

Appendix

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A. Project brief

FOR OUR
future

IDE Master Graduation

Project team, Procedural checks and personal Project brief

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

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

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

STUDENT DATA & MASTER PROGRAMME

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

family name	<u>van Loon</u>	Your master programme (only select the options that apply to you):
initials	<u>S.C.</u> given name <u>Carine</u>	IDE master(s): <input type="radio"/> IPD <input type="radio"/> Dfl <input checked="" type="radio"/> SPD
student number	<u>4282531</u>	2 nd non-IDE master: _____
street & no.	_____	individual programme: <u>- -</u> (give date of approval)
zipcode & city	_____	honours programme: <input type="radio"/> Honours Programme Master
country	_____	specialisation / annotation: <input type="radio"/> Medisign
phone	_____	<input type="radio"/> Tech. in Sustainable Design
email	_____	<input type="radio"/> Entrepreneurship

SUPERVISORY TEAM **

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

** chair	<u>Mieke van der Bijl-Brouwer</u>	dept. / section: <u>MOD</u>
** mentor	<u>Charlotte Kobus</u>	dept. / section: <u>MCR</u>
2 nd mentor	<u>Marise Schot</u>	
	organisation: <u>Ontzorghuis</u>	
	city: <u>Delft</u> country: <u>the Netherlands</u>	
comments (optional)	<u>Marise is a DFI educator at the TU Delft, who is initiating a NGO startup called Ontzorghuis.</u>	

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



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



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

APPROVAL PROJECT BRIEF

To be filled in by the chair of the supervisory team.

Mieke van der Bijl-Brouwer
 Digitally signed by Mieke van der Bijl-Brouwer
 Date: 2021.02.17 18:43:46 +01'00'

chair Mieke van der Bijl-Brouwer date 17 - 02 - 2021 signature _____

CHECK STUDY PROGRESS

To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair. The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: _____ EC YES all 1st year master courses passed

Of which, taking the conditional requirements into account, can be part of the exam programme _____ EC NO missing 1st year master courses are:

List of electives obtained before the third semester without approval of the BoE

name _____ date - - signature _____

FORMAL APPROVAL GRADUATION PROJECT

To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **. Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: APPROVED NOT APPROVED

Procedure: APPROVED NOT APPROVED

comments

name _____ date - - signature _____

A systemic design approach to improve support for special needs families project title

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

start date 09 - 02 - 2021 16 - 07 - 2021 end date

INTRODUCTION **

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

This project is for Ontzorghuis, an initiative by Marise Schot. It is located in the Netherlands, and strives to relieve families who give informal care to their special needs child. Ontzorghuis is currently trying to gain status as a foundation, and is in the startup phase. Marise has gathered a team of experts to further develop Ontzorghuis. They plan to become a foundation before March 2021, and receive government funding.

Ontzorghuis currently has a main goal: to help relieve the burdens of parents taking care of special needs kids. Their parents need to reinvent their lives and balance their time, in order to be able to constantly provide care for their kid. The child who needs extra care, is fully dependent on receiving this from their parents. 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.

The family context is important, but also those surrounding them: the care sector, with all the different stakeholders involved which differ per situation. Many parents need extra trips to health experts and hospitals. Many parents also get government aid which gives them budget to spend on extra care, another sector to deal with. 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.

Ontzorghuis also has a clear long-term goal: to get the health sector 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 live together. This would allow them to share their government budgets, and have 24/7 care, and 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 cafe). Currently, the team of experts is developing plans to realize these communities, and are running tests like weekends to learn about the families.

Apart from that, Ontzorghuis is striving to become a platform for a wider community, 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. One tool that was just developed by a DFI graduate, is based on reflection, and sharing these. The idea is that these products could be sold to or used in health care.

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introduction (continued): space for images

TO PLACE YOUR IMAGE IN THIS AREA:

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image / figure 2: _____

PROBLEM DEFINITION **

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

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 health care system focuses only on taking care of the child, whilst the parents are left alone to deal with all the changes in their context. There are many stakeholders involved, such as the health care but also government sector, and families' private lives. Ontzorghuis is trying to alleviate the stress and help parents deal with these changes.

The issue I will be tackling in this project, is how to approach the greater systemic change Ontzorghuis is trying to achieve. Their vision is to change the mindset of all stakeholders supporting special needs families: from only focusing on the child, to a mindset that includes the whole family. Currently, there are plans for a physical house, and the foundation is in startup phase, and there are no concrete plans how to grow into a care community for more families then just those living in the physical Ontzorgh-homes. The opportunities and optional directions are unclear, and there is no concrete future plan, just a dream of systemic change in the health care. This means the foundation is currently developing individual projects, and working on a lot of different fronts, to move forward. Apart from realizing the Ontzorgh-houses, it is uncertain what they strive to achieve the next 5 years.

ASSIGNMENT **

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

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.

My graduation project will be about the vision to achieve systemic change for special needs families in the health care and governmental sectors. I will zoom out, and look at the bigger picture and all the stakeholders involved, and put Ontzorghuis and its ideals into context. I will 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 means I will make a deliverable of an actual visual representation of the bigger picture - a systems map.

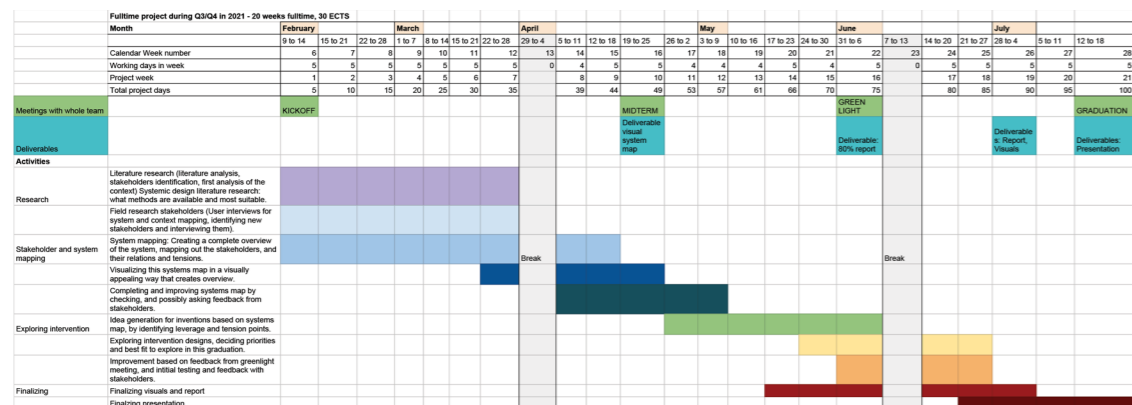
This systems map will include relations, tensions and leverage points, which I will use to reveal the opportunities for Ontzorghuis to grow. By defining the future direction, and diving into these leverage points, I will explore the possibility space. This will lead to an advised strategic intervention model, mapping out a path of small steps that achieves the intended systemic change.

It depends greatly on the outcome, but the steps should be developed in such a way, that Ontzorghuis can actively start pursuing them. This can be in the form of a roadmap of actions, but may also include new value propositions, and/or product or service suggestions, and possible partnerships, etc. The idea is that the strategy can be translated into several smaller action points or projects, to be done by Ontzorghuis or other graduation students. During this graduation, I will not explore all of these intervention points, but certainly will explore designing for one in further detail, and get feedback on it.

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 9 - 2 - 2021 16 - 7 - 2021 end date



My planning includes two main phases, which are illustrated and explained in the gantt chart above. The first phase is a combination of framing, listening to and understanding the system. This includes actions like literature research, and field research. To create the system frame and help understand it, I will map the system, and make many iterations based on the new knowledge acquired. The second part of the project exists defining the desired future, exploring the possibilities and designing an intervention model. This includes actions like identifying relationships and tension points within the map, and designing systemic interventions. This is followed by a period of exploring, designing and testing/receiving initial feedback about these interventions, a more iterative cycle. At the end of this second phase, the intervention model is finalized, and along with this also my graduation deliverables.

MOTIVATION AND PERSONAL AMBITIONS

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

I chose this graduation project, because I want to use my SPD skills to have a social impact, with a special focus on using systemic design to improve people's lives.

During my SPD master, I have acquired some competences and skills that I want to prove and practice. These include being able to use research as the building blocks for long term designs like a strategy, and the different tools that are needed like context-, stakeholder- and trend- research. I also learned how to use this research to gain insight into different levels of strategy, (e.g., resources, connections, core values) and link these together to form opportunities for growth and an overall strategy. I did the SPD media track "sketching" and I loved the process of making a "big-picture" visual, as it helps me to finalize and edit the research I did, and I would love to practice this. Furthermore, I enjoy linking these strategy skills to my people side, which I developed through my electives creative facilitation and context mapping skills: I practiced how to perform context mapping interviews and workshops, and analysis, and would love to practice this and prove it. I also gained experience with social enterprises, both through the elective social venturing (about loneliness in young people), as through my extracurricular activities with Hartige Samaritaan (I developed a game to help people empathize with immigrants). I learned the real challenge of developing a social impact startup: to balance the social impact with the financial side, and that choosing what to focus on can be a real struggle.

Working with social enterprises gives me internal motivation, which is the main reason I chose this graduation project. I want to gain more experience in working in the field of social ventures and foundations, and eventually discover if this suits me in the long term. Social innovation projects are often about lifting those up in society, that need a bit of extra help, and I think design is a very suiting method of providing this help. Design allows us to zoom in and out, and account for the complexity of the subject, as there are often multiple sides to empathize with. I want to try out a period of diving into people's struggles, make it my own, and really let my design come from the heart. Ontzorghuis is a good opportunity for this, with young parents it is easy to empathize, and design for not only them, but also the people in the sectors around them, trying to care for them.

On top of this, I want to learn how to use systemic design to create social impact on a bigger level. Systemic design was always part of my personal interests in SPD projects, but never the focus. I want to use this graduation project to dive deeper into this area, and discover and learn skills and methods, and learn to cope with the complexity of systemic design. Systemic design combines the "big picture" or analytical systems thinking, with the more actionable design thinking, which is a perfect match for me. 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. Systemic design will allow me to learn methods of how to frame these contexts in a way that includes all the stakeholders in one map. This motivates me, as it is interesting to learn about this new and upcoming design field, and to be able to contribute.

FINAL COMMENTS

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

B. Interview details

Government

Policy researcher Mantelzorg NL

Introduction

- Mantelzorg NL is has an association, and a foundation, these are separate entities.
- The association does lobbying towards the government, and receives money to do research about informal care nationally. You can become a member as an organisation or informal carer.
- The foundation makes its own money, by doing assignments and giving advice.
- The association does a lot of work with the government in the Hague, either with the Ministry of Public health, welfare and sport, or directly with the house of representatives through motions.
- Her job as policy researcher is to gather signals throughout the country from different sources, and bundle them to argue a motion.
- She gathers signals through the informal care line, sending questionnaires to the national panel of informal care, by asking organisations in the associations, and by looking at research from SCP and universities.
- If clear signals arise from the research, I try to either do a press release, inform members of parliament, or contact the ministry VWS.

Role in system

- Our manager has a meeting with the ministry every two weeks, and the contact is good, they are willing to make things happen, and have an eye for informal caregivers.
- Not everything that we want can happen, and sometimes it means we face dilemma's together, choosing between groups of people, but generally, the ministry is trying hard.
- "Het idee achter het wettenstelsel is de gemeente staat dicht bij de burger, en die heeft meer inzicht bij wat de burger nodig heeft, dus die kan maatwerk leveren, en dus ook goedkoper. Omdat het allemaal landelijk was, en de grote rol van CIZ, die indicaties deed, dan kan je ook zeggen er zit veel overhead op, het was wel duur, log en geen maatwerk kon leveren. Het idee is dat de gemeente het zo kan inrichten dat zij het meest gunstig de zorg kan leveren die nodig is maar voor zo min mogelijk geld"

Needs and drive

- She needs signals from informal carers and organisations, and the ability to send out questionnaires to them
- She also needs her team of colleagues, who all have different tasks like contacting the press, ministry, specific lobbies, track the house of parliament.
- She loves doing research, and thinking of a questionnaire, and its satisfying to hand it over to support the work of a colleague.
- But most of all, it is of course great non-profit work to help people!

Perspective: frustrations and experiences system

- After the decentralisation in 2015, the city councils have more freedom in making policy, and so the government's influence has diminished.
- This creates tension: the government also sees the downside of letting city councils decide, and the shortages in the social domain.
- In particular, you see huge differences between city councils, and what support they offer informal carers.
- Informal care is increasingly recognized as an important role in society, and appreciated. This was due to the change in laws, which forced city councils to support informal carers.
- Even so, many city councils don't have enough money to support informal carers, and family care support is under pressure.
- CSN parents are a small group, and a bit different then most informal carers.
- "Het proces loopt bij ouders met een gehandicapt kind een beetje anders. Aan de ene kant weet je meteen het is anders bij ons, aan de andere kant hoort het ook bij kinderen dat je voor ze zorgt"
- Informal care is very diverse, the spectrum is large and many problems overlap with other area's of life. This makes it more complex to solve, as there is also overlap with ministries (like housing or work), which means it is hard to find a quick solution.
- "Vaak zijn oplossingen pleisters, en is het grote probleem eigenlijk de ingewikkeldheid van ons zorgstelsel".
- Decentralisation had some positive effects, but problems arise when people don't fit into one of the laws or processes.
- An 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.
- "Decentralisatie heeft wel voordelen gehad, maar we zien nu wel heel veel problemen met dat mensen tussen wal en schip vallen, dat ze de van zorgverzekeraar naar WMO heen en weer gestuurd worden omdat het onduidelijk is wie wat oppakt."
- "Dan voelt niemand zich eigenaar van het probleem, het probleem is er, dat snapt iedereen, maar niemand voelt zich eigenaar, en dus er weinig vooruitgang te boeken, en dat is wel frustrerend voor ons werk"
- "Blijkbaar wordt respijtzorg nu steeds meer gegeven aan mensen als ze al overbelast zijn, in plaats van een tijdje daarvoor om te voorkomen dat ze overbelast raken."
- The city council can give informal care support, but if the informal carer collapses, it doesn't cost the city council anything, it actually shifts the financial responsibility to the social support law WMO.
- "De gemeente kan wel investeren, maar het geld wat het oplevert komt vaak niet bij hen terecht, dat is ook wel het grote probleem met die zorgwetten"
- There are some small steps and pilots from the government, but its very slow.
- To improve the system, a bit of control should be taken from city councils, back to the national government, so there aren't these big differences between city councils.
- She is positive there will be a big change for informal carers the next coming years.

- "Vaak zie je golfbewegingen in beleid, van iets nieuws bedenken en dat wordt het dan helemaal, en dan zie je er zitten ook wel wat nadelen aan en dan gaan ze toch bijsturen, en ik denk dat het ook gaat komen met de WMO."
- "Je kan ook niet heel snel zeggen, oh we gaan weer terug naar hoe het was, want gemeenten hebben enorm geïnvesteerd in beleid en er hard aan gewerkt om het op poten te zetten. Dus je kan ook niet zeggen we gaan terug naar het oude, het heeft ook tijd nodig om weer naar een oplossing te kunnen werken"
- Informal care is hard to measure, and there are no standardized qualities, or researchers done proving effectiveness. The only researches are done on very specific target groups. This means its often the sector that undergoes budget cuts.
- "Dat geldt voor de hele zorg en welzijn, we hebben allemaal het idee dat het werkt, en wat gebeurd goed is, maar er zijn geen keiharde cijfers over. Als er zulke bezuinigingen zijn, dan is dit al gauw de sector waar een beetje geschaafd wordt"

Municipal council

Member youth team: Casemanager

Introduction

- Casemangers have a big variety of tasks, one of which is to support CSN parents
- Supporting means understanding their needs, their rights and arranging budget and help
- First parents register, then parents are on the waiting list, and I arrange a meeting.
- I have 35-40 children as cases, and my job is 28 hours/week.
- Some families take longer, others need less time, depending on the requests for help. Some need a couple of appointments, some will always stay a case, and in between.

Role in system

- Before the decentralisation, the kids were split: A group that had an IQ above 80 was not above her responsibility as jeugdzorg. Those were tended by the organisation CIZ, who would guide them into adulthood too.
- Lots have changed in the system: bureau Jeugdzorg had less time per family, but less options: either plan A or B. Now I need have more tasks, and am also responsible for broader city councils support.

Needs and drive

- I need openness and honesty from parents: if they tell me too little, I cant help them properly
- 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.
- I need enough time to do my job, and social skills to maneuver conversations
- As an organisation, we want to help give the kids the best care for them, but also need to balance it with the budget we have. "Je wilt de juiste hulp inzetten, en wat nodig is dat doe je, maar je wilt geen hulp inzetten voor iets wat niet nodig is."

- My drive is helping the kids and families get the help they need, so they don't need me in the end.

Perspective: frustrations and experiences system

- 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.
- I need the care organisations to have shorter waiting lists
- We have more time per family, and this allows us to build a relationship.
- It is easier to customize care, and find the right organisation
- There is a lot of overlap between laws: parents that are overloaded with care for their child, need care from WMO, but they don't answer parenting questions. "Daar moet je goed mee samenwerken wil je dat plaatje ook zo goed mogelijk voor ouders willen regelen."
- The CSN needs more, specialized and more expensive care, for a longer period of time, which strains the city council's budget. "Dus dit soort kindjes zijn een hele aanslag op het budget wat de gemeente heeft voor de hele Jeugdhulpverlening. Als er dingen anders moeten, dan zouden we daar moeten beginnen."
- "Ik weet niet of organisaties heel veel beter zijn gaan samenwerken, de frustratie blijft, het is gewoon echt maatwerk. De ene organisatie is beter in dit, de andere organisatie is beter in dat. Die WLZ zit bij dit soort kindjes wel echt in de weg, daar loop ik echt heel erg tegen aan."
- There is a grey area between WLZ and Jeudgwet. We can apply for WLZ, but sometimes it's rejected 6 times, or only accepted when the kid is an adult. WLZ often pays less, but sometimes you need its indication to get into a daycare spot.
- Also, if we as a city council guarantee a couple of years of budget, the kids change address and city when they become adults, and the money for their spot is no longer guaranteed (as each city council has its own rules.)
- The biggest frustration is for the parents: they hope for a spot, and I need to disappoint them time and time again.
- But it is frustrating for me too, because it's hard to find the right spot for them. Maar mijn frustraties zijn er ook, omdat het mij dus elke keer niet lukt om een goede plek te vinden waar iedereen achter staat en zegt hier gaat een kindje gelukkig worden of echt op zijn plek zitten."
- Making the WLZ a bit more lenient, it would solve a lot for these kids. That needs to come from the government, as city councils will always have differences.
- "Ik denk dat als je het bij de gemeenten laat, dat er altijd een verschil zal blijven."

Municipal council member

Introduction

- My role in the local council is to see that the municipality properly supports it residents. For informal carers, I am responsible to see if we give this support adequately, and that can be quite a challenge.
- If I receive signals, I try to bring it to the attention of the national government of my own political party.

- Informal carers can reach me by calling, and I will visit them. My phone number is on the website. If they have a policial point to make, they can also send a letter and I can discuss it with the local council.
- I read a lot of cases with a lot of personal stories, and see where we can help.
- My role is compensated, but not enough to be a real job. It is part time.

Role in system

- Term of mantelouder is unknown, though I do understand what it means
- The municipality organises an informal care day with workshops. But a lot of informal carers don't have the opportunity or time to come, so we told the council to investigate and broaden their methods to fit the target group better.
- It depends on the target group if they are the responsibility of the municipality. Children with handicaps are not our responsibility, they get medical daycare which allows the parents to have some time off.
- We are responsible for allowing home improvements for these families.
- The city council is partially responsible for respite care.

Needs and drive

- I need information, and stories to come my way, though I can also try to actively find the target group.
- I can ask the council to research a certain target group and its issues and size.
- I also need to know about the national law to see what options there are for people who need care.
- My drive is to represent the voice of those who do not stand up for themselves and are vulnerable.
- "Een stem geven aan mensen die geen vuist maken - de klagers in ons land weten je wel te vinden - mij drijft juist het feit dat er in ons land er mensen zijn die veel harder hulp nodig hebben, die het veel zwaarder hebben, maar die geen tijd of geen puf hebben, of zich murw gebeukt voelen, en dus niet meer voor hun recht zelf strijden. Ik vind dat je daar dan voor in de politiek zit, om dat belang wel goed te verdedigen."
- My political party is all about seeing the government for people who can not manage themselves. Society can handle a lot itself, so the government and its influence does not need to be big, but they do need to represent those people who are most vulnerable.
- I find personal visits very motivating, even if the stories are sometimes hard to hear. You can not take away their problem, or heal their child, but it does drive me to start change for improvement.
- Informal carers are so busy caring, they dont complain but just continue, so it is harder to hear their stories. It helps to have someone in your network who represents this group.

Perspective: frustrations and experiences system

- As local council, we don't often think about CSN parents, since the problems should often be tackled on a national level.
- For example, the combination of work and care - if you can't work because your child is sick, the taxes should be distributed more fairly, but now the taxes are in favor 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.

- Also, 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.
- I think the municipality does not have a good overview of all CSN parents in Delft, and doesn't know their needs.
- Most CSN parents probably dont know they can supply for help at the municipality
- The distribution of responsibilities between the municipality and health insurers seems clear, but in real life it often is complicated. When is help enough? There are meetings with health insurers, but I dont know if they discuss these types of responsibilities.
- A frustration is that a lot of parents with children that need mental health care, are stuck in Jeugdzorg: there is a tension between how big our budget is and how much parents we can help.
- 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 situations worsens.
- Thats another frustration: we are 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.
- 50 years ago, parents would fix these problems themselves, and now its the responsibility of the government. I think the government should give priority to CSN parents.
- In Delft, we have a nice organisation, but budget shortages like 2 million for next year, make it a complicated situation.

Former team manager youth care

Introduction

- I have a history in working for the social domain, also for people entering the job market, but I continued in youth care as a policy manager of the city council.
- Right after the decentralisation I was the manager of youth care, afterwards the manager of the CJG in the Hague.
- As manager, I was in charge of managing the managers of all the teams.
- There were 15 teams in the Hague, 2 of them being specialised in indicating PGBs.
- Now I am a freelancer, who does work in the social domain.
- My role as top manager involved making sure the teams were focused on the familyplan: focus on 1 family, 1 plan, 1 director. I needed people to focus on that, because it is the best way towards a sustainable solution, which you wont achieve if you focus on the child only.
- A youth care team consisted of several professions: youth protection, welfare, multi-problems, behavioural experts, who all worked really well together and were focused on improving the situation for the child.

Role in system

- The system is very complicated, as are held accountable by the local council, which gives a strange method of steering the organisation.
- The decentralisation did not solve any problems, because there is just not enough money.
- FVV is a trade union that is passionate about eliminating bureaucracy, and bringing the money back to help the child.
- The overall organisation for municipalities, the VG, is also working on this.
- A child is only prioritized, if their safety is in jeopardy, if they need emergency care.
- There is a difference between youth care, which is about welfare organisations and municipality care. And youth health care, which is the municipality and the CJG all together in a networkorganisation.
- The child is often seen in the system of the family: if the family does well, it has a big effect on the child too.

Needs and drive

- Giving care to a child is always in a context, and I wanted the child to remain in their own situation at home as long as possible, because that is the best for them. That was my aim: to support the network of the child, and make them stronger and able to care for them.
- My heart goes out to the vulnerable people in our society, so I deliberately started working here, to improve their situation.
- In the municipality, a lot of people care about society, and do their job with the best intentions. There is a lot of passion and drive in their work, to do it well and also as fair as possible.

Perspective: frustrations and experiences system

- Care professionals that work for the municipality have done an education, they are registered, and they keep to their professional ethics code. Still, because of how the municipality works, I need to tell them how to do their jobs, even though they are experts. This is because of pressure from higherup (the city council and directors manage the budgets). This got so complicated, I was overburdened, and got a burnout.
- "Er zat zoveel idiote druk op, en iedereen wist het zoveel beter, en ik stond tussen de professionals en het hoger kader, er werd zo aan me getrokken dat ik het uiteindelijk niet volhield"
- We should give more responsibilities to the professionals, since we are experts.
- On the other hand, care professionals are currently taught only to care, and you can never care enough, it is never finished. So there needs to be someone looking at the business side of things, and the financial picture, and their expectations need to be managed: is a 7 enough? Do we really need the 8, or can we switch to caring for another child?
- Since the system is so complicated, I think it would help if municipalities are smaller, or if the bureaucracy was a bit looser, and allowed more flexibility.
- "Het is zo idioot en complex, ik weet gewoon dat het mij gaat frustreren, omdat het ... eigenlijk geloof ik er niet zo in zoals het in Nederland aangepakt wordt"

- 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.
- 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.
- Often parents ask for help too late, when they are already overburdened and tired, which makes it hard for the municipality to help on time, since the waiting lists are long. Prevention should be talked about more, and become more normal, I understand asking for help is hard though, and people don't realize how much they need it, or are embarrassed.
- Independent client supporters are a good idea, and really help families who are overburdened.

Care domain

Insurance administrator

Introduction

- I see my job as an indirect healthcare supporter, because I try to help client find the best care for them.
- I have a lot of contact with parents, they call themselves 90% of the time.
- Our whole team works with the target group of CSN parents.
- A lot of people have people in their personal network helping them, and with the PGB these people can be paid, which allows them to make a clearer agreement on the hours they care.
- We check the files, and do housevisits, to talk about how care can support them.
- We know where to refer people for the right care, sometimes its a grey area, but generally we know.
- My role is an administrative worker in care domain, we handle requests, assign PGBs, enter agreements, check files, and talk to people on the phone a lot, if they have questions about the PGB or payments and help them go through the forms.
- "Wij proberen zoveel mogelijk mensen te woord te staan, dat je ze kan helpen, want vaak weten mensen niet zo goed waar ze moeten zijn met hun vraag"
- We don't have a list of healthcare providers to choose from, but we do refer a lot. People get a lot of freedom at DSW where they arrange their care.
- I see myself as a specialist in referrals, people sometimes call us when they really need to go somewhere else, and I point them in the right direction.
- Especially after they are 18 they need to be referred to the WLZ or WMO.
- I know my clients well, because usually they are with us for a long time, and we have quite a small region and team.

Role in system

- Many CSN parents learn from each other how to request care at locations like daycare.
- Most people have a complicated journey, going from the city council to the health insurer, to the WLZ.
- It remains the GP that should refer people to health insurers like us.
- It's often a parent's first time talking about PGB, and I have to explain to them that they can not provide more than 40 hours of unpaid care to their child, especially if they work next to it, they will become overburdened.
- Single parents, I advise having a backup group that can help if you suddenly get sick, because a small child can not go to a care hotel.

Needs and drive

- I want to do my job well, because I am being paid to do it.
- I need certain knowledge, but DSW gives me courses to follow, so that is how I learn.
- Over time you also acquire experience, which helps in handling different situations, as you have already experienced it before.
- I am proud of our new digital system, which lets people pay their carers independently, giving them more control.

Perspective: frustrations and experiences system

- People have often fought through a few years before they get a PGB budget, which is sad, as most people are overburdened before they realize they can request care. It is due to the complicated laws, that people have a hard time realizing where to get a budget.
- "Die decentralisatie in 2015, ik snap niet dat ze dat ooit hebben kunnen doen, vroeger was alles AWBZ, dat heb ik ook gedaan, toen was er 1 verstrekker, en nu zijn er 3 loketjes, en ze moeten van het een naar het andere loket voordat ze doorhebben waar ze dan onder vallen "
- As health insurers, we didn't mind the decentralisation, but many target groups did, as suddenly everything was unclear. Some target groups disappeared, or became the responsibility of city council.
- We see many people that changed to city council come back to us, because they do get a WLZ indication in the end.
- It would be good for people to have 1 contact person, who can help them navigate where to get care.
- For me its important to realize parents are overburdened when I go talk to them, they see filling in forms as a burden, but I can not just give them money, I need to justify it
- "Het is wel een aardig bedrag wat u tot uw beschikking krijgt, we willen wel zeker weten ook dat u er goed mee om kunt gaan, en dat u goed van te voren bedenkt wat ik ermee doen: wie ga ik inkopen, wat ga ik betalen aan die persoon, kom ik dan uit in dat budget, dat zijn dingen die we van te voren al willen bespreken"
- "Dat is met PGB, je moet toch wel iets invullen, het niet zovan ik bel even en ik krijg geld, dat gaat gewoon niet"

Community nurse

Introduction

- I work at the Centrum van Jeugd en Gezondheid in the team responsible for cities Delfgauw-- Nootdorp. My organisation is split up into regions, and I work at CJG Zuid Holland west.
- A team consists of pediatricians, assistants and community nurses.
- The manager of the team gets budget from the municipalities for the basic care provisions like consultations and vaccinations.
- She works with kids from 0-4 years, and monitors their growth.
- She gets a notification from the municipality that a new baby is born, and goes on a house visit. Most people gladly accept the visit, and their kids are routinely checked and vaccinated.
- She does small tests to check the development of the child, and if something is off, the refer to the medical professional, or even the hospital for a checkup. Examples are if a kids has trouble pushing itself up, or is very late with talking.
- For every test she has 15 minutes, and if the test deviates, she gets the pediatrician to check.
- Most kids are seen on the planned time slots, but a lot can happen in between those times.
- There is also a walk in consultancy hour, and they are available by phone, but most times, parents don't call to inform them of any changes.
- She has some extra tasks, called "stevig ouderschap", which means she supports vulnerable and overwhelmed parents with parenting questions.
- If parents have too many questions, she refers them to other charities, like Humanitas Doorstart, who have volunteers that help parenting for a day per week.
- You can recognize a CSN child by how much care and attention they need, but some babies start out needing a lot of attention, like crybabies, which is slowly solved over time.

Role in system

- The municipality can buy extra packages like "Stevig ouderschap". Every year, they negotiatie with us how many people can receive such help. The policymanager visits the city council with an expert, to try to convince them it is worth the money.
- The city council also has a policy official to communicate for them. They decide the budget, and ultimately how many children are helped.
- There are special budgets for children with speaking development problems for example
- Our organisation is not part of the kernteam, don't know why. The kernteam consists of all parts of health care, and it depends per city who is in there. It is a team of local care, and are the focus of the city council, and receive a big budget.

Needs and drive

- If we detect something, some parents can start to panic and worry, and that can be hard to deal with. It is important to keep doing the research, to make sure what is wrong, and to make sure the child gets help as soon as possible.
- I need to be able to deal with a big variety of parents and cope with their different situations.
- Some parents are actually very glad someone listens to them, because they have been worrying for a while, and saw a development change in their child. They feel heard and taken seriously.
- Other times, parents don't feel taken seriously, because they are being sent from one professional to another, and are worrying about their child. If the situation gets too complex, we refer them to foundation MEE or Integrale Vroeghulp
- Some parents are overburdened, and they need help, so then the kernteam or city council can help them. This can be due to different reasons: the family being overtired, other psychological problems, domestic violence.
- We pay special attention to these cases, and give tips via phone conversations. It is important to monitor those closely, but we don't always have the time and budget for it.
- It can be hard to confront someone, and I always try to side with the parent: how are you managing all this? How do you take care of children? Then usually they open up.
- Sometimes parents think they need to do everything themselves, and are afraid to ask for help, or don't know who to ask. Then she helps them go through their network.

Perspective: frustrations and experiences system

- It is hard because I only see parents for a short time period. If I refer them, I do call them after their appointment, to check up.
- It is a hard part of my job, because you can only refer people, and not guide them.
- It can be hard to figure out the reason for a problem in such a short time period. Usually it helps to do a house visit, and see them in their natural situation, which helps us connect the dots. For example a child who sleeps badly, because they watch tv all day.

Remedial Educationalist

Introduction

- I work in an organisation that works a lot with special needs children, we do process diagnostics.
- I am a remedial educationalist. Any child that comes, has a language development problem, and my role is to observe the children, and do psychological tests to determine the reason and how to treat them.
- I am in three teams, and all teams have 8 kids. The teams also have pedagogical practitioners, physiotherapists and parent counsellors.
- The children are very young, I work with ages 2-5. Children come to us 3 half days per week.
- Their language and speech development is slow, so after they have been to the audiological centre, they are sent to discover the reason: is it a disorder, or deprivation,

or something else that influences their behaviour, or social-emotional development or cognition.

- If I suspect a syndrome, sometimes the parents are already in the process of testing, or I refer them to it.
- Afterwards, we look what the child needs for the transition to a school, and which type of education would fit best.
- It is really at the beginning of the process, and often parents just discovered their child is not developing as expected.
- Parents have a hard time accepting this change. Often, I am the first person to tell them their child can not attend regular school (or at least not yet).
- "En wat je ziet waar ouders vooral tegenaan lopen is het acceptatieproces waar ouders inzitten"
- "Zovan: Ik merk eigenlijk er is iets met mijn kind, ik had gedacht mijn kind gaan gewoon naar het regulier onderwijs, maar er is zoveel aan de hand, het is niet haalbaar. En dan kom je heel erg bij een acceptatieproces van ouders waar ze inzitten"
- It is a process I undergo with the parent, since they are with us for a year, and we support them about the change that is happening: what is a language development disorder, how will the child develop, what does it mean for the family.
- "Soms is dat ook heel verhelderend voor ouders, ja dat is net mijn kind, precies mijn kind"
- We use Hadden, which is a method for language development disorders.
- I try to guide the parents in the process and involve them. We pay attention to how the parents handle the child at home, and if they run into problems.
- Our organisation has a parent counsellor, and we offer psycho-education about the children, as well as trainings, courses and workshops.
- It is mandatory to attend these trainings, to be able to get a spot, since they are the main educators of their child!
- "Als je kijkt naar de afgelopen jaren, dan is de trend in de zorg dat je ouder veel meer actief deel wil laten nemen in de behandeling. Je wilt ze veel meer een rol geven in de behandeling."
- At the end of the year, we celebrate and say goodbye with a little party.

Role in system

- Childrens development is tested at the youth health care, consultation center. A lot of early detection happens here.
- Usually then either the youth health care doctor refers them to a speech therapist.
- They refer them to an audiological center, which does research, and they give an indication of the development, which they need to be referred to me.
- The youth health care doctor can also refer them to an organisation like Integrale Vroeghulp, which help the family find the best path for care of their child.
- Or they refer to the social team of the municipality, for extra help for the family. These social teams can also refer to us, in situations.
- If children get an indication, they enter a 9-month treatment with us. Up to 9 months it has proven effect, and afterwards it declines, so we only get 9 months, and then the child is referred to another place.

- The health insurance pays for the treatment. We have contracts with health insurers.
- When children get an indication of their development, it is also used as an indication for the health insurer.
- "We hebben als organisatie contracten met de zorgverzekeraar, zovan we schatten in dat we 1000 kinderen van uw zorgverzekeraar gaan behandelen, en als we ze behandelen, dan ziet zo de behandeling eruit: we besteden zoveel minuten tijd aan dit, zoveel minuten aan dat, het is best wel strak ingericht. Dus dat koop je dan in en dan stellen we samen een contract op."
- The health insurance has 3 types of financial budgets, one is for disabled care.
- The municipality gives separate indications every year, for care.
- The municipality also buys their care every year, and they compare organisations, looking at prices, number of kids, effectiveness.. They care about preventive, accessible help that is close to the parent, and cheap.
- Going from hospital to hospital has a big influence on a child's development, so they should be sent to us!
- Many parents do not like the medical world, as it is a traumatic experience for their children, and so indirectly to them. Many kids need trauma care after they experienced that.
- It would be great if there was guidance starting at the consultation center, into the medical world, as many parents struggle with this.

Needs and drive

- I need a multidisciplinary team, who have knowledge on all sides of the development: motor skills, language, social-emotional, because it all connects and overlaps. Our team is great,
- I need a lot of expert knowledge, and time to observe the child. We get a lot of trainings, which is great. I am intrinsically motivated and interested in the development of a child.
- I think its important to invest in my relationship with the parents.
- "Zelf vind ik het wel belangrijk om dicht bij het gezin te staan, dus je moet zorgen dat je investeert in de werkrelatie met de ouder"
- What I like very much, is offering that first progress, development or insight in their whole life journey. You can always see a big development in a year.
- Parents are the center of the family, so we try to help them in different ways.
- "Ouders zijn uiteindelijk het belangrijkste van het gezin, dus je wil ze wel graag de goede richting op wijzen voor hoeverre dat kan"
- Either by looking at their capacity vs responsibilities, with the Yucel method, or the OBVL, which looks at how they are handling stress, and if they need help.
- Or referring them to local initiatives for kids, to broaden their network.
- I need parents to be open to learning in our trainings, online its harder.
- One of the ways that helps, is breaking the language and cultural barriers, with my foreign colleagues, they usually have an automatic click.
- I need to be able to handle different reactions parents give, as a syndrome or development problem gives a lot of uncertainty. Their future is hard to plan, as you don't know what will happen.

- I always allow them to express their emotions, and they are allowed to be sad or confused, because it is quite a lot to handle if your child is not developing as expected.
- Here are some reactions:
- Parents are very different: some worry a lot, have been waiting a long time, and others don't worry as much.
- Some are in the denial phase, and refute everything I say, giving arguments.
- Others are angry; how dare you say my child lags behind!
- Some just ignore it all, and hope it goes away if they don't pay attention to it.
- Others just choose to see where it goes, and those are easiest to work with, as they are willing to try everything.
- There are parents who want to keep control, and complain about everything. They actually slow down the process of diagnosing their child, because they dont feel ready.
- Some parents have children who have a lot of development issues, and they don't mind. Others, who have milder development issues, can be completely thrown. For example, a higher-educated couple who were expecting their child to also do higher education.
- "En je hebt ouders die hebben een hartstikke beperkt kindje, en die houden van dat kind zoals het is, en vinden dat ook goed, en elk stapje dat hij zet zijn ze heel trots op. En die hebben alletwee een fulltime baan en dat gaan dan prima"
- "Die ouders kunnen daar helemaal kapot van zijn. Ze willen eigenlijk dat het kind gefixt is ook, het liefst zo veel mogelijk, ze willen het zoveel kansen bieden, dat is hun drive ook, dat vinden ze belangrijk, om het kind te juiste kansen te bieden om toch zo ver mogelijk te komen, en die gaan er zelf aan kapot"
- There is also a big difference between parents who have learned their child has a syndrome during pregnancy, or those who have just recently discovered it at the 2 year age mark.

Perspective: frustrations and experiences system

- The waiting lists are long, especially for special education.
- It is hard to get in, because you need different indications to get a spot, and they think in strict boxes, so if you deviate a little, they don't admit you, it takes a long time to get approved.
- It 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.
- "Ik snap het ook wel dat je als ouder heel onrustig wordt als je nog geen zicht hebt op een plekje op een school, terwijl je dat als ouder heel belangrijk vind"
- The children sitting home are often the most vulnerable situations. These children are hard to handle, and parents are struggling to care for them, as also waiting lists for other help are long.
- "Die zitten wel in de overlevingsstand, totdat er meer hulp komt"
- "Daar proberen we ouders zo goed mogelijk in te ondersteunen en te horen, maar we kunnen het ook niet altijd oplossen. We kunnen ze het wel uitleggen hoe het werkt, en een stukje wegnemen, dat denk ik wel dat we als organisatie veel doen is dat we een stukje stress van de ouders wegnemen, dat we een stuk van de regie pakken en het proberen voor hun te regelen, maar dat kan ook niet altijd "

- There is just not enough money, not enough special education teachers, and not enough spots available, it's a problem all over Holland. That makes working together with these organisations hard.
- "Het is met het probleem van de scholen, dat kunnen we niet echt oplossen"
- The finances for the special needs schools are based on numbers before our whole sector transitioned. So, while many doctors, and kindergartens improved on preventive early detection, the financial situation for the special education does not match.
- Some parents have a more passive attitude, so we need to actively seek them out. Some innovation works, like online meetings, and apps where we send photos, but face-to-face always works better.
- The privacy law is hard to work with. Many families get help from several organisations, and we can not view each others work. It is up to the parents to be open about it, and it happens that crucial information is missing from my files.
- "Je bent gewoon heel erg afhankelijk van de informatie die een ouder je biedt"
- There is an index, that allows organisations to share information.
- "Het werkt wel heel goed, maar het kost wel allemaal meer tijd, dat moet je ervoor maken. Je moet alles drie keer vastleggen, schriftelijk laten ondertekenen wil je toestemming krijgen om het naar een school te sturen"
- Sometimes working together with other organisations is frustrating, as the communication is off, and many issues overlap.
- "Met verschillende organisaties is het best wel pittig samenwerken soms, de afstemming met waar zijn jullie mee bezig, het overlapt soms, en dan is de communicatie niet goed van waar is iedereen mee bezig"
- Some parents struggle with managing everything, and if I see this, I refer them to the municipality social teams. Parents really need a case manager.
- "Ik vind dat vaak heel prettig, ook als ik ze doorverwijs voor psychiatrisch onderzoek, of genetisch onderzoek of alles tegelijk, omdat er gewoon meer duidelijk moet komen op verschillende vlakken, dan is dat voor ouders vaak best wel een rollercoaster, en als je het dan niet helemaal overziet en het al best wel pittig hebt, dan is het heel fijn als er iemand echt voor de ouder er is, en naast de ouder kan staan, samen kan bellen."
- I also meet parents that need help themselves but aren't receiving it, like after a traumatic experience, or other reasons.
- Many parents will deny needing help, or on long waiting lists, and it is not really our responsibility, but it does really affect the child, as it makes the family vulnerable.
- "Dat is wel heel lastig, want daar moeten ouders zelf naar toe kunnen bewegen, we kunnen het op een gegeven moment als tip geven, zolang we zien dat het u veel doet, misschien kan met de POH (psycholoog in huisartsen praktijk) arts eens praten, dat zie je wel veel"
- We also have many families that don't have a network, because they are foreign. Then culture plays a big role, and if they can share with their families.
- Some parents struggle leaving after treatment. We guided them and built up a relationship, they feel safe, like a "warm bath", and it's a hard transition to the education of their child.
- "Ik hoor bijvoorbeeld heel veel ouders, dan is het kind 3 als hij bij ons start, die dan in z'n gesprek zeggen: Ik hoop dat mijn kind kan blijven tot hij 5 jaar is. Dan snap ik het

wel vanuit het gevoel van ouders, maar op een gegeven moment ontgroeit het kind het ook"

- The same thing happens when a child is ready to go from special to regular education, and every year, they need a new indication, and things can change, which makes everything very uncertain.
- Most parents have gone through 10 different care organisations, and that can be a lot to handle.
- Also, education is more focused on the child, and there is less guidance for parents.
- The downside of the decentralisation, was that a lot of specialist knowledge was lost, as it was not gathered anymore at one point.
- "Doordat er zo wegbezuinigd is op die hele specialistische hulp, heb je gewoon minder groepen, wat aan de ene kant goed is, aan de andere kant zijn er gewoon kinderen die het echt niet redden binnen de bestaande vormen. En daar zijn dus wachtlijsten voor, en dat zijn wel vaak de meest zorgelijke kinderen, die dan bijvoorbeeld thuiszitten"

Outpatient care provider

Introduction

- As outpatient care provider, I get paid by the city council, and citizens with a request for care are referred to us.
- We visit and care for people in their own homes.
- We are a small company, only 6 people, so we have easy communication, but do similar work as bigger companies like Leger des Heils or Sherpa. However, they are larger and less flexible.
- Since we are so small, we know our colleagues well, and also their clients, and can easily substitute for them.
- We used to also take care of kids, but we had to specialise our company.
- My role is to give kids the ability to see their own problems, to help them self-reflect and understand how to overcome the problems that most occur for them.

Role in system

- Currently I don't have clients below 18, but I did use to, usually the parents are still very involved though around this age, and that's why they requested care.
- Parents have a hard time letting go of their child, but if they give their child more space, they usually become more responsible.
- Parents usually request care at the city council, who talk to parents about what kind of care they need and why.
- Usually, the parents have already tried many things and are giving up, and a fresh pair of eyes can do wonders in such cases. Before we come, the family is usually very tense.
- "Voordat wij komen is er vaak veel spanning in het gezin"

Needs and drive

- I need feedback from my team. We have team meetings and anonymously discuss cases, and I appreciate the feedback, especially on multiproblem cases.
- I also have a meeting with my boss about my clients, and how I am struggling, sometimes it is hard to keep motivated in my job, so she gives us tips of new activities to do.
- We are close as a team, and regularly inspire each other by sharing tips and photos.
- Since we are alone with clients, these feedback moments are really important to me.
- I love helping people with things they struggle with, like administration, it gives me great satisfaction if they succeed their task.
- I need to make sure I don't really become invested and their friend, to them I need to seem like a friend but I need to keep a strict boundary that I am a professional.
- To handle the emotions, I talk to someone, and also writing the reports after visits helps me to process.
- I am most proud of moments where we say goodbye to someone, because they learned enough to continue on independently. Then you are proud of yourself and the youth.
- There is usually a really clear moment where we have completed our care, but if someone needs care for a longer period, we usually switch clients within our team so that we stay motivated.
- Its frustrating when people bail on me, or they don't communicate well.

Perspective: frustrations and experiences system

- The government gives us many rules and processes to follow, which can be very frustrating.
- I understand why I need to make a report, but there are many administrative tasks that are bothersome, like a domestic violence check that we need to do routinely. For example, if a couple is fighting, I need to write a report about it, though it can just be a fight.
- We also need to read our clients our report, which most of them don't want to read.
- "Er komt steeds meer bij, nu komt erbij dat ze hun dossier moeten inzien, daar zitten ze helemaal niet op te wachten! Dan moet ik met ze inloggen en code geven zodat ze mijn rapportage kunnen lezen, en hebben ze zoiets van ik geloof wel wat je opschrijft, ik vind het wel prima, dat hoeft ik niet te lezen - maarja we moeten het wel aanbieden vanuit de overheidsregelingen"

Regional manager day care centers

Introduction

- I have worked for this organisation for 37 years. I started out as a group supervisor, and now I am regional manager.
- I am regional manager of 3 KDC (child service centres) and some "gardens" which are small forms of treatment at daycares.
- I am the manager of the employees and responsible for the organisation things like the personnel and financial policies, together with the manager who is more responsible for the content of the day care activities.

- Since I worked a lot with parents, I always try to remember their situation, and I realise they put the responsibility of caring for their child in our hands.
- I only talk to clients when something is wrong, and when we have our meetings with the client council.
- Since I know a lot about the history, I also have the function of a living archive, having overview of the big picture, and who works where.

Role in system

- Our finances come from the government. It used to be 75% WLZ and 25% Jeugdwet, but now it is flipped around. Most young kids start at the Jeugdwet.
- The budget you get from the WLZ and tariffs, are a bit lower than the Jeugdwet.
- We used to have this organisation H10, a purchasing office, who organised everything. After the decentralisation, the municipalities make their own budgets.
- H10 still organises the finances, it is now a group of 10 municipalities that bundle their budgets. The budget is based on the budget from last year. If we are too much above or below, we discuss together what the reason behind it is.

Needs and drive

- I always try to balance thinking from the parents' perspective, as well as the business perspective. For example, if children are absent a lot, it costs us money, so we try to improve this.
- I need time, and a positive work environment to ensure that we can all grow as employers, and that we provide the best care to our employees, and indirectly to the children.
- I need an open atmosphere, where I am free to decide my activities, and I also try to give this to my employees.
- What also drives me is innovation, someone looking from another perspective, and maybe helping people in a different way or with other problems.
- I am also driven by my job, I love to lead, and combining it with human focused work.
- I try to balance the mindset of my employees: on the one hand, I want them to think with our company, and be flexible for what is needed at the time. On the other hand, I don't want them to be overloaded with work, there should be an end to the work.
- "Het gesprek wat ik ook wel vaak heb, is wanneer is goed nou goed genoeg?" "Ik vind ook dat die meiden echt keihard werken en hun hele ziel en zaligheid aan die kinderen geven, of in het begeleiden ervan stoppen. Dat ik ook soms denk: maar ergens stopt het, altijd maar doorgaan schiet ook niet op!"

Perspective: frustrations and experiences system

- 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.
- "De WLZ is eigenlijk steeds kritischer wanneer een kind WLZ financiering krijgt, en de gemeentes die willen eigenlijk het liefst steeds sneller een kind in de WLZ financiering krijgen, want dan scheelt dat hun weer geld."

- The last period of time, our finances have been worrisome, as we are dependent on the Jeugdwet, where there keep being budget cuts, and the tariffs are declining.
- On the other hand, the amount of kids that need help is increasing, and sometimes in horrible situations, where families are at the brink of collapse. Kids need to be treated earlier, or everything escalates.
- "Als je het niet doet op jonge leeftijd, krijg je het driedubbel om je oor als ze straks wat ouder zijn en finaal uit de bocht vliegen".
- There are more one on one meetings with municipalities, and for us its frustrating, because we have to deal with a lot of them, and they all have their own policies.
- There are big differences between them: Delft has case managers linked to each kid, Zoetermeer doesn't have anyone responsible, which is hard to search for someone to solve problems with.
- The decentralisation changed a lot, made the focus more on money.
- "Het feit ook dat het alleen maar om dat stomme geld gaat, of veel om dat stomme geld.."
- I understand though, that municipalities had budget cuts, and now struggle to meet the rising demand. I feel like the government should take action, but they just talk.
- "Dit is nu al de zoveelste keer, hoe vaak moet dat nou gebeuren voordat er ook echt iets gebeurd"
- 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, and there isn't always someone from municipalities to work through the financial side, which makes it very complex.
- "Ik vind echt dat er voor deze doelgroep bijzonder weinig wordt uitgetrokken"
- Innovations are not always easy to implement. Learning to work with the new client systems are an extra burden for group supervisors, even though its better in the long run.
- "Niet elke vernieuwing wordt juichend ontvangen"
- Doing activities online for parents makes things more accessible, though it takes time to adjust. It's important parents stay involved, because we need them to continue working with their child at home.

Charities

Informal care consultant

Introduction

- Her role as an informal care consultant, she helps a variety of informal carers. People with a CSN are only a small percentage.
- She does not have a prominent role for CSN parents, as many of them have a lot of caregivers around them. Her role is paid, but she matches people to volunteers. She refers them to organisations, sometimes health insurers.

- Her role varies from giving advice and information, encouraging people, helping people find practical or financial help or administrative support, but also emotional support and sometimes coaching.
- People find her either by referral within their personal network, or from a medical professional or health insurers, or they find her independently through internet searches.
- Other cities also have informale care consultants, sometimes they are part of the welfare or social work, other times they are provided by charities like MEE, or day cares.
- Most cases there is not 1 person directing it all, as there is no money for it, and my job is to find someone who can do it, even if its in the personal network.

Role in system

- Three main money streams in the system: the health insurer, the WLZ (Zorgkantoor) and WMO and Jeugdwet (responsibility of city councils).
- City council gives her organisation assignments. They come together as equal parties, and discuss the needs for informal carers, but ultimately the city council decides the assignment and what budget goes to them.
- She works together with volunteer organisations, especially for respite care. All these charities have their special target group, and she matches them to her clients.

Needs and Drive

- I need time and space to talk to people, and not have to rush. Quality is important to me, if I can, I will keep it short, but if quality is compromised, I will take more time.
- "Bij mij staat kwaliteit hoog in het vaandel, dus daarin maak ik ook afwegingen, als het kan houd ik het kort, maar als kwaliteit in het gedrang komt, dan neem ik meer tijd."
- Sometimes I need to rearrange my meetings, and give priority to talking to people to create time. Or I hand them to my colleagues, when I don't have enough time.
- Trust from the employer that I am going to use my time well.
- I am driven by the fact that this job suits me well, and I can combine the experiences from all the jobs I previously had.
- I am driven by the meaning I can provide for other people knowing you did something to help someone continue for some time.
- I have faith that I can trust people to be able to manage a lot themselves
- Many clients feel supported, and heard after our talks.
- My job is to acknowledge that people are trying to take care of each other, and discover their opportunities. If I can find the cause of disbalance in their lives, I can help them bring their situation to a better equilibrium. Sometimes it even means listening to the kid, who knows what they want.

Perspective: frustrations and experiences system

- Especially the target group of CSN parents is hard to match to volunteers, since they need very specialized 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.

- Some people don't recognise they are informal carers.
- She wants more medical professionals to refer informal carers to her, as currently they rarely do.
- "Ik zou wel willen dat meer organisaties de mantelzorgers in contact brengen met ons!"
- She wants to be involved earlier on in the process, to prevent escalation. If you start earlier, you have more time to improve small steps, and there is a chance you avoid them becoming overburdened.
- "Wat ik graag zou willen, is als ik wat vroeger bij mensen in het proces betrokken zou raken, want hoe vroeger ik betrokken raak, hoe kleiner het risico op ontsporen en overbelast raken is."
- It would help many informal carers to ask their network what they would like to contribute, even if its something like making some phonecalls for them.
- She experiences tension in how professional carers look at the informal carers. They need to prioritize the personal relationship with the client, and take the experience of carers seriously. They need to facilitate to this relationship, and make sure the family does not become unbalanced and overburdened.
- "Faciliteren dat mensen die relatie kunnen houden en dat ze ook de ouder kunnen blijven, je moet samenwerken en afstemmen met ze."
- "Buitenstaanders zeggen het is vrijwillig, het is een keuze. Maar dat voelt niet zo! Het is je vader, je moeder je kind! Je hebt een relatie met iemand, en die relatie maakt dat je voor die ander wilt zorgen."
- The informale carer can also initiate this conversation, but not all informal carers have that ability. Especially the more vulnerable ones easily overburden themselves.
- When an informal carer becomes overburdened, they enter fighting mode or recoil into themselves, and don't communicate well with professional carers.
- "Iemand die voortdurend in een vechtmodus zit, die blijf altijd weerstand bieden, die vind het nooit goed, maar op het moment dat je goed naar iemand luistert en daar tijd en energie in steekt, dan krijgt die klant wat hij nodig heeft en hoeft hij niet meer te vechten."
- Finding balance also means managing expectations, and lowering the bar.
- "Soms moet je niet voor de 10 gaan, maar moet je met elkaar afspreken dat een 7 goed genoeg is. Wordt het nu weer onvoldoende, ok dan gaan we met elkaar aan tafel zodat het weer een voldoende wordt."
- The newsletter of my organisation is a nice initiative, and I think people need to be reminded, even if they don't read it, they will remember us and know where to go when the situation arises.

PR coordinator Mantelzorg NL

Introduction

- She is responsible for matching informal carers's stories with the right media pr.
- She urges informal carers to show their struggles, ambitions and needs, and encourages them to share their stories.
- They have a big list of stories, and try to wait and match them with the perfect media opportunity, sometimes they push stories that are urgent.
- They goal is to get attention from the government and organisations, to make sure change happens.
- Change can either be from the governmental side, but it is often from the informal carer, who tackles their life differently.
- They do press and media and talks at schools, universities, professionals, or for paid projects.
- They work with 30 volunteers: who have different tasks, like presenters, bloggers, ambassadors, legal advice, coaches..
- They help to catch signals that Mantelzorg NL then warns the government about.

Role in system

- She tries to understand as many perspectives as possible, reading people's stories on social media, it helps her empathize and keeps her from judging someone during conversations, by being curious about their experiences.

Needs and drive

- I love helping people, and igniting change in informal carer's lives, she has a lot of respect for the work.
- "Ik denk dat mantelzorgen heel mooi is, en ook voldoening kan geven. Maar als je daarin alleen voelt staan, of je verhaal niet kwijt kan of geen waardering krijgt van wie je dat nodig hebt, (verschillend: overheid, omgeving) dat is vrij dramatisch. Dus als ik daar iets in kan doen om het te veranderen, elke persoon is schitterend om te helpen"
- She is proud if someone gets to tell their story.
- She needs have enough energy and focus to listen to someones story.
- She is an informal carer herself, and she tries to keep this separated from her job. She knows which personal questions to ask because of her experience, and builds trust.
- "Gaandeweg leer ik begrijpen en het gesprek aangaan" "Als je goed luistert, dan begrijp je ook: dit is voor jou de beste keus geweest, en je doet wat je kan, en dat is ok"
- She is striving for social change, that people start asking more after one another, and caring for each other in small day to day ways.
- "Het gaat niet om iets groots, het gaat om elkaar zien"
- This is not part of our Dutch culture, to think nuanced, everyone always has an opinion right away, and we need to develop more respect and understanding for each other.
- Everyone needs different types of help, and it should become normal to ask people what they can do for you/ Niet "kan ik wat voor je doen" maar "ik wil graag dit voor je doen"

-

Perspective: frustrations and experiences system

- Every story deserves attention, and media can be unpredictable, and suddenly cancel their story.
- CSN parents find it hard to ask for help, and the ZEVMB children co-pilot idea is a good one, as it supports parents over long term in the way they need.
- CSN parents often don't have a community like other parents to confer, as their child's development is unique. Some parents don't want attention, others crave it, so there is a lot of difference between them.
- My perspective on medical professionals and doctors, is that they 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.
- Municipalities can improve by 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.
- You need people that break through informal carer's walls, and ask the difficult questions: "zorg nou eens voor jezelf, je gaat toch niet je hele leven voor je kind zorgen?"
- You need people that wake others up, and call them to action to find solutions: "Dus wat ga je eraan doen?"
- The law system is hard to people, because they are pushed in a certain way, and have no more freedom to decide.
- New generations of informal carers need new platforms. Maybe tiktok or podcasts? They need to be more visible, and it should be normal to see them in society.
- A campaign can also help increase visibility, and put responsibility for care back to society.
- There is so much bureaucracy and complex systems, there should be 1 contact point for CSN parents, so they don't have to tell the same story over and over, as often it is very painful to tell.
- 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.

Independent coach

Introduction

- A coach, who supports CSN parents in conversations, emotionally and practically.
- Started because she missed that role in her own life, and noticed that as a CSN parent the attention is on the child, not on the parents, and it only shifts after it escalates.
- Try to aim at the earliest time, for preventative and accessible support.
- She also started UP foundation, which provides a pamper day for CSN parents.

Role in system

- Tries to fill the gap or problem of the attention being on the child, not on the parents, and that this only shifts after it escalates.

Needs and drives

- It should become more normal to talk about what is happening to you as a parent
- "gewoon dat het normaler is om te praten wat het met jou doet als ouder"
- A need is to be known, for parents to know she exists.
- She is driven by her love for helping people find their way, practically and emotionally.
- "Ik gun het ouders gewoon ook om zich iets meer gesteund te voelen, en niet alles zelf uit te hoeven zoeken"
- She is intrinsically motivated since she can use her experiences in one job
- She is proud because people are satisfied and that she can handle difficult situations.
- She needs to make sure to guard her boundaries, and refer people to other professionals in situations she can't handle (like divorce).

Perspective: frustrations and experiences system

- City councils have a lot of rules, and she can not be paid by them, because she wants to be more flexible with her approach. It would be ideal if her work can be compensated, so all parents can afford it.
- A big tension point for parents is the many parties they have to deal with, and it would be better if there was direct communication, or someone in charge.
- Also many parents lose a lot of energy because the care is so complicated to arrange.
- An initiative is ZEMVB co-pilot, where parents are matched with someone who arranges the care for their child for a long period of time, and can deal with changes.
- Professionals should have more empathy for CSN parents.
- eg taxi drivers that don't show up: how much it can impact parents.
- "Het zou mooi zijn als mensen die in deze wereld werken nog beter weten hoe het is voor deze ouders en zich in zouden kunnen leven"
- Eg "dit is de zoveelste logopedie opdracht, hoe past dat erbij voor jou als ouders"
- 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 and make it less complicated to arrange respite care.

C. System map metaphor story

System relations

Kunnen ze weer gaan samenwerken en het systeem in balans brengen?



National government

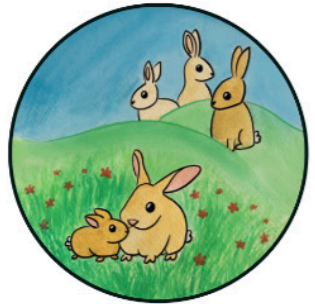
Meet Gov the ox:
Gov is very tall, and can see the overview of the animals living in the area. Gov wants to make sure the health care system can be paid for by the group, and is excited to try out this new, better idea. The idea is that the animals put all their effort into caring for themselves and each other.

"I want you to take charge!"

Gov wants to encourage the network to take care of each other. However, certain rules he has thought keep the network from doing this at full potential.

Meet Net, the bunny:
Net is a bunny with a family, living in the herd. Their children play together, bunnies go to work and check in with each other regularly at social gatherings.

"I don't really know how to help"



Network

Net used to be friends with Capa, but since the birth of CSN, they hang out less. Net told Capa to call for help, but doesn't know how much pressure Capa is under. Capa doesn't show up to social gatherings anymore, and Net doesn't know how its been going. Net is busy too, so the two grow apart.

Gov is excited for the new idea that animals should try to take of themselves, and ask for help around them. Gov only has a vague idea of how many animals live like Capa, and doesn't know how to recognise this situation. Capa is not good at asking for help, and is left to deal with too much alone.

Gov has high ideals for a sustainable care system. Mun's job is to work towards those ideals. However, Gov's unrealistic expectations the quality and efficiency of work Mun can do, always checking up and monitoring makes Mun very stressed.

Meet Munco the deer:
Mun got a new challenge from Gov, and is trying their best to follow the new strict processes. They are missing some resources and money, and are managing many problems amongst the animals. It is a big task, and sometimes they get stressed, defensive and skittish.

"You are on my todo list"



Municipal council

Mun is responsible for helping Capa and is trying to do so in a fair way. This means Mun is torn between giving the best help and being strict on what help they can offer. Capa has to wait a long time, and doesn't always trust Mun to choose the right help.

CSN parents

Meet Capa the hedgehog:
Capa is a care parent, who is responsible for a CSN. Taking care of a CSN adds a lot of responsibilities to the todo list, and can be emotionally tiring. Sometimes this makes Capa stressed and lonely, and needing help. But Capa is focused on the CSN, doesn't realize help is needed, and often asks for help when its too late.

"Is it okay to ask for help?"



Founda checks in with Capa regularly, to see how things are going. When Capa is too tired to ask for help, Founda can do it, and even ask Care, Mun or Gov for extra help.

Foundations

Meet Founda the bird:
Founda and the flock flit between the different animals, to see how things are going. This way, they build up the community. The network of birds can help fill in gaps when geese or deer can't help. They often know the change needed, but are too small on their own to make a big difference.

"We see change is needed, but can't do it alone"



Mun has to work together with Care. The stress and budget cuts Mun deals with are also Care's problem and they are stressed together. When they are stressed they get defensive and dont trust each other. They get their job done, but dont benefit from the collaboration. They wish they had time to get feedback, reflect and improve their work.

Care and the flock directly take care of Capa's special needs child. They are very professional and know how to help the child efficiently and well. They don't have much time to check in with Capa, to discuss if things are going well or other care is needed.

Meet Care the goose:
Care is only one of a big flock of geese, caring for the other animals in their own way. Some help animals navigate the flock to find the best help. There are the white doctor geese who are specialists in medical topics. Some mother geese love to take care of those who need it.

"I want to help more but Im bound"



Care domain

D. Final design



Behoudens de in of krachtens de Auteurswet van 1912 gestelde uitzonderingen mag niets uit deze uitgave worden verveelvoudigd, opgeslagen in een geautomatiseerde gegevensbestand, of openbaar gemaakt, in enige vorm of op enige wijze, hetzij elektronisch, mechanisch, door fotokopieën, opnamen of een andere manier, zonder voorgaande schriftelijke toestemming van de auteur of gemachtigden.

Eerste druk: November 2022

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Uitgever: Willemijn van Loon

Met dank aan: Marnix de Jong, Anne-Marie de Jong en Marise Schot

Eindontwerp voor afstuderen bij SPD, IDE TU Delft

In samenwerking met: Ontzorghuis

Mama egel de Mantelouder

Carine van Loon voor Ontzorghuis



Diep in het bos wonen een mama egel en haar egeltje. Egeltje heeft speciale stekeltjes. Hij kan niet alleen zijn en eet niet zo goed. Mama egel helpt hem met alles.



Op een dag krijgen ze een krant in de brievenbus. In de krant staat een bericht van koe: "Er is een nieuw plan. De konijnen gaan voor de egels zorgen. De groeten, boe!"



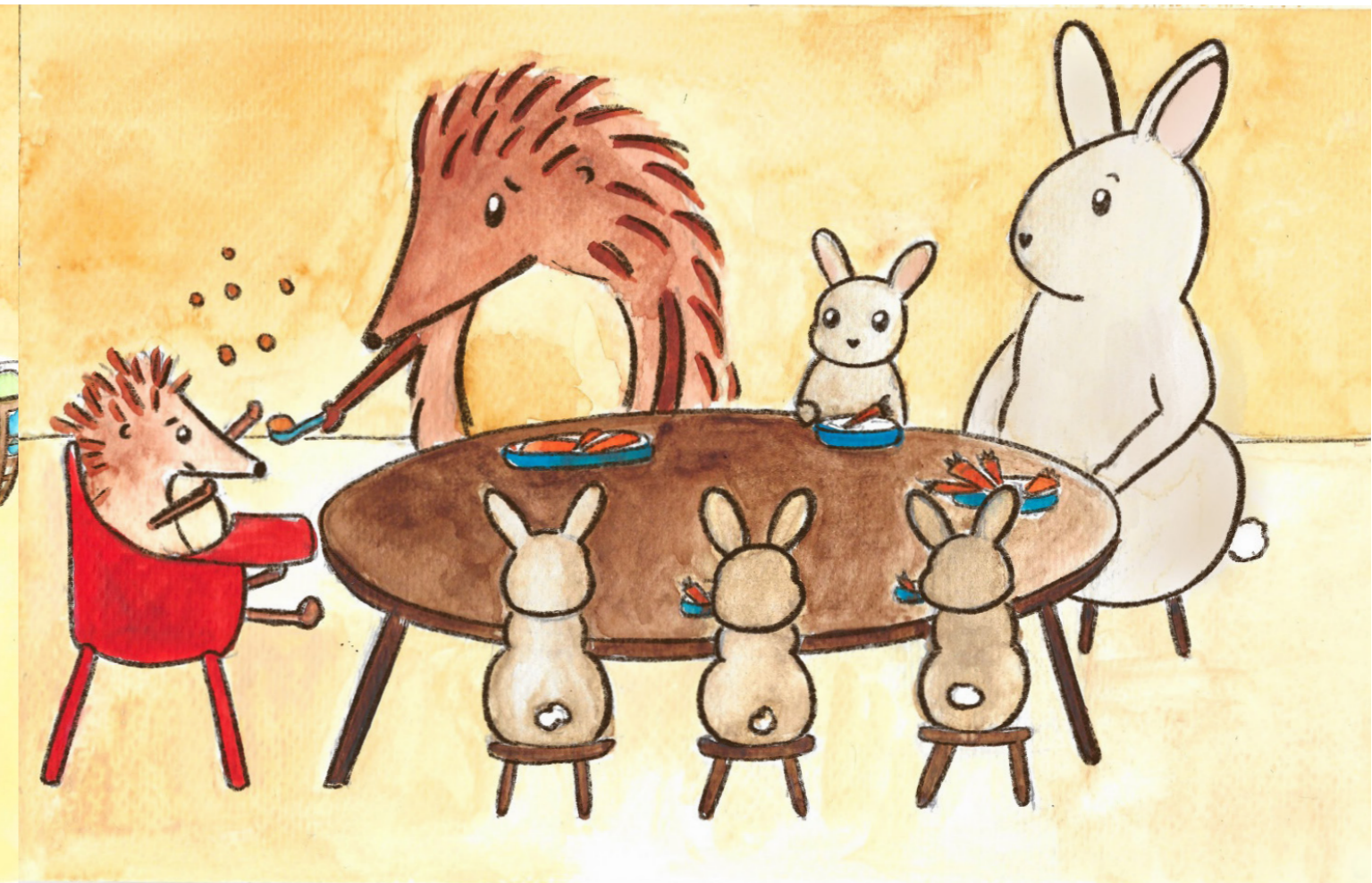
Mama egel geeft egeltje zijn speciale voedingsrijke eten. Ze heeft verschillende hapjes gemaakt. Egeltje lust er maar eentje. "Tot konijn komt zorg ik zelf wel voor egeltje." denkt ze.



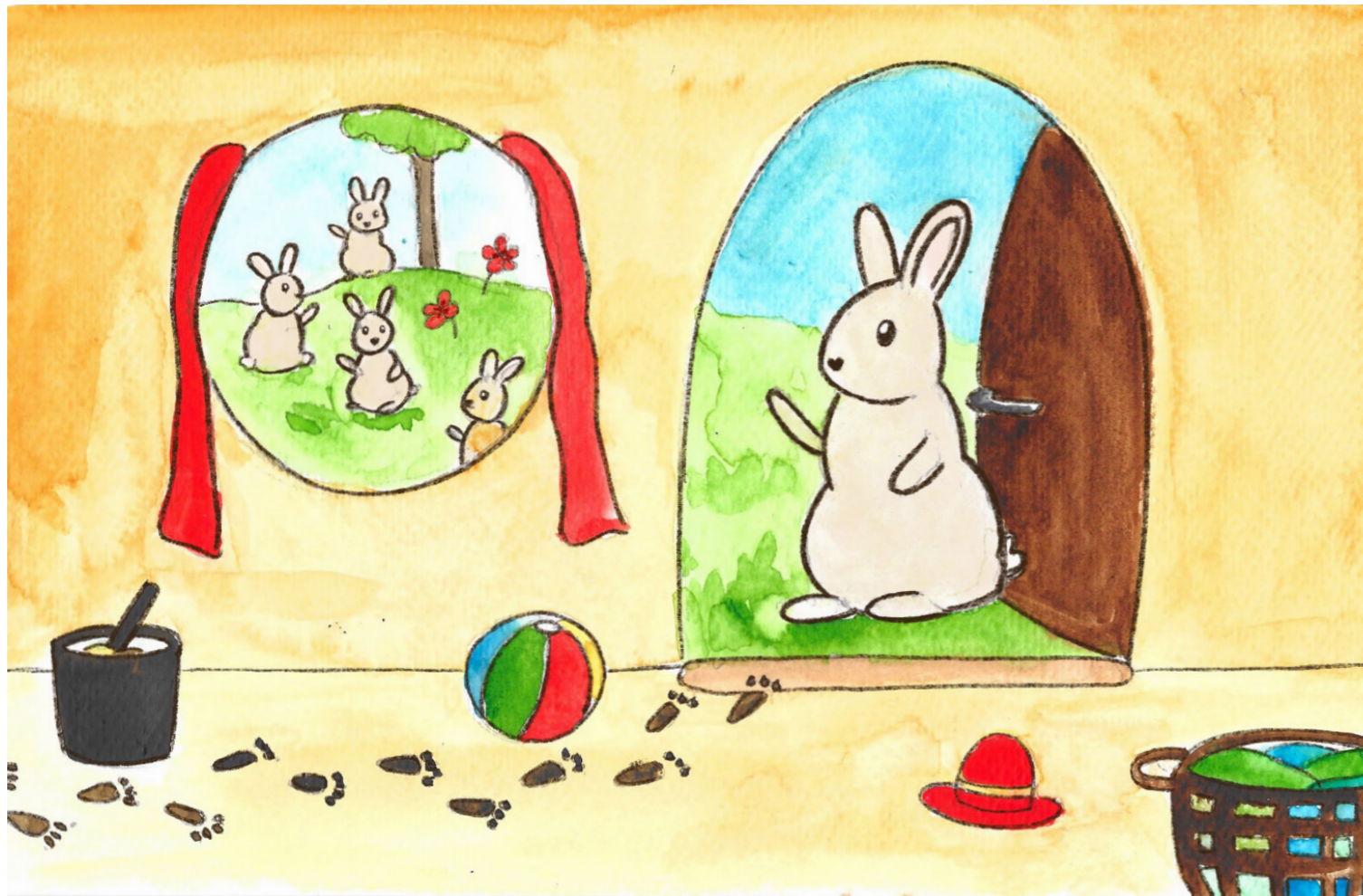
Egeltje kan niet goed slapen. Mama egel knuffelt hem net zo lang tot hij rustig wordt. Daarna ruimt ze het huis op. Die avond dekt ze egeltje toe met haar mantel. Ze doet haar best om op tijd naar bed te gaan. Dat lukt haar om 10 uur.



De volgende ochtend komt mama konijn al vroeg op bezoek. Ze heeft haar vier kindertjes meegenomen. De mama's drinken thee en de kinderen spelen. De konijntjes vragen: "Waarom praat egeltje niet, hij is toch ouder?" "Sommige kindjes praten en andere niet." legt mama egel uit.



Even later gaan ze aan tafel eten. "Egeltje kan nog steeds niet goed eten," zegt mama egel, "kan jij daarmee helpen?". "Oh, mijn konijntjes eten juist erg veel!" zegt mama konijn. "Dus ik weet het niet. Misschien kan dokter gans helpen?"



De konijntjes gaan weer naar huis. "Kom je binnenkort worteltjestaart eten?" vraagt mama konijn. "Laat maar weten als je hulp nodig hebt!" En ze zwaaien met zijn vijven. "Ik zal het zelf wel even opruimen." zegt mama egel. Die avond dekt ze egeltje toe met haar mantel. Ze doet haar best om op tijd naar bed te gaan. Dat lukt haar om 11 uur.



Een paar weken later komt dokter gans op bezoek. Hij loopt gelijk naar egeltje, en doet wat onderzoek. Hij zegt "Egeltje moet nog veel leren. Hij is te dun. Hij moet meer eten, en krijgt sondevoeding. Ik moet eerst een plan maken met hert." Met een vlugge wuif stapt hij de deur uit.



Mama egel knuffelt egeltje. "Goed gedaan hoor bij dokter gans!" Ze stopt egeltje in bed. Die avond dekt ze egeltje toe met haar mantel. Ze doet haar best om op tijd naar bed te gaan. Dat lukt haar om 12 uur.



Een maand later gaat de bel. Hert komt op bezoek. Hij vraagt of mama egel hulp kreeg van mama konijn. "Die heeft 4 kindjes en heeft het erg druk." zegt mama egel.



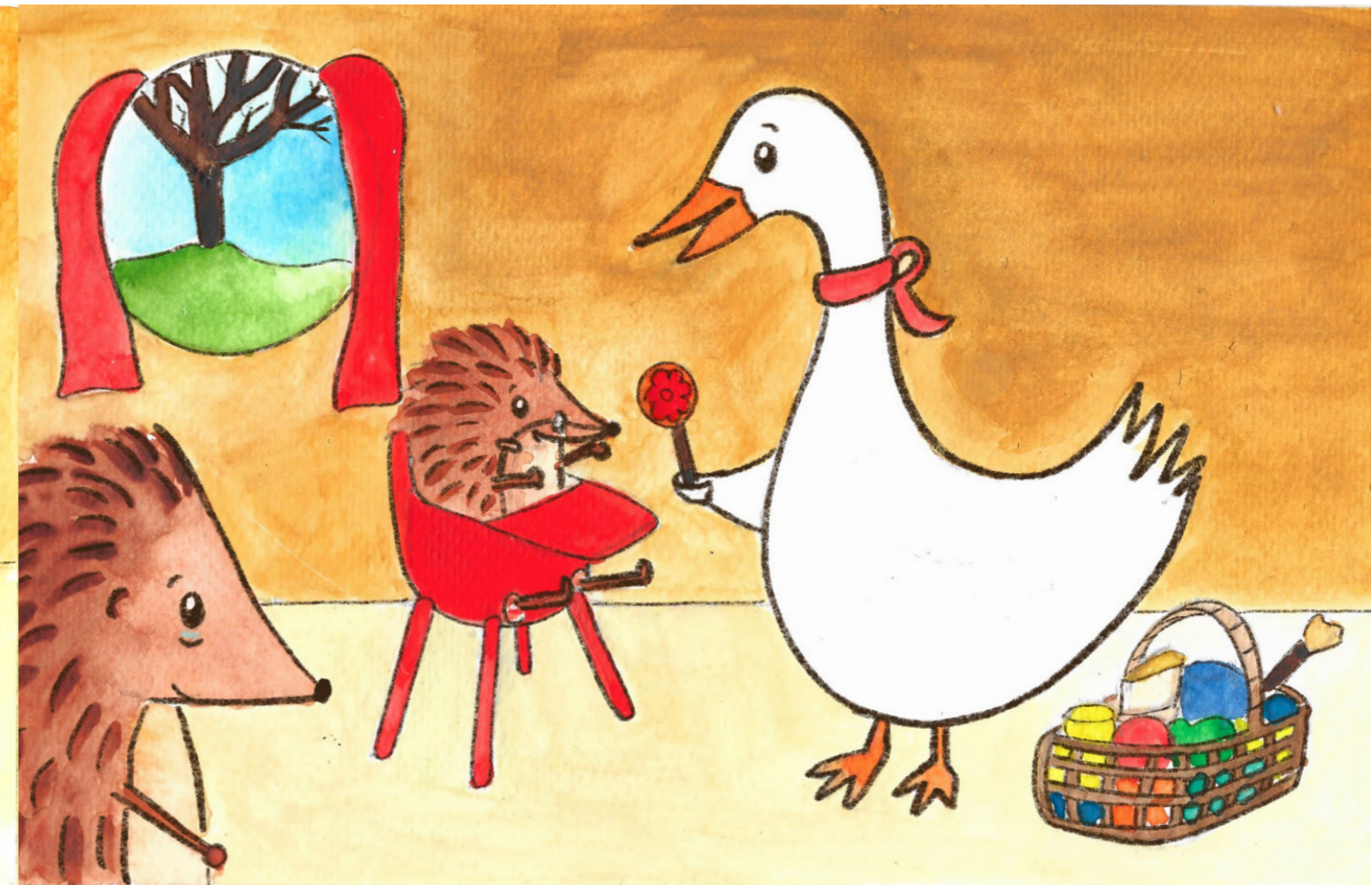
"Ik ga kijken wat ik voor je kan doen." zegt hert. "Maar eerst moet ik een plan maken en een afspraak met moeder gans." "Ik hou het nog wel even vol." zegt mama egel. Ze zwaait hert uit.



Egeltje lust die avond zijn eten niet. Mama is bezorgd, hij moet wel goed eten! Dus kookt mama egel nog een keer. Dat is veel werk, en egeltje spuugt het telkens uit. Mama egel voelt paniek, maar ze probeert niet boos te worden op egeltje. "Over een tijdje wordt alles beter." zegt ze. Ze maalt al het eten en doet het in de sonde.



Ze stopt egeltje in bad. Ze kietelt egeltje, en hij lacht. Na het bad probeert ze nog een keer eten te geven. Die avond dekt ze egeltje toe met haar mantel. Ze doet haar best om op tijd naar bed te gaan. Dat lukt haar om 1 uur.



Drie weken later komt Moeder gans langs. "Hallo! Waar is egeltje?" zegt ze. Ze geeft hem een dikke knuffel. "Vandaag gaan we oefenen met eten!" zegt Moeder gans. Ze heeft speciale spullen bij zich. Ze laat mama egel zien hoe het moet.



Moeder gans oefent een uurtje met egeltje. "Ik ga er weer vandoor, want ik ga nog langs drie andere egeltjes!" lacht moeder gans. "Maar ik heb met hert afgesproken dat ik elke week terugkom!". "Dag!" Mama egel en egeltje zwaaien haar uit. "Goed gedaan!" zegt mama egel, en ze geeft egeltje een knuffel.



Egeltje gaapt. Mama egel legt hem snel op bed. Ze ruimt de spullen op, en doet andere taakjes in huis. Ze heeft extra taakjes gekregen van moeder gans. Het lukt haar niet om alles af te krijgen, en ze huilt een beetje. Die avond dekt ze egeltje toe met haar mantel. Ze doet haar best om op tijd naar bed te gaan. Dat lukt haar om 2 uur.



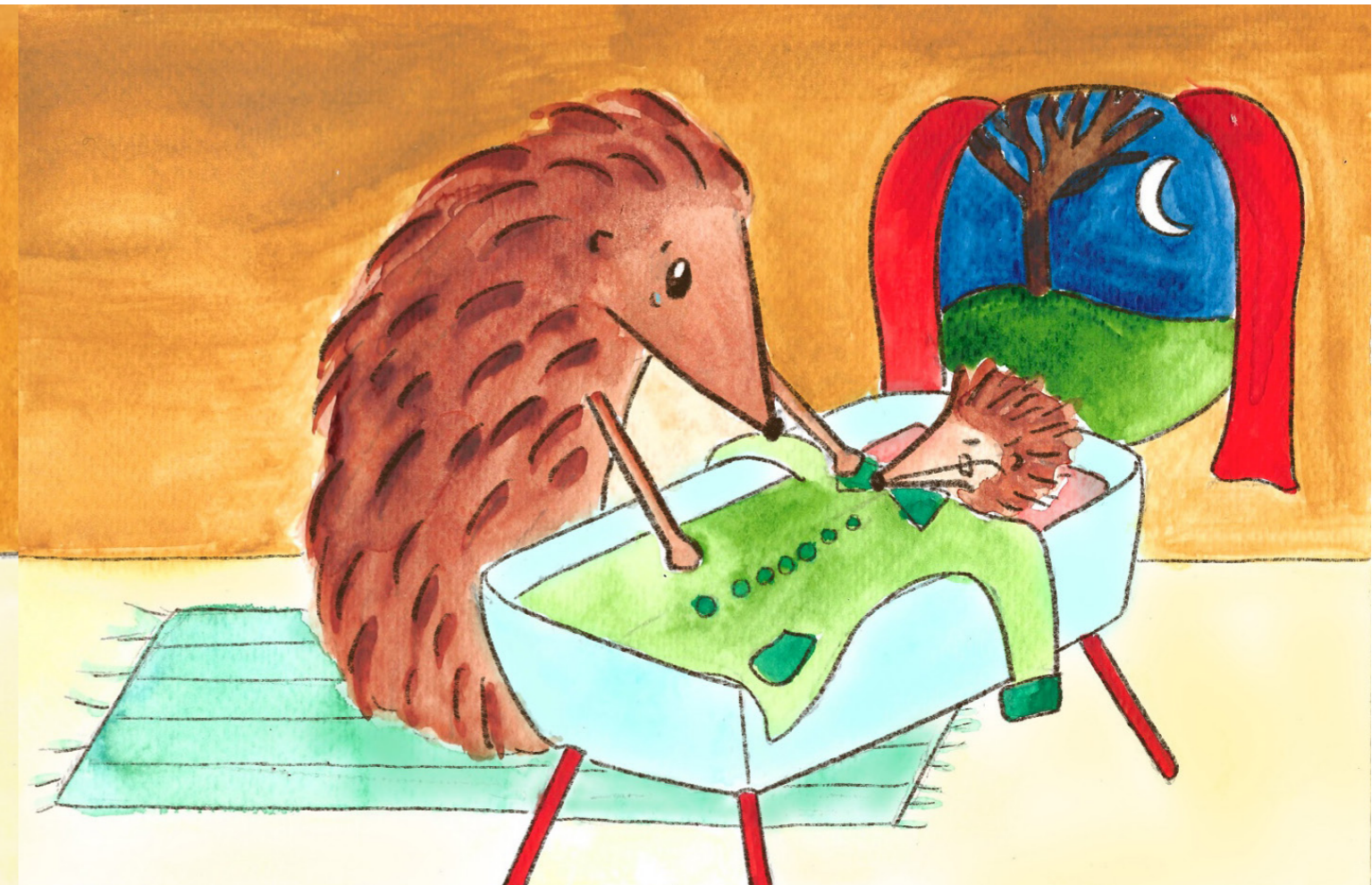
De volgende ochtend verzamelt mama egel besjes voor het avondeten. Vogeltje komt aanvliegen "Ik kan wel meehelpen, ik help vaker egeltjes!" zegt hij en vliegt weg. Mama egel gaat door met zoeken.



Even later heeft mama egel de mand gevuld. Vogeltje komt terug met drie besjes "alsjeblieft!". "Bedankt!" zegt mama egel vrolijk. Ze loopt samen met egeltje naar huis.



Mama egel maakt bessensalade en bessentaart. Ze helpt egeltje met eten, maar hij wil niet. Hij rolt zich op in een bal en prikt mama: "Auw!" roept ze. Ze denkt: "Niet boos worden, want egeltje kan er niets aan doen". Ze boent hem schoon, geeft hem een knuffel en legt hem in bed.



Mama egel ruimt de keuken op en doet de afwas. Ze is wel erg moe. Die avond dekt ze egeltje toe met haar mantel. "Ach ja, ik ben nu eenmaal een mantelouder" zegt ze.

Einde

Wat en wie zijn mantelouders?

Een mantelouder is een ouder van een kind dat meer zorg nodig heeft dan andere kinderen. 'Mantelouders' is een nieuwe term, een term door ouders zelf in het leven geroepen. Mantelouders zijn ouders met een mantelzorgtaak voor hun kind(eren).

Een ouder die de mantelzorger is voor zijn/haar kind klinkt misschien bijzonder. De zorg die je voor je kind hebt, is vrij vanzelfsprekend. Echter bij sommige gezinnen is de zorg vele malen groter dan bij een regulier kind. Er komen zorgtaken bij zoals sondevoeding geven, eettraining, vernevelen, communiceren met ondersteunende middelen zoals pictogrammen of gebarentaal. Maar denk ook aan het veelvuldig contact onderhouden met meerdere artsen, therapeuten, gespecialiseerde opvang centra, zorgverleners, zorginstelling en budgetverstrekkers. Mantelouder-taken zijn de taken die een regulier kind niet heeft: de bovengebruikelijke zorg. In de medische wereld is een zorgintensief kind, een kind wat 8 uur of meer extra zorg nodig heeft per week. In het begin is dit lastig te herkennen. Een mantelouder ben je als het kind levenslang extra zorg nodig heeft.

Mantelouders worden vaak de case manager van hun zorgintensieve kind. Zij zijn de spil tussen alle betrokkenen, om te zorgen dat hun kind de zorg krijgt die het nodig heeft. Mantelouders zijn als het ware de behoeftenmanagers van hun kinderen, diegenen die hun welzijn en geluk bewaken. Mantelouder word je zonder voorbereiding of opleiding. Mantelouders moeten overeind blijven om goede zorg aan hun kind te kunnen geven.

In dit boekje is gekozen voor mama egel, voor het alliteratie effect, maar het had ook papa egel kunnen zijn. Vaak staan ze er ook samen voor en zijn er nog meer kinderen in het gezin, naast het zorgenkindje. Om het verhaal simpel te houden, representeert mama egel de mantelouders.

Bron: www.ontzorghuis.nl

Waar gaat het verhaal over?

Het is een metafoor voor de leefwereld van mantelouders. Mama egel is de mantelouder en egeltje het zorgenkindje. De mantelouder heeft met andere dieren te maken, die zijn deel van het systeem:



Egel: Mama egel is een mantelouder, die zorgt voor egeltje het zorgenkindje. Zorgen voor een zorgenkindje betekent dat ze veel verantwoordelijkheden heeft en een lange to-dolijst. Dit maakt mama egel soms moe en gestresst. Eigenlijk zou ze dan wel wat hulp kunnen gebruiken. Maar mama egel let alleen op egeltje en realiseert zich vaak pas te laat dat ze hulp nodig heeft. "Is het wel ok om (meer) hulp te vragen?"



Koe: De koe is de nationale overheid. Hij is erg groot en heeft zo overzicht over alle dieren in de buurt. De koe wil graag dat het zorgsysteem betaald kan worden door de groep dieren en is enthousiast om een nieuw idee uit te proberen. Het nieuwe idee is dat de dieren meer voor elkaar proberen te zorgen. "Ik wil dat jij initiatief toont!"



Konijn: Konijnen zijn de vrienden en familie van egel: het netwerk. Konijn heeft een grote familie en woont in een groep. Mama konijn was goede vriendinnen met mama egel, maar sinds egeltje is geboren zien ze elkaar niet zo veel. Mama konijn weet niet zo goed hoe het met mama egel gaat. Mama konijn heeft het zelf ook druk, dus ze groeien langzaam uit elkaar. "Ik weet niet zo goed hoe ik moet helpen."



Gans: Ganzen zijn de zorgverleners. Er zijn veel soorten ganzen, die allemaal op hun eigen manier voor andere dieren zorgen. Sommige ganzen koppelen dieren aan elkaar. Anderen zijn dokters met specialistische medische kennis. En dan heb je nog moeder ganzen, die hulp geven aan hen die het nodig hebben. "Ik wil wel meer helpen maar dat kan niet."



Hert: Hert is de gemeente. Hert heeft een nieuwe uitdaging gekregen van koe en doet zijn best om de strenge processen te volgen. Hij mist wat middelen en geld, en beheert veel problemen van verschillende dieren. Het is belangrijk werk, maar ook een grote taak en soms wordt hert risicovermijdend. "Je staat op mijn to-do-lijstje."



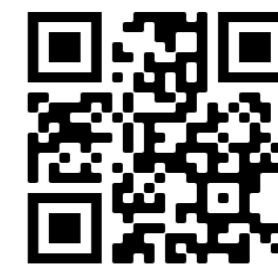
Vogel: Vogeltje is een goed doel. Samen met de andere vogels fladdert ze tussen de dieren om te kijken of iemand hulp nodig heeft. Zo bouwt ze de gemeenschap op. Het netwerk van vogels kan helpen om dingen op te vangen wanneer ganzen of herten niet kunnen helpen. Ze weten vaak welke verandering nodig is, maar zijn op zichzelf te klein om een groot verschil te maken. "We zien dat er verandering nodig is, maar kunnen het niet alleen."

Vragen om over na te denken

- Wat doet het met je om dit verhaal te lezen?
- Begrijp je het verhaal?
- Begrijp je de metafoor?
- In welk(e) dier(en) herken je jezelf?
- Ken je een mama egel in jouw omgeving?
- Wat zijn de 3 dingen die je zou kunnen doen om iemand zoals mama egel te helpen?
- Wat moet er niet veranderen en wat juist wel?
- Hoe zou je dit boekje gebruiken in jou positie?

Over Ontzorghuis

Ontzorghuis wil dat mantelouders en hun kinderen ondersteund worden, zich kunnen verbinden en hun kracht kunnen ontwikkelen. Ontzorghuis zet zich in voor mantelouders, door middel van community, verhalen, workshops, tools en nog meer.



Meer weten?
Check dan www.ontzorghuis.nl

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Dit boekje is gemaakt als afstudeerproject op Industrieel Ontwerpen van Carine. Ze heeft systemisch design onderzoek gedaan naar het systeem wat ouders met een zorgintensief kind omringt. Dit boekje is haar eindontwerp.



Carine van Loon, November 2022
Afstuderen voor Strategic Product Design, IDE, TU delft
In samenwerking met: Ontzorghuis



