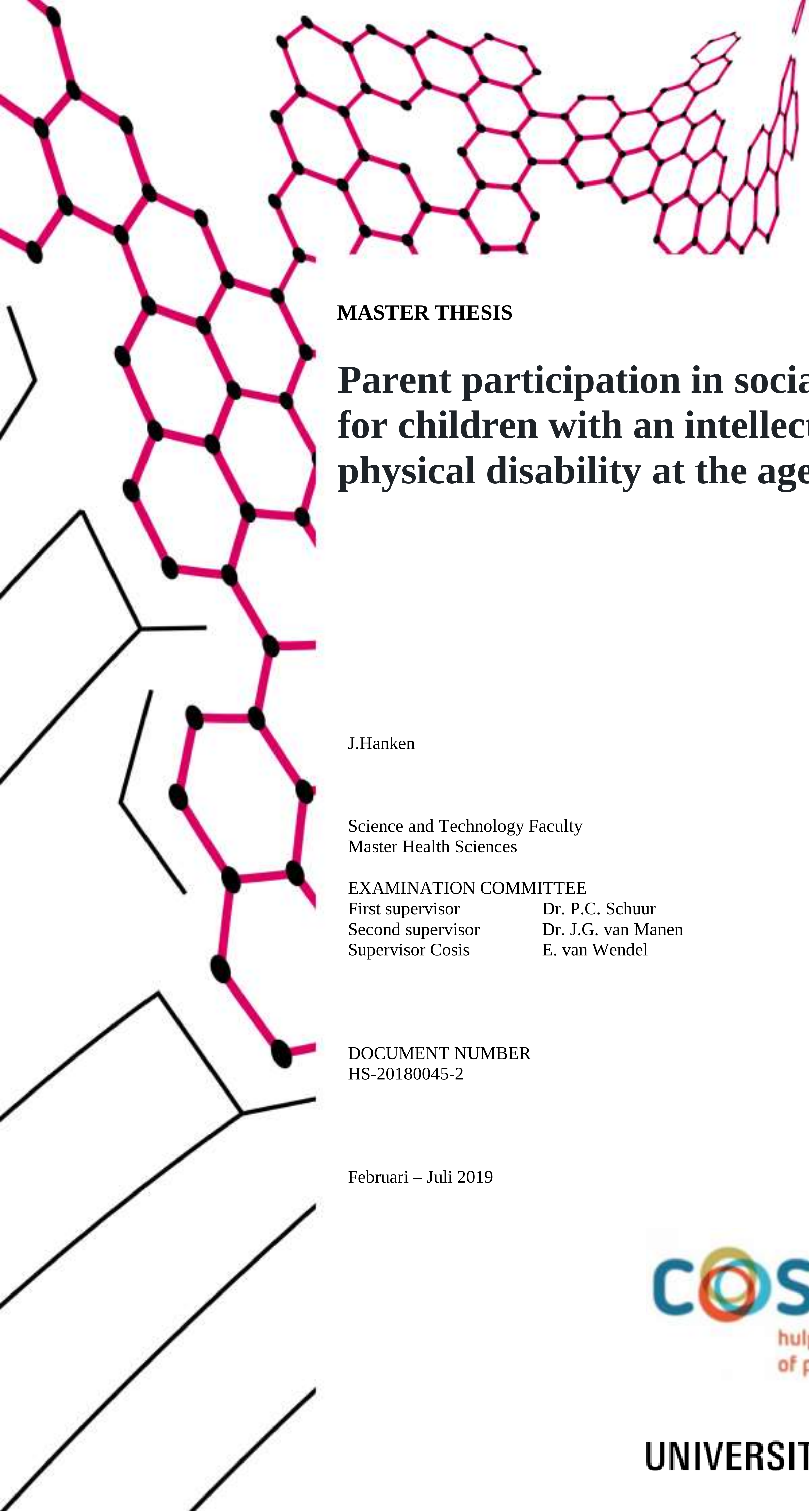

MASTER THESIS

Parent participation in social healthcare for children with an intellectual and/or physical disability at the age of 0-18

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cosis
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UNIVERSITY OF TWENTE.

Parent participation in social healthcare for children with an intellectual and/or physical disability at the age of 0-18

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Abstract

Background: The approach of the healthcare system in the Netherlands has changed over the years. The vision changed from “decisions are made by the healthcare professional” to “self-management of the patient”. The aim of this approach is that the patient contributes to achieve a higher quality, safety, and efficiency of healthcare. However, not all patients can take this responsibility on their own in which case it could be done by a legal representative.

Aim: The aim of this paper is treble. First, to explore which elements of family-centered care are rated badly by parents of intellectual and/or physical disabled children at the age of 0 to 18 years old in social healthcare and whether the variation in these scores could be explained by patient characteristics. At last, to investigate which improvements parents of intellectual and/or physical disabled children at the age of 0 to 18 years old in social healthcare suggest for the bad scoring elements of family-centered care.

Method: The approach of this study was a mixed method. For the quantitative part of the study a questionnaire was used and for the qualitative part two semi-structured focus group interviews were carried out. For the questionnaire and the interviews was the measure of processes of care (MPOC) used, which includes five subjects of parent participation.

Results: Parents were the least satisfied with the subject of the MPOC ‘providing general information’ and were the most satisfied with the subject ‘respectful and supportive care’. Two patient characteristics influenced the scores given by parents: 1. the number of disciplines of care involved in the care process, 2. how often parents had contact by phone or email with the personal mentor. Some improvements parents had experienced are: they want to be better informed about dates of activities and/or meetings, requests of allowance, and specific information about therapy.

Conclusion: There are already a lot of possibilities for parents to participate in the care process of their child in social healthcare. However, not all parents do know these possibilities because they have to ask for it by themselves. Parents all had their own preferences concerning their participation in the care process of their child. Therefore, by parents it is seen as an added value that the personal mentor asks for the preferences of each individual parent and mention the possibilities of the location concerning parent participation at the start of the care process. Further research is needed to prove if the current possibilities offered by the location to parents is the best.

***Keywords**: parent participation, family-centered care, patient-centered care, MPOC-20, intellectual and/or physical disabled children, social healthcare.*

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1. Introduction

The approach of healthcare in the Netherlands has changed over the years. The vision changed from “decisions are made by the healthcare professional” to “self-management of the patient”. This shift originates from the law of participation and due to the obligation of healthcare professionals to inform the patient about the treatment, the risks, and the consequences of a disease or health condition (Sassen, 2010). The law of participation is a law for municipalities to involve patients and their representatives in the process of determining and performing the policy of healthcare (Sok, n.d.). Involving patients in making decisions is not only occurring in the policy-making process but also in the individual clinical decision-making processes. This means that the patient participates and takes the responsibilities of his own health conditions and care process. The aim of this approach is that the patient contributes positively to a higher quality, safety, and efficiency of healthcare (Ouwens, Van der Burg, Faber, & Van der Weijden, 2012). Terms that refer to this approach are shared decision making, self-management, self-empowerment, and patient-centered care.

To accomplish this approach in an organisation it is important that caregivers identify the wishes and needs of the patient and invite the patient to participate in his own care process, it is called client participation (Ouwens et al., 2012). In this way, the patient can make his own decisions during the care process. However, not all patients can take this responsibility on their own in which case it could be done by a legal representative. In the healthcare of disabled children at the age of 0 to 18 years old, parents are often the legal representatives. Therefore, parents should be involved in the care process of their children. This is called parent participation. This term will be used hereafter in this paper. Ninety per cent of the parents in the social healthcare judge it as extremely important to be involved in the care process of their child (McNeilly, Macdonald, & Kelly, 2017).

Studies of the last 20 years which are focussing on parent participation are measuring the level of satisfaction of parents on several subjects of parent participation (see section 2.1). These studies are performed in different countries. In the Netherlands is this study only performed in the rehabilitation setting and there are neither results available of the social healthcare setting (Siebes et al., 2007). The results of these studies show variation in the level of satisfaction for different patient characteristics such as family structure or developmental age of the child (Almasri, An, & Palisano, 2018; Jansen, van der Putten, & Vlaskamp, 2017). However, these studies do not show the needs of parents on how to improve the negative measurements of the level of satisfaction of parents. To promote parent participation, it is useful to know parents' opinion about which of the negative measurements should be improved in practice, and how.

The aim of this paper is treble. First, to explore which elements of family-centered care are rated badly by parents of intellectual and/or physical disabled children at the age of 0 to 18 years old in social healthcare and whether the variation in these scores could be explained by patient characteristics. At last, to investigate which improvements parents of intellectual and/or physical disabled children at the age of 0 to 18 years old in social healthcare suggest for the bad scoring elements of family-centered care.

2. Background of parent participation

2.1 Exploration of the literature

Literature shows that previous studies prove that parent participation leads to positive outcomes, such as improved patient satisfaction, better-informed patients, higher therapy compliance, and an improved patient-provider relationship (Dunst, Trivette, & Hamby, 2007; Sassen, 2010; Turchi et al., 2014; Zorg voor beter, n.d.). Three subjects that were mentioned in literature are measurement tools to measure the level of satisfaction of parents on several subjects of parent participation, parameters which influence the extent of satisfaction of parents, and experiences of parents concerning parent participation.

The Measure of Process of Care (MPOC) is seen as the gold-standard method to measure parents' satisfaction with their participation in the care process of their child. The MPOC consists of 56 items (MPOC-56), or a shorter version with 20 items (MPOC-20) (see appendix 1). All of the items measure to what extent parents feel satisfied with an aspect of the parent-provider partnership or family-centredness. These items are divided into five subjects: 'enabling and partnership', 'providing general information', 'providing specific information about the child', 'co-ordinated and comprehensive care', and 'respectful and supportive care' (Almasri et al., 2018; Schreiber, Benger, Salls, Marchetti, & Reed, 2011).

Results of previous research that used the MPOC show that parents are most satisfied with the items related to the subject 'respectful and supportive care' with average scores between 5.81 and 6.40 on a scale from 1-7. About the subject 'providing general information' parents are the least satisfied with average scores between 4.38 and 5.28 on a scale from 1-7 (Arcuri et al., 2015; Bellin, Osteen, Heffernan, Levy, & Snyder-Vogel, 2011; Fordham, Gibson, & Bowes, 2011; Schreiber et al., 2011; Shevell et al., 2018; Terwiel et al., 2017).

The results also show that the level of satisfaction of parents varies for different patient characteristics. These characteristics are family structure, calendar age of the child, developmental age of the child and maternal education (Almasri et al., 2018; Jansen et al., 2017). Generally, parents of children with a severe disability or a disability with a huge impact on the family are less satisfied than parents of children with a mild disability or which have a smaller impact on the family. Furthermore, parents of children older than twelve are less satisfied than parents of children younger than twelve (Bjerre et al., 2004; Wood et al., 2009). Furthermore, the results showed that there were parents who felt not being listened to by the professionals (Lundeby & Tøssebro, 2008).

2.2 Cosis

In the north of the Netherlands (Groningen and Drenthe), an organisation that provides care services to people with an intellectual and/or physical disability is Cosis. Cosis has 3700 employees and 1500 volunteers. They support people with difficulties in daily life in a way that fits the patient best with the intention to give a clear overview in their life. This could be difficulties in making social contact, to find a job, or living on their own. The aim of the services of Cosis is to increase the independence of the client. Cosis delivers long- and short-term care at home or at one of the locations of Cosis. The core care activities delivered by Cosis are, treatment at home, living facilities, daycare, and family support (Cosis, n.d.-b).

An example of family support is the expertise centres. There are five centres of Cosis in Groningen and four centres in Drenthe. An expertise centre is an alternative school for children (0-18 years old) who cannot go (yet) to a regular school due to intellectual and/or physical disabilities. There are 180 professionals divided over several care disciplines, such as behavioural scientists, physiotherapists, speech therapists, play therapists, and music therapists. They provide daycare, which is in line with the educational request from the parent. Every child has his own goals which are in line with the possibilities of the child. On average there are five groups at one centre with five to twelve children in each group. Dependent on the developmental age of the child they are doing group activities and they get individual treatment (Cosis, n.d.-a).

An expertise centre in Drenthe is expertise centre Meppel, which is the subject of this study. In Meppel they give high priority to parent participation. They started with the 'STEK' methodology to improve parent participation in 2018. This is a method that helps an organisation to achieve its goals together by making small improvement steps. They created one group with two stakeholders, a few parents and a few healthcare professionals, dependent on registration. There were discussions about the question of what was needed to improve parent participation. Two main subjects to improve were 'communication' and 'the position of the parents'. They started with one implementation in September 2019. Parents received an invitation for the multidisciplinary consultation of their child. The experiences of parents about this implementation are contradictory. To get an overview of the needs of all parents, this study has been started.

3. Method

3.1 Study design

The approach of this study was a mixed method. For the quantitative part of the study a questionnaire was used to explore which elements of family-centered care scores badly and whether patient characteristics influence the variance in scores parents gave. For the qualitative part, two semi-structured focus group interviews were carried out to explore for which elements of family-centered care parents see some improvements.

3.2 Participants

The parents (n=52) of the children of one location of the expertise centres (see section 2.2) were invited to participate in the study by filling out a questionnaire. This invitation was sent by email through the location manager. Parents who were included by getting an invitation have one or more children who go to the expertise centre and are the legal representatives of the child.

The interview was carried out twice. The parent council of two different locations were invited separately to participate in the interviews. The first parent council existed of four parents, and the second parent council existed of three parents and two location managers. Two location managers were incidentally present, due to a transition of the location manager. The parents of the parents' council also met the inclusion criteria set up for the respondents of the questionnaires.

3.3 Measurements

For this study, the MPOC-20 was used (see section 2.1). The 20 items of the MPOC measure to what extent parents feel satisfied with an aspect of the parent-provider partnership or family-centredness. The Dutch translation of the MPOC-20 has been found to be valid (Siebes et al., 2007). For this study, the existing MPOC-20 questionnaire was supplemented with open questions. In these open questions, parents were asked to indicate the importance of the items for them, to argue which activities do or do not contribute to their level of satisfaction, and by which activities their level of satisfaction could be improved. The questionnaire was written in Dutch (see appendix 2). The questionnaire was sent to 52 parents of children with an intellectual and/or physical disability who are all visiting the same location of Cosis (see section 2.2).

For the semi-structured focus group interviews performed by the researcher, a topic list was used (see appendix 3). The five subjects of the MPOC were used as topics. First, parents were asked which activities do and do not contribute to their level of satisfaction about the current situation of the topics. Second, parents were asked to think about the improvements they see in the current situation. Thereafter, the results of the questionnaire were shared with the parents to ask them if they could conceive the scores given by all other parents, what could be the cause of it, and how could it be improved. This was done because the parent council are the representatives of all parents of one location. By doing this there was not only asked for the improvements parents of the parent council see but also improvements they know other parents see.

3.4 Methodological quality

To assess the face validity of the questionnaire a pilot test was done. During this pilot test, the questionnaire was sent to ten relatives and friends of the researcher. They were asked to fill out the questionnaire and to give feedback. This feedback focused on clarity of formulation, missing information, logical order of the subjects, and technically well-functioning of the questionnaire. Seven useful feedback forms were sent back. Some questions were difficult to understand or were misinterpreted by the respondents, therefore the formulation of these questions was changed. Technical missing functions mentioned by the respondents, such as the number of the question and the option to go to the previous question, were added.

To improve the reliability of the results of the focus group, member checking for the interviews was performed. For both interviews, the results were sent back by email to the interviewees. The interviewees checked if all their answers were interpreted correctly by the interviewer and gave their approval.

3.5 Ethical approval

Human participants were invited to participate in this study. Therefore, the concept of the study design is sent to the ethical commission of the Faculty of Behavioural, Management and Social sciences of the University of Twente with request number 190209. The ethical commission gave their permission to perform this study. In addition, the participants signed an informed consent before participating in the study (see appendix 2 and 4).

3.6 Data analyses

To analyse the results of the questionnaire the Statistical Package for the Social Sciences (SPSS) was used. In SPSS the averages of the items of the MPOC-20 and the importance rate for every subject were calculated. To analyse if there was a relation between the scores and patient characteristics the Mann-Whitney U test was used. This test was used due to group sizes smaller than 30 and due to nominal variables.

The focus group interviews were transcribed and encoded in ATLAS.ti. Encoding means that the empirical text will be linked to conceptual codes. This process consists of the following three phases: the exploration phase, the specification phase, and the reduction phase. The exploration phase implies open coding. This means that the whole text will be read and important text fragments will get a code. Subsequently, codes with the same subject will get combined in the specification phase. This will create the main and subcodes. Lastly, in the reduction phase, it will be evaluated whether there is coherence between the codes and the link between the different codes is made (Baarda et al., 2013).

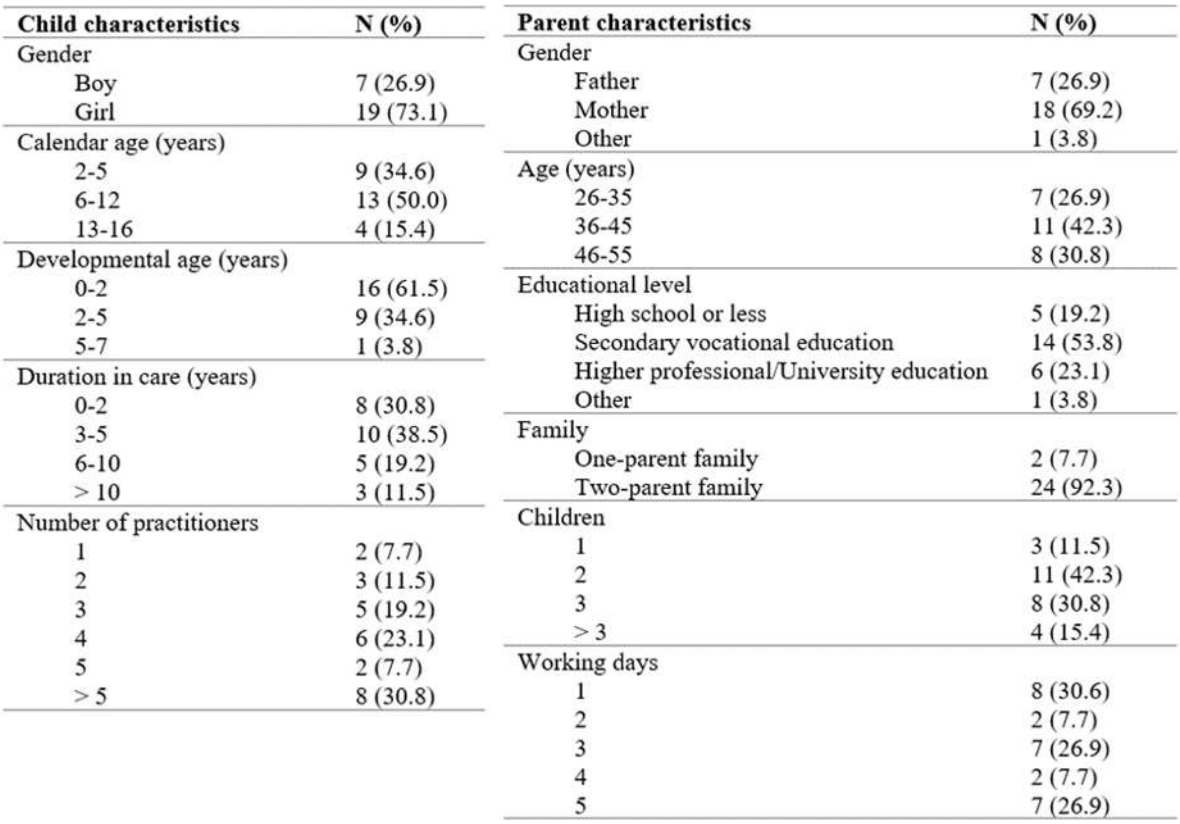
4. Results

4.1 Quantitative data

4.1.1 Findings MPOC

Thirty-seven parents (response rate of 71.2%) filled out the questionnaire. In total 26 (70.3%) questionnaires were filled out completely and were included in the analysis part of this paper. Most respondents who did not fill out completely the questionnaire (10 out of 11) stopped filling out the questionnaire by reaching the open question part of the questionnaire. One respondent reported that it felt useless to fill out the questionnaire because most of the questions were not applicable to his

Table 1, characteristics study population



Child characteristics	N (%)
Gender	
Boy	7 (26.9)
Girl	19 (73.1)
Calendar age (years)	
2-5	9 (34.6)
6-12	13 (50.0)
13-16	4 (15.4)
Developmental age (years)	
0-2	16 (61.5)
2-5	9 (34.6)
5-7	1 (3.8)
Duration in care (years)	
0-2	8 (30.8)
3-5	10 (38.5)
6-10	5 (19.2)
> 10	3 (11.5)
Number of practitioners	
1	2 (7.7)
2	3 (11.5)
3	5 (19.2)
4	6 (23.1)
5	2 (7.7)
> 5	8 (30.8)

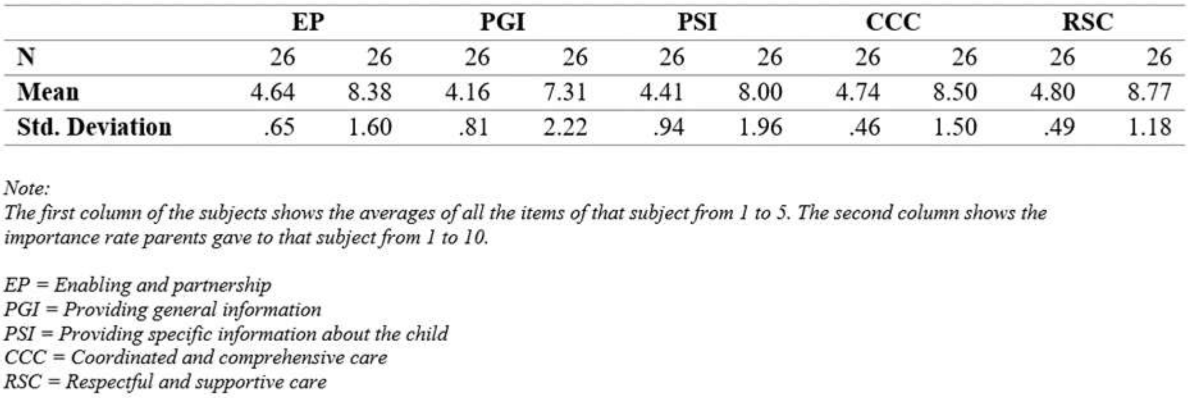
Parent characteristics	N (%)
Gender	
Father	7 (26.9)
Mother	18 (69.2)
Other	1 (3.8)
Age (years)	
26-35	7 (26.9)
36-45	11 (42.3)
46-55	8 (30.8)
Educational level	
High school or less	5 (19.2)
Secondary vocational education	14 (53.8)
Higher professional/University education	6 (23.1)
Other	1 (3.8)
Family	
One-parent family	2 (7.7)
Two-parent family	24 (92.3)
Children	
1	3 (11.5)
2	11 (42.3)
3	8 (30.8)
> 3	4 (15.4)
Working days	
1	8 (30.6)
2	2 (7.7)
3	7 (26.9)
4	2 (7.7)
5	7 (26.9)

situation. The study population characteristics are shown in table 1. In the left table the characteristics of the children are shown, and in the right table the characteristics of the parents are shown.

Parents rated the subject 'respectful and supportive care' as the most important for them, scoring an 8.77 (out of 10), see table 2. The subject 'providing general information' was rated by parents as least important, scoring a 7.31 (out of 10). These subjects were also scoring as best (4.8 out of 5) and worst subject (4.16 out of 5). To give insights into the number of parents who were not satisfied with the care they received, the percentages of parents scoring a 3 or lower for each item of the MPOC-20 are shown in table 3. Between 25% and 40.91% of the parents were not satisfied with the items for the subject 'providing general information'. For the subject 'respectful and supportive care' was this percentage between 3.84 and 11.54.

There were two significant correlations out of sixteen correlations tested between scores and patient characteristics. The Mann-Whitney U test was used to prove the correlations. The first correlation was shown between the number of different disciplines of care, such as logopaedics or physiotherapy, and the score parents gave for the quote 'to what extent does

Table 2, average results of the elements of the measure of processes of care

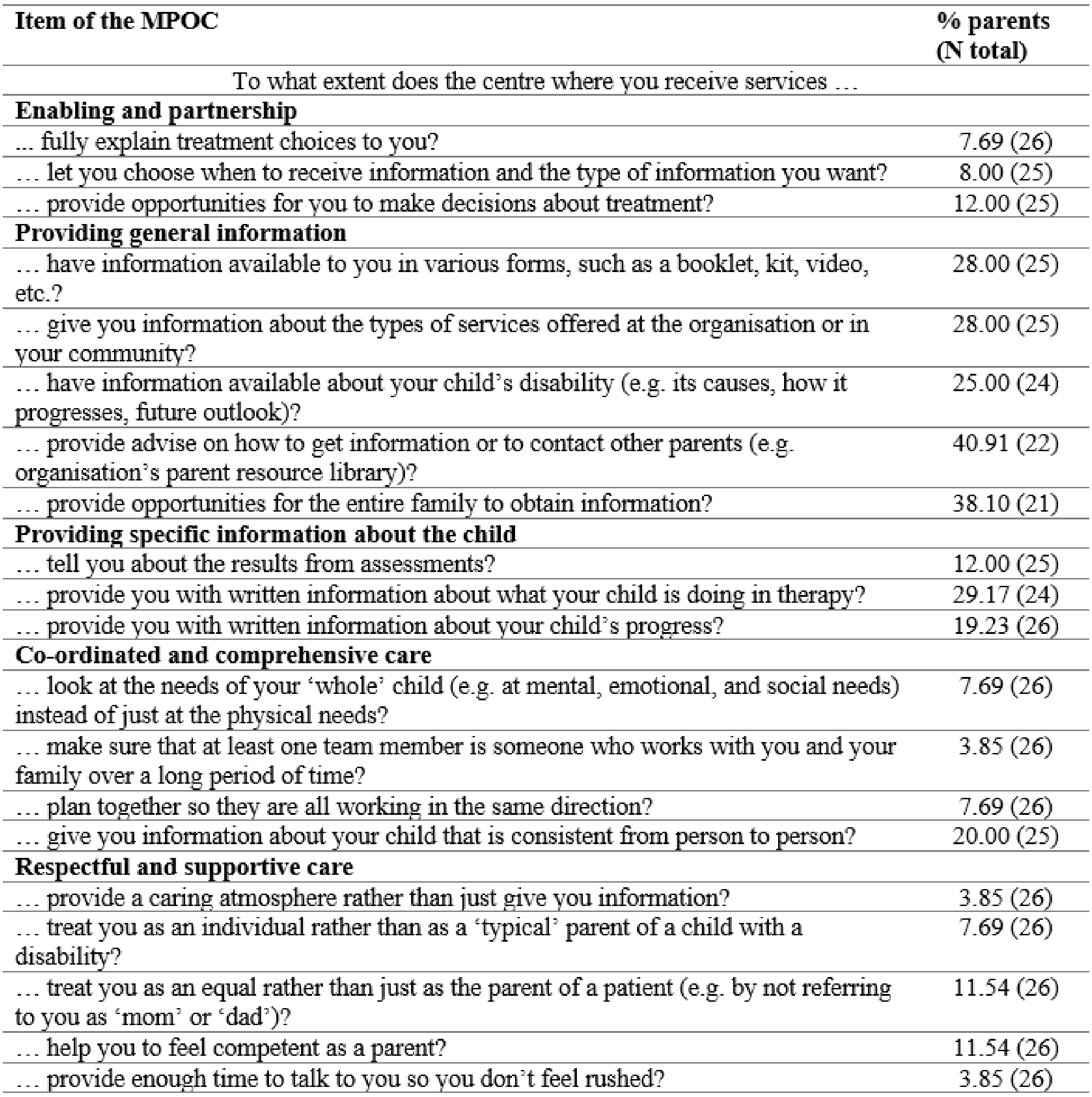


	EP		PGI		PSI		CCC		RSC	
N	26	26	26	26	26	26	26	26	26	26
Mean	4.64	8.38	4.16	7.31	4.41	8.00	4.74	8.50	4.80	8.77
Std. Deviation	.65	1.60	.81	2.22	.94	1.96	.46	1.50	.49	1.18

Note:
The first column of the subjects shows the averages of all the items of that subject from 1 to 5. The second column shows the importance rate parents gave to that subject from 1 to 10.

EP = Enabling and partnership
PGI = Providing general information
PSI = Providing specific information about the child
CCC = Coordinated and comprehensive care
RSC = Respectful and supportive care

Table 3, percentages of parents who are not satisfied for each item of the MPOC-20



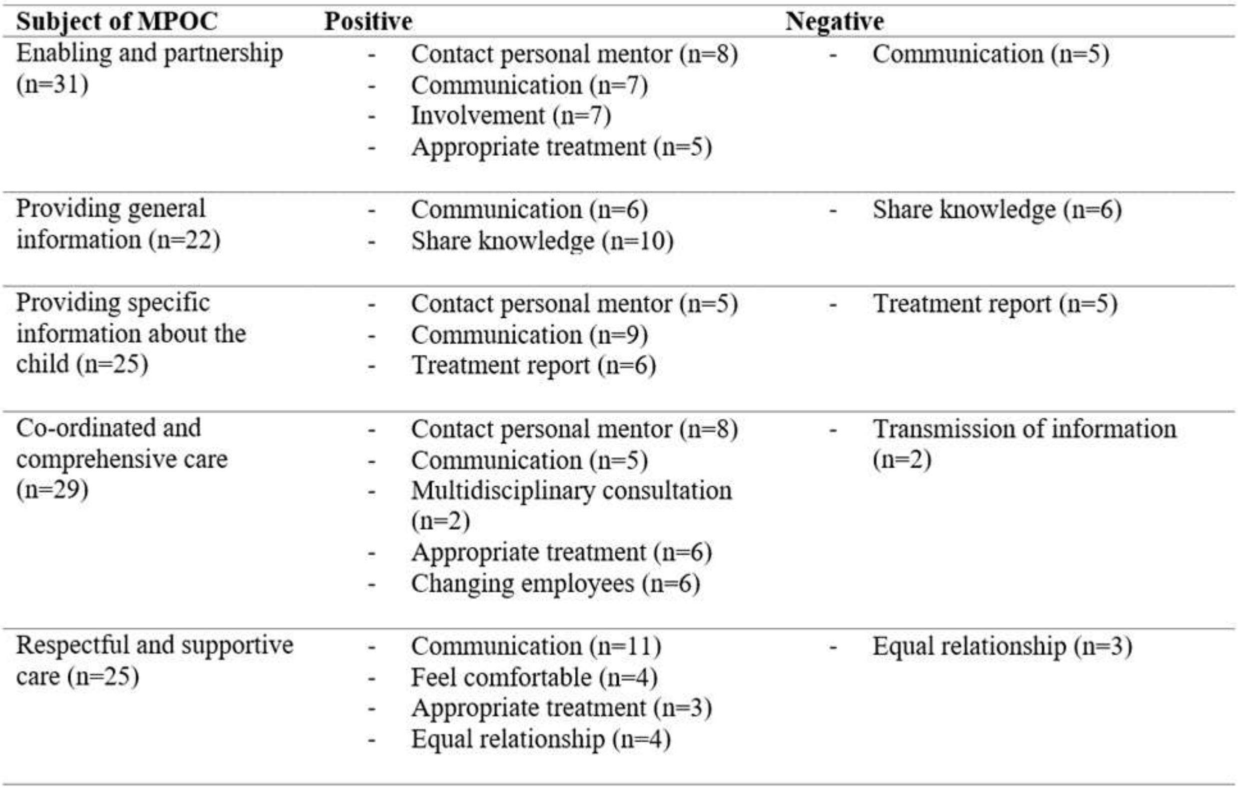
Item of the MPOC	**% parents (N total)**
To what extent does the centre where you receive services …	
Enabling and partnership	
... fully explain treatment choices to you?	7.69 (26)
… let you choose when to receive information and the type of information you want?	8.00 (25)
… provide opportunities for you to make decisions about treatment?	12.00 (25)
Providing general information	
… have information available to you in various forms, such as a booklet, kit, video, etc.?	28.00 (25)
… give you information about the types of services offered at the organisation or in your community?	28.00 (25)
… have information available about your child's disability (e.g. its causes, how it progresses, future outlook)?	25.00 (24)
… provide advise on how to get information or to contact other parents (e.g. organisation's parent resource library)?	40.91 (22)
… provide opportunities for the entire family to obtain information?	38.10 (21)
Providing specific information about the child	
… tell you about the results from assessments?	12.00 (25)
… provide you with written information about what your child is doing in therapy?	29.17 (24)
… provide you with written information about your child's progress?	19.23 (26)
Co-ordinated and comprehensive care	
… look at the needs of your 'whole' child (e.g. at mental, emotional, and social needs) instead of just at the physical needs?	7.69 (26)
… make sure that at least one team member is someone who works with you and your family over a long period of time?	3.85 (26)
… plan together so they are all working in the same direction?	7.69 (26)
… give you information about your child that is consistent from person to person?	20.00 (25)
Respectful and supportive care	
… provide a caring atmosphere rather than just give you information?	3.85 (26)
… treat you as an individual rather than as a 'typical' parent of a child with a disability?	7.69 (26)
… treat you as an equal rather than just as the parent of a patient (e.g. by not referring to you as 'mom' or 'dad')?	11.54 (26)
… help you to feel competent as a parent?	11.54 (26)
… provide enough time to talk to you so you don't feel rushed?	3.85 (26)

the centre where you receive services fully explain treatment choices to you' U = 45 (p = 0.018). The variable number of disciplines of care had two values, 1 (n = 16) and 0 (n = 10). One meant that there were more than three different kinds of disciplines of care and zero meant there were three or less different kinds of disciplines of care. This meant that parents were less satisfied if they had more than three different kinds of disciplines of care in comparison to parents who had three or less different kind of disciplines of care. The second correlation was shown between how often parents had contact by phone or email with the personal mentor and the score of importance they gave for the subject 'respectful and supportive care' U = 42 (p = 0.037). Whereby the variable had two values, 1 (n = 10) and 0 (n = 16). One meant that the parents had contact once in a month or less often with the personal mentor and zero meant that parents had contact twice a week or more often with the personal mentor. This meant that parents found the subject 'respectful and supportive care' more important if they had contact twice a week or more often by phone or email with their personal mentor in comparison to parents who had contact once a month or less often.

4.1.2 Findings open questions

The codes for every subject of the MPOC of the open questions in the questionnaire are shown in table 4. In general, parents were positive about their current participation in the care process of their child. There were 107 positive citations against 21

Table 4, overview of the codes for the subjects of the measure of processes of care. Given by parents in the open questions in the questionnaire



Subject of MPOC	Positive	Negative
Enabling and partnership (n=31)	- Contact personal mentor (n=8) - Communication (n=7) - Involvement (n=7) - Appropriate treatment (n=5)	- Communication (n=5)
Providing general information (n=22)	- Communication (n=6) - Share knowledge (n=10)	- Share knowledge (n=6)
Providing specific information about the child (n=25)	- Contact personal mentor (n=5) - Communication (n=9) - Treatment report (n=6)	- Treatment report (n=5)
Co-ordinated and comprehensive care (n=29)	- Contact personal mentor (n=8) - Communication (n=5) - Multidisciplinary consultation (n=2) - Appropriate treatment (n=6) - Changing employees (n=6)	- Transmission of information (n=2)
Respectful and supportive care (n=25)	- Communication (n=11) - Feel comfortable (n=4) - Appropriate treatment (n=3) - Equal relationship (n=4)	- Equal relationship (n=3)

negative citations. The three most mentioned reasons why parents were satisfied are: 1. the communication from the expertise centre to parents is clear, open, and transparent, 2. parents have good contact with their personal mentor, 3. parents are satisfied with the treatment and notify that the treatment fits their child.

The negative citations had for every subject of the MPOC another code, clear communication, share knowledge, treatment report, transmission of information, and equal relationship. Surprisingly, most of the negative citations were by other parents designated as positive. Parents suggested improvements for these negative experiences. For clear communication parents noticed the following improvements:

> *'Reduce the number of forums to just a single forum which makes it clear where to find information.'*
>
> *'Reduce the time between asking a question and getting an answer.'*

For share knowledge parents noticed the following improvement:

> *'Bundle the knowledge of all the parents together and share it with new and other parents.'*

For treatment report parents noticed the following improvements:

> '*Solve problems with logging in on forums.'*
>
> *'Only online reports are not enough and are often negative, continue with the written reports.'*

For transmission of information parents noticed the following improvement:

> *'If the child is going to another location, organise a meeting with the previous and next personal mentor.'*

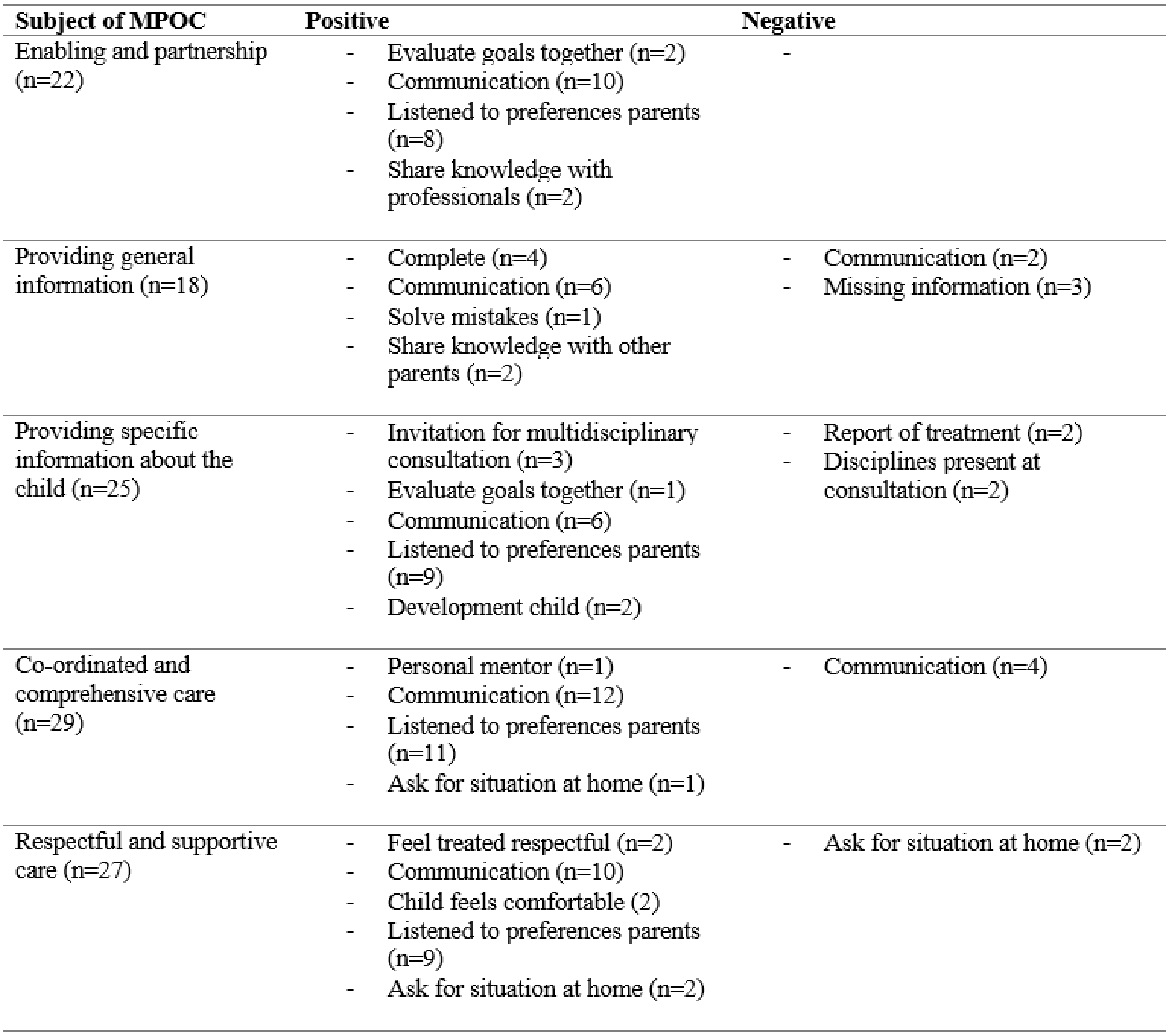
For equal relationship parents noticed the following improvement:

> *'Treat the parent as a fellow professional.'*

4.2 Qualitative data

During the interviews, every subject of the MPOC has been discussed. An overview of the codes for the interviews are shown in table 5. The improvements mentioned by parents were about the way of communication, and the tasks of the personal mentor. For every subject of the MPOC there were some improvements mentioned by the parents except for the subject 'enabling and partnership'. In the sections 4.2.1 up to 4.2.4, the improvements mentioned by parents for the other four subjects of the MPOC will be discussed.

Table 5, overview of the codes for the subjects of the measure of processes of care. Given by parents during the focus group interviews



Subject of MPOC	Positive	Negative
Enabling and partnership (n=22)	- Evaluate goals together (n=2) - Communication (n=10) - Listened to preferences parents (n=8) - Share knowledge with professionals (n=2)	-
Providing general information (n=18)	- Complete (n=4) - Communication (n=6) - Solve mistakes (n=1) - Share knowledge with other parents (n=2)	- Communication (n=2) - Missing information (n=3)
Providing specific information about the child (n=25)	- Invitation for multidisciplinary consultation (n=3) - Evaluate goals together (n=1) - Communication (n=6) - Listened to preferences parents (n=9) - Development child (n=2)	- Report of treatment (n=2) - Disciplines present at consultation (n=2)
Co-ordinated and comprehensive care (n=29)	- Personal mentor (n=1) - Communication (n=12) - Listened to preferences parents (n=11) - Ask for situation at home (n=1)	- Communication (n=4)
Respectful and supportive care (n=27)	- Feel treated respectful (n=2) - Communication (n=10) - Child feels comfortable (2) - Listened to preferences parents (n=9) - Ask for situation at home (n=2)	- Ask for situation at home (n=2)

4.2.1 Providing general information

New parents experienced some problems with the request of allowance for their children. They did not felt the support of the location to help them with this request. There were a lot of parents who did the request in the past. Some parents noticed *'it feels like re-inventing the wheel'*. Therefore, parents think it is useful to bundle the experiences of parents to help the new parents by their request for allowance. It could be bundled as 'tips and tricks' and this could be added to the information parents get if they are new at the location. It is an added value for parents if the personal mentor checks whether parents have received all the information they need at the beginning.

Moreover, parents see improvements by planning meetings or activities for parents. It happened that parents hear the date for a meeting or activity one week before. Parents would like to know these dates earlier. This could be done by making a yearly calendar with all important dates on it. To improve the subject 'providing general information' there could be added some general information on the back of every week of this calendar. In addition to this, some meetings could be organised for parents, where a guest speaker gives some information about a specific subject. These subjects can be suggested by parents.

4.2.2 Providing specific information about the child

Parents received an invitation for the multi-disciplinary consultation (MDO). It happened that not all practitioners were present at the consultation. Mind you, two locations were interviewed, at one location parents filled out a paper with their questions before the MDO took place. If there were questions for a specific practitioner he was present during the MDO. At the other location, this was not the case. It functions correctly, so it would be useful to introduce this at both locations. Besides this consultation, practitioners can communicate with parents by an electronic patient dossier (EPD). However, not all disciplines of care did use this system. Parents regarded it as an improvement if they knew what all disciplines of care did observe during therapy.

4.2.3 Coordinated and comprehensive care

All parents had their own preferences on how they will participate in the care process of their child. Some parents asked about the possibilities, but not all parents did. Parents thought it would be an improvement if the personal mentor asks parents at the beginning how they want to participate in the care process of their child. The personal mentor has to share all the possibilities of the location with the parents. If the parents knew the possibilities, they could share their preferences. The personal mentor has to share this information with all disciplines of care.

4.2.4 Respectful and supportive care

Expectations from parents to the personal mentor were that they know what is going on in the home situation. Do parents experience some difficulties or do they need some help? Some parents had a personal mentor who knows this, but there were some personal mentors who did not. Parents think all personal mentors had to do so because if they know this, they can take this into account and offer the right services.

5. Discussion

Similar to previous studies, parents judged their participation in the care process of their children as important with average scores between 7.31 and 8.77 (out of 10) (McNeilly et al., 2017). As also shown in literature, parents were in general satisfied with the current situation, with the highest score of 4.80 and the lowest score of 4.16 (out of 5) on the subjects of the MPOC, with regard to their participation in the care process of their children. The subject ‘respectful and supportive care’ was scoring best and ‘providing general information’ was scoring worst. (Arcuri et al., 2015; Bellin et al., 2011; Fordham et al., 2011; Schreiber et al., 2011; Shevell et al., 2018; Terwiel et al., 2017).

These average results seem to be a good score and indicated just a minimal space for improvement. However, further analysis showed that for each item of the subjects between 3.85% and 40.91% of the parents gave a score of 3 or lower (out of 5). This means that 40.91% of the parents were dissatisfied for the worst scoring item of the subjects of the MPOC.

The results of this study show some similarities in the reasons why parents were satisfied and the reasons why parents were not satisfied with their participation in the care process of their child. This could be explained due to individual preferences or incidents, but also due to collaborating with other employees than other parents. Nijhuis et al. (2007) proved differences in the service delivery of employees working with children with an intellectual and/or physical disability due to their own norms and values. Other studies did relate these differences to patient characteristics, such as family structure, calendar age of the child, developmental age of the child and maternal education (Almasri et al., 2018; Jansen et al., 2017). Surprisingly, these relations were not demonstrated in this study. However, there were two other significant relations shown. The first relation was shown between the number of different disciplines of care, such as logopaedics or physiotherapy, and the score parents gave for the quote ‘to what extent does the centre where you receive services fully explain treatment choices to you’. An explanation for this relation may be that parents need more support if there are three or more disciplines involved in the care process of their child, because of a more complex care process. It could be helpful if the personal mentor regularly summarises the treatment reports with the parents to give them a clear overview. The second relation shown was between how often parents have contact by phone or email with the personal mentor and the score of importance they gave for the subject ‘respectful and supportive care’. This sounds logical if parents have more often contact with the personal mentor, the way the personal mentor treats you is more important.

At the ‘STEK’ methodology, as mentioned in section 2.2, two subjects to improve were mentioned: communication, and the position of the parents. Surprisingly, the improvements mentioned by parents in this study are about the way of communication, and the tasks of the personal mentor. The tasks of the personal mentor were about what parents of the personal mentor expect. One of these tasks mentioned was:

> '*A personal mentor should ask parents how they want to participate in the care process of their child and mention the possibilities of the location.'*

This is in line with the subject the position of parents of the 'STEK' methodology, see section 2.2. Subsequently, in previous studies is this improvement also recommended and is communication mentioned as a need of parents in participating in the care process of their child (Alsem et al., 2013; Nijhuis et al., 2007).

The parents in this study were enthusiastic about their contact with the healthcare professionals. Parents felt being listened to, they had a say about the treatment goals and these fitted to their child. However. In previous studies, parents felt stress due to the way of communication with healthcare professionals. They felt not being listened to by the professionals and felt the need to fight for their child to express their preferences in the treatment goals (Lundeby & Tøssebro, 2008; McNeilly et al., 2017).

5.1 Limitations of the study

The questionnaire had a high response rate of 71.2%. This gives a clear overview of the current situation of parents at one location. The results are similar to previous studies and the locations of Cosis do pursue all the same vision which lead to nearly the same care service delivery. Therefore, the results of this study will probably be generalisable to all parents with a child with an intellectual and/or physical disability at the age of 0-18 who are visiting an EC of Cosis. The measurement tool used for this study was the Dutch translation of the MPOC-20. This is a valid method to measure the extent to which parents feel satisfied with an aspect of the parent-provider partnership or family-centredness (Siebes et al., 2007; Van Schie, Siebes, Ketelaar, & Vermeer, 2004).

The interviews were performed at two locations with the parent council. These parents were involved in issues at the location and were enthusiastic to think about solutions for these issues. For this reason, the participants of the interviews belonged to the early adopters of the whole study population. Therefore, the results of the interviews should be used with some caution to the whole study population. Parents who do not belong to the early adopters may not want to be actively involved in issues at the location and in the care process of their child. These parents could give other improvements to the current situation.

The parents of the parent council of one of the locations were also invited to fill out the questionnaire. This could lead to information bias. These parents already got information about the study by getting the invitation to fill out the questionnaire. If these parents filled out the questionnaire, then they could think about the subject before participating during the interview and they could discuss the subject with relatives and friends before. The parents of the parent council of the other location heard the questions for the first time and gave their first reaction. If they also had discussed the subjects with their relatives and friends this could influence their answers and this could lead to more critical answers.

At one location there were incidentally two location managers present during the interview. This could withhold parents to share negative experiences and this could lead to fewer improvements mentioned by parents. In contrast, during the interview at the other location only parents were present. During this interview more improvements were mentioned by parents which indicated that the parents at this location were less satisfied with the current situation.

The transcripts of the interviews are coded by one researcher. This could influence the credibility of the results of the interviews. However, the transcripts of the interviews and the elaboration of the interviews were checked by the interviewees and they agreed with the content.

5.2 Organizational recommendations

Based on the results of this study a recommendation for the social healthcare setting is to organise a meeting between parents and the personal mentor at the start of the care process of the child. During this meeting the personal mentor should ask for parents preferences and mention the possibilities of the location concerning parent participation. The agreements made during this meeting should be implemented during the care process of the child.

The healthcare system is changing very fast, therefore it is important to evaluate constantly parents expectations and their level of satisfaction with their participation in the care process of their child.

5.3 Research recommendations

Before implementing the recommendations mentioned in section 5.2, it is worthwhile to carry out a study like this with staff members. By doing so the expectations of parents could be compared with the expectations of staff members concerning parent participation. It is important to know if there are differences in the expectations of parents and staff members, and why.

The relation between patient characteristics and parents' preferences were not shown in this study due to small group sizes. However other studies did relate these differences to patient characteristics. There were a lot of differences in the preferences of parents in this study shown. Therefore, it is worthwhile to further analyse the impact of patient characteristics with bigger group sizes.

The different locations of Cosis offer nearly the same care service. However, there is one big difference, at some locations parents are joining the multidisciplinary consultation and at other locations they do not. It is worthwhile to check whether the results of this study are generalisable to parents who are not joining during the multidisciplinary consultation.

6. Conclusion

There are already a lot of possibilities for parents to participate in the care process of their child in social healthcare. However, not all parents do know these possibilities because they have to ask for it by themselves. Parents all had their own preferences concerning their participation in the care process of their child. This resulted in a lot of variation in the improvements parents saw. Therefore, by parents it is seen as an added value that the personal mentor asks for the preferences of each individual parent and mention the possibilities of the location concerning parent participation at the start of the care process. By knowing this, the preferences of parents could be taken into account in the individual care process of the child. This will hopefully increase parents' satisfaction with their participation in the care process of their child. However, further research is needed to prove if the current possibilities offered by the location to parents is the best.

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Appendix

Appendix 1, MPOC-56 and MPOC-20

The table below shows which items are included in the MPOC-56. If there is a 'yes' in the last column then it is also an item in the MPOC-20.

To what extent does the centre where you receive services …	
Enabling and partnership	
... fully explain treatment choices to you?	Yes
… offer you positive feedback or encouragement (e.g. in carrying out a home programme)	No
… tell about options for treatment or services for your child (e.g. equipment, school, therapy)?	No
… trust you as the 'expert' on your child?	No
… anticipate your concerns by offering information even before you ask?	No
… make sure you have a chance during visits to the centre to say what is important to you?	No
… let you choose when to receive information and the type of information you want?	Yes
… tell you about the reason for treatment or equipment?	No
… provide opportunities for you to make decisions about treatment?	Yes
… answer your questions completely?	No
… recognise that your family has the final say when making decisions about your child's treatment?	No
… consult with you when discussing equipment or services?	No
… tell you about details about your child's services, such as the reasons for them, the type of therapies and length of time?	No
… make sure you have opportunities to explain what you think are important treatment goals?	No
… make you feel like a partner in your child's care?	No
… listen to what you have to say about your child's needs for equipment, services, etc.?	No
Providing general information	
… have information available to you in various forms, such as a booklet, kit, video, etc.?	Yes
… give you information about the types of services offered at the organization or in your community?	Yes
… promote family-to-family- gatherings for social, information or shared experiences?	No
… provide opportunities for special guests to speak to parents on topics of interest?	No
… provide support to help cope with the impact of childhood disability (e.g. organisation's parent resource library)?	No
… have information available about your child's disability (e.g. its causes, how it progresses, future outlook)?	Yes
… provide advise on how to get information or to contact other parents (e.g. organization's parent resource library)?	Yes
… provide opportunities for the entire family to obtain information?	Yes
… have general information available about different concerns (e.g. financial costs or assistance, genetic counselling, dating, sexuality)?	No
Providing specific information about the child	
… explain what they are doing when you are watching your child in therapy?	No
… tell you about the results from assessments?	Yes
… provide you with written information about what your child is doing in therapy?	Yes
… provide you with written information about your child's progress?	Yes
… notify you about the reasons for upcoming case conferences, meetings, etc. about your child?	No
Co-ordinated and comprehensive care	
… suggest therapy plans that fit with your family's needs and lifestyle?	No
… explain things to your child in a way that your child understands?	No
… take the time to establish rapport with you or your child when changes occur in your services?	No
…discuss with you everyone's expectations for your child, so that all agree on what is best?	No

… make sure that your child's skills are known to all persons working with your child, so the skills are carried across services and service providers?	No
… provide ideas to help you work with the health care 'system'?	No
… recognise the demands of caring for a child with special needs?	No
… look at the needs of your 'whole' child (e.g. at mental, emotional, and social needs) instead of just at the physical needs?	Yes
… show sensitivity to your family's feelings about having a child with special needs (e.g. your worries about your child's health or function)?	No
… follow up at the next appointment on any concerns you discussed at the previous one?	No
… make sure that at least one team member is someone who works with you and your family over a long period of time?	Yes
… develop both short-term and long-term for your child?	No
… plan together so they are all working in the same direction?	Yes
… make sure you are informed ahead of time about any changes in your child's care (e.g. therapists, programmes, equipment)?	No
… seem aware of your child's changing needs as he/she grows?	No
… make themselves available to you as a resource (e.g. emotional support, advocacy, information)?	No
… give you information about your child that is consistent from person to person?	Yes
Respectful and supportive care	
… accept you and your family in a non-judgemental way?	No
… remember personal details about your child or family when speaking to you?	No
… provide a caring atmosphere rather than just giving you information?	Yes
… treat you as an individual rather than as a 'typical' parent of a child with a disability?	Yes
… treat you as an equal rather than just as the parent of a patient (e.g. by not referring to you as 'mom' or 'dad')?	Yes
… help you to feel competent as a parent?	Yes
… provide enough time to talk to you so you don't feel rushed?	Yes
… treat you and your family as people rather than as a 'case' (e.g. by not referring to you by diagnosis, such as 'the spastic diplegic')?	No
… have support staff that are polite and courteous to you and your family?	No

Appendix 2, questionnaire (Dutch version)

Ouderparticipatie

U bent van harte uitgenodigd om deel te nemen aan een onderzoek "Ouderparticipatie in de sociale gezondheidszorg voor kinderen van 0-18 jaar". Dit onderzoek wordt uitgevoerd door Janiek Hanken voor haar studie gezondheidswetenschappen aan de Universiteit Twente.

Met dit onderzoek worden uw ervaringen met betrekking tot ouderparticipatie in kaart gebracht. Hierbij wordt gekeken wat er op dit moment als positief wordt ervaren en waar de verbeterpunten liggen. Dit zal ongeveer 15 minuten duren. Uw antwoorden zullen worden gebruikt om de zorgverlening binnen het expertise centrum van Meppel te verbeteren.

Deelname aan dit onderzoek is geheel vrijwillig. U kunt uw medewerking aan het onderzoek op elk moment stoppen, zonder hiervoor een reden op te geven. U bent vrij om vragen te beantwoorden met "niet van toepassing".

Ons inziens zijn er geen risico's bij deelname aan het onderzoek. De antwoorden in deze studie zullen vertrouwelijk blijven. Om uw antwoorden niet te kunnen herleiden zal er niet om uw naam gevraagd worden. Vragen over persoonlijke eigenschappen zullen in categorieën worden opgedeeld, zoals leeftijd. Leeftijd zal worden verdeeld in de volgende categorieën, jonger dan 18, 18-25, 26-35, 36-45, 46-55 en ouder dan 55. Zodra de enquête is gesloten voor deelname zullen de antwoorden worden opgeslagen op een beveiligde USB-stick en zullen de antwoorden online verwijderd worden.

Voor vragen kunt u contact opnemen met de onderzoekster Janiek Hanken, e-mailadres: j.hanken@cosis.nu

☐ Ik heb bovenstaande doorgelezen en zal vrijwillig deelnemen aan het onderzoek.

En ..

☐ Ik ben op de hoogte dat mijn antwoorden anoniem verwerkt zullen worden en geef toestemming dat deze gebruikt mogen worden voor dit onderzoek en hiervan eventueel afgeleide publicaties.

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De volgende vragen gaan over uw zoon/dochter. De afkorting EC staat voor Expertise Centrum en zal verderop in de vragenlijst gebruikt worden.

1. Ik vul deze vragenlijst in over mijn ...

▼ Zoon (1), Dochter (2), Anders (3)

Voor het gemak spreken we in de vragenlijst over zoon/dochter.

2. Wat is de kalenderleeftijd van uw zoon/dochter?

○ Jonger dan 2 (1)

○ 2-5 jaar (2)

○ 6-12 jaar (3)

○ 13-16 jaar (4)

○ Ouder dan 16 jaar (5)

3. Wat is de ontwikkelingsleeftijd van uw zoon/dochter?

○ 0 tot 2 jaar (1)

○ 2 tot 5 jaar (2)

○ 5 tot 7 jaar (3)

○ 7 tot 12 jaar (4)

4. Hoelang is uw zoon/dochter bij Cosis in zorg?

○ 0-2 jaar (1)

○ 3-5 jaar (2)

○ 6-10 jaar (3)

○ Langer dan 10 jaar (4)

5. Hoeveel verschillende behandelaren zijn er bij de zorgverlening van uw zoon/dochter betrokken? Onder behandelaren vallen: arts, fysiotherapeut, logopedist, spel- en muziektherapeut, etc.

○ 0 (1)

○ 1 (2)

○ 2 (3)

○ 3 (4)

○ 4 (5)

○ 5 (6)

○ Meer dan 5 (7)

Hieronder volgen enkele vragen over uzelf:

6. Wat is uw eigen leeftijd?

○ Jonger dan 18 (1)

○ 18-25 (2)

○ 26-35 (3)

○ 36-45 (4)

○ 46-55 (5)

○ Ouder dan 55 (6)

7. Wat is uw relatie tot uw zoon/dochter?

○ Vader (1)

○ Moeder (2)

○ Wettelijk vertegenwoordiger (3)

○ Anders (4)

8. Wat is uw hoogst afgeronde opleiding?

○ Basisonderwijs (1)

○ Lager beroepsonderwijs (LBO, VMBO) (2)

○ Middelbaar algemeen voorbereidend onderwijs (MAVO) (3)

○ Middelbaar beroepsonderwijs (MBO) (4)

○ Hoger algemeen voorbereidend, wetenschappelijk onderwijs (HAVO, VWO) (5)

○ Hoger beroepsonderwijs (HBO), of wetenschappelijk onderwijs (WO) (6)

○ Anders (7)

9. Wat is uw gezinssamenstelling?

○ Alleenstaande ouder (4)

○ Twee-ouder gezin (5)

10. Hoeveel kinderen heeft u?

○ 1 (1)

○ 2 (2)

○ 3 (3)

○ Meer dan 3 (4)

11. Hoeveel uur werkt u gemiddeld per week?

○ 0-8 (1)

○ 9-16 (2)

○ 17-24 (3)

○ 25-32 (4)

○ 33-40 (5)

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De volgende vragen gaan over het aantal contactmomenten dat u heeft met de medewerkers van Cosis. Neem hierbij het antwoord wat het vaakst voorkomt.

12. Hoe vaak per jaar bent u aanwezig bij een zorgplan bespreking?

○ 0 (1)

○ 1 (2)

○ 2 (3)

○ meer dan 2 (4)

13. Bent u aanwezig bij een multidisciplinair overleg (MDO)?

○ Ja (1)

○ Nee (2)

---

14. Hoeveel dagen in de week brengt of haalt u gemiddeld uw zoon/dochter naar of van het expertise centrum?

○ 0 (1)

○ 1 (2)

○ 2 (3)

○ 3 (4)

○ 4 (5)

○ 5 (6)

---

15. Hoe vaak heeft u gemiddeld telefonisch of mail contact met de persoonlijk begeleider van uw zoon/dochter?

○ Elke dag (1)

○ 2 á 3 keer per week (2)

○ 1 keer per week (3)

○ 1 keer per twee weken (4)

○ 1 keer per maand (5)

○ Minder dan 1 keer per maand (6)

○ Deze spreek ik nooit telefonisch of per mail (7)

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16. Hoe vaak wordt er door begeleiders een bericht op klasbord geplaatst? (digitale communicatieve omgeving)

- ○ Elke dag (1)
- ○ 2 á 3 keer per week (2)
- ○ 1 keer per week (3)
- ○ 1 keer per twee weken (4)
- ○ 1 keer per maand (5)
- ○ Minder dan 1 keer per maand (6)
- ○ Hier wordt geen gebruik van gemaakt (7)

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Voor het volgende onderdeel wordt uw mening of ervaring over de huidige situatie gevraagd. Hierbij kunt u het bolletje dat voor u het meest van toepassing is aanvinken. Daarna zal gevraagd worden of u een cijfer wilt geven met betrekking tot de voorgaande aandachtspunten en zullen twee open vragen gesteld worden. Deze open vragen geven inzicht in wat u goed vindt gaan en wat er volgens u beter zou kunnen binnen het EC. De onderstaande aandachtspunten gaan over de mate waarin u in de zorg wordt betrokken en in welke mate er wordt samengewerkt.

17. In welke mate bent u tevreden over de manier waarop ...

	Zeer ontevreden (1)	Enigszins ontevreden (2)	Neutraal (3)	Enigszins tevreden (4)	Zeer tevreden (5)	Niet van toepassing (6)
… u uitleg krijgt over de keuzes die de zorgverleners maken? (1)	○	○	○	○	○	○
… het EC de keus aan u laat op welk moment u welke informatie wilt ontvangen? (2)	○	○	○	○	○	○
… het EC u van de mogelijkheid voorziet om keuzes te maken in de behandeling? (3)	○	○	○	○	○	○

18. Hoe belangrijk zijn bovenstaande aandachtspunten voor u? (Waarbij 1 helemaal niet belangrijk is en 10 extreem belangrijk)

0 (1) ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

19. Welke activiteiten dragen er op dit moment aan bij dat u WEL tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

20. Welke activiteiten dragen er op dit moment aan bij dat u NIET tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

21. Wat heeft u nodig of welke activiteiten zouden eraan bijdragen om uw mate van tevredenheid op bovenstaande aandachtspunten te verbeteren?

____

Page Break

De onderstaande vragen zullen op dezelfde manier gesteld worden als de vorige vraag, maar dan over een ander onderwerp: verstrekken van algemene informatie.

22. In welke mate bent u tevreden over de manier waarop ...

	Zeer ontevreden (1)	Enigszins ontevreden (2)	Neutraal (3)	Enigszins tevreden (4)	Zeer tevreden (5)	Niet van toepassing (6)
... het EC algemene informatie voor u beschikbaar heeft in verschillende vormen, zoals een boekje, filmpje, etc.? (1)	○	○	○	○	○	○
... het EC u informatie over verschillende services geeft, zowel binnen als buiten de organisatie om? (2)	○	○	○	○	○	○
... het EC informatie voor u beschikbaar heeft over de diagnose van uw kind (bijv. over de oorzaak, de voortgang, de toekomst)? (3)	○	○	○	○	○	○
... het EC u van advies voorziet hoe u aan algemeen bruikbare informatie kunt komen? (4)	○	○	○	○	○	○
... het EC u van informatie voorziet over hoe u in contact kunt komen met andere ouders? (6)	○	○	○	○	○	○
... het EC het hele gezin van mogelijkheden voorziet om informatie te verkrijgen? (5)	○	○	○	○	○	○

23. Hoe belangrijk zijn bovenstaande aandachtspunten voor u? (Hierbij is 1 helemaal niet belangrijk en 10 is extreem belangrijk)

0 (1) ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

24. Welke activiteiten dragen er op dit moment aan bij dat u WEL tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

25. Welke activiteiten dragen er op dit moment aan bij dat u NIET tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

26. Wat heeft u nodig of welke activiteiten zouden eraan bijdragen om uw mate van tevredenheid op bovenstaande aandachtspunten te verbeteren?

____

Page Break

De onderstaande vragen zullen hetzelfde gesteld worden als de vorige vraag, maar dan over een ander onderwerp: voorzien van specifieke informatie over uw kind.

27. In welke mate bent u tevreden over de manier waarop ...

	Zeer ontevreden (1)	Enigszins ontevreden (2)	Neutraal (3)	Enigszins tevreden (4)	Zeer tevreden (5)	Niet van toepassing (6)
... zorgverleners u over de uitkomsten van een onderzoek informeren? (1)	○	○	○	○	○	○
... zorgverleners u van schriftelijke informatie voorzien over wat uw kind doet tijdens therapieën? (2)	○	○	○	○	○	○
... zorgverleners u van schriftelijke informatie voorzien over de voortgang van uw kind? (3)	○	○	○	○	○	○

28. Hoe belangrijk zijn bovenstaande aandachtspunten voor u? (Hierbij is 1 helemaal niet belangrijk en 10 is extreem belangrijk)

0 (1) ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

29. Welke activiteiten dragen er op dit moment aan bij dat u WEL tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

30. Welke activiteiten dragen er op dit moment aan bij dat u NIET tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

31. Wat heeft u nodig of welke activiteiten zouden eraan bijdragen om uw mate van tevredenheid op bovenstaande aandachtspunten te verbeteren?

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De onderstaande vragen zullen hetzelfde gesteld worden als de vorige vraag, maar dan over een ander onderwerp: gecoördineerde en uitgebreide zorg voor kind en gezin.

32. In welke mate bent u tevreden over de manier waarop ...

	Zeer ontevreden (1)	Enigszins ontevreden (2)	Neutraal (3)	Enigszins tevreden (4)	Zeer tevreden (5)	Niet van toepassing (6)
... het EC rekening houdt met de verschillende behoeften van uw kind (bijv. mentaal, emotioneel en sociale behoeften)? (1)	○	○	○	○	○	○
… het EC ernaar streeft dat minstens één medewerker over een langere periode uw aanspreekpunt is (bijv. persoonlijk begeleider)? (2)	○	○	○	○	○	○
… het EC gezamenlijke plannen maakt, zodat alle neuzen één kant op staan? (3)	○	○	○	○	○	○
… het EC u specifiek informatie geeft over uw kind wat per kind kan verschillen? (4)	○	○	○	○	○	○

33. Hoe belangrijk zijn bovenstaande aandachtspunten voor u? (Hierbij is 1 helemaal niet belangrijk en 10 is extreem belangrijk)

0 (1) ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

34. Welke activiteiten dragen er op dit moment aan bij dat u WEL tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

35. Welke activiteiten dragen er op dit moment aan bij dat u NIET tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

36. Wat heeft u nodig of welke activiteiten zouden eraan bijdragen om uw mate van tevredenheid op bovenstaande aandachtspunten te verbeteren?

____

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De onderstaande vragen zullen hetzelfde gesteld worden als de vorige vraag, maar dan over een ander onderwerp: respectvolle en ondersteunende zorg.

37. In welke mate bent u tevreden over de manier waarop ...

	Zeer ontevreden (1)	Enigszins ontevreden (2)	Neutraal (3)	Enigszins tevreden (4)	Zeer tevreden (5)	Niet van toepassing (6)
… het EC voor u als een vertrouwde omgeving voelt en niet alleen een plek om informatie te verkrijgen? (1)	○	○	○	○	○	○
… het EC u als individu behandelt in plaats van een van de vele ouders met een kind met een beperking? (2)	○	○	○	○	○	○
… u een gelijkwaardige relatie heeft met de zorgverlener en wordt u niet als de ouder van … benadert? (3)	○	○	○	○	○	○
… het EC u helpt om u als ouder competent te voelen? (4)	○	○	○	○	○	○
… het EC genoeg tijd vrij maakt om met u te praten zodat u zich niet opgejaagd voelt? (5)	○	○	○	○	○	○

38. Hoe belangrijk zijn bovenstaande aandachtspunten voor u? (Hierbij is 1 helemaal niet belangrijk en 10 is extreem belangrijk)

0 (1) ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆ ☆

39. Welke activiteiten dragen er op dit moment aan bij dat u WEL tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

40. Welke activiteiten dragen er op dit moment aan bij dat u NIET tevreden bent over de uitvoering van bovenstaande aandachtspunten?

____

41. Wat heeft u nodig of welke activiteiten zouden eraan bijdragen om uw mate van tevredenheid op bovenstaande aandachtspunten te verbeteren?

____

42. Heeft u nog op- of aanmerkingen of wilt u nog iets kwijt over het onderwerp 'ouderparticipatie'?

____

Dit is het einde van de vragenlijst. Bedankt voor uw deelname.

Appendix 3, topic list interview

Topic	**Vragen**
	Huidige situatie
Algemeen	- Laten we eerst heel algemeen beginnen, wat is het eerste waar u aan denkt bij ouderparticipatie? - Bent u over het algemeen tevreden over hoe de zorgverlening rondom uw kind georganiseerd wordt? - Wat maakt dat u wel tevreden bent? - Wat maakt dat u niet tevreden bent? - Wat zou voor u hierin helpen om dit te verbeteren?
Betrekken en samenwerken	- Voelt u zich op dit moment betrokken bij de zorgverlening van uw kind? (worden keuzes uitgelegd/kunt u zelf keuzes maken?) - Wat maakt dat u zich wel betrokken voelt? - Wat maakt dat u zich niet betrokken voelt? - Waar ligt voor u op dit moment een verbetering? - Voelt u zich op dit moment gehoord bij de zorgverlening van uw kind? (Heeft u het gevoel dat er naar u geluisterd wordt?) - Wat maakt dat u zich wel gehoord voelt? - Wat maakt dat u zich niet gehoord voelt? - Waar ligt voor u op dit moment een verbetering? - Voelt de omgang met de medewerkers gelijkwaardig? - Wat maakt dat u dit wel als gelijkwaardig ervaart? - Wat maakt dat u dit niet als gelijkwaardig ervaart? - Wat zou er voor u aan bijdragen om dit te verbeteren?
Verstrekken van algemene informatie	- Wordt u goed op de hoogte gehouden over algemene zaken rondom de zorgverlening van uw kind? (zoals andere service verleningen/ ziektebeelden/contact andere ouders buiten het EC om/verwachtingen algemeen) - Wat maakt dat u zich wel op de hoogte gehouden voelt? - Wat maakt dat u zich niet op de hoogte gehouden voelt? - Waar ligt voor u op dit moment een verbetering?
Verstrekken van specifieke informatie over uw kind	- Wordt u goed op de hoogte gehouden over de zorgverlening van uw kind? (uitkomsten onderzoek/ informatie over therapie/voortgang) - Wat maakt dat u zich wel op de hoogte gehouden voelt? - Wat maakt dat u zich niet op de hoogte gehouden voelt? - Waar ligt voor u op dit moment een verbetering?
Gecoördineerde en uitgebreide zorg voor kind en gezin	- Wordt u “goed” op weg geholpen zodat u thuis aan dezelfde doelen kan werken? - Wat maakt dat u hierover wel tevreden bent? - Wat maakt dat u hierover niet tevreden bent? - Waar ligt voor u op dit moment een verbetering?

	- Houdt het EC genoeg rekening met uw persoonlijke situatie? - Wat maakt dat u hierover wel tevreden bent? - Wat maakt dat u hierover niet tevreden bent? - Wat zou eraan bijdragen om dit te verbeteren?
Respectvolle en ondersteunende zorg	- Voelt u zich op u gemak/thuis/vertrouwd als u op het EC bent? - Wat maakt dat u zich wel op uw gemak voelt? - Wat maakt dat u zich niet op uw gemakt voelt? - Wat zou eraan bijdragen om dit te verbeteren? - Heeft u het gevoel dat de medewerkers op het EC u persoonlijk kennen en hier rekening mee houden? - Wat maakt dat u hierover wel tevreden bent? - Wat maakt dat u hierover niet tevreden bent? - Wat zou eraan bijdragen om dit te verbeteren?
Uitkomsten vragenlijst	Uit de vragenlijst komt naar voren dat het onderwerp ‘verstrekken van algemene informatie’ het laagste scoort. - Hoe zou dit kunnen? - Wat kan ervoor zorgen dat er hoger wordt gescoord voor dit onderwerp? - Wat ziet u graag verbeteren op dit gebied? Ook komt naar voren dat ouders moeilijkheden ervaren bij het aanvragen van bepaalde financiële zaken. - Wat zou u kunnen helpen om dit makkelijker te maken?
Afsluiting interview	- Terug komen op de inleidende vraag - Samenvatten - Concluderende zin, wel/niet tevreden, grootste en belangrijkste verbeterpunten die genoemd zijn nog even samenvattend laten terug komen.

Appendix 4, informed consent interviews (Dutch version)

INFORMED CONSENT FORMULIER

Naam van het onderzoeksproject
"Ouderparticipatie in de sociale gezondheidszorg voor kinderen van 0-18 jaar"

Doel van het onderzoek
Dit onderzoek wordt geleid door Janiek Hanken. U bent van harte uitgenodigd om deel te nemen aan dit onderzoek. Het doel van dit onderzoek is om inzicht te krijgen in uw ervaringen op het gebied van uw betrokkenheid bij de zorgverlening van uw zoon/dochter. Hierbij wordt gekeken wat er op dit moment als positief wordt ervaren en waar de verbeterpunten liggen.

Gang van zaken tijdens het onderzoek
U neemt deel aan een focus groep interview waarin aan u vragen zullen worden gesteld over uw huidige ervaringen op het gebied van ouderparticipatie. Een voorbeeld van een typische vraag die u zal worden gesteld: "Wat maakt dat u zich op dit moment gehoord voelt door zorgverleners?".

U dient tenminste 16 jaar te zijn om deel te nemen aan dit onderzoek. Daarnaast is het van belang dat u de wettelijke vertegenwoordiger van het kind bent.

Tijdens het interview zal, aan de hand van een topic list, dieper worden ingegaan op uw huidige ervaringen en wat u als meerwaarde ervaart voor de toekomst. Van het interview zal een audio-opname worden gemaakt, zodat het gesprek later ad-verbum (woord voor woord) kan worden uitgewerkt. Dit transcript wordt vervolgens gebruikt in het verdere onderzoek.

Potentiële risico's en ongemakken
Er is enig ongemak verbonden aan uw deelname aan deze studie, vanwege de gevoelige aard van het onderwerp. U hoeft geen vragen te beantwoorden die u niet wilt beantwoorden. Uw deelname is vrijwillig en u kunt uw deelname op elk gewenst moment stoppen.

Vergoeding
U ontvangt voor deelname aan dit onderzoek geen vergoeding. Door deel te nemen aan dit onderzoek zult u meer inzicht krijgen in de huidige situatie met betrekking tot ouderparticipatie en wat hier eventueel voor nodig is om dit te verbeteren. Het bredere doel van dit onderzoek is: om de zorgverlening op het expertise centrum continue te verbeteren.

Vertrouwelijkheid van gegevens
Uw privacy is en blijft maximaal beschermd. Er wordt op geen enkele wijze vertrouwelijke informatie of persoonsgegevens van of over u naar buiten gebracht, waardoor iemand u zal kunnen herkennen.

Voordat onze onderzoeksgegevens naar buiten gebracht worden, worden uw gegevens anoniem gemaakt: geanonimiseerd. Enkele eenvoudige voorbeelden hiervan:
- uw naam wordt vervangen door anonieme, op zichzelf betekenisloze combinatie van getallen.

Bij de start van ons onderzoek krijgt uw naam direct een pseudoniem; uw naam wordt gepseudonimiseerd ofwel 'versleuteld'. Op deze manier kan wel worden onderzocht wat u in het gesprek aangeeft, maar weten de getrainde onderzoekers niet dat u het bent. De onderzoeksleider is zelf verantwoordelijk voor dit pseudoniem en de sleutel en zal uw gegevens niet delen met anderen.

In een publicatie of presentatie zullen of anonieme gegevens of pseudoniemen worden gebruikt. De audio-opnamen, formulieren en andere documenten die in het kader van deze studie worden gemaakt of verzameld, worden opgeslagen op een beveiligde locatie bij de Universiteit Twente en op een beveiligde (versleutelde) USB-stick van de onderzoekers.

Vrijwilligheid
Deelname aan dit onderzoek is geheel vrijwillig. U kunt als deelnemer uw medewerking aan het onderzoek te allen tijde stoppen, of weigeren dat uw gegevens voor het onderzoek mogen worden gebruikt, zonder opgaaf van redenen.

Dit betekent dat als je voorafgaand aan het onderzoek besluit om af te zien van deelname aan dit onderzoek, dat dit op geen enkele wijze gevolgen voor u zal hebben.

Als je tijdens het onderzoek besluit om jouw medewerking te staken, zal dat eveneens op geen enkele wijze gevolgen voor je hebben. Echter: de gegevens die u hebt verstrekt tot aan het moment waarop uw deelname stopt, zal in het onderzoek gebruikt worden, inclusief de bescherming van uw privacy zoals hierboven beschreven. Er worden uiteraard geen nieuwe gegevens verzameld of gebruikt.

Als u besluit om te stoppen met deelname aan het onderzoek, of als u vragen of klachten heeft, of uw bezorgdheid kenbaar wilt maken, of een vorm van schade of ongemak vanwege het onderzoek, neemt u dan aub contact op met de onderzoeksleider: Janiek Hanken, email-adres: j.hanken@cosis.nu .

Toestemmings-verklaring
Met uw ondertekening van dit document geeft u aan dat u minstens 16 jaar oud bent; dat u de wettelijk vertegenwoordiger van het kind bent; dat u goed bent geïnformeerd over het onderzoek, de manier waarop de onderzoeksgegevens worden verzameld, gebruikt en behandeld en welke eventuele risico's u zou kunnen lopen door te participeren in dit onderzoek

Indien u vragen had, geeft u bij ondertekening aan dat u deze vragen heeft kunnen stellen en dat deze vragen helder en duidelijk zijn beantwoord. U geeft aan dat u vrijwillig akkoord gaat met uw deelname aan dit onderzoek. U ontvangt een kopie van dit ondertekende toestemmingsformulier.

Ik ga akkoord met deelname aan een onderzoeksproject geleid door Janiek Hanken. Het doel van dit document is om de voorwaarden van mijn deelname aan het project vast te leggen.

1. Ik kreeg voldoende informatie over dit onderzoeksproject. Het doel van mijn deelname als een geïnterviewde in dit project is voor mij helder uitgelegd en ik weet wat dit voor mij betekent.

2. Mijn deelname als geïnterviewde in dit project is vrijwillig. Er is geen expliciete of impliciete dwang voor mij om aan dit onderzoek deel te nemen.

3. Mijn deelname houdt in dat ik word geïnterviewd door een onderzoeker van de Universiteit Twente. Het interview zal ongeveer 60 minuten duren. Ik geef de onderzoeker toestemming om tijdens het interview geluidsopnames te maken en schriftelijke notities te nemen. Het is mij duidelijk dat, als ik toch bezwaar heb met een of meer punten zoals hierboven benoemd, ik op elk moment mijn deelname, zonder opgaaf van reden, kan stoppen.

4. Ik heb het recht om vragen niet te beantwoorden. Als ik me tijdens het interview ongemakkelijk voel, heb ik het recht om mijn deelname aan het interview te stoppen.

5. Ik heb van de onderzoeksleider de uitdrukkelijke garantie gekregen dat de onderzoeksleider er zorg voor draagt dat ik niet ben te identificeren in door het onderzoek naar buiten gebrachte gegevens, rapporten of artikelen. Mijn privacy is gewaarborgd als deelnemer aan dit onderzoek.

6. Ik heb de garantie gekregen dat dit onderzoeksproject is beoordeeld en goedgekeurd door de ethische commissie van de BMS Ethics Committee. Voor bezwaren met betrekking tot de opzet en of uitvoering van het onderzoek kan ik me wenden tot de Secretaris van de Ethische Commissie van de faculteit Behavioural, Management and Social Sciences op de Universiteit Twente via ethicscommittee-bms@utwente.nl .

7. Ik heb dit formulier gelezen en begrepen. Al mijn vragen zijn naar mijn tevredenheid beantwoord en ik ben vrijwillig akkoord met deelname aan dit onderzoek.

8. Ik heb een kopie ontvangen van dit toestemmingsformulier dat ook ondertekend is door de interviewer.

Naam deelnemer	Handtekening	Datum
1.		
2.		
3.		
4.		
5.		
6.		
7.		

Naam onderzoeker	Handtekening	Datum