recognize them?

So, the biggest impact in the system can be reached by looking at the following leverage points: no clear definition of CSN parents, leading to a lack of recognition, and a lack of preventive attention. On the system map, these points are highlighted in yellow, see figure 20.

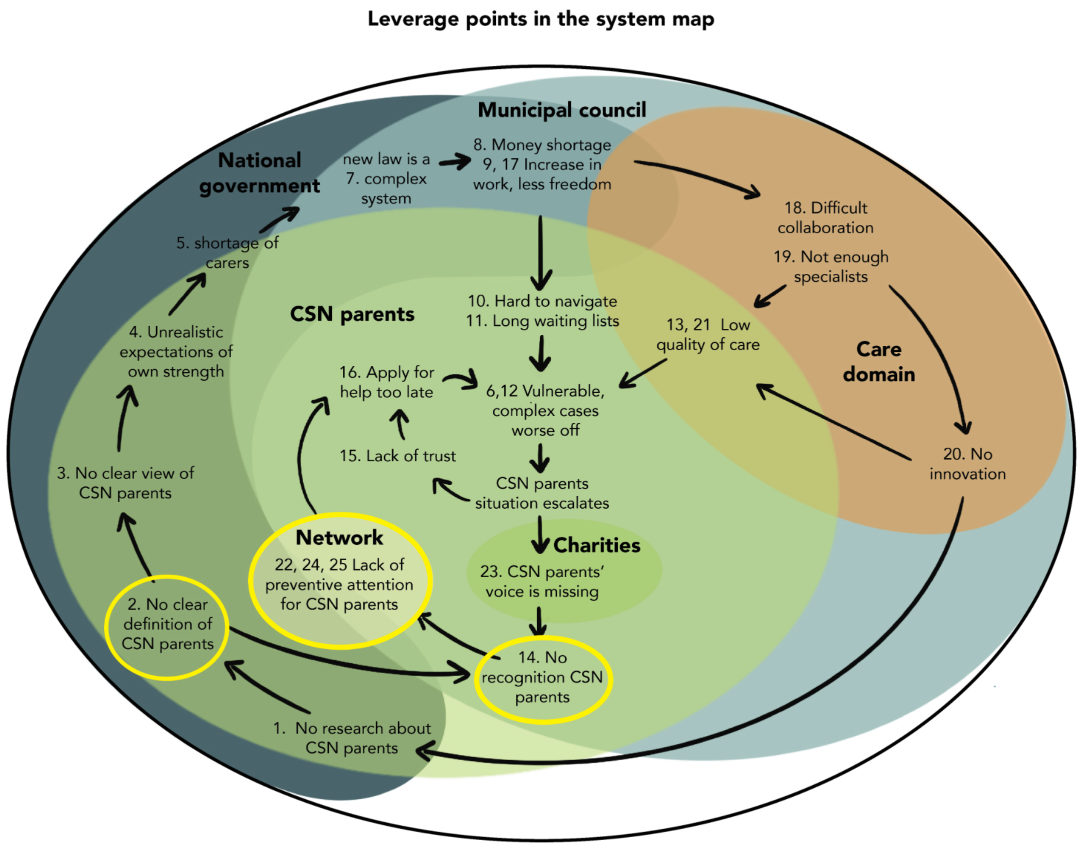


Figure 20: Leverage points on system map.

The leverage point for this system is quite abstract. Donella calls this "paradigms - the mind-set out of which the system — its goals, structure, rules, delays, parameters — arises." (Meadows, 2012). Paradigms are the unstated beliefs that are shared and known by everyone in the system. They are often unspoken, because everyone already knows and understands them. They differ per culture, but in this system, they are shared.

The paradigm in this system was explored by looking at the key leverage point: recognising CSN parents. Why are CSN parents hard to recognise? They currently just fall under the category of parents. All actors seem to want CSN parents to stay as independent, and as close to normal 'parents' as possible. The mindset of everyone in the system is: **CSN parents should take care and raise their special needs child by themselves, just like any other parent.** The mindset is focused only on the parents: the responsibility of caring for their child in everyday life, is expected to be done by the parents. Taking care of their CSN is seen as a regular task, and not as an informal caring activity. So, this does not include the mindset towards the child, which is mostly being treated differently.

This is actually the most natural occurrence; every parent wants to bring up and care for their own child. It feels natural to be responsible for your child, and for special needs children this is the same. This sentiment is shared by the national government. As I wrote in the chapter relations, CSN parents are not seen as informal carers and not immediately eligible for support in bringing up their child. The policy maker I spoke to explained this contradiction: *"The process is a little different for parents with a CSN. On the one hand you immediately know it is different for them, on the other hand it is also part of having children that you take care of them"* (policy researcher).

The current mindset of the system is that any parent should be able to take care of their child, even if that child has special needs. This means that when parents have a CSN, they assume they will be able to handle the responsibility. When the care becomes too much for them, they are disappointed, and feel like they "failed" the expectations. It makes it hard for them to ask for help, and hard to admit they cannot carry the responsibility alone. When they do realise, they need help, they often have to fight for recognition, and lack the words to explain it. The whole network and system around them have the same expectations, and are not looking to help with parental responsibility, they only focus on the child.

Step 4: Defining the desired future

This system is set in a meritocratic society, where everyone's wellbeing is their own responsibility. If society would see a child with special needs as a situation that should not just be the responsibility of the parents but also those around them, it would greatly disrupt this vicious cycle. It could mean more support for CSN parents. The envisioned change for this system is therefore a mindset shift of people becoming aware that parenting for a CSN child is not the same as parenting a child that does not need extra care. Changing the expectation would create a new perspective and level of respect for CSN parents and would encourage opportunities for people to support CSN parents. It would alleviate CSN parents from overburdening themselves, and then having to fight for the right help, instead making it normal for them to receive help. This fits exactly the goal of Ontzorghuis, whose goal it is to support CSN parents.

Step 5: Exploring the possibility space

The intervention that would have a big systemic impact, is therefore to change this mindset: **Changing the mindset to normalising that CSN parents need support.** It includes guiding people to see that CSN parents have a lot of responsibilities compared to other parents. This would change the expectation they should be able to handle this alone. This step is the conclusion of the explanation in this chapter, which explores the possibilities around the leverage points.

A mindset leverage point is very impactful, but is a long-term goal. It is very complex, and can feel counterintuitive: why would you make CSN parents stand out more, when all they want to do is blend in? However, it is important to make them recognisable, to make sure they get the opportunities for support they need. Furthermore, everyone I spoke to, mentioned their motivation of helping those in need, and to do so in a fair, sustainable way. It fits their long-term goal of a caring society, so the mind shift is therefore necessary to achieve this goal.

Strategy for Ontzorghuis

Following the systemic design process, steps 3-5 were just explored, determining the desired future and mindset change. Step 6 and 7 are about translating this into a working model for Ontzorghuis, designing for systemic change.

Step 6 Designing the intervention model: this is a series of design concepts that are a strategy to make a systemic change together (Curatella, 2021).
Step 7: Fostering the transition: means you make a roadmap to make sure the interventions can be done step by step, and keep pointing towards your desired future (Curatella, 2021).

The future has been envisioned, but together with Marise I also developed a way to start having an impact towards this future in the long term. The intervention model is the strategy for Ontzorghuis, see figure 21. It is a step-by-step roadmap, showing the goals and different design concepts that are necessary to move towards making systemic change.

Strategy for Ontzorghuis

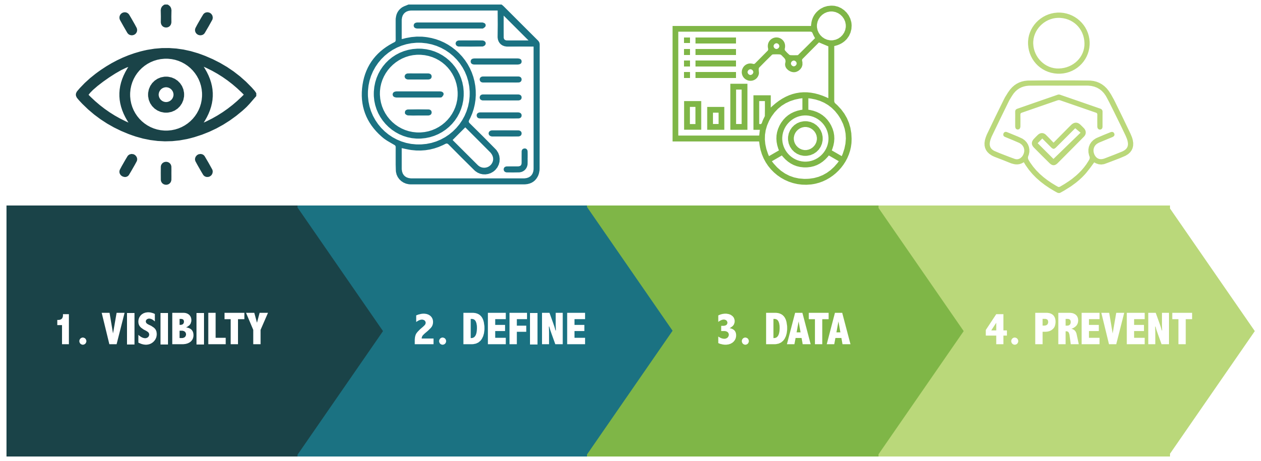


Figure 21: Strategy for Ontzorghuis.

Step 1: Make CSN parents visible within the system
Currently there is no recognition for CSN parents. It is not an accessible group, and there is no overview of them, so they are invisible in society. CSN parents are seen as apart from the other actors, whereas they are in the midst of the system, the central point. Ontzorghuis can visualise the system, and show people the role of CSN parents, which will make them more visible. It will also allow people to reflect on the system, their position in it, and how CSN parents can be more supported.

Research question: How do you make actors reflect on the system?
Design concepts:
- Visualise the system
- Reflection tool for actors

Step 2: Define CSN parent
The second step is to make the group of CSN parents recognisable and identifiable. This makes the target group more accessible to people who are not in direct contact with CSN parents, but also for those who are. For many people it is unclear where the boundary is between a parent who is having a harder time or a CSN parent, whereas for CSN parents it is clearer. For this information to be wider known, it needs a clearer definition.

Research Question: When is someone a CSN parent and how do you recognize them?
Design concepts:
- Customer journeys of CSN parents: to show the variety
- Quiz: are you a CSN parent
- Scale of how much care your child needs/ comparison visuals
- Hours of care counter: translation into FTE

Step 3: Gather data of CSN parents, create an overview
When the definition is agreed upon, Ontzorghuis together with partners can start gathering data to understand the amount of CSN parents in Holland, municipal councils and create an overview. Currently, most media attention consists of empathetic storytelling that shows the importance of support, but it lacks the numbers and data to back up the size of the problem. Combining these stories with numerical data will help create an overview of the CSN parents in Holland. Actors will need to be able to recognize CSN parents when they meet them. Ontzorghuis could develop several methods for different domains, with simple questions or actions that help determine whether someone is a CSN parent. Ontzorghuis could design a way to keep track of the results, and visualise them.

Research question: How to gather data of CSN parents, and create an overview?
Design concepts:
- Process to identify CSN parents on larger scale
- Map with number of CSN parents per city
- Literal numbers on the websites of each municipal council
- Not just numerical data, but also make eg. a blog of examples of systemic problems

Step 4: Teach actors to prevent CSN parents from overburdening themselves
When CSN parents are measurable, the term should become more normal, and people have an overview. However, they still need to receive preventive attention. Preventive attention fits perfectly into the vision of the national government, to prevent expensive care, by avoiding escalation. This is the main mission of Ontzorghuis: to keep designing and experimenting with ways in which different actors can give preventive attention to CSN parents.

Research question: How can you design methods for preventive attention for different actors?
Design concepts:
- Preventive tools for different themes (like previous Ontzorghuis' graduates have made)
- Adaptive tools to situation and context

Design statement

6. Design statement

This chapter is about deciding the goal for my final design. In this project, I chose to look at the first step of the strategy that I proposed for Ontzorghuis, which is "**Make CSN parents visible within the system".** I chose this to give Ontzorghuis a starting point, and show them what kind of projects can come of the proposed strategy. Right now, CSN parents are invisible in society, so people don't get a chance to relate to them. Ontzorghuis is the perfect community and foundation to help make them more visible. In the strategy, I explain that visualising the system around CSN parents, and helping people reflect on their role, is the first step towards systemic change.

Making my design statement, meant finding a way to translate this first step of the strategy to a project goal that was fitting within this graduation context. Finding the right wording for the design statement helped me to clarify the details in how I wanted to set out and achieve this, and I went through many versions. First, I was aiming too big, and wanted to "change the mindset" of people. Changing a mindset is not only a very large task, it is also hard to measure, and it takes time, longer than a graduation project permits. Secondly, I wanted to "activate" people to support CSN parents. This is more the final goal of the whole strategy, which is not clear enough for a final design, and also still too far out of reach. Thirdly, my wording was directed to helping people recognise CSN parents, which is a secondary goal. What I ended up realising, is that for my final design, I mainly want to help people reflect on the workings of the system, and relate to it. I want them to see the vicious cycle of the system, and their role in the escalating problem around CSN parents.

As a form, I used the ViP method of writing a statement, which ‘My goal is to ...[goal]... by ...[mechanism]...’ (Lloyd, P., Hekkert, P., & van Dijk, M., 2006). The goal is for people to reflect, and my mechanism is metaphorical storytelling. My mechanism is explained further in the rest of this chapter. Usually, in ViP statements, it is very short and concise. I deviated a bit from this in order to include all the information needed for the statement to stand on its own. This led to the final design statement:

My goal is for people to reflect on their role in the system surrounding CSN parents, by using metaphorical storytelling to emphasise the escalating nature of the system, and how they are a part of its workings.

For my final design, I need actors to realise they are stuck in a vicious cycle together. I need them to reflect on their position in this system, as this could make them more open, and lead them to think of ways they can support CSN parents. Instead of me developing concepts for each actor, I want them to think for themselves. They know better than I do, how to change the system from their position. I want to make sure there is empathy for each actor, and nobody gets the blame, but that people understand the current system is not working nonetheless. Since my main goal is to help actors reflect, I want to reach all actors in the system.

Storytelling in systemic design

Whilst writing the chapter of relations, I realised I was missing a dimension of my research I couldn't easily convey in report style. I wanted the reader to gain empathy for the actors, try to understand their perspectives, and the nuances in the relations. I was missing the personal side of the story, which I had experienced whilst talking face to face with these people. I needed more nuance than just a picture or icon could solve. I started to look at metaphors to describe the relations, and fit the story. I eventually decided to go with animals instead of people, as they are more ambiguous, and hopefully actors can see themselves in them. As this metaphor grew, so did the story between the actors, the relations became clearer. That's when I decided that storytelling would be a good fit for telling the outcomes of my systemic design.

This is backed by research, and what I stumbled upon intuitively, actually makes sense if I aim for the right goal. Storytelling is a very powerful tool to communicate systemic research. Systemic storytelling would fit my research well, as to "combine analytical reasoning typical in classical systems thinking with the imagination and empathy triggered by storytelling." (Talgorn & Hendriks, 2021, p. 46). Since the actors in the system are so diverse, storytelling will help convey the message of the system in a way that is accessible to all levels of understanding.

Many who do systemic research choose to make a system map, a visual representation of the system and connections between the stakeholders. However, this system is both complex, but also important to understand in its entirety. A visual representation allows the viewer to just read a part, or look at the whole without stopping to read the details. It would be very dense with information. This would lead to some viewers not having grasped the systemic change I am aiming for. Therefore, I choose to employ storytelling as the mechanism to convey the system, as "storytelling allows for thorough understanding of complex systems with limited time investment and without requiring expertise on systems design."(Talgorn & Hendriks, 2021, p. 50).

It also fits my goal of activating actors to think of ways to support CSN parents themselves. Storytelling "has the power to unlock imagination for the storyteller and their audience and to get them out of the logical flow to spark new ideas or perspectives" (Quesenbery & Brooks, 2010, as cited in Talgorn & Hendriks, 2021). Designing the system and its message as a story, will allow readers to become more open to changes, and encourage them to think of ideas themselves.

Apart from this, the way the system is conveyed needs to encourage empathy not just for the CSN parents, but also for the other actors. Stories allow for nuances, without fully explaining the reasoning behind it, allowing empathy for more characters than just one. The story "has the power to change bias and trigger action through awareness creation" (Talgorn & Hendriks, 2021, p. 49). None of the actors should get the blame for the system not working, but the story should still convey that something needs to change. Putting it in story form, will allow me to guide the reader through the changes of mindset I want to achieve. The system explanation in chapter relations has many details as well. Putting it in story form will "highlight the most relevant or critical parts of the system reflecting the interpretation and intuition of the system analyst to create meaning as well as communicating uncertainties." (Talgorn & Hendriks, 2021, p. 47). This means I can use the story to help actors understand the key message of the system, guide them to change their mindset, spark their ideas and gain empathy for the other actors at the same time.

Design requirements

So, to translate the goals into a final design, I made a list of design requirements.

I want to make a design that:

- Can be made in amount of time left
- Can be made by using my research for this project
- Tells the whole story of the system
- Fits Ontzorghuis as a design by itself
- Excites me and fits my skills
- Can be used flexibly, not only by one particular group
- Encourages empathy and has nuances
- Is memorable
- Is easy to relate to
- Is a not too complex to understand, accessible for almost all actors and their situations and backgrounds

Target group

The target group includes all actors from the system: grown-ups active in relation to CSN children and parents. This is a broad overview of the target group:

- Care domain:
  - Consultation centre workers, paediatrician
  - Carers for a CSN, day care centres and at home
  - Specialists working with a CSN
  - Doctors and nurses working with children in the hospital
  - Medical insurance business
  - Transportation of CSNs
- Social domain
  - Anyone handling municipal council cases with children or families
  - Anyone involved in making the planning, budget or list in youth care
- Government
  - Policy makers that are focused on family and youth care
  - Policy makers that are focused on equal rights
  - Researchers in the care domain
- Charities
  - Targeted towards supporting CSN
  - Spreading information and supporting families of CSN
  - Volunteers directly helping CSN or their families
- Network
  - Anyone that has kids
  - Anyone that is close to people with a CSN
  - Anyone that has a CSN
  - Employers that have employees with CSN
- CSN parents
  - Parents themselves
  - Their family or people they want to gift it to, to communicate their needs and situation.
- Language: Dutch
- Ontzorghuis' target group: CSN parents, design has to be accessible to them
- Level of language difficulty: elementary school

User scenario

For the user scenario, my goal was to stay close to previous Ontzorghuis projects, in order to make sure it was feasible. Up until now, they have developed a quiz and app for different CSN parents, a booklet introducing a ritual, and a game that is used as a workshop. I wanted to stay in the same realm, so something that is easy to understand can be spread by Ontzorghuis as part of their story and community.

The user scenario at this point is still quite vague, since it includes so many different actors. I want people to take a moment to reflect, and hit them deep. I want them to get information via storytelling but not take up too much of their time or overcomplicate things. Ideally, it is something they can revisit later, as it is a reflection tool.

The user scenario is that the actor comes across this tool in a way that is accessible for them. This means, it is either in their direct surroundings, they receive it from someone, or hear about it and look it up online. It can be a physical meeting as well, or workshop, since it gives the opportunity for discussion and reflection. It should be very accessible, and not expensive, and also not take up too much energy or time. The user scenario is therefore; they gain interest, immerse themselves in the story for about 15 minutes to half an hour, and afterwards reflect. Since there are so many options, the final design chapter shows how I made my decisions.

Final design

7. Final design

In this chapter, I will briefly guide you through the design process and choices made. This will help the reader understand the final design, and the arguments behind it.

The metaphor

The mechanism metaphor was chosen, as I had developed it very naturally whilst writing the report. Originally, I developed the metaphor after noticing the lack of empathy and interaction between the reader and the report I was writing. I wanted the reader to engage with the actors, and understand more about them than just the facts I had gathered and researched. First, I had tried to show this by showing faces of each actor, but it lacked the complexity and variety of the actors. So, I intuitively developed a metaphor for the actors, seeing them as a Dutch ecosystem of different animals. Every animal represented a different actor, and their qualities. Whilst reading the chapter of relations, it would help the reader keep track of the actors, and recognize their way of thinking. As I was brainstorming for my final design, as my coaches pointed out that my report was just going to be read by them, and the graduation committee. They saw potential in the metaphor outside of the report, and encouraged me to follow my intuition, and explore if I could use it in my final design.

I will explain the metaphor first so that further explanations of the iterations are clearer. As mentioned briefly, I chose a different animal for each actor in the system. All animals can also be found in the Netherlands. I had specific reasons for each animal, shown in table 2 below:

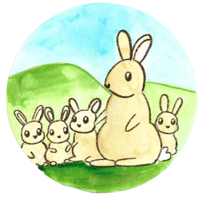
Actor	Animal	Qualities & reasoning
CSN parents 	Hedgehog	Hedgehogs live on their own, just like CSN parents often end up being isolated. They are generally peaceful animals, and have a soft heart. But if you attack them, they can be quite spiky and protective. This is similar to CSN parents, who can become defensive but also need to protect themselves in creative ways.
Network 	Rabbit	Rabbits are similar in size to hedgehogs. They live in big groups, and have big families. This means they are always busy taking care of each other, and are a good resemblance for friends and family of a CSN parent.
National government 	Ox	The Ox is very large compared to the hedgehog, and has a very different perspective. It is also strong, heavy imposing, bulky and maybe a bit slow to react. This shows the national government compared to the CSN parent: it is intimidating, but also far away from their perspective, and slow to react.
Municipal council 	Deer	Deer are very graceful, and quite large compared to a hedgehog. However, they are skittish and calculating, and not risk takers. It represents the municipal council well, who is larger than a hedgehog and intimidating towards a CSN parent. But also risk averse, and always acting according to plan.
Care domain 	Geese	The care domain is so broad, that these animals need to range from health insurers, to doctors, to caretakers. Geese are very strong, and quite protective animals. There is a well known idea of mother goose, who protects young ones. But I also saw potential for a goose to be an expert doctor, in a white suit. They are taller than hedgehogs, but have less power than the ox.
Charities 	Bird	Charities I mostly saw as communicators, exchanging information. Birds can be part of a flock, but each have their own little local spot, to keep track of. They are also quite small and approachable for hedgehogs.

Table 2: The actor- animal metaphor explained.

The metaphor gave me the chance to develop the interaction of the different actors, in a way that is empathetic and realistic at the same time. It allows me to highlight the nuances. It also allows exploration for not only the CSN parent to interact with the actors, but also the actors with each other.

Iterations and concept choice

My initial iteration was the story itself. It was to combine the most crucial information of the system map and also the metaphorical storytelling to tie it all together. It could be posted to the Ontzorghuis website. It would be an overall visual all shown below, supplemented with necessary information for the system map. The actors would be introduced using the metaphor to create storytelling and empathy. This was the moment my coaches encouraged me to brainstorm using this metaphor, see figure 22.

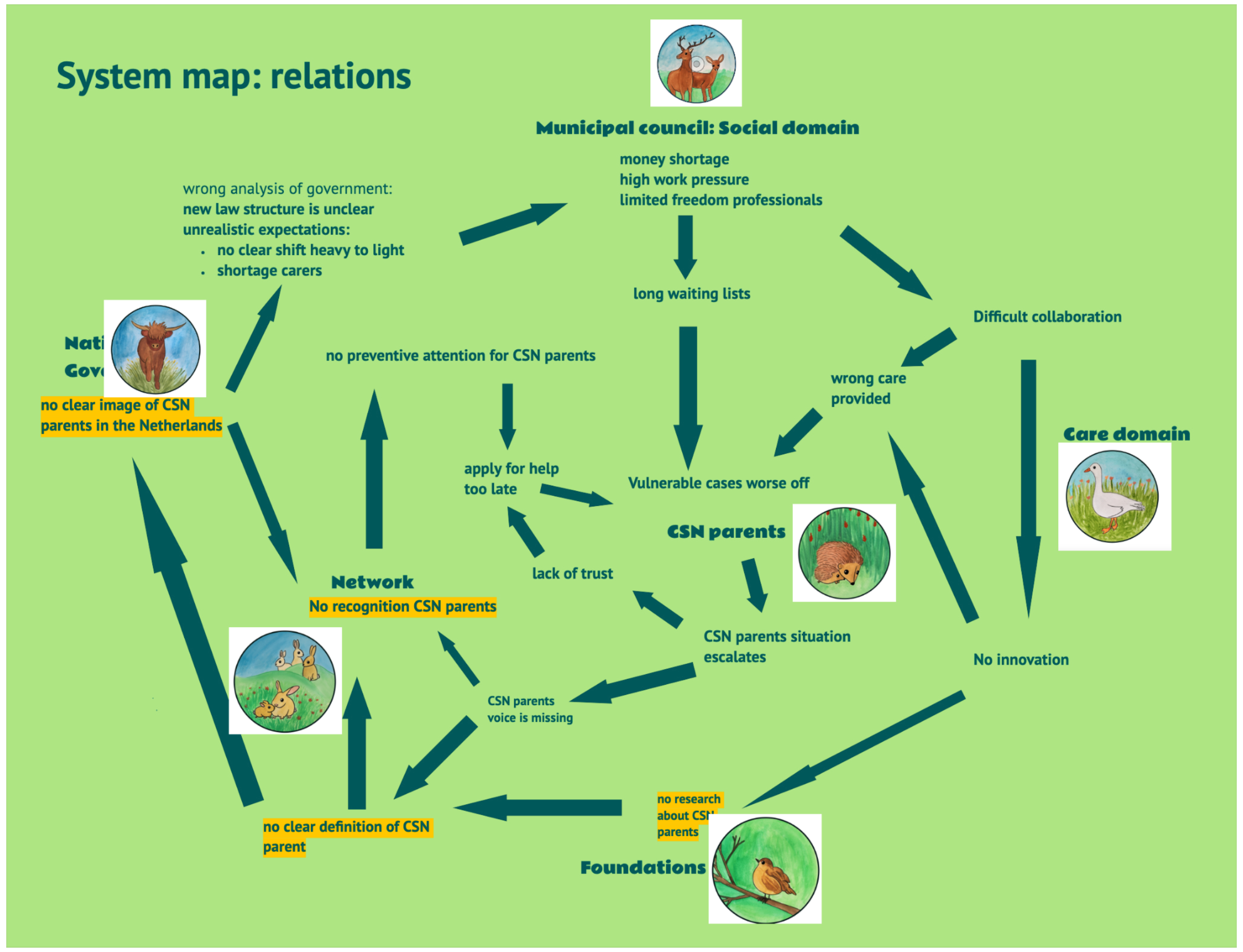


Figure 22: Iteration of the system map with my first concept of the animal metaphor.

The brainstorming of different concepts and the selection process went quite fast. Using the metaphor as a base for my idea and content, I deliberated: a movie, a game, posters, an online game or experience, a turntable with different perspectives, a deck of cards with questions, a theatre play, a workshop and a book. You can see the visualisation of the different ideas below at figure 23.

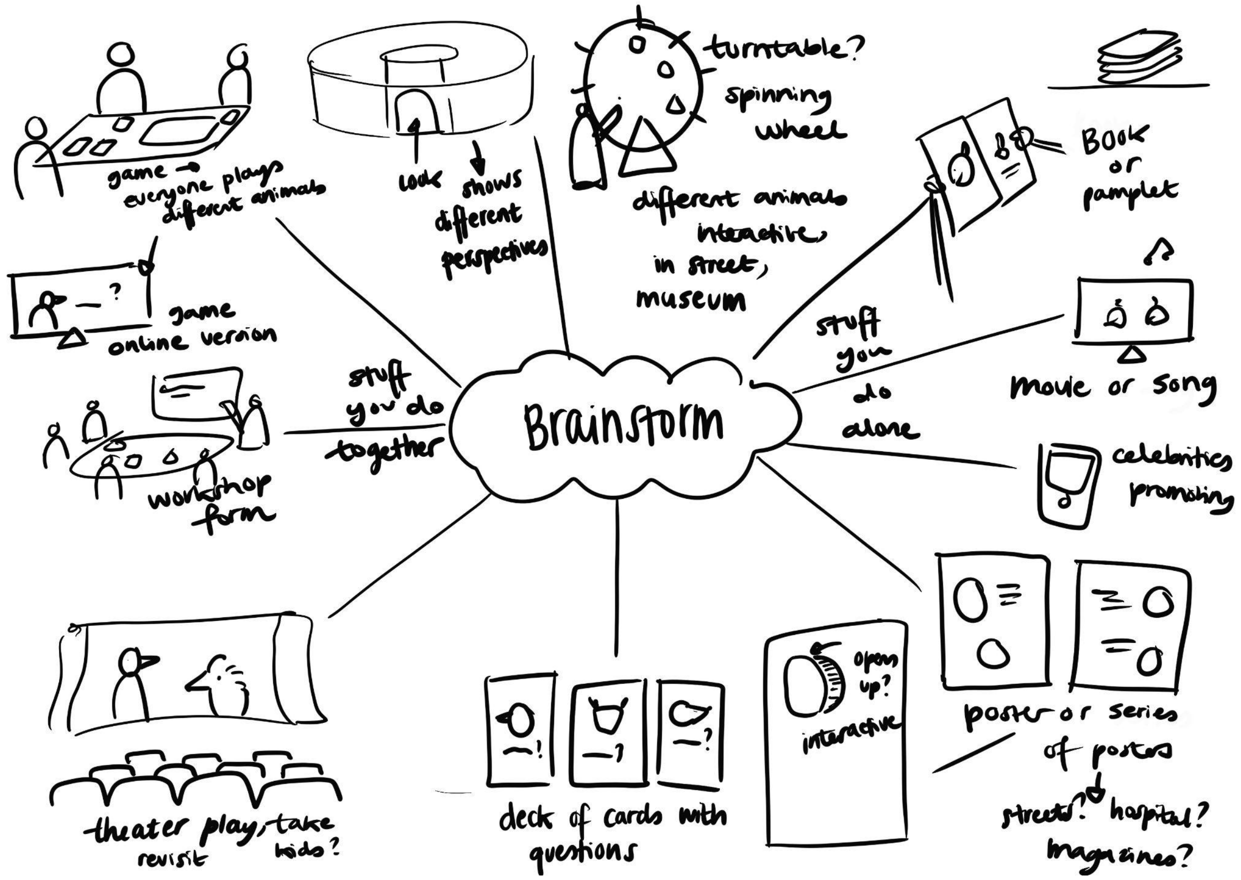


Figure 23: Brainstorm of concepts what to do with the system map for my final design.

The requirements were used to make my decision. All concepts fit my skills and knowledge, and Ontzorghuis, and were opportunities for memorable, relatable and empathic experiences that could be used flexibly. The requirements hardest to meet were:

- Can be made in amount of time left
- Tells the whole story of the system
- Is a not too complex to understand, accessible for almost all actors and their situations and backgrounds

For more complex designs such as a game or workshop or play, I simply did not have enough time for iterations, to make a design that makes sense. My goal was also for the user to gain understanding of the system as a whole, not only immerse themselves in a part of it. A poster, turntable, or card deck allows the user to potentially experience only part of the story, and stop, so it didn't feel like the best option. That left me with the arena of a book or movie, which is also feasible.

However, a book can easily become informative, which I wanted to avoid. Using the metaphor in combination with factual information about the system is the most convincing. I wanted to write a version of this graduation report that is accessible to the public: an informative pamphlet that also evokes empathy. During my research for this graduation, I came across a lot of different reports that were informative and had some form of visualisation to help the reader. Since it is such a complex story, these reports always take some time to read, and provide you with a lot of information. This does not translate well to the goal of my final design of being accessible: you need time and a certain level of education to gain understanding. I brainstormed ways to make this combination of facts and story more appealing, and more memorable, see figure 24.

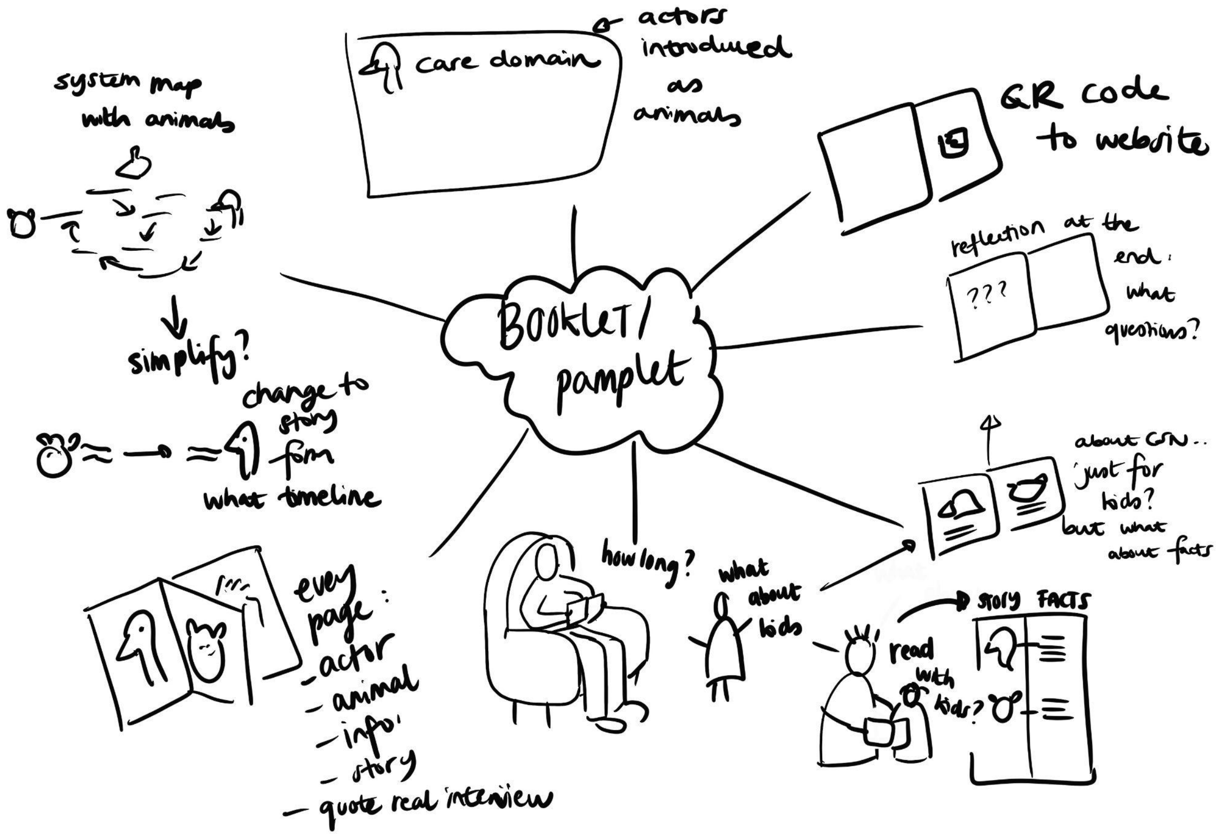


Figure 24: Brainstorm of story concepts for my final design.

I chose to simplify the map to a visual telling the story of the system, where the different challenges and relations are shown in the form of a story. It left me wondering, how to visualise this in a booklet, as it is not a linear approach, but a crisscross pattern.

Approaching the metaphor linearly, I decided to focus on the CSN parent, and their way of living whilst introducing the actors gradually. This led to a storyline that was more the style of a linear book. The system map was simplified in a way that all actors would understand. This means it has the low education needed, and even children can understand the language, see Appendix C for the visual.

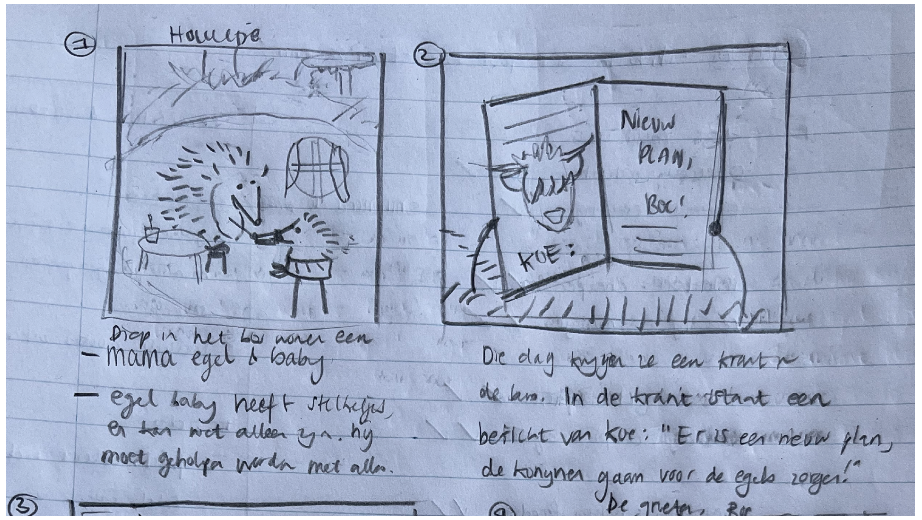
Ultimately, I chose to make it in the form of a children's book, as it provides a way to tell the story of the whole system in a non-complex way. A children's book can also be read with the special needs child, or other children, giving more options for the reader scenario. The complexity of the metaphor is stronger when it is repeated and the reader gets a chance to reflect every time they reread the book. A book can easily be combined with a workshop or game later on, but for this graduation it is more feasible to make a prototype in the time left.

Designing the book

The book has a Dutch target group of grown-ups active in relation to CSN parents. The design needs to be accessible to several levels of education, so it can be read by anyone. Since it is a children's book, the level of difficulty is: kindergarten or elementary school.

Children's books were researched to gain inspiration for the book. The elementary school level books usually have a lot of pictures. Visual style ranges from very detailed, to very clean, digital images. The visual style I chose was simple to allow me to make it in time. I chose to work mostly on paper, and digitise it later. This allows the characters to have a lot of expressions. The language is elementary school level, and the story quite simple, but still allowing for the complexity the metaphor requires.

The storyline was iterated on several times, trying to balance the focus on the CSN parent, but also the other actors. I decided to focus the story on the CSN parents living their life, with the actors visiting one by one, and interacting with each other in the background, outside of the story. This keeps the story simple, and straightforward. It also allows for repetition, as each day a visitor comes, it ends the same way, with the CSN parent managing their tasks and getting ready to sleep. Initially, I wanted to include the other actors relating to each other in the story, but it made it too complex. I made a first draft of the story, with quick sketches and text as seen in figure 25.



Diep in het bos wonen een
- mama egel & baby
- egel baby heeft stekeltjes, en kan niet alleen zijn. hy moet geholpen worden met alles.

Die dag krijgen ze een krant in de bus. In de krant staat een bericht van koe: "Er is een nieuw plan, de konijnen gaan voor de egels zorgen!" De geiten,

Figure 25: Quick sketch of storyline, and first text

To iterate, I discussed this draft with a paediatrician, with a Dutch language expert and with Ontzorghuis' Marise, and asked for her opinion on the story. The language was simplified, and better examples were chosen to illustrate the life of a CSN: for example, the feeding tube. The examples chosen also portrayed the escalation of many CSN parents: more tasks. It was important for the CSN parent to have a recognisable struggle, of the tension between too much work but still being independent. I asked an art academy student to help me decide the layout details for the prototype. Personally, I focused on correcting the nuances of the different actors, making sure the animals were all behaving similarly to what I found in my research. Once the story was decided, I used watercolours to paint the illustrations by hand, scanned them and made a layout including the text, see figure 26. The text was still changed subtly, and then the prototype was printed and bound as a book.

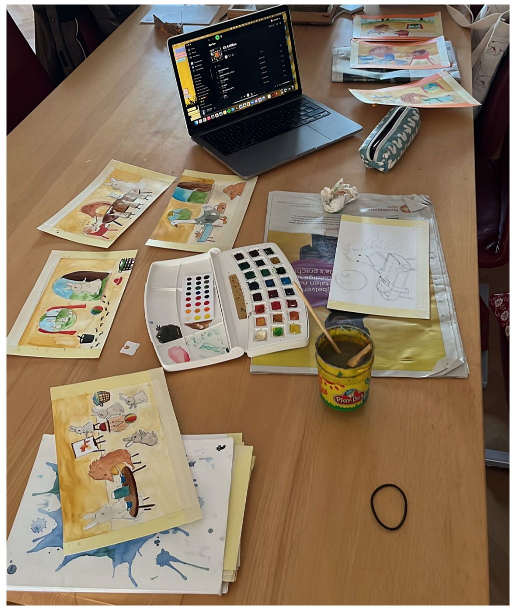


Figure 26: Process of making the illustrations.

The book is to be a pleasant, coherent story, with recognisable characters and an open ending that makes you reflect. The reader is guided to learn about the metaphor, and what the different animals stand for, at the explanation at the end of the book. It is followed by a guided reflection, in the form of questions. The reflection invites the reader to reflect on the deeper levels of the story, and compare it to their lives. The order of the explanation and questions were changed during the evaluation of the book, when I discovered people needed to learn about the metaphor in order to answer the questions.

The questions and english translations included are:
Wat doet het met je om dit verhaal te lezen?/ How does reading this story make you feel?
Begrijp je het verhaal?/ Do you understand the story?
Begrijp je de metafoor?/ Do you understand the metaphor?
In welk(e) dier(en) herken je jezelf?/ With which animal(s) do you identify the most?
Ken je een mama egel in jouw omgeving?/ Do you know a mama hedgehog in your community?
Wat zijn de 3 dingen die je zou kunnen doen om iemand zoals mama egel te helpen? / What are the 3 things you could do to help someone like mama hedgehog?
Wat moet er niet veranderen en wat juist wel? / What shouldn't change and what should?
Hoe zou je dit boekje gebruiken in jou positie?/ How would you use this booklet in your position?

Final design

The final design can be found in the Appendix D. To create some overview in this report, I will briefly explain how the initial project brief led to this final design.

My initial project brief was:
I will research, frame and visualise the bigger context of Ontzorghuis, in order to determine their opportunities to achieve their long-term goal of systemic change. I will build on their future vision and design strategic interventions to achieve systemic change, and design it in such a way, that it is actionable for Ontzorghuis.

In my report, I show the process and results of researching the bigger context of Ontzorghuis. The system map is the visual, and my report explains the details of the research. The leverage points were then translated to a strategy that is intended for systemic change. This final design, the book, is the first step towards strategic intervention, which gives Ontzorghuis a very concrete method of starting out the strategy. My initial project brief did not specify what my final design should achieve, but in the end, it fits well with the systemic design research. The booklet shows my systemic design research in a way that is approachable to all the actors in the system.

It simultaneously is a start to the first intervention of the strategy: ***Step 1: Make CSN parents visible within the system.*** The booklet aims to show the actors around CSN parents, and their role and relations to each other. By showing the role of CSN parents and how they interact, the book asks the reader to reflect on the value of CSN parents and the support they deserve. CSN parents are currently not seen in the system, and do not have a big voice of their own, so this book shows their journey and makes them more visible.

My design statement shows my goal for this book: ***My goal is for people to reflect on their role in the system surrounding CSN parents, by using metaphorical storytelling to emphasise the escalating nature of the system, and how they are a part of its workings.*** As I explained, the design statement was chosen to fit the first of the strategy, of making CSN parents visible. The method of speaking to people's emotion and empathy by using storytelling, helps actors to reflect. The book therefore helps direct people's attention to start seeing the role CSN parents play. It ultimately guides readers towards seeing CSN parents, their role and some might feel activated to support these parents, which is the overall goal of Ontzorghuis and the strategy.

Evaluation

8. Evaluation

I conducted several interviews in order to evaluate my final design. Firstly, I remind you of my design statement, then follows a list of my possible target group, and my user scenario. My design statement was adapted to my research question of this evaluation, which is seen below at the method section. The chapter ends with the summaries of my interviews and a short overall summary.

Design statement:
My goal is for people to reflect on their role in the system surrounding CSN parents, by using metaphorical storytelling to emphasize the escalating nature of the system, and how they are a part of its workings.

Target group

The target group was discussed in detail at the design requirements, but to summarise, it includes all actors. This means anyone who has CSN parents in their network, or is related to them in some way, in their personal or professional life. Anyone who is working with children with special needs, will automatically also be in relation to the parents, and be part of the target group. Anyone who is in relation to a CSN parent is also part of the target group, even if they are not actively involved in their lives. CSN parents themselves are also part of the target group, as it is also a chance for them to reflect on how they can be more visible.

Final user scenario

- It's a reflection tool, a booklet that Ontzorghuis uses as one of their tools to communicate their message.
- They either read or hear about it somewhere, see it on the Ontzorghuis website, or get it as a gift. It could also be part of a physical location like a waiting room or consultation office. It could also be promoted in a media campaign, or as part of a workshop or theme evening.
- It can also be watched online as a video with the same content, or downloaded as a pdf. This would be free.
- The physical version could be cheap and easily accessible.
- People that are part of the target group hear about it in their workfield, and are curious. They read the booklet, either with their kids if they have them, or on their own. They are already aware of the CSN, but they are reminded of the role CSN parents have. They are invited to reflect on their own situation, and how they relate to CSN parents. It is a small reminder that sparks their thinking. It doesn't necessarily give them any suggestions, and since it is open ended, they are invited to think of their own solutions, and to share them on the Ontzorghuis website. They are also invited to share the book with their colleagues.
- They also learn about Het Ontzorghuis, and about their mission.

Method

In order to evaluate my final design in the amount of time I had left, I decided to try to interview one person representing each actor. The government is not included, as it was not possible in the time, I had to make my evaluations. All evaluators remain anonymous, for privacy reasons. The table 3 below shows who I interviewed:

Actor	Evaluators	Form of book
CSN parents	A single mom with a CSN and another son	digital
Network	A mom of four kids, her job is coaching illiterate citizens	digital
Municipal council	A member of the municipal council in Delft	physical
Care domain	A community nurse (same as in interviews)	physical
Charities	PR Manager for Mantelzorg NL (same as in interviews)	digital

Table 3: Who I interviewed for the evaluations

Each evaluation had the form of a meeting that ranged from half an hour to an hour in time. I first asked interviewees to read the book, either physically or digitally, as shown in the table. After they were done reading, we talked about the book and I took notes. This was my research question whilst evaluating:

Does this book help actors reflect on their role in the escalating system surrounding CSN parents?

During the interviews, I followed this series of questions, based on the research question:
Questions

- What is their initial reaction?
- Do they initiate a conversation about the reflection questions?
- Do they compare themselves to the situation in the book?
- Do they understand the story?
- Do they understand the metaphor?
- Which animal do they most relate to?
- Do they recognise the term CSN parent (mantelouder)?
- Any recommendations how they would use or distribute a story like this in their position

Evaluation

For each actor, find a summary of their answers to the questions below.

CSN parent

The CSN parent I spoke to was a mom of two kids, one of whom is a CSN. She was moved by the book, and told me she had tears in her eyes at the end. She said the story was very recognisable to her, as a single parent. She reflected that "everyone comes to visit, but they don't do much," and "it all falls on her", referring to the care needed for the CSN. She compared herself to the book, and said that apart from a few details, it represented her story, and she related to the hedgehog mom. The question about a CSN parent was inapplicable to her, but she does relate to the word 'mantelouder'. Moreover, we spoke about ways she would use the book, or places she could see it being used. She mentioned the child health centres, and schools as places for people to discover it, as well as libraries and the building of the municipal council. Overall, she was very positive, and for her case, my story is her story.

Network

This woman was moved by the story, that nobody can really help the hedgehog mom, and she is stuck in survival mode. She reflected the attention all goes to the baby hedgehog, the CSN, and none of it to the mom, even though only the mom really knows what her baby needs. The open ending left her wondering "how it was going to end with the mom". She said the book "really makes it clear how hard it is for a CSN parent, that's very good", it made a bigger impression than an article would have. She said she didn't know many hedgehogs, but she was a rabbit herself, but she respects them even more now. She understood the story and metaphor gradually, apart from recognising the geese were both the care domain. The "mantelouder" was a clear term for her, and she used it consistently throughout our meeting. Her biggest remark was the missing family of the hedgehog: why is she female, where are the other children and her husband? Another suggestion was to include some "softer" reflection questions, like "how does it make you feel" instead of "what do you want to do", as these were more suited to her experience. She could see the book being at a general practitioner, schools and other waiting rooms, but also used by officials.

Municipal council

For this member of the council, the story and metaphor were recognisable almost from the start. He felt the tension rise throughout the book, and feared the escalation. His first reaction was to be very activated: "what can I do? I want to do something!", and he started brainstorming ways to help. He related most to the cow in the story, who is far away but making the rules, as that is his function in the municipal council. He told me that usually in these types of themes, his initial reaction is to think along the lines of 'dont be so overdramatic, you are overreacting'. However, when he read the book, he had to dig a bit deeper, and he realised the situation is very complex. He recognised the situation is hard to solve for, and most of what the care and social domain do is symptom control, not getting to the roots of the problem. He immediately adopted the term mantelouder, and used it throughout the conversation. He was very excited to use this book as a reflection piece, and conversation started in his role as municipal council member. He could see giving it to the right people to stir up attention, and organising a council café evening about CSN parents with this book as the starting point.

Care domain

The community nurse I interviewed thought the story and metaphor was both recognisable and moving. She especially thought the 'mantel' metaphor was very moving, and the 'mantelmoeder' definition stuck to her. She reflected that she knew a lot of parents that are stuck in survival mode: "how hard it is to ask for help... it's clearly shown". She could easily emphasise with the hedgehog, and "how incredibly hard it is for a mother like that". She reflected on the fact that many parents she meets have a conviction of wanting to independently care for their child. From the perspective of her job, she identified herself with the mother goose, especially the slogan. She sees herself as signalling and helping, but also being a temporary help. She also reflected the cooperation between the animals was missing. In her position, she would love to give it to parents who are stuck in survival mode. But also recommends giving it to other parents so they recognise it happening. She suggested giving a bit more explanation, it would need an introduction or context before someone can be given the book.

Charities

Her initial reaction was that the story is refreshing, and that the booklet was beautifully made. She liked that all the different parties have a role in the story. She also liked the image of the 'mantel' which is a wordplay and a metaphor for the 'mantelzorg' or informal care the mother gives. Informal care is often seen as boring, she explained, but this story makes it warm and lovely. She said the book was an easy way to access this complex information, and she said this was important, as CSN parents or people around them often don't have time to read through lengthy leaflets. She herself identified with the bird, as well as the hedgehog, since she is a CSN parent herself. She recommended either getting media attention by combining it with a story about this part of the care domain if one came up in the news. She also suggested adapting the book to revalidation houses and Integrale Vroeghulp (an organisation helping CSN and their parents), as they can give it to CSN parents. It would be "a soft way of introducing the CSN parent lifestyle" to them. Another recommendation was to adapt it for use at schools: for young CSN carers, who have a sibling who is a CSN. This children's story is a good medium to inform children about the different lifestyle, and start a conversation about it.

Overall summary

Throughout all the interview evaluations, each person reflected on their own way. Some were emotionally moved by the story, and really understood the predicament of CSN parents in a different way. The CSN parent herself also recognised herself in the story. Whilst some were activated to think of ways they wanted to distribute the book, or use it. These suggestions will be part of the recommendations in the next chapter. Apart from these interviews, I also got feedback from other people I showed my book to, either from my own or in Marise's network. The feedback was overwhelmingly positive, with people finding the main story recognisable, and understanding the metaphor. Many also give a few pointers and recommendations of how to improve the book, or what they were missing. Especially feedback from CSN parents was important for this research, as I didn't interview any myself, and had to check they felt represented by the story, which they do.

Conclusion

9. Conclusion

Discussion and recommendations

In this chapter, I will reflect on the relevance, limitations and recommendations of the different parts of this graduation project. Afterwards, I wrote my personal reflection. The discussion is divided up in 3 sections: systemic design research, the strategy for Ontzorghuis, and lastly the design of the book

Systemic design research

Relevance

Choosing Ontzorghuis as the basis for a systemic analysis was a good match. Ontzorghuis currently has an overall goal, and a couple of separate projects. They do not have a systemic strategy, whereas they are eager to have a big societal impact. This means for systemic design, it is a good match: a societal problem, many stakeholders with complex relations and undefined boundaries. This systemic analysis was to find out what leverage points there are that can be used as starting points for Ontzorghuis' impact. What also makes this project relevant in the field of systemic design, is the combination of logical analysis with empathy. It is an example of using storytelling and metaphors to communicate systemic research, but also the first step towards systemic change.

Limitations

Due to restricted time, I only interviewed one or a couple of people for each actor. I would have made a better representation if I had interviewed more people for each actor. It would have allowed me to compare their experiences. Similarly, I only had restricted time to find and read through available reports, to spot relevant information for this system. This limited my literature sources and due to the broadness of the research, it was hard to keep up to date on the latest developments and research in the field around CSN parents, but also the other actors. It could easily be that I overlooked potential solutions and information.

Another limitation was the actor of CSN parents. I relied on information provided by Ontzorghuis' previous graduates, and of Marise, to gather information on the actor CSN parents. This might have limited my understanding. Furthermore, not working in a team was a definite limitation, though one I could not have changed due to the nature of graduation. Although I sought out plenty of feedback from coaches, peers, friends and family, the research is still based on my own undoubtedly biased intuition.

Recommendations

These recommendations are based on if I had more time to do more work on this project for Ontzorghuis. I would choose a local area to focus specific systemic changes on, when doing further research for Ontzorghuis. This is to enable collaboration and codesign, and start local connections.

Additionally, I would communicate briefly the systemic change that Ontzorghuis envisions on the website, and use it in introductions to other parties. This might help them recognize the context, and their relations to each other. It is important to take time to communicate this systemic outlook, and also the change in mindset Ontzorghuis is striving for. Not everyone has the same knowledge about CSN parents, and it is important to take time to explain this, so you are all on the same page. This way potential collaborators can see the relevance for Ontzorghuis. I would make sure there is an easily accessible report or document they can download for further questions about the system and research, and relevant data.

Strategy for Ontzorghuis

Relevance

Currently Ontzorghuis does not have a longer-term strategy, though they do have some long-term goals. It is more efficient to work towards these goals with a strategy, and divide it up with small steps. It is also easier to communicate with potential collaborators if there is a clear strategy. They can then have a debate about how to tackle this together. My strategy is made up of smaller, but still conceptual steps, in order for Ontzorghuis to have flexibility in how they will achieve them.

Limitations

A limitation of my proposed strategy is that it is still very broad, and not very measurable. In order for it to work, each step would need to be filled in more precisely by the people who will work on them. Therefore, the strategy would have been of better quality if I had collaborated with potential people Ontzorghuis wants to work together with, whilst creating it. This way, potential partners would have a say in the strategy, whereas now this is lacking. I also didn't get any feedback from the experts I interviewed about the strategy, which is a big limitation since it lacks credibility. This would be the first thing I would do if I had more time.

Recommendations

The strategy is written from a systemic viewpoint: so the different steps needed to achieve a mindset change. I recommend Ontzorghuis to start implementing this strategy. To translate this into smaller projects, I would divide it up per step, and not do it all at once. If I had more time, I would start initiating a project about the "definition" of a CSN parent, the next step. It would require finding someone who is interested in taking on the challenge of this quite undefined project.

More specific recommendations included in the design concepts of the strategy. They are sort of project brief concepts that someone could start to look at and some of the practical information Ontzorghuis could start developing and gathering.

The strategy goes from very abstract to more specific. It starts with definition and recognition, which can be national wide research. When it comes to informing and preventing, it can differ a lot per local area. Therefore, the last steps can differ a lot in scope depending on what connections Ontzorghuis has at that time. These steps can be more predefined projects, with a clearer target group and goal. But they can only be specified at a later time.

Design

Relevance

The final design fits in Ontzorghuis' current design collection, so it is feasible for them to use it. It sums up my research of the system in an approachable way, and is a way to communicate this to the actors. The design is the embodiment of the first step in the strategy, as it is a design that communicates the existence of CSN parents, and makes them visible. It therefore fits my initial design brief, as it is both actionable to Ontzorghuis, as a strategic intervention striving towards systemic change. Additionally, it invites the reader to reflect on their role in the system, how they relate to CSN parents and other actors.

The evaluation had the following research question: ***Does this book help actors reflect on their role in the escalating system surrounding CSN parents?***

From the responses of the 5 face-to-face evaluations, and several online, it appears everyone was inclined to reflect. The evaluators all reflect in their own way, and different parts of the story and book speak to them. All of them recognised the story and metaphor, and they understood the escalating nature for CSN parents. They all started reflecting on their own experiences, relating back to real life or coming up with solutions or similar situations. It invited them to think about it. I am not sure if it activated them to go and support CSN parents, but it definitely made them reflect on their position in the system towards them.

Limitations

If I had more time, I would make more iterations after this round of evaluating. I would also conduct more evaluations. Getting feedback from all the different actors is crucial to understand if the desired impact is achieved. Another limitation of the design is that it was made independently of any publisher. Their input about the story, illustration and concept is lacking, which might limit how fast this design can be finalised.

Recommendations

I personally see potential for this design to be published or spread, either digitally or in print. I do think it should be tested in several rounds, on the actors, and maybe changed accordingly. There were some observations from evaluators that I did not include in the recommendations, things like the font, colours, chosen format. I did not want to include it, as it will be adapted anyway, and it is very subjective, this is just a prototype that needs extra work to be a professional product. I recommend asking professional illustrators, editors and partners of Ontzorghuis to look at the details before spreading it. Perhaps, if circumstances allow it, I can continue working on it a bit after graduation.

I also would recommend exploring if there are other themes Ontzorghuis wants to communicate about, or perhaps a more in-depth story with each actor. This would be the start of a series of books that are easily accessible. For example, there might be interest in looking at information siblings of CSNs, so the book should be adapted to include other siblings and their relations. It could also be in different contexts or settings, like a hospital: to relate to those in that situation. My main recommendation is to seek out partners, and gauge their interest to work together on this.

In the evaluation chapter I explained most of the recommendations come from the actors themselves. I recommend therefore to do more research with the book, and get more partners to think about where to use it. Below is a list of recommendations from evaluators:

What contexts the book is recommended to be used at/for:

As a handout or just in the waiting room

- child health centres: schools
- libraries
- the building of the municipal council
- general practitioner
- Hospital or healthcare waiting rooms

Conversation starters, part of a workshop or meeting

- municipal council meeting
- councilcafé evening about CSN parents
- Giving to parents who are stuck in survival mode
- Giving other parents (network)
- revalidation houses, as a "soft introduction"
- Integrale Vroeghulp (an organisation helping CSN and their parents)
- Jonge mantelouders: adapt it for use at schools: for kids who have a sibling who is a CSN.

Media attention

- media attention: Jeugdjournaal etc, in combination with current news
-

Some following adaptations I recommend:

- Give a general introduction or provide context for the form a handout
- Adapt as conversation starter as beginning of a workshop, presentation or debate
- Include in an educational video

Personal reflection

Let me start off by stating the obvious: this graduation project was not a normal process like I had expected, being interrupted by a burnout just after the midterm. I know a graduation project is a memorable project, but I'll remember mine also due to the extraordinary circumstances. I want to take time to reflect on this unforeseen event, but also take time to reflect on the "normal" ambitions within a graduation.

Goal: design for social impact

First off, I want to look at my personal goals, and reflect on all I have learned. For my graduation, I sought out a project that was going to have a social impact, and be focused on people. I wanted to experience if it would change my internal motivation towards a project that is based on "lifting up those in society that need more help" (Appendix A). Designing with the goal of social impact was an interesting experience for me. In the project brief, I said: "Design allows us to zoom in and out, and account for the complexity of the subject, as there are often multiple sides to empathise with."

To reflect, I definitely chose the right project to experience this complexity with. Beforehand, I could not have anticipated how complex researching a whole system would be. At times, I felt very overwhelmed, especially at the thought of forgetting to research a certain branch of the field. I was scared my own bias would blindside me from a part of the system. The positive side was that I could empathise with people who were in conflict, without having to pick a side, or argue from one case. It fits my personality to shift perspective, and see the situation from a different side. It means not having to focus just on the target group, since I usually pick up the signals from those around them subconsciously anyway. In the end, I had to let go of my idea of providing a perfect overview of the system, if I wanted to be able to summarise it in some way.

I think what I didn't expect was my lack of empathy for a while towards the actor: the government. Many of the materials and interviews I used for my research were either from the perspective of the government, or blaming them for everything. None of the other actors seemed to appreciate the government's methods. It took me some time to accept that whilst the government could be traced as the root of big problems, it didn't necessarily mean their intentions weren't right. That is what finally helped me empathise with the whole system: they are all trying to help. Only their perspectives and way of helping differ so much, that the result is the opposite. My optimism wavered during the time of research, since everything seemed to be "doomed" and very negative, researching the tensions. Even though I myself couldn't see the solutions right away, my internal motivation was strong. During research my empathy for the actors and situation grew. I also trusted in the process of systemic design, of finding the "leverage points" later when I couldn't in the beginning. I think the social impact has a big role in my motivation as a designer, which is especially important in long-term projects, or systems with big problems. It will be important for me to consider this when searching for a job later.

Goal: learn systemic design

The second thing I wanted to experience was working from a systemic design mindset. I wrote in my project brief "Whilst designing, I am often wondering about the long term implications on the context, and usually the framing of the context intrigues me the most as well." I set out to learn how to frame a context that includes all stakeholders in one system map. I also wanted to see how design could have a social impact on a bigger level.

Ontzorghuis was a great choice for this, since they are just starting out and don't have a clear long-term strategy, whilst they do have a clear goal in mind. This meant Marise was very open to my input, and I didn’t have as much resistance to a systemic strategy as you might have with a bigger organisation. I think, though my project took a longer time than expected, the biggest thing I came to realise was that systemic change is slow, and very unpredictable. There are many factors to consider, including the resources of the organisation you are working for. I can be very idealistic and too optimistic with the impact I dream of having (as I guess most young designers are). I learned, next time it is good to manage my expectations of the impact I can have, and the time it will take.

Secondly, I think I am well suited to work with systemic design. I don't mean to sound too overconfident, but I do feel like it suits me better than most design processes I have gone through. Systemic design allows me to be very empathic, but also analytical whilst trying to figure out the puzzle of the system interactions. I think most design processes have this, but I like the enormous complexity you are faced with at the beginning, meaning you don't know what the end result will be. It motivates me to try and make sense of it, and simplify it. I also found out simplifying comes easier to me then I thought: I simply get too impatient and need to choose. I also really liked how I could use my intuition as a designer to guide me towards understanding the system. It is very refreshing to have a process so free that you have space for intuition in this way. I do think I am easily prone to taking the responsibility of all the problems I encounter during research. Next time, I would want to work together, and share this burden and relativize it. I also would like to mention that I am not good at keeping track of the latest progress or trends in a field, it doesn't come naturally to me. And since system design is an upcoming field, this would be crucial to keep in mind, so the work is relevant. I experienced systemic design in a lot of facets, and learned a lot about it, but feel like I have a lot of methods and theories to learn.

Personal

This was a very pivotal time in my life. It was a unique experience having a burnout just after my midterm. On the one hand, I feel like it gave me extra tension, an unfinished project that I wanted to complete. It was hard to let go of my need to finish it, and be patient. On the other hand, I feel like I was destined for burnout sometime, and now was a time where I just had my own responsibility, no financial burdens, kids or guilt towards an employer to deal with.

I changed my perspective of myself during this year. During SPD, I saw myself as a group leader, motivator, planner, someone who is efficient, productive and gets great results. Often my motivation felt greater than other teammates, and COVID doubled this feeling of responsibility. As I was doing my courses, I felt that I had to prove I could be a productive individual for society. I especially compared myself to others, which was natural, being constantly graded and compared to other students.

As I started my graduation, I was nervous like the rest of the students, but very determined to keep this same attitude. I made sure to stay on top of the planning and gave priority to my results, even over my own wellbeing. My graduation project fit me so well that I could do it with less energy than normal. I was still giving enough results, even if I didn't feel well. I just accounted my physical and mental stress to normal graduation stress, and told myself I would recover after I had graduated. Shortly after the midterm, I crashed and then came my burnout period.

In this period, I slowly let go of the huge amount of expectations of myself. I allowed myself the freedom to experience what I intrinsically wanted to do, and not what I wanted myself to be like. I wanted to be a productive person who always has energy, but I honestly don't like being in charge and perfectly planned all the time. Especially being fully planned takes a lot of my energy. I discovered that, whilst I work efficiently, this costs me a lot and I need more recovery time. On top of that, my creative ideas only come if I have freedom to relax, and wonder about the world. It is actually crucial for me to take time off, and wander around, in order to be a good designer. Doing this, also helped me in my graduation project to allow space for my intuition, which resulted in the metaphor I used in my design.

I also discovered that whilst stressed, my first instinct is to try to finish my to-do list, instead of take time to relax. I don't check others' expectations of me, but just assume and try to meet them. I think for a future employer this is really important to know, to make sure I know exactly what they are expecting, and I don't waste energy worrying. My coaches reacted very pleasantly to my burnout, never second guessing me, and supporting me this whole time. They were honest and direct about their expectations, and didn't rush me into finishing, but gave me time to recover. It restored my faith a bit, that people who will ultimately judge my work can still be lenient and understanding in the process. I appreciate how they helped me slowly recover, and also helped me in different things I usually would have needed help with. It was also a unique experience getting to work such a long time period together, it doesn't often happen at IDE. Overall, I look back at my graduation with a pleasant feeling, grateful I got to finish this project, and also very happy with the end result of my report and design.

I want to take this small space to thank those who helped me through this journey of a graduation project. Firstly, a big thank you to my coaches Mieke, and Charlotte, for helping me complete this project and supporting me. Secondly, I want to thank Marise for being so open about her experiences, always making time for me and being patient in this process. I want to thank Milene for jumping in at the end so I could graduate. Personally, I want to thank my husband, family and friends who supported me during this process. They were there for me countless times to help me talk through confusing parts of the system, decide things about my project, but also emotional support. Thank you for being there for me.

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