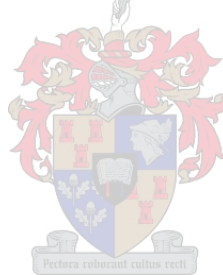


# Occupational balance of mothers and fathers raising a child with special needs in Flanders

By

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“Thesis presented in partial fulfilment of the requirements for the degree of Master of  
Occupational Therapy in the Faculty of Medicine and Health Sciences at Stellenbosch  
University”

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# Declaration

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# Abstract

After the birth of a first child, a new role appears. Successful integration and performance of this parent role will positively affect the well-being of both parents, which in turn will enhance child and family well-being. Being a parent of a child with special needs, leads to extra parental occupations. A new distribution of all these different occupations within the occupational pattern urges and can be viewed from three different perspectives, namely: occupational areas, occupational characteristics and time use.

The aim of the study was to explore occupational balance as experienced by mothers and fathers rearing a child with special needs in Flanders. Objectives related to this study were to explore the influence of occupations on the occupational balance of mothers and fathers and to explore the differences and similarities between ‘mothers’ and ‘fathers’ perceptions of occupational balance.

A qualitative research methodology with semi-structured interviews of 12 parental couples was used. Participants were selected by purposive sampling through chain referral. Once both parents agreed to participate voluntarily a semi-structured interview was conducted, audio-taped and transcribed verbatim.

Results, obtained through thematic analysis, showed that extra time for special needs was primarily found in the change of the occupational pattern. So called we- and me-time occupations were reduced. We time was lacking most, as both parents prioritized facilitating the me-time of their spouse above the joyful moments together as a couple. As so called necessary support was already provided by the grandparents, asking extra assistance to obtain time as a couple felt uncomfortable and therefore was often ignored.

Although gender related differences were limited, generally mothers were less active at the labour market but conducted more household, care and support activities when compared with fathers. Gender dissimilarities were available in special needs caring and supporting activities. Direct care and support were mainly provided by mothers while fathers were more active in indirect care. To give an example the father takes care of the siblings (indirect care) while the mother is attending the child’s therapy (direct care).

Besides the three above mentioned perspectives to view the occupational pattern and to determine the occupational balance, two perspectives were added.

Specific characteristics of an individual parent, labelled as personal factors had an effect on the occupational pattern, on the perception of the desired and needed occupations, on the coping strategies and therefore on the perceived occupational balance of each parent.

External factors of support were components of support to be transmitted from one individual to another. On the one hand giving support and on the other hand receiving support had an influence on the occupational pattern and balance. Some occupations had to be included while other occupations could be skipped as they were conducted by someone else.

To conclude two perspectives namely, personal factors and external factors of support were added to the concept as initially used in this study. All five perspectives are intertwined and used to view the occupational pattern towards the subjectively perceived occupational balance which is a layered and dynamic concept. Focusing on the occupational balance of both parents provides new and valuable information in order to improve parents' occupational balance.

# Opsomming

Na die geboorte van 'n eerste kind verskyn daar 'n nuwe rol. Suksesvolle integrasie en uitvoering van hierdie ouerrol sal die welwees van albei ouers positief beïnvloed wat op sy beurt kinder- en gesin welwees sal bevorder. Om 'n ouer van 'n kind met spesiale behoeftes te wees, lei tot ekstra ouer Aktiwiteite. 'n Nuwe verdeling van al hierdie verskillende Aktiwiteite binne die Aktiwiteitspatroon vereis en kan beskou word vanuit drie verskillende perspektiewe naamlik: Aktiwiteitsareas, Aktiwiteitskenmerke en tydbesteding.

Die doel van hierdie studie was om Aktiwiteitsbalans te verken soos dit ervaar word deur moeders en vaders wat 'n kind met spesiale behoeftes grootmaak in Vlandere. Doelwitte met betrekking tot hierdie studie was om die invloed van Aktiwiteite op die Aktiwiteitsbalans van moeders en vaders te ondersoek en om die verskille en ooreenkomste tussen die moeders en die vaders se persepsies van Aktiwiteitsbalans te ondersoek.

'n Kwalitatiewe navorsingsmetodologie met semi-gestruktureerde onderhoude van twaalf ouerpare is gebruik. Deelnemers is gekies deur doelgerigte steekproeftrekking deur middel van kettingverwysing. Nadat albei ouers ingestem het om vrywillig deel te neem, is 'n semi-gestruktureerde onderhoud gevoer, wat opgeneem is en verbatim getranskribeer is.

Resultate, verkry deur tematiese analise, het getoon dat ekstra tyd vir spesiale behoeftes hoofsaaklik in die verandering van die Aktiwiteitspatroon gevind is. Sogenoemde ons- en my-tyd Aktiwiteite is verminder. Ons-tyd het die meeste ontbreek, aangesien albei ouers geprioritiseer het om die my-tyd van hul gade bo die vreugdevolle oomblikke saam te stel. Omrede die nodige ondersteuning alreeds deur die grootouers voorsien is, het dit ongemaklik gevoel om hulle te versoek vir ekstra hulp om ekstra tyd as egpaar te kon kry en gevolglik is dit geïgnoreer.

Alhoewel geslagsverwante verskille beperk was, was die meeste ma's minder aktief in die arbeidsmark, maar het hulle meer huishoudelike-, sorg- en ondersteuningsaktiwiteite uitgevoer in vergelyke met die vaders. Geslagsverskille was in spesiale sorg en ondersteunende aktiwiteite. Direkte sorg en ondersteuning is hoofsaaklik deur moeders verskaf, terwyl vaders meer aktief was in indirekte sorg en ondersteuning byvoorbeeld, vaders sal omsien na sibbe (indirek sorg) terwyl moeders terapie van kind bywoon (direkte sorg).

Benewens die drie bogenoemde perspektiewe om die Aktiwiteitspatroon te beskou en die Aktiwiteitsbalans te bepaal, is twee perspektiewe bygevoeg. Spesifieke eienskappe van 'n

individuele ouer, wat as persoonlike faktore aangedui word, het 'n uitwerking op die Aktiwiteitspatroon; op die persepsie van die verlangde en nodige Aktiwiteite; op die hanteringstrategieë en dus op die waargenome Aktiwiteitsbalans van elke ouer.

Eksterne faktore van ondersteuning was komponente van ondersteuning wat van een individu na 'n ander oorgedra word. Aan die een kant om ondersteuning te gee en aan die ander kant om ondersteuning te ontvang, het albei 'n invloed op die Aktiwiteitspatroon en balans gehad. Sommige Aktiwiteite moes ingesluit word terwyl ander Aktiwiteite oorgeslaan kon word omdat dit deur iemand anders uitgevoer kan word.

Ten slotte, twee perspektiewe naamlik, persoonlike faktore en eksterne ondersteuningsfaktore is bygevoeg tot die konsep wat aanvanklik in hierdie studie gebruik is. Al vyf perspektiewe is verweef en gebruik om die Aktiwiteitspatroon te beskou na die subjektiewe ervaring van Aktiwiteitsbalans wat 'n komplekse en dinamiese konsep is. Deur te fokus op die Aktiwiteitsbalans van albei ouers bied dit nuwe en waardevolle inligting om die ouers se Aktiwiteitsbalans te verbeter.

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# Clarification of terminology

Terminology as defined in this study:

- Occupations: *“refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do.”* (1).
- Occupational balance: *“The individual’s subjective experience of having the right amount of occupations and the right variation between occupations in his/her occupational pattern.”* [ (2)p.326].
- Occupational pattern: *“a regular way of acting or doing something”* [(3)p.3] which can be viewed from different aspects (2) such as for example work, leisure, rest, sleep, obligation, free choice, level of challenge, ...
- Roles: *“a pattern of behaviour that involves certain rights and duties that an individual is expected, trained and often encouraged to perform in a particular social situation”* [(4)p.105]
- Children with special needs: are diagnosed (diagnosis described within the DSM V (5)) or experience limitations within their functionality (6).

As occupation is the core business of occupational therapy, occupational therapists look at people’s ability to engage in their needed and desired occupations (7). These occupations are derived from a person’s roles and lead to an occupational pattern during daily life performances. Equally important for occupational therapists is the fact that an experienced harmonious combination of different occupations in everyday life has a positive influence on the person’s perceived well-being (8).



# Chapter 1: Introduction

## 1.1 Background and rationale

After the (first) child's birth new occupations, skills and competencies related to the parental role, such as infant care activities, have to be learned. A strong feeling of parental competence leads to a better development for the children while parental stress is associated with adverse outcomes (9, 10). All different kinds of difficulties faced by parents will influence their caregiving. In his attachment theory, Bowlby (11) stressed that being a sensitive and responsive caregiver is extremely important for the well-being of the child. Other psychologists such as Klein (12), support this idea. Klein established MISC which is on the one hand an abbreviation for 'Mediational Intervention of Sensitizing Caregivers', to focus on the reciprocal interaction between the caregiver and the child and on the other hand for 'More Intelligent and Sensitive Child'. The better the parents understand the signals and needs of the child, the better the child's development will be supported. Parenthood is critical for the child's development and well-being (13). As a consequence, becoming a parent requires new occupations, skills and competencies. Therefore time needs to be divided differently as the new role as parent appears in addition to the other existing roles, as for instance an employee, a wife or husband, etc. Luckily one can learn from role models such as one's own parents and from friends and neighbours (14) who are already combining parenting with their other tasks.

On becoming a parent of a child with special needs, there are extra demands on the parents in order to support their child in meeting his/her needs. Extra occupations such as therapy visits have to be added and extra skills and competencies have to be learned, often without a role model in the near environment, as one's own parents would not necessarily have experienced a similar situation (14). This difficult and uncertain new role can lead to parental anxiety, stress and depression (15). A comparison of everyday infant care activities of Canadian parents of children with and without special needs shows that a higher level of everyday infant care activities is experienced by the parental group of children with special needs (16). The extra time needed for daily childcare and extra tasks related to the child's well-being are taken from the parents' work-related and leisure activities and from time spent with other family members (16). This alteration of the number and variety of parent's activities increases the risk of occupational imbalance. Well-being of the family may suffer due to the parent's choice in order to have extra time for the child's special needs (16). Furthermore, this decision may create

parental stress (16). If mothers and fathers understand their child's specific characteristics and if they have the necessary skills to raise their child, parental stress will be less (15). This set of knowledge and skills seems to be important as especially children's behavioural problems are associated with higher parental and psychosocial discomfort. If these behavioural difficulties are combined with financial problems and a lack of social support, the impact on parental stress is even bigger. Like all parents, those of a child with special needs question how they can harmonize the needs of each family member (17). Hence, equipping mothers and fathers with knowledge and skills to be able to address each family member's needs in order to ameliorate family well-being and harmony seems to be important. In addition, a healthy emotional relationship between the parent and child can be affected if stress arises from providing for the special needs even though this is fundamental to the child's development, well-being and future life (18). Likewise De Belie and Van Hove (14) defined the experienced imbalance between effort and result as 'parenting under pressure' (14). Another important consideration is that satisfaction in life and a personal feeling of health is influenced by the experience of occupational balance (19).

In Belgium families of children with special needs face similar difficulties. "De Gezinsbond" is an institution that advocates for all families in Flanders and Brussels by lobbying at policy level on family related issues such as creating opportunities to balance work and family life, child care for young children and education (20). In 2015 they published an online dossier on experiences of families who care for a member with additional support needs. The report demonstrates a tendency for parents of children with special needs to undergo a positive or negative transformation in their marital relationship due to the extra challenges, such as financial and psychosocial discomfort, related to their child's special needs. Sometimes a stronger marital bond will be experienced but the challenges can also lead to misunderstanding and divorce. Differences in the rhythm of acceptance, feelings of guilt, sense of emotional burden and fear of the future are examples of causes of these misunderstandings (20). Therefore, a focus on parental well-being has to be part of child related intervention for the sake of the whole family and especially for the children with special needs and their siblings. A report from UNICEF Belgium, published in 2007, on how youngsters with a disability experience their rights, stated that parents are indispensable advocates in these teenagers' lives (21). Consequently, this means that mothers and fathers have to be strong in their parental role in order to facilitate their children's perceived human rights. A demanding responsibility for a lot of parents, as for the group of family related caregivers, those who take care of their own child

or spouse, have more health problems and experience a higher subjective burden as those who take care of their own parent or sibling (22).

De-institutionalisation of children's services is still a fairly recent policy within Europe and Belgium. Nevertheless a country report on Belgium written by the European parliament in 2013 (23) highlighted that of all Western countries, Belgium has the highest level of institutionalisation (23). This is a result of the fact that in Belgian society, institutionalisation of persons with special needs was seen as the best option for the person's development and well-being. A consequence of this mind-set is that institutionalisation is still the most common option due to a shortage of affordable housing for persons with a disability within the community and due to a lack of community-based-services (24). On the other hand, Budgets for Personalized Assistance (BPA) are available in order to allow persons with disabilities to make their own service related choices. Still it is necessary to note that the waiting list for BPA is long. Alternatively, a law on personal funding, that has been (which will) progressively (be) implemented from the year 2016 onward, allows persons with a disability the right to select services and providers tailored to their needs (25). Consequently parents who have a child with special needs have to organize the support necessary for their child themselves. On the one hand parents need to find extra time for their engagement in special needs-related activities and on the other hand align their supporting network with possible regular services. This means that parents themselves have to organize the fulfilment of extra demands even though a balanced life and experiencing the right amount and variation of occupations is indispensable for harmonious parenthood.

There are a number of occupations related to the child's special needs that their parents have to fulfil along with other needed and desired occupations and roles. An important part of occupational therapy is to enable a person to balance his/her roles and occupations in order to experience occupational balance. In this study occupational balance will be defined as: "*The individual's subjective experience of having the right amount of occupations and the right variation between occupations in his/her occupational pattern*" [(2)p. 326]. This is challenging for everybody but as Stein, Loran and Cermak's (26) research indicates, some people are more vulnerable than others, such as parents of children with special needs (26). On the one hand if occupational therapists enable clients and their family units to ameliorate their occupational skills and on the other hand support people to harmonize their occupational pattern in order to experience occupational balance, clear communication and reciprocity between a client, the client's family unit and the therapist are needed. Accordingly a therapist/health professional's

communication, client-centred focus and sense of reciprocity facilitate an understanding of the meaning given by the person/family to different occupations and of the way occupational balance is experienced. In addition, searching the literature on parenting a child with special needs showed that most of the studies were conducted with mothers only or often the published results did not distinguish between mothers and fathers (27, 28).

An additional reason to focus on the individual occupational balance of both parents relates to the fact that in Belgium women represent almost 50 % of the active members of the labour market. Mothers more easily choose to combine work with family responsibilities such as taking care of the children, while the first focus of most fathers is job related. Although most of the Belgian families are dual-income families, fathers are usually regarded as the breadwinner who provides material well-being for his family. Despite the fact that their first focus is being a provider, fathers also spend time on childcare, education and household activities but less so in comparison to their spouses (29).

### 1.1.1 Experiential context

As a practitioner in Flanders, the Dutch-speaking region of Belgium, the researcher's experience is that many issues concerning each particular child need attention. Examples are coordinating different therapies, extra stimulation of the child's development at home to fulfil the child's potential or explaining to other people such as grandparents, aunts, uncles, friends and often also teachers how to deal with the child's difficulties. In order to make this possible the therapist and parent(s) need to collaborate as allies striving for a better outcome.

Another practice observation is that mostly mothers accompany their child during therapies. As a strong feeling of parental competencies leads to ameliorated child development (9) and knowing that parents often borrow time from work related occupations and leisure to create extra time for the child's special needs (16) might affect both parents' experienced occupational balance. Knowing that since the 1970s, on the one hand more women are represented in the labour market (30) and considering on the other hand that less research is conducted on father's parenting (27, 28), leads to the following research question.

## 1.2 Research Question:

How do mothers and fathers of children with special needs perceive their occupational balance?

## 1.3 Significance of the study

Well-being and life satisfaction in parents lead to more responsive parenting which is, according to Bowlby's (11) attachment theory, important for a child's well-being (11). As there is a relationship between occupational balance, well-being and satisfaction in life (19, 31, 32) the more people are satisfied with their occupational pattern, the more they feel balanced (4). An understanding of both parents' occupations, of their individual occupational patterns and of the way each experiences their occupational balance, is needed in order to attain insight into occupations influencing the subjective feeling of occupational balance. Looking at differences and similarities between 'mothers' and 'fathers' occupational patterns and perceptions of balance are an added value of this study as previous research has focused mainly on mothers (27, 28). Furthermore, fathers who actively share parental responsibility and who are involved in intervention programs of their child experience better parental competencies, marital satisfaction, self-esteem and faith in the future. This results also in an improvement of the family's achievements (33).

Since 2016 the implementation of a new Flemish policy, related to children and persons with special needs is in transition. More attention towards an inclusive society with extra responsibilities and rights for persons with a disability and/or their parents has been provided by the Flemish government. Transparency and coordination between the different administrations are still missing and lead to difficulties in the accessibility of information for persons with a disability and/or their parents. This information is a prerequisite to make an inclusive life possible for a person with a disability within the community (24). Consequently this complicates the parents' search for the best available option for their child, which will also influence the variety of occupations of these parents.

Focusing on the occupational balance of both parents of a child with special needs may provide new and valuable information about occupational balance in parents. Thus recommendations can be made to occupational therapists working with children and families and to the occupational therapy body in Flanders/Belgium in order to improve parents' occupational balance which in turn may enhance the child's development and harmony within the family.

## 1.4 Aim of the study

The aim of the study was to explore occupational balance as experienced by mothers and fathers rearing a child with special needs in Flanders.

### 1.4.1 Objectives

The objectives of the study were:

- to explore the occupational patterns of mothers and fathers;
- to explore the influence of occupations on the occupational balance of mothers and fathers;
- to explore the differences and similarities between mothers' and fathers' perceptions of occupational balance.

As indicated in this chapter parenting a child with special needs is at moments demanding and time consuming. Time required for special needs related occupations have to be borrowed from time allocated to other occupations. To explore the occupational balance of fathers and mothers with special needs in Flanders, information on the Belgian context, on parenting and occupational balance will be provided in the following chapter.

# Chapter 2: Literature review

## 2.1 Introduction

Occupational balance is a well-known concept within occupational therapy as occupation is the core business of occupational therapists. When a role is added to someone's life, like for instance the role of a parent, new occupations will appear in the overall repertoire of performed occupations. As a consequence parents have to find a new balance as also extra time needs to be found for these new occupations. Furthermore it takes time for people to become skilled in their new roles. The changes will probably be bigger if the child needs extra support and might influence the occupational balance of those mothers and fathers. For this reason a literature search was undertaken using the following method.

## 2.2 Method of literature review

In order to find relevant literature, the databases EBSCO and Web of Science were mainly consulted using the following key words:

- occupational balance AND concept\*
- parent\* AND/OR parenting style
- parent\* AND competen\*
- occupation\* AND parent\* AND child with a disability
- life satisfaction AND parent\* AND child disability OR special needs

A snowball search technique, searching in the reference lists of high quality articles was used as well, in order to find interesting literature mostly based on systematic reviews, qualitative research, meta-analysis and surveys. Some older literature related to the Flemish situation, occupational balance and on parenting was selected due to its influence and value in the academic world.

Some policy documents were read to have a better understanding of the Belgian context.

Meanwhile articles for the literature study were selected and grouped. Finally, they led to the following themes: Belgian Context, Parenting styles, Parental roles, Balancing roles, Occupational balance and Impact on raising a child with special needs.

## 2.3 Belgian context

Flanders or the Flemish Region, where the study was conducted, is one of Belgium's three regions besides the Walloon Region and the Brussels - Capital Region. According to the population figures of 2017 by the Belgian ministry of Internal Affairs, Belgium counts 11,303,528 inhabitants of whom 6,509,894 live in Flanders, 3,610,089 in Wallonia and 1,183,545 in the Brussels – Capital Region, spread over a total surface of 30,582 km<sup>2</sup> (34).

As shown in figure 2.1, Belgium has different types of households. Married couples will not only consist of different sexes, as same - sex marriages are legal. It is important to state that unmarried couples can decide to live together without any official arrangement or can make a declaration of legal cohabitation. People with a different kind of relationship, for example brothers and sisters or friends can cohabitate as well (35).

The figures on households below date from 2015 and give the following information:

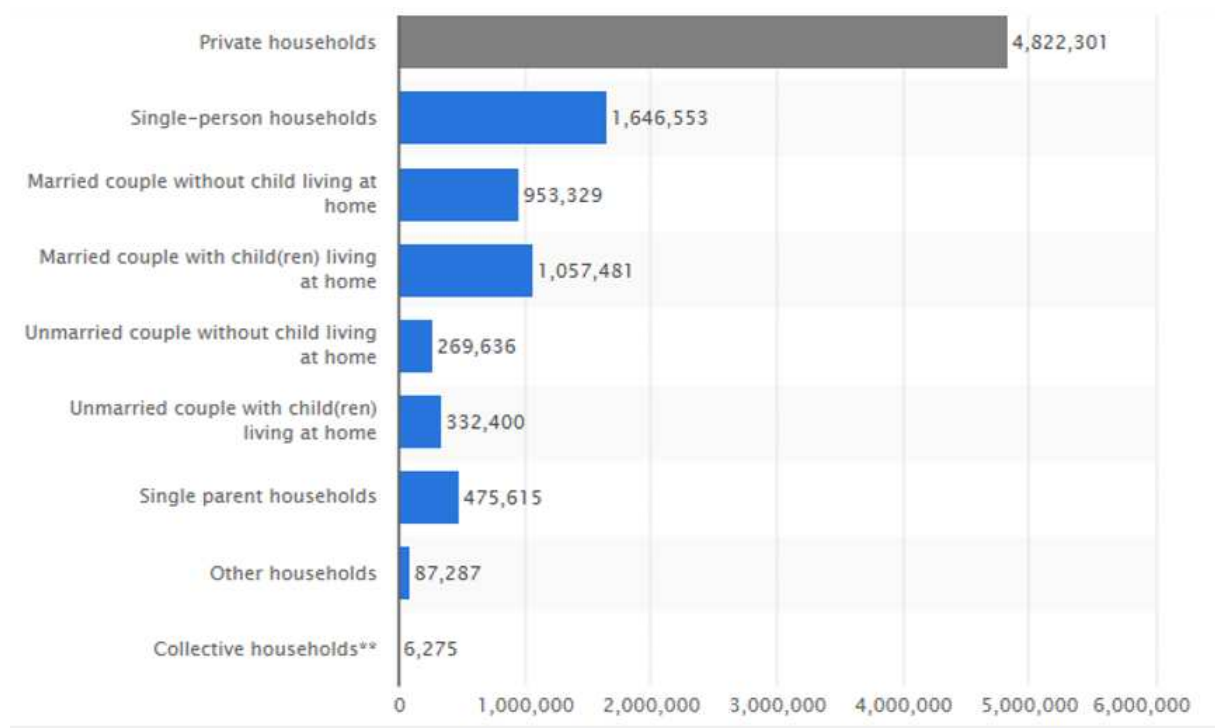


Figure 2.1: Belgian households (35)

The above mentioned figure does not provide information on post-divorced family structures. As divorce related agreements, such as when, where and how long the children stay with each parent are validated at the court, no exact statistical data on these new family compositions are available (36).



### 2.3.1. Men and women in the labour market

Since the 1970s overall female participation in the labour market has risen. Due to this increase, women made up almost half of Flanders work force in 2016 (30). However, according to the labour statistics, men still dominate the fulltime sector (8.1 % work part-time) while women dominate the part-time sector (46.2 % work part-time). Part-time employment differs in amount of working hours and is influenced by diverse reasons. The decision to work 4/5<sup>th</sup> (80% of fulltime employment), is meant to create some extra time for personal and/or family life regardless of gender. A 50 % of full-time job, seems an obligatory choice for most men. Despite the preference of fulltime employment, a 50 % part-time job is chosen as no similar fulltime work is available. In contrast, women most often voluntarily choose a part-time (50 %) job to improve flexibility in household and caring activities (29). Some employers give their employees the possibility or even request to do some overwork, which can be compensated in extra earnings or in extra leave. Subsequently, the combination of work and family life within (nuclear) dual income families will influence the time use of mothers and fathers in their daily life.

### 2.3.2 Time use of Belgian citizens

A comparison of time-use of Belgian citizens in the year's 1999, 2005 and 2013 was conducted by the Algemene Directie Statistiek – Statistics Belgium (AD) and the research group Tempus Omnia Revelat (TOR) of the Vrije Universiteit Brussel (VUB) (37). Participants reported their performed activities during a week and weekend day. Comparison of these three time-use surveys showed that time division on paid work, household, childcare and educational activities, education, personal care, sleeping and taking a rest, social participation, free time and travel time, remained almost constant for men and women over the years. Nevertheless small changes in time use on household, child care and educational activities are visible over the last 15 years. Women spend less time on household activities than before, while men keep the same amount of time available for these tasks. Both sexes spend more time on child care and educational activities but the gender differences within these activities subsist. Although men had less free-time in 2013, there was still a significant dissimilarity in leisure time between men and women (a difference of 6 hours and 17 minutes a week in favour of men). Social participation and engagement has declined for men and women. At the same time most of those who were active in society, often made more time available for social engagement than before (37). One can think of different reasons why people do not or cannot free up time for social

engagement or why engagement is high but participants need to be questioned to understand their reason.

### 2.3.3 Children with special needs in Belgium

In 2009 the Belgian government ratified the Convention on the Rights of Persons with Disabilities. Despite this ratification, the World Report on Disability showed that Belgium, with a slight difference between Flanders and Wallonia (the two biggest regions of Belgium) has the highest rate of segregated schooling in Europe (24). As children with special needs are not well integrated in the Belgian society, many people experience a discomfort and often do not know how to behave or react when encountering a person with a disability. This experienced discomfort differs depending on the type of disability. Respect and sympathy are more often shown towards persons with a physical disability compared to persons with an intellectual disability. Feelings of pity and concern are more often related towards an intellectual disability. Twenty percent of the Flemish citizens try to avoid contact with a person with an intellectual disability (20). Consequently, parents have to advocate for their children and show others how to behave and react towards their child. This opinion is confirmed by a report from UNICEF Belgium (2007) (21) on how youngsters with special needs experience their rights. Within this report it is stated that parents are indispensable when these teenagers talk about love, other peoples' interest in them as a person, support, self-esteem and the ability to become part of a social network(21).

As for Belgian politics, education is a regional responsibility, the Flemish government has taken some measures to facilitate the inclusion of children with special needs. Since September 2015, the "Measures for pupils with specific education needs - decree" (M-decree) (38) has been implemented by the Flemish government in order to decrease segregated schooling and increase inclusive education. Within the United Nations 2030 agenda for Sustainable Development (39), a commitment on the organisation of inclusive and equitable quality education at every educational level is made and every human being should have access to education during his/her whole life span (39). Muiznieks (24), the Commissioner for Human Rights for the Council of Europe, is positive about the M-decree, but he nevertheless expressed his concerns as full inclusion cannot be guaranteed through this decree. As long as many schools and many people within society see people and children with special needs from a medical point of view, it will be difficult for people with disabilities to be included and build a social network for themselves (40). In December 2014 a documentary broadcast by the Dutch-speaking channel Vlaamse Radio en Televisie (VRT) was shown. The journalists used a survey with 100 respondents. This

survey showed that 56 % of the Flemish teachers were convinced that inclusive education will facilitate an inclusive society. Nevertheless only 18 % of the interviewed teachers agreed that inclusive education is feasible. The other 82 % were convinced that much more information and support were needed to make qualitative inclusive education possible (41). This means that on the one hand parents have to prepare their children for a society with a lot of barriers (to integration/inclusion) and on the other hand they need to influence the community and the broader society to remove these obstacles. (42) A decrease in social participation of Belgian citizens in the last 15 years (37) will negatively influence the possibility to build a social network for children and families with special needs. Additional and challenging roles with related activities and occupations appear (42) especially because parents try to harmonize the needs of all their children (17). The extent to which parents succeed in harmonizing their children's needs impacts their parenting styles. (43)

## 2.4. Parenting styles

Parenting style is defined by Darling & Steinberg (44) “as a constellation of attitudes toward the child that are communicated to the child and that, together, create an emotional climate in which parent's behaviours are expressed” (44). The developmental psychologist Baumrind (45) initially introduced, three parenting styles: the authoritarian, the permissive and the authoritative. Later, the disengaged, directive, good enough, and democratic parenting styles were added to differentiate parenting styles more precisely (45, 46). Although these styles were introduced decades ago, they are still influential and used as frames of reference in research on parenting. According to Vansteenkiste and Soenen (43), two Belgian academics, Baumrind's parental styles are used in every reference book on parenthood (43). As shown in figure 2.2 parenting styles arise by the interconnectedness of responsiveness and demandingness. In this approach, responsiveness is about warmth, acceptance and involvement shown by parents towards their child. Demandingness is about demands made towards the child's abilities by the executed parental control and supervision (43).

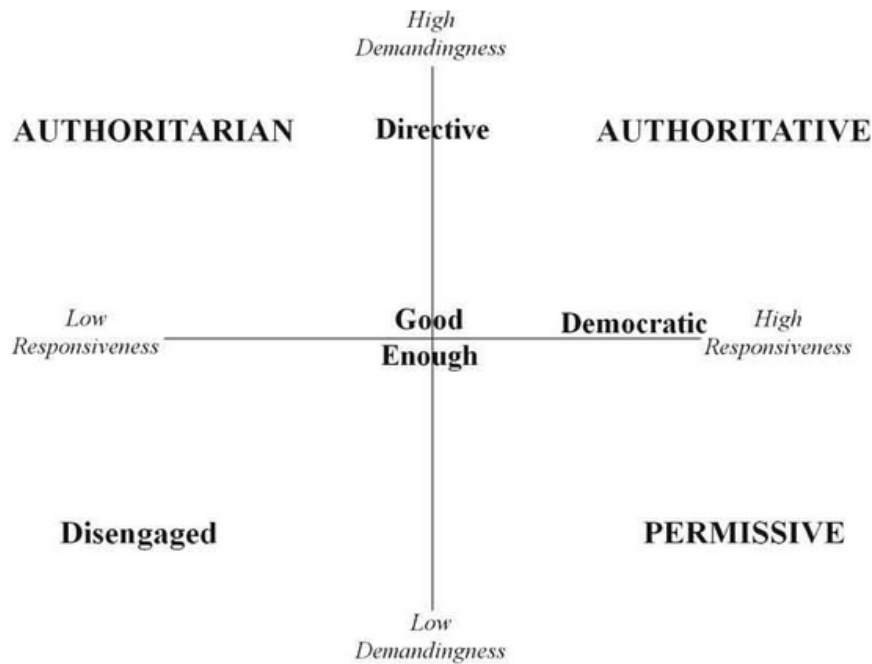


Figure 2.2: Diagram of parenting styles (47)

Combining the level of demandingness with the level of responsiveness leads to one of the above-mentioned parenting styles.

The authoritarian parenting style is characterized by a deficiency of responsiveness merged with a high level of demandingness. In other words children's needs are underestimated as authoritarian parents are lacking warmth, involvement and emotional support, while the expectations and the level of control towards the children are high (43).

Directive parenting is seen as an alternative viewpoint towards the authoritarian parenting style. It is presented as being highly strict and directive without the harmful effects found in authoritarian parenting. The largest difference between the two styles is reciprocity. Directive parents have a high degree of control over their children but recognize and respect their individuality and the importance of special circumstances (48).

The disengaged parenting style is the opposite of the authoritarian as it gives a lot of freedom without supportive structure or control and it is featured by inconsiderate responses (46).

Parents in the permissive parenting style are also characterized with low demandingness but combine this with high involvement towards their child. Fulfilling almost every wish and need of the child results in an illusion of a world where everything is provided due to a main parental focus on the child's satisfaction. The major difference between permissive and disengaged

parenting is the reciprocity level. Although children benefit from autonomy, the disengaged parent takes it to the extreme (48).

Parents who meet the child's basic needs attuned to Maslow's hierarchical needs and subsequently show responsiveness are using a good enough parenting style. Development of the child is facilitated while consistent boundaries are set up in a satisfying loving and caring context (49).

The democratic parent holds democratic ideals as being the central foundation of their parenting style. Notions such as mutual respect, equality, and personal freedom all exemplify values of the democratic parent. The child has an active role in decision making as well as in shaping his/her own future. Critical to this parenting style is the concept of sharing the parental role with the child's role. The child is seen as an individual with the right to shape his or her own future on the basis of human equality (50).

Authoritative parents can be recognized by their high level of responsiveness and demandingness. This means that parents give their children responsibility and freedom in order to develop their potential. At the same time some parental support is given and children can explore within a clear overall controlled frame (51). Baumrind (52) is convinced that parents with an authoritative parenting style are able to combine a high degree of responsiveness while keeping the right amount of control towards their children's behaviour. Consequently this parenting style is seen by Baumrind (53) as the most convenient style within parenthood but differs from a democratic parenting style where parents give their children a bigger voice in decisions. "Authoritative parents do not think it is necessary to first consult their children before setting and enforcing standards and limits" (53).

Lamborn et al (54) conducted important research in the United States on parenting styles and the influence on the adolescents' psychosocial adaptation. Approximately 10,000 adolescents (15 - 18 years old) were questioned on the responsiveness and demandingness of their parents. Moreover, researchers inquired about the effects of the applied parenting styles on adolescents' personal well-being and behaviour. This study concluded that the authoritative parenting style is seen as the most preferable one as adolescents, raised within this style, perform well at school, reach a high level of psychosocial competence, while the scores on interpersonal and behavioural problems seem lower (54). Eve et al (55) focused on opinions given by professionals (involved in child protection) on good parenting in their mixed method study. Most professionals agreed that good parenting is based on responsiveness to the child's day to

day and long term needs. Insight in the child's personal needs and the availability of required parental skills and competencies to react appropriately are prerequisites for good parenting. Additionally supporting the child's development and recognizing one's limitations as a parent are essential requirements as well. It is indispensable that parents react in a consistent but flexible way (55). Accordingly this can be linked to the authoritative parenting style.

Although figure 2 gives the impression that the impact within parenting goes from parent to child, evidence is found that there is a reciprocal relation between parenting and child developing outcomes, which means that the influence is bidirectional (56). Besides parent's and child's personal features, Eve et al (55) added the effect of the broader sociocultural context on parenting. Firstly, understanding the child's needs and secondly, showing a consistent but flexible reaction to these needs within a broader sociocultural context will guide parents to a good parenting style. It is clear that this is only possible on the condition that parents have the ability and willingness to do so (55).

#### 2.4.1 Parenting styles of a child with special needs

The above mentioned reciprocal relation between parenting and child developing outcomes is also seen in a study from Zhou and Yi(57). A grounded theory approach was used in order to gain insight into parenting styles and in the related influence of parental behaviour on the child's symptoms and behaviour. Four different parenting styles, which can change over the years, were named and discussed after interviewing 32 parents raising a child with Autism Spectrum Disorder (ASD) in China.

Firstly, the training-priority style was mentioned. Within this parenting style with high expectations towards their child's progress, parents put a lot of effort in training sessions with their child. Some of these parents try to find clues to enable them to reject the diagnosis as their most prominent emotion is concern and anxiety (57). As a consequence this leads to a high demanding and low responsive parenting style and can be linked to Baumrind's (52) authoritarian parenting style as: "The authoritarian parent attempts to shape, control, and evaluate the behaviour and attitudes of the child in accordance with a set standard of conduct ..." (52). Furthermore the above mentioned parental emotions can increase the symptoms of the child with ASD due to the experienced parental behaviour (57). Snyder et al. (58) explained that parents' negative moods can lead to a lack of parental responsiveness. Accordingly the parental reaction will not be adjusted to the child's shown actions or behaviour (58).

Secondly, the relationship precedence style shows a mainly caregiving parenting style featured by searching for strengths and joyful moments. Some parents try to enhance the abilities of their children in a positive way as they are convinced that positive emotions are prerequisites for learning. This parental behaviour is the result of the adjusted expectations towards their children's abilities (57) and can be linked to Baumrind's (52) authoritative parenting style, recognisable by a good mix of responsiveness and demandingness (52, 53). While parents in this second style become more relaxed, due to their new expectations, their children not only progress faster but also show fewer negative symptoms (57). The importance of this parental insight is strengthened by Suzuki et al (15) who identified that "knowledge on the child characteristics" leads to appropriate parental behaviour (15).

Thirdly, the alternating parenting style is a combination of both above-mentioned patterns. Within this style, parents move from one style to another, guided through emotions as they sometimes see strengths and other times failures. Correspondingly, most of these parents do not sense a link between their personal emotions and their children's symptoms and behaviours. Nevertheless, few parents were aware of the relationship between their own emotions and behaviour and the visibility of the children's symptoms (57).

Finally the letting alone parenting style is a consequence of despondency. These parents subsequently give up their training sessions and perform as a weak caregiver as well (57). As a matter of fact this latter parenting style resembles most closely to Baumrind's (52) neglectful or disengaged parenting style (52, 53). Only one out of three parents within this neglecting parenting style saw the effect of personal parental emotions on the child's symptoms. Zhou and Yi (57) concluded that expectations towards the behaviour and symptoms of their child on the one hand and emotions experienced by parents on the other hand influence the parenting style. According to both researchers (57) professionals working with families have to take into consideration that parents need to understand that their own emotions are influencing their child's mood, behaviour and symptoms. Therapists/ professionals have to focus not only on the ability of parents to regulate their emotions but also on balancing the parental roles of caregiver and coach. A healthy balance between the role of caregiver and trainer/stimulator is also important for the well-being of parent and child (57). Keeping in mind that parental styles imply a reciprocal influence between parent and child (55) presumably also societal changes guide a parent to a preferable parenting style (59). The guidance to a certain parental style is also affected by the applied parental role as discovered by Trifan et al (59).



## 2.5 Parental roles

Trifan et al (59) executed a large-scale Swedish study on changes observed within parental roles over the last 50 years (1958, 1981 and 2011) (59). Both the performance of authoritarian parenting styles and parental roles have been studied. Results showed a gradual decrease in authoritarian parenting styles in the second half of the last century. Simultaneously traditional parenting roles shifted into a more equal distribution of roles which means that fathers no longer remain the only decision-makers within the family. Another important change is the fact that fathers are seen as an asset of support towards mothers in their caregiving role (59). Similar findings were discovered by Vacca (33), who conducted an ethnographic qualitative research study in the United States where fathers described their fatherhood as being responsible for the family income, being a caregiver, educator, householder, fellow player, nurturer and finally being their wives' helpers (33). Parker and Wang (60) had similar findings after analysing on the one hand two American public opinion surveys (2007-2012) and on the other hand time use surveys of American citizens (1965 till 2011) (60). The initial surveys (opinion surveys) were focused on work and family life, while the latter ones (time use surveys) had a focus on time division related to paid work, leisure, household and childcare occupations performed by mothers and fathers. Although a greater intertwining of parenting roles appears, fathers and mothers in general retained their traditional roles. As an example mothers preferred a job with flexible working hours while fathers valued a job based on the paid salary. Accordingly the preservation of traditional roles is confirmed by the fact that mothers spend an average of 14 hours per week on child care while fathers reach the average of 7 hours per week (60).

Also in Belgian families, traditional roles related to household, childcare and paid work still exist. As an illustration mothers spend one and a half hour per week more on childcare and education occupations as their partners. Men spend about 6 hours more time on paid work while women perform approximately 8 hours more in household occupations (37). The preservation of this classic pattern within most families, is also reflected in the fact that despite the clearly visible shift within the parental roles, mothers have been seen as the person children mostly rely on over the last 50 years (59).

### 2.5.1 Supplementary roles related to the child with special needs

Besides the new roles of parenthood, parents of a child with special needs have to take up extra roles in order to give and to organize the necessary support for their child. Van Hove et al (42) collected several metaphors, as mentioned by fathers and mothers of a child with special needs,



during three different research projects (42). Two of these studies have been conducted in Flanders while one study was executed close to Flemish-Dutch border. The common ground of these studies is the pioneer position of the different parents. By fulfilling the role of a pioneer, parents use metaphors in order to paint a vivid picture of their experiences or to acquire a profound understanding of what they are saying. Within these studies, it is obvious that the used metaphors are intertwined with occupations and therefore with complementary parental roles. As an example one of the metaphors parents used is ‘I became a strategist/diplomat’. Being a strategist seems to be greatly important for a parent of a child with special needs. Parents need to think strategically and they have to use all their diplomacy skills in order to achieve whatever they feel is important for their child. Another example is the metaphor of an explorer. By searching for solutions to empower their child in a certain situation, parents discover new talents, feel stronger and enable themselves to engage in discussions with policy makers or to present advocacy lectures to university students (42).

Similar findings has been revealed by Woodgate et al (61). Twenty Canadian parents participated in a study on parenting roles while caring for a child with severe special needs. Information was collected by using in-depth interviews and resulted in an overall experience that parenting a child with severe special needs is intensive due to for instance the ongoing care or the confusion caused by delayed developmental stages. Being a student, a teacher, an advocate, a guard and even a detective are roles which appeared as being related to parenting a child with special needs (61). Learning new skills and teaching others how to deal with the child with special needs, advocating for and protecting the child’s rights, as well as searching for solutions and for experts with the necessary knowledge and skills are often important occupations for these mothers and fathers (42, 61). Therapists even expect parents to support therapeutic programs (16).

### 2.5.2 Experienced difficulties to support child and therapy

A survey on parents’ support of therapeutic programs related to family-life was part of a three-year study conducted in Alberta, Canada (16). The responded families were raising a child with a long-term physical or mental condition, with learning difficulties or with health problems. A stratified random sampling (age 0-5, 6-12, 13-18 of the child with special needs) was used. This survey found the fit of therapy-based occupations within daily routines to be significant with respect to the effort experienced by parents (16). 72 % of the 538 participating families confirmed that they exercise and stimulate their child on the recommendation of a professional but only 11,5 % of the parents succeed in full implementation of the home therapy program.

Many parents found lack of time, arising from the extra parenting demands of looking after a child with special needs (16, 27) Turn taking seems to be an important coping strategy in order to face the challenges they meet. Coordinating the use of available services and the extra role, related to their child's special needs, often negatively impacts parents' health (61). Therapists/health professionals have to take into consideration that there is a correlation between the well-being of the parents and the well-being of their children. Equally important is the ability of parents to make the most of their already existing efforts (14, 16). Consequently, this means that parents need to have the correct knowledge and skills to be able to be responsive to all the needs of their child with special needs (62) without neglecting the other children.

Hogets et al (63) conducted a mix method study on the impact of family-centred services on mothers raising a child with autism in Canada (63). A survey was completed by 139 mothers. 19 of them were asked to broaden and clarify previous answers on the survey by means of a semi-structured interview. Mothers of children raising a child with special needs adjusted their working hours according to their child's therapy requests. 46 out of 139 mothers diminished working hours or even stopped their paid job to liberate time for therapies even though they wished to work more and had planned their career differently. Although children grew up and went to school, this did not impact mothers' work-related life in another way. Time after school had to be liberated in favour of the child's therapy visits and exercises. Moving the family closer to the services was a measurement 28 mothers took to facilitate therapy. Besides work, limitations in leisure time had an impact on their lives as well. Mothers prioritized leisure occupations with the family. Subsequently less leisure time was adult-focussed. Although therapists work family-centred, the impact of their advice on the whole family is often still overlooked (63).

### 2.5.3 Required parental skills

As previously mentioned parents of children with special needs have to be supported to learn new skills as parental stress decreases if the necessary knowledge and competencies to raise their child with special needs is attained (15). Accordingly, if parents are able to adjust their expectations to the abilities of their child they feel more relaxed (57). Certain knowledge and skills are requisites for parents in order to adjust all occupations and to be responsive to the different requirements of their child with special needs (16, 17, 62) without neglecting the other children. These required skills and knowledge are not the same for all parents and will change over the years as Adler et al (62) discovered after conducting a literature review on parental knowledge requirements while raising a child with special needs (62).

Newland (64) confirmed that there is a relationship between well-functioning families and positive parenting (64). After reviewing articles published between 2000 and 2014 on family and child well-being, several essential competencies of good parenthood were derived: be responsive, show age-relevant affection to the children, educate, stimulate and encourage them, be engaged in their activities, enable a qualitative parent-child relationship and be an ally in the parenting process of the other parent (64). These competencies are in line with the authoritative parenting style, where parents are combining responsiveness with required standards and limits in order to enable the child to bring out his/her potential (53).

Parents' feeling of positive parenthood depends not only on having the right skills and competencies but also on the ability to align work, family and care needs (16). How well parents succeed in balancing their roles, influences their feeling of competent parenting. For example, parents who are able to spend sufficient time with their children, are more inclined to think they are doing a great job as parents, compared to those who fail to spend the right amount of time with their children (60).

## 2.6 Balancing roles

Although roles of fathers and mothers have changed over the years, working mothers still spend more time on household and child care occupations than their spouses. Nevertheless the overall workload (combination of time spend on household, childcare and paid job) of both parents seems approximately the same. Parker and Wang (60) looked at the experienced balance of work and family life and discovered that approximately half of the working mothers and fathers are struggling to find a balance between work and family.

### 2.6.1 Occupational shift

Once becoming a parent, an occupational shift with extra occupations and a realignment of the occupations will appear together with different emotions and experiences. A new occupational pattern arises and needs to be adapted (65) until the occupational balance is more or less perceived. Knowing that many parents are struggling to find a balance between work and family life (60), parents raising a child with special needs, have to free up even more time in order to support their child (15-17, 62). Often it is seen that parents who generate extra time from their personal free time, family-time and time from their work-related occupations to fulfil the demands linked to the child's special needs, experience less harmony and coherence within their family due to the shift in occupations (17, 27, 66) The fact that some parents have

difficulties relying on their family to take care of their child with special needs is another added challenge (17), especially when parents would like to go out together. Hence it is desirable to look at the parent's occupational balance and at the ability to adapt the occupational pattern and/or the accompanied feeling. This is especially important because of the correlation between the well-being of parents and those of their children (16). Furthermore, well-being and health are intertwined as, according to the World Health Organization (WHO) (67) health is seen as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*" (67). The above mentioned literature indicates that occupational therapists within a family centred practice might need to support parents in enhancing their time division and in balancing their needed and desired occupations due to this occupational shift.

#### 2.6.1.1 Time use while raising a child with special needs

As time spent with children is influencing parental competencies, time use by parents of children with special needs is an important study subject of many researchers. A systematic review of thirty-two studies executed in Europe, Australia, Canada and Israel on "*The daily patterns of time use for parents of children with complex health needs*" [(27)p. 26] resulted in three main conclusions. Firstly, more time is allocated to the usual childcare occupations by parents of children with complex special needs compared to time spent by parents of typically developing children and this does not reduce as the child's age increases. Secondly, more alertness during supervision of their child is required and therefore difficult to combine with other activities. Finally, extra time to carry out new parental occupations related to the child's special needs, such as for instance medical procedures, is essential (27). Consequently the required extra time will affect the amount of time remaining for other needed and desirable occupations such as spending enough time with the other children of the family (16, 66).

For the child with special needs extra time is anticipated for therapy, to fulfil his/her needs, but the family as a whole experience less well-being although the goal for this shift in occupations is to create a harmonious family in which all members receive the necessary opportunities (16, 17). The choice for this time division is made by parents who live in cultures where facilitating therapy for their children is seen as a moral parental duty (66).

An additional challenge is the fact that some parents have difficulties relying on their family to take care of their child with special needs (17). Sometimes respite care seems to be important for parents so as to get the coveted time for activities such as extra sleep and personal occupations. Extra time released by respite care can be spent with the siblings of the child,

which is important in strengthening the relationships between the parents and their other children (66). Parker and Wang (60) brought attention to the correlation of time spent with the children and the feeling of parental competence. Parents who spend sufficient time with their children, experience greater competence compared to those experiencing a lack of joint spent time (60).

## 2.7 Occupational balance

Although research regularly focuses on balance perceived in life, a clear identification and naming of the concept is missing (2). Not only is there a difference in naming occupational balance within occupational science and occupational therapy but also content variations exist within different definitions and explanations (2, 31, 32, 68). Despite the difference in name and content while talking about occupational balance, the positive relationship between this concept, a personal feeling of health, well-being and satisfaction in life is clear and unambiguous (19, 31, 32, 69). Backman, as described in Christiansen and Townsend (4) stated that if someone perceives satisfaction within his/her occupational pattern and simultaneously experiences occupational balance, this perception will positively influence his/her health and well-being (4).

In their proposed lifestyle balance model Matuska and Christiansen (31) underline five dimensions within a person's occupations as prerequisites for well-being. These dimensions can be associated with Maslow's hierarchy of needs, the psychological well-being scale of Ryff and the self-determination theory of Deci and Ryan (2000). *"Lifestyle patterns must consist of a congruent array of occupations that enable people to: meet basic instrumental needs necessary for sustained biological health and physical safety; have rewarding and self-affirming relationships with others; feel engaged, challenged, and competent; create meaning and a positive personal identity; organize their time and energy in ways that enable them to meet important personal goals and renewal"* [(31)p.11]. An approximate equilibrium within these five mentioned aspects is essential to positively influence health and well-being. First of all eating, doing some physical exercise and sleeping, are examples of occupations linked on one's biological needs and influence one's health (26). Secondly, occupations enhancing social relations have a positive effect on someone's life as stress reduces due to feelings of belonging. Thirdly a feeling of competence while a person performs meaningful and challenging occupations leads to a better balance in life. Fourthly, engagement in meaningful occupations will add value to one's life and as a consequence to one's personal identity. Finally, the ability

of combining all the different needed and desired occupations while also realizing personal objectives can enhance life-balance (31). Some of these dimensions cannot be seen separately from each other (26). For example: performing complex meaningful occupations such as taking care of children, correctly will not only lead to a feeling of competence but will in this case also influence a parent's sense of identity.

Jonsson and Persson (32) elaborated on the concept of occupational balance and developed the 'Experiential Model of Occupational Balance' and its 'Inner Dynamics'. Within this model the relationship between occupations, their challenges and the abilities to perform them are highlighted (32). For this reason mothers and fathers need to have a set of skills and knowledge, related to the special needs of their children. If those parents understand their children's specific characteristics, and know how to handle these, parental stress will be reduced (15).

A good mix of occupations in daily life, performed by a person, where challenges are equal to, higher or lower than their competencies, is needed to experience a healthy occupational pattern and balance. Consequently this mix can probably be seen as a prerequisite for personal progression, value, well-being and input to their social environment and context. The terms "Exacting, flowing and calming experiences"[(32) p.69] are used to label the experiences of performing occupations with challenges higher than, equal to, or lower than a person's abilities. Exacting experiences are essential to learn new skills while flowing experiences lead to a feeling of competence and calming experiences provoke a feeling of relaxation and/or give a person energy. A good mix of these experiences is important to feel balanced. As people do things, their competencies grow and consequently experiences of balance and imbalance will alternate. This is important as being imbalanced for a shorter period of time will help people to develop themselves in the future (32). Whereas a prolonged imbalance leads to stress and illness (4). Stein, Loran and Cermak's (26) indicate that parents of children with special needs, replace some desired occupations by special needs related activities (26). Subsequently these parents form part of the group, that is vulnerable to experiencing occupational imbalance (26).

Wagman, Håkansson and Björklund (2) reviewed forty-three studies to arrive at a concept analysis on occupational balance. The analysis led to the definition of occupational balance which will be followed and used within this study: "*The individual's subjective experience of having the right amount of occupations and the right variation between occupations in his/her occupational pattern.*" [(2)p.326]. *This subjectively correct occupational pattern is viewed in relation to three perspectives: occupational areas, occupations with different characteristics, and time use* " [(2)p.324]. If people look at the variety within their occupational areas, they can

look at the distribution of work, household, leisure, rest and sleep. Apart from this variety the characteristics of these occupations need to be examined as well. Are these occupations chosen or not? What about the level of challenge? Are these occupations performed alone or do people perform these occupations together? What about the ratio between, for instance, physical and mental activities? Are these occupations valued by others and/or by the person him/herself or not? These are some examples of possible occupational features given by an individual person to a certain conducted occupation. Equally important is the time spent on the different occupational areas and characteristics (2). A point often overlooked is the fact that subjective experience of the passage of time may not match the actual passage of time. If a person does or does not like a certain occupation he/she can experience time quite differently, respectively shorter or longer compared to the actual amount of time. As mentioned by Stein, Foran and Cermak (26) the dimensions underlined by Matuska and Christiansen (31) cannot be seen separately from each other, and the perspectives highlighted by Wagman, Håkansson and Björklund (2) are intertwined as well. For this reason it is important to question why people are not satisfied with their occupational balance and what exactly is missing.

## 2.8 Dual-income parenting and occupational balance

Wada et al (70) conducted in 2012 a study in Canada on the perception of occupational balance by dual-income parents raising at least one young child below six years of age (70). Fifteen parental couples, purposefully selected were twice interviewed separately with the use of semi-structured interviews.

Respondents felt balanced once they were able to adjust the different needs they came across in their daily life. These needs were on the one hand collective and on the other hand individual. The first identified needs were seen as managing life while the second had to do with a variety of occupations necessary for one self (70). Individual needs are in line with the occupational balance concept as defined by Wagman, Håkansson and Björklund (2) as the combination within the different occupations is important (2).

Moments of conflicting collective and individual parents' needs limit first of all the personal desires and especially, are a measurement in favour of family and work related requirements. Negation of personal wishes do not mean that every desire is left out as some collective needs could be part of the individual need also. Due to a sense of responsibility towards family-life occupations mainly mothers feel better balanced when a satisfied combination of work and family occupations are perceived. Imbalance is experienced once parents cannot finalise their



necessary and desired occupations. As a consequence availability of time is crucial within occupational balance. Being totally involved in the occupation without being distracted by other occupations is a prerequisite to feel balanced. Wada et al (70) concluded that parents have to manage their occupations and to fulfil the collective and individual needs in their daily lives in order to feel balanced (70).

## 2.9 Parenting a child with special needs and occupational balance

As previously discussed good parenting is influenced by various aspects such as, for example, being a responsive and sensitive caregiver (12). Positive parenting and the good functioning of families are related and consequently have an effect on the well-being of each family member. The literature indicates, that if an additional role becomes part of someone's life, such as parenting a child with special needs, the combination of occupations changes. Accordingly an adaptation of the balance between all the desired and obligatory occupations will occur and will lead to occupational balance or imbalance. How occupational balance is perceived, is closely related with the perception of health and well-being (4, 19, 20), especially because health is more than the absence of a disease but is related to well-being as well (67). Finally striving for an experienced occupational balance by parents while raising a child with special needs will impact the well-being of parents and children because their respective senses of well-being are undeniably intertwined (13, 17, 57). An additional value of parental well-being is the relation with positive parenthood which in turn facilitates the development of the child (57, 64).

### 2.10 Effect on parenting a child with special needs

The above mentioned effect of raising a child with special needs is fairly demanding. However, parents also mention positive influences associated with the special needs of their child. Suzuki et al (15) selected 424 parents of children diagnosed with a developmental disorder from six different medical institutes spread over four districts in Japan. An exploratory factor analysis was used and resulted in the identification of three factors, namely: "*knowledge of the child's characteristics*", "*perceived social supports*" and "*positive perceptions of parenting*" [(15) p.8]. The outcomes of this study, conducted between 2012 and 2015, can be identified as follows: first of all, if parents have sufficient knowledge of how to act in order to raise their child with special needs, parental stress decreases (15). Accordingly, Zhou and Yi (57) stated that realistic parental expectations towards the abilities of their child leads to more relaxed



parenting (57). Secondly, if parents experience quality social support, positive effects on their quality of life appear. Finally a positive perception of one's parenting facilitates the ability to adapt to the challenges of raising a child with special needs (15).

### 2.10.1 Benefits experienced by parents

In 2009 McConnell et al (71) gathered information on benefits experienced by parents while rearing a child with special needs. A stratified random sampling (age of the child with special needs / age groups: 0-5, 6-12, 13-18) was used to select possible respondents. The responding families were raising a child with a long-term physical or mental condition, with learning difficulties or with health problems. Data was collected by means of a survey completed by 538 out of 1,300 parents raising a child with special needs in Canada. The researchers started with different hypotheses to find out if the experienced benefits are 'cognitive artefacts of stress-processing' or if they can be viewed as 'transformational outcomes'. Two thirds of the Canadian parents experienced positive influences derived from raising a child with special needs. Looking for benefits is by the respondents not seen as a coping strategy in difficult times. However the search for positive influences on their family life sometimes helps to better handle the challenging situation. The benefits most often expressed by parents are a transformation in the enrichment of their life, stronger family cohesion and social connections. This transformation may not be seen as resulting from negative experiences but as a logical consequence of becoming a parent of a child with or without a disability (71).

## 2.11 Conceptual framework of the study

Therapists/health professionals provide parents with essential skills and knowledge to support their child with special needs. From the literature it is evident that the well-being of parents and children are intertwined (13, 17). Being aware that it is important to figure out if parents are able to rear and support all their children while still having time for themselves and for each other as a couple is a challenge therapists/health professionals face.

This study is focused on the effect of occupational balance on the caregiving of parents. More specifically on the occupational balance of mothers and fathers while raising a child with special needs. The concept by Wagman, Håkansson and Björklund (2) was chosen to enhance understanding of the occupational balance in a parental caregiving context as it is tailored to daily life performance (2) and forms the basis of the conceptual framework for this study. An occupational pattern can be viewed from different perspectives such as occupational areas,

characteristics and time use. Firstly, this pattern will lead to a subjective experience of the amount and variation of occupations and thereafter to the experience of balance and imbalance.

## 2.12 Measuring participants' experiences

A qualitative research methodology enables a researcher to understand experiences (72) for instance, on how occupational balance is perceived. In order to collect relevant data and to get a clear understanding of what participants see as important, related to the research topic, interviews can be used. The most common approach in this is a semi-structured interview (72).

### 2.12.1 Semi-structured interview

Researchers using a semi-structured interview draw up an interview guide in order to collect similar data and to stay focussed on the research topic. The occupational balance questionnaire set up by Wagman & Håkansson (73) based on the above mentioned perspectives was used as a guide for probing questions during the semi-structured interviews of parental couples raising a child with special needs to explore their occupational balance. As the questionnaire was developed to determine someone's occupational balance, it was suitable to be used, due to its relation to the concept of occupational balance used in this study.

Flexibility is a feature of this type of interview as firstly the researcher asks open-ended questions, secondly it allows for a change in the order of the questions and finally, questions can be added if needed. Although these added questions are originally not included in the interview guide, they are derived from the gathered responses so far and are seen as relevant by the researcher to further explore the topic. Another example of this flexibility is the use of probes which are useful to increase understanding and asks participants for clarification of certain answers.

Interviewing is a skill which needs to be developed. For this reason, it is advisable for novice researchers to plan the interview precisely, to transcribe each interview before conducting the following one and to listen together with experienced researchers to the interview recordings in order to ameliorate the interviewing skills (72). Hence a semi-structured interview was a relevant choice to conduct this study on occupational balance as experienced by fathers and mothers of children with special needs.

More detailed information on the used methodology is explained in the following chapter.

# Chapter 3: Methodology

## 3.1 Study design

In order to answer the research question: ‘How do fathers and mothers of children with special needs perceive their occupational balance?, a qualitative research methodology has been selected. According to Plochg et al (74) an open research question focussing on one phenomenon within a specific group is typical for a qualitative research design. The above mentioned research question is firstly an open question as the researcher asked ‘how the experience of fathers and mothers is’. Secondly there is a focus on one phenomenon, namely ‘occupational balance’ and finally, the specific group of people who are questioned are ‘fathers and mothers raising a child with special needs living in Flanders, Belgium’. Both parents have been interviewed in order to obtain the following objectives:

- to explore the occupational patterns of mothers and fathers;
- to explore the influence of occupations on the occupational balance of mothers and fathers;
- to explore the differences and similarities between mothers’ and fathers’ perceptions of occupational balance.

The achievement of the above mentioned objectives has led to the overall aim of this study:

- to explore occupational balance as experienced by mothers and fathers rearing a child with special needs.

### 3.1.1 Hermeneutic phenomenological approach

Within this qualitative paradigm a phenomenological approach has been chosen. Husserl, a German mathematician and philosopher, is seen as the founder of phenomenology (74). Searching for an answer to the fact that neither positivism nor subjectivism could give an answer to current social issues, he explained that realities had to be seen as experienced phenomena from which knowledge could be derived (74). Different philosophers elaborated on and revised Husserl’s work. Consequently phenomenological concepts appeared, for instance, the hermeneutic phenomenological approach which has been selected for this study (75). Within the hermeneutic phenomenological approach knowledge is derived from the interpretation given to the phenomenon within their context (75). The approach allows individuals and groups to express their personal lived experiences and this allows the researcher

to uncover the character and meaning thereof (75). Common ideas of the researcher and participants, as well as previous experiences, could affect the sensitivity of the researcher in interpreting meanings shown by participants within their stories (72). Nevertheless it is important to realize that a clear description of experiences has to be displayed without hindrance of prejudgements or theories (75). At the same time this approach fits well with occupational therapy practice as occupational therapy is a client-centred profession (7). In other words the therapist will respectfully take his/her client's point of view into consideration. Valuing the person's context, his/her daily life experiences, knowledge and wishes will be the leading thread in therapy (76).

### 3.1.2 Study population and sampling

For this study purposive sampling was used as parents were selected according to specific selection criteria:

- Parents of children with special needs who:
  - lived in Flanders,
  - lived in a nuclear family
  - both accepted the invitation to participate voluntarily
- Their children with special needs:
  - had lived fully at home with their family (making use of respite care from time to time is still regarded as living fully at home)
  - had received therapy at least once a week, from one or more applied health professionals for one year or longer
  - were between 4 and 14 years old
  - Families who received Budgets for Personalized Assistance or Personal Funding were excluded in this study as they were able to get funded assistance while other parents did not.

Reasoning behind the selection criteria is as follows:

- The families need to live in Flanders, as for Belgian policy, the Ministry of Welfare, Health and Families and the Ministry of Education are regional authorities. This means that they are governed by the Flemish regional parliament and government.
- Generally children start nursery school at the age of 2.5. Primary school ends at the age of 12. Children with special needs often start at a later age at nursery school and can stay in primary education until the age of 14.

- Parents within a nuclear family could give a clearer understanding of the occupational differences and similarities between fathers and mothers as they lived as a family together and had to decide on who was doing what, when and how to make their parental and other roles possible.
- De-institutionalisation of children's services is a policy within Europe and Belgium. Nevertheless a country report on Belgium by the European parliament (23) in 2013 highlighted that of all Western countries, Belgium has the highest level of institutionalisation (23). For this reason it was important to focus on the occupational balance of parents whose children with special needs lived fully at home.
- As occupational balance and imbalance had altered parents' needs they needed to have time to (re)find balance when they suddenly had to take up extra occupations. If therapy had been ongoing for at least one year, they had had time to adapt and organize their occupations to the new situation.

Within the purposive sampling, a maximum variation is obtained by interviewing parents with different educational levels namely:

- One parent who did not complete secondary education
- Twelve parents who completed secondary education
- Eleven parents who finished tertiary education

No difference was made regarding place of residence as Flanders has a surface area of 13,682.38 square km and a population of 6,509,894 inhabitants in January 2017 (77). As a result nobody lived very isolated which means that services are available to all at a reasonable distance.

As the aim of this study was to explore occupational balance as experienced by mothers and fathers rearing a child with special needs, it was important that parents' personal experiences were captured. Consequently a small sample size allowed the researcher to describe the uniqueness of certain experiences. Twelve parental couples were selected. Three different groups were formed. Eight parental couples consisted of mothers and fathers with the same educational level. In one group of four couples, both parents finished tertiary education, while the other group of four couples had obtained a secondary school degree. The third group existed of three parental couples with a different educational level namely one parent with a secondary educational level while the other one completed tertiary education. The remaining couple consisted of one parent with and another one without a secondary school degree.

Chain referral has been used as therapists such as occupational therapists, physiotherapists and speech and language therapists were contacted in order to act as gatekeepers and to contact possible participants who met the selection criteria for this research. Firstly, an explanation concerning the objectives of the study was provided to the therapists. As they knew the parents and their child very well therapists were asked to contact possible participants for the study. Parents who showed a possible interest in participating, received an appointment for further clarification of the study. Informed consent was obtained once both parents expressed their willingness to participate in the study. Unfortunately only one parent who did not complete secondary school was found. Centres for rehabilitation of children with special needs complained of already being overwhelmed with questions from master and doctoral students to participate in their research. Private therapists who were consulted did not have the opportunity to select parents who had an educational level less than a secondary school degree. Finally, two parental couples did not participate as the fathers did not feel comfortable joining the study. Both mothers who had felt overwhelmed by the extra occupations related to their children needs regretted the rejection of their spouse.

### 3.2 Data collection

Data was collected through a semi-structured interview by both parents at the same time. A short introduction talk to get to know each other was important for researcher and respondents to feel at ease. To facilitate free speaking, they were assured that each person could have his/her own point of view based on personal knowledge and experiences. Whatever parents expressed, felt, thought or said was accepted without judgement. Under these circumstances, parents could hear, support and complement each other during the interview. Similarities and differences of interpretations on certain aspects sometimes emerged. Extra non-verbal communication and interactions between the two parents proved also valuable for this study.

The interview guide can be found in Appendix C. The main questions focused on the occupational pattern of both parents. The probing questions were based on the content of the Occupational Balance Questionnaire developed by Wagman & Håkansson (73) as published in the article *“Introducing the Occupational Balance Questionnaire”* (73). Questions were answered alternatively by both parents. While one spouse was talking the other one often provided some additional information.

As parents had to give insight into their occupational pattern and explain how they experienced the overall balance and satisfaction of this occupational pattern, a relationship of trust and

mutual respect was a prerequisite for this study. The interviews were conducted at the parents' home at a time which was convenient for both of them. The duration of each interview was approximately one hour as both parents needed to create time within the same day or evening. Interviews focused on the occupations and the meaning(s) given to these occupations by each parent. A second focal point was the occupational balance as experienced by the mothers and fathers individually. A second interview (member checking) was conducted with each parental couple regarding insights gained through conducting this study and to verify if each parent recognized his/her personal input.

Permission was obtained from the parents to tape-record the interviews. This ensured that the entire interview was captured and that the researcher could focus fully on what the person was saying and doing. The attitude of a listener could be retained as the researcher was able to listen carefully, to maintain eye-contact and to observe gestures and interactions between the parents as well. Summarizing to check if what had been said was captured correctly, was easier as the researcher only needed to listen. Even though the interviews were recorded a possible pitfall was the attention span of the interviewer. It was important that the attention level was constantly high as the best questions had to be chosen for each individual interviewee (78). Notes were made immediately after the interviews, in the use of a field journal in order to capture parents' non-verbal communication and expressions as accurately as possible in order to make later reflections and analysis possible.

### 3.3 Data analysis

Analysing data of semi-structured interviews is complex and iterative which means that the researcher needs to continuously shift from data collection to data analysis (72). A verbatim transcription of each recorded interview was made. Also field notes observations provided important information as responses contained more than just the words used. Gestures while talking, the tone of voice while answering and the interaction between both parents are examples of valuable extra data. Each transcription and field note was followed by ordering and organizing the perceived data in order to create themes derived from expected and unexpected aspects. (79). Accordingly new questions and prompts arose to enrich the interviews and later on the entire study. Ziebland and McPherson (79) describe different steps to analyse the gathered data as follows:

- Transcription

A detailed verbatim transcription was made, which means that hesitations, differences in voice, ... were noted as well. In order to eliminate possible errors, each transcription was compared with the related record. This was done immediately after each interview and mostly before the following interview started. The answers of mothers were typed in blue while the fathers' answers were written in green.

- Elaborate on the data

It was relevant to keep memos to facilitate the coding process for possible themes derived from collected data. Immediately after each interview reflections on what and how answers have been expressed were noted down.

- Coding

While repeatedly reading each transcription, related information was grouped into themes. After a first reading, answers were highlighted and named very closely to what was said. Rereading was necessary to bring certain answers together. In between, the collected information and primary coding were compared to the literature and the conceptual framework of this study as the interview guide was based on the occupational balance questionnaire of Wagman & Håkansson (73). Although researchers would like to look with an open and uninfluenced mind, a researcher is influenced by theory and knowledge gained before the data collection took place. Bendasolli (80) identified that inductive qualitative research is not theory-free. Which means that the influence of a researcher's knowledge is undervalued when talking of inductive data analysis (80). For this study the in-between position was used and is an analysing process close to induction. Although the direction of the coding was indicated, it did not serve as a hypotheses for a possible outcome but was a tool to code more efficiently (81). It was necessary to discuss the coding process with an experienced colleague and supervisors.

- Analysis

The collected information was analysed by means of several readings in order to group data within themes. Subsequently it was important to ensure that the collected information was applicable under its theme and that, additionally, all information belonged to at least one theme. Finally, the selected information needed to be connected with the context as obtained during the interview. To facilitate this analysing process, NVivo, a software program for data analysis was used. Pen and paper were used as well to visualise thoughts and relations. Figure 3.1 is an example of this.



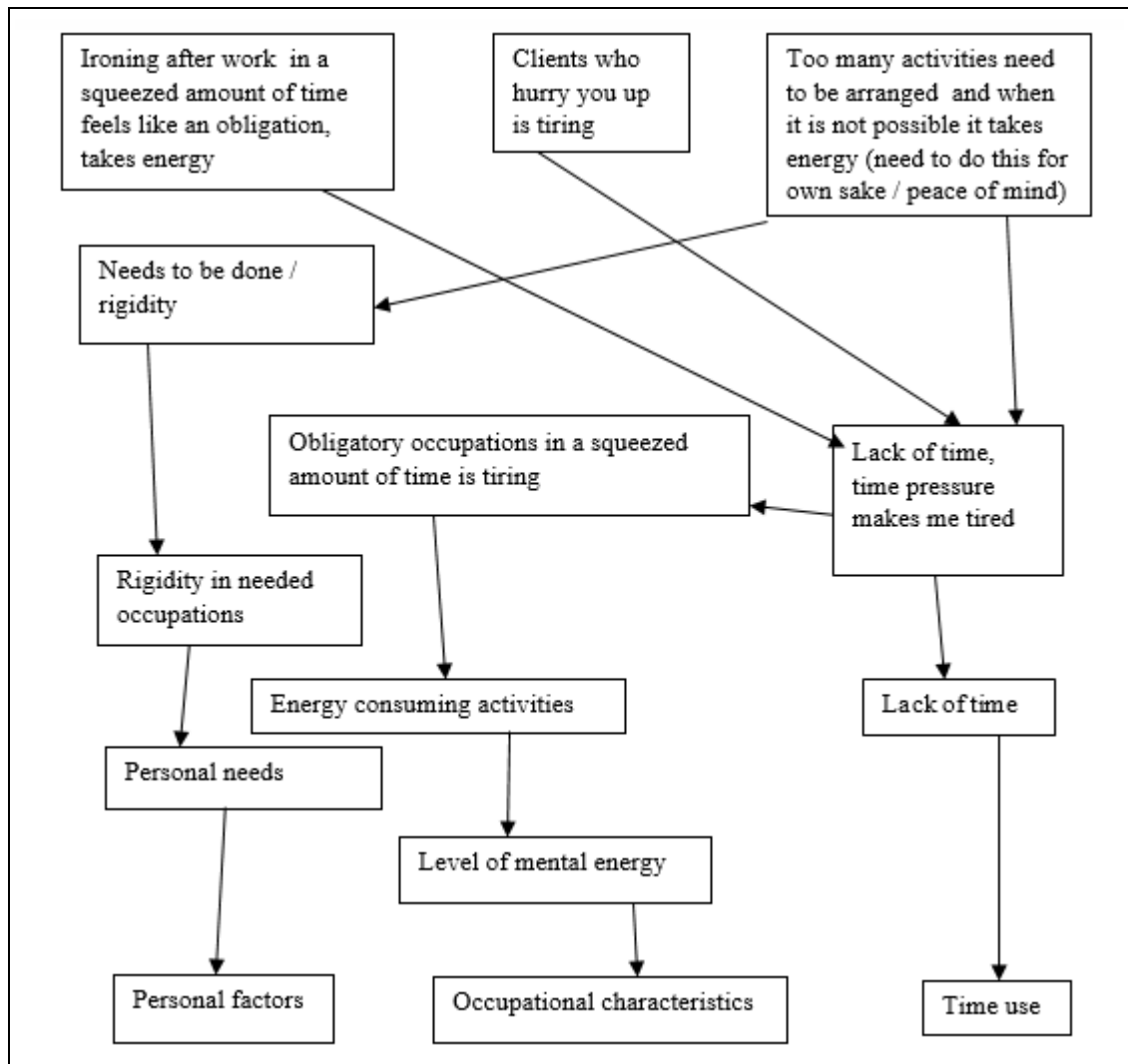


Figure 3.1: Visualisation of networks of categories and subcategories

- OSOP (one sheet of paper) method

The aim of this method was to summarize each theme by re-reading the dataset and to note the various derived aspects on one piece of paper. The different items derived after all these readings (categories and subcategories) had to be written on one sheet of paper. Once this was done, the different issues needed to be clearly linked to the corresponding anonymous identity of the participant. This analysis system to collect the information of one theme on one sheet of paper was repeated for all the selected themes. Finally a variation of themes, facilitated by the different “one sheet of paper” were brought together in umbrella themes as described by Ziebland (79).

- In depth analysis

The obtained understandings were linked with the literature in order to develop further comprehension. An additional literature search to support some findings was done. New

insights were gained also by reflecting on the findings with other professionals, such as a sociologist, a physiotherapist and a speech and language therapist as they viewed data from different perspectives. Furthermore checking the findings in between with some of the participants added value during the analysing process and illustrated the iterative.

At the end of this whole process a member checking interview (2<sup>nd</sup> interview) was held to verify and discuss the final draft of the findings with all the participants as indicated in “data collection” (3.2) above. It was important as well to explore if participants would like to share any further issues. Parents recognized their feelings, thoughts and perspectives in the final draft and agreed with the authenticity of the final version of the study.

- Writing up

Before disclosing the findings, it was important to think through the results of the research. Which part of the results were new and what confirmed already known findings? Once the interpretations of the study were categorised in line with the above mentioned criteria a decision was made on the representation of the data and its results. It was equally important to ensure that results derived from different perspectives were represented within the research report. Examples of stories told by mothers and fathers were selected to emphasize the derived findings with lived experiences (79).

### 3.4 Quality assurance

Ensuring rigour and trustworthiness is essential in qualitative research. Positivists often show scepticism as validity, reliability, confirmability and objectivity cannot be obtained in the same way through qualitative research as quantitative research. Cuba, as described in Shenton (82), addressed four alternative concepts. Credibility, transferability, dependability and finally confirmability, which refer to the above mentioned terms.

#### 3.4.1 Credibility

Credibility means that participants retrieve their own perception and truth, within the findings of the study (72).

- Reflexivity: During the whole process the researcher was aware of possible personal opinions, actions and emotions as these might indirectly guide the findings in a certain direction. Reflection was needed on one’s own experiences, on the relationship and collaboration between participants and researcher and on the meaning of written language within the study (72). The researcher’s personal views, viewpoints,

background and feelings had to be distinguished from the readers'. As a consequence the researcher needed to reflect on all these aspects to explicate them within the text.

- Member checking: During the interviews member checking was important to ensure that information was interpreted by the researcher as meant by the participant. The researcher paraphrased regularly what was said. Sandelowski, as described in Holloway (72), pointed out that although it seems quite simple to do, an important pitfall can be found in the fact that researcher and participant both have different reasons to work together. The close relationship between participant and researcher, necessary within qualitative research, can be seen as a disadvantage as the participant might adapt his/her answer to an expected response of the researcher.
- Peer review: Within qualitative research, the researcher is part of the research; this demands a lot of reflection in order to avoid inappropriate subjectivity. Despite the researcher's intentions to avoid the influence of personal perceptions, the research process could still undergo decisions derived from one's own perspectives and prejudices. For this reason it was important that peers and supervisors within this qualitative research approach gave feedback on the data analysis and research process in order to avoid personal perceptions and to ensure that necessary changes in the research process were identified.

### 3.4.2 Transferability

As the aim of the study was to recognize the occupational balance of mothers and fathers rearing a child with special needs, the experiences of both parents were described in detail. As a consequence findings cannot be generalized but only transferred which means that findings can be applied in similar contexts or with other respondents. It is the reader's responsibility to judge the suitability of the findings within his/her context (72). Transferability was achieved by the following actions:

- Thick description: A detailed description of the research will enable readers to understand the research process and the participants' feelings and experiences. This will enable them to elicit conclusions similar to those of the researcher.
- Purposive sampling: Purposive sampling was used as parents were selected according to specific criteria. Within the sample parents with a maximum variation in relation to educational level were recruited.

### 3.4.3 Dependability

Dependability refers to the accuracy and consistency of the research process (72) and was achieved by the following activities:

- Audit trail: A detailed description of the research process was made to allow the reader to picture the research path in order to understand how and why choices were made (72).
- Peer review: On a regular basis discussions were held with peers, colleagues and research supervisors in order to elaborate on the feedback given. Coding was checked by an experienced researcher who was not involved in the supervision of the student.

### 3.4.4 Confirmability

Confirmability is about objectivity, which means that findings may not be derived from the researcher's earlier suppositions (72). An audit trail setting out the raw data and describing how the themes and categories were derived from this data was indispensable. The researcher's personal ideas and experiences related to the study were clearly disclosed in the field journal. Findings were discussed with peers, colleagues and experienced researchers. Equally important was the search for confirmation of the findings in the existing literature.

## 3.5 Ethical considerations

*"Ethics for health professionals/researchers is concerned with guiding professionals to protect and safeguard the interest of clients" [(72)p.54].* For this reason it was important to pay attention to the interests of (possible) participants. Ethical approval was obtained by the Health Research Ethics Committee at Stellenbosch University (Ethics Reference: S16/09/72) and by the Health Research Ethics Committee at Ghent University (Ethics Reference 2016/1173).

### 3.5.1 Respect, Justice and Autonomy

In this study it was important to find participants from different socio-economic groups based on their educational level. An almost equal division of parents was secured, as twelve parents finished secondary and eleven parents tertiary education. Only one parent did not obtain a secondary school degree. Four out of twelve couples had a different educational level. As a lot of parents do not receive Budgets for Personalized Assistance, or in the near future Personal Funding, those who do receive these additional budgets were not selected or invited to participate. This would have given a distorted outcome, as those not in receipt of the additional funding would be at a relative disadvantage to pay for supplementary support.

Therapists acted as gatekeepers and informed possible participants. Possible participants were contacted by the researcher who explained the aim and objectives of the study. If parents considered to participate a full explanation with regard to the research process was given by the researcher. Mutual expectations were discussed and allowed parents to make a well-informed and independent decision. If parents decided to participate an informed consent form was signed by father and mother. Nobody needed more time in order to think things over but two fathers refused.

As parents participated voluntarily, they had the possibility to withdraw at any stage of the research. For the sake of the participants' privacy, numbers were used for the different parents and pseudonyms for the children in order to fully anonymise all of them.

### 3.5.2 Beneficiaries

Although there were no direct benefits for the participants, insight into their personal occupational patterns could eventually lead to better occupational balance for them, which in turn might enhance the child's development and harmony within the family. Flemish occupational therapists working with families can benefit from the research findings as these will be disseminated within the Flemish occupational therapy association. Study results will also be shared with participants and students of the occupational therapy department of University College Ghent.

### 3.5.3 Non-maleficence

Predicting possible harm due to participation in this study is quite challenging; at first glance, there will be none. Nevertheless it was essential to be aware of possible negative impact on the emotional well-being of a participant as this study could possibly bring up unprocessed feelings, due to some sensitive matter. As soon as the participants were known some specialised professionals from the participants' neighbourhood were listed. This collected information could be provided to the concerned parents if necessary.

### 3.5.4 Confidentiality

From the start of the research it had to be clear that the participant/researcher relationship was confidential. All personal information on parents was kept confidential. Answers received in the semi-structured interviews by parents were also confidential and were not recognisably spread. Participants were completely anonymous, as numbers and fictitious names were used within the given examples of this research report.

Detailed findings derived from the data collection and analysis process are described in chapter 4 Findings with ‘underlined quotes’ from participants. To obtain anonymity, parents will be referred to as Mother or Father followed by a number while pseudonyms will be used for the children.

# Chapter 4: Findings

## 4.1 Introduction

The findings that emerged during the data collection will be described in this chapter. A profile of the participant parents is provided. The themes, categories and subcategories derived during the analysing process of this study are presented in a table overview. Afterwards each theme is shown in its scheme together with the associated categories and subcategories which are described and supported by quotes given by the participant parents.

## 4.2 Participants

Twelve parental couples were interviewed. The age range of these parents was between 34 and 49 years old. All fathers in the study had a fulltime job. One father had a second job as an independent salesman. Only two mothers worked fulltime. All others worked part time in the range of 50 to 80 percent of a full-time job. An introduction of the participant families is provided in Table 4.1. Ten out of twelve families had two children. One family raised three children and another family existed of six family members namely two parents and four children. The oldest child within these families was 25 and the youngest one was 3 years old. Five families had two children who needed supplementary attention due to special needs.

Table 4.1 Profile of research participants

Family	Parent	Age	Educational level	Working time	Children		
					Gender	Age	Diagnosis
1	Mother 1	37	Secondary school and one year extra specialisation	Full time: 100 % Shifts	Girl	12	Dysphagia
					Boy	8	None
1	Father 1	42	Did not finish secondary school	Full time: 100 %	Girl	5	Overall developmental delay and Assessed for Autism Spectrum Disorder (results yet unknown)
				Remaining available time was used for his second job (independent salesman)			
2	Mother 2	47	Tertiary education	Part time: 50 %	Boy	10	None
2	Father 2	47	Tertiary education	Full time: 100 % Regularly abroad	Girl	8	Dyscalculia
3	Mother 3	43	Tertiary education	Part time: 50 %	Boy	12	Autism Spectrum Disorder, Developmental Coordination Disorder and Attention Deficit Hyperactivity Disorder
3	Father 3	45	Secondary school	Full time: 100 %			
					Boy	11	None



Family	Parent	Age	Educational level	Working time	Children		
					Gender	Age	Diagnosis
4	Mother 4	37	Secondary school and one year extra specialisation	Part time: 50 %	Boy	8	Developmental Coordination Disorder and on the waiting list to be assessed for Autism Spectrum Disorder (results yet unknown)
4	Father 4	38	Secondary school	Full time: 100 % Regularly abroad		6	
5	Mother 5	34	Secondary school and one year extra specialisation	Part time: 80 %	Boy	5	None
5	Father 5	42	Secondary school	Full time: 100 %	Girl	5	Developmental Coordination Disorder and Metabolic disorder
6	Mother 6	40	Secondary school and one year extra specialisation	Part time: 80 %	Boy	16	Autism Spectrum Disorder, Developmental Coordination Disorder and Attention Deficit Hyperactivity Disorder
6	Father 6	44	Secondary school	Full time: 100 %		11	
					Boy		Developmental Coordination Disorder and Disharmonic developmental profile, verbal strong, performance weak

Family	Parent	Age	Educational level	Working time	Children		
					Gender	Age	Diagnosis
7	Mother 7	36	Secondary school and one year extra specialisation Is studying for a bachelor degree	Part time: 60 %	Girl	10	Dyscalculia
				40 % Remaining available time is used to study	Boy	6	Developmental Coordination Disorder and was born premature and dysmature with a congenital disorder (intestines)
				Full time: 100 %			
8	Mother 8	37	Tertiary education	Part time: 80 %	Boy	8	Developmental Coordination Disorder
8	Father 8	38	Tertiary education	100 %	Boy	5	None
9	Mother 9	38	Tertiary education	Part time: 80 %	Boy	10	Attention Deficit Hyperactivity Disorder
9	Father 9	42	Tertiary education	Two part time jobs of both 50 %	Boy	8	None

Family	Parent	Age	Educational level	Working time	Children		
					Gender	Age	Diagnosis
10	Mother 10	49	Tertiary education	Part time: 70 %	Girl	25	None
10	Father 10	49	Secondary school and one year extra specialisation	Full time: 100 %	Girl	17	None
					Boy	12	Cerebral Palsy: diplegia (mild)
					Girl	11	Speech Developmental Disorder
11	Mother 11	36	Secondary school	Part time: 80 %	Girl	6	Attention Deficit Disorder and Developmental Coordination Disorder
11	Father 11	36	Tertiary education	Full time: 100 %	Girl	3	Congenital muscle disease
12	Mother 12	37	Tertiary education	Full time: 100 %	Boy	8	Developmental Coordination Disorder and verbal developmental dyspraxia
12	Father 12	41	Tertiary education	Full time: 100 %	Boy	6	None

### 4.3 Summary of the findings

This study focused on the occupational balance as experienced by mothers and fathers while raising a child with special needs. Wagman, Håkansson and Björklund (2) 's concept was chosen to enhance understanding of occupational balance in a parental caregiving context as it is tailored to daily life performance (2).

Five themes were derived during the analysing process: Occupational areas, Occupational characteristics, Time use, Personal factors and External assistance. The first three were named according to the occupational balance concept of Wagman, Håkansson and Björklund (2). Additionally Personal factors and External factors of support emerged as affecting the occupational balance.

The themes, categories and subcategories analysed will be discussed in the following sections and are illustrated in table 4.2.

Table 4.2 Analysed themes, categories and subcategories

Theme	Category	Subcategory
Occupational areas	Work	Flexibility around working hours
		Scaling down on working hours
	Family-life	Household
		Regular care and support
		Supplemental care and support
	Leisure	Family-time
		Me-time
		We-time
	Rest and Sleep	
Occupational characteristics	Level of mental energy	Energy generating occupations
		Energy maintaining occupations
		Energy consuming occupations
	Social occupations	Social occupations as a family-unit
		Social occupations as an individual
		Social occupations as a couple
Time use	Lack of time	
	Adequate amount of time	
	Extra time	
Personal factors	Personal needs	Rigidity in needed occupations
		Sense of responsibility
		Knowledge and skills related to the child's special needs
	Coping strategies	
External factors of support	Giving support	Supporting the child with special needs
		Supporting the child(ren)
		Supporting the aging parents of the parents
	Mutual support	
	Receiving support	Support from professionals
		Support from service providers
		Support from family members

### 4.3.1 Theme1: Occupational Areas

Occupational areas is the umbrella term to host the different activities described by the participant parents when talking about their occupational pattern. Four different areas were derived from the way participant parents talked about certain activities and how they categorized these themselves as work, family-life, leisure and rest and sleep.

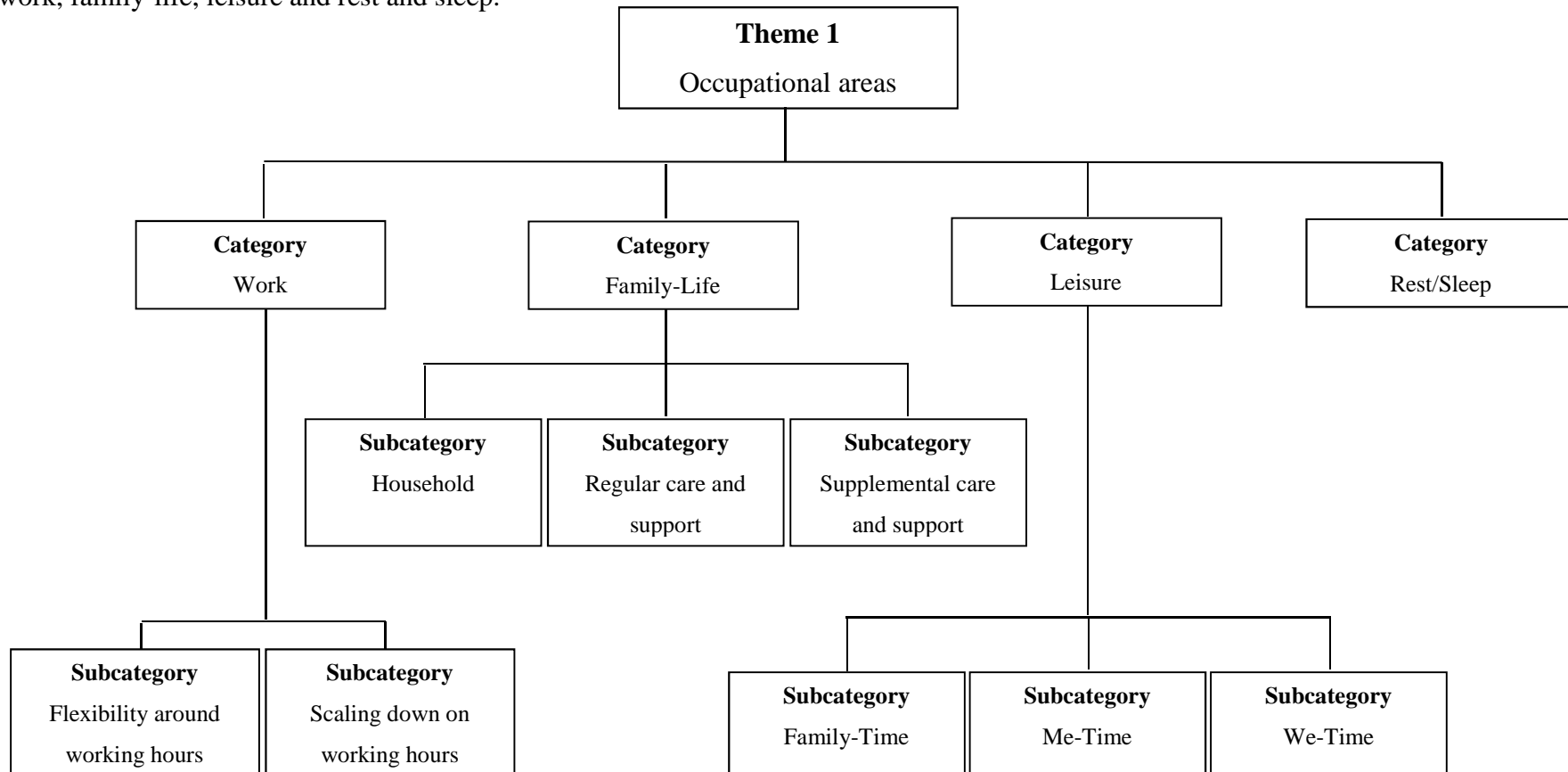


Figure 4.1 Occupational areas

### 4.3.1.1 Work

All participant parents used the word work when talking about activities related to the paid job. Other activities such as doing the household chores or maintaining the garden did not belong to the paid job and were therefore not mentioned as work when talking about their occupational pattern.

#### 4.3.1.1.1 Flexibility around working hours

Most of the participant parents had a rigid schedule around their working hours. In some working environments, employees have flexible working hours where people within a certain time range, can choose when they start and stop working. In this study, participant parents within this kind of working-hours system used this opportunity to account for their parental activities. Some activities they would like to do for their children were made possible while others increased in quality.

Most of the time I arrange it, so that we can have (Father 4) breakfast together (Mother 4). I will bring the children to school (together with his wife). So, I will do this because when I come home around 9 p.m. I will not be able to see the children (Father4).

I have a very flexible time schedule at work. I have promised my son, 'Boy, this is your final year in primary school. You do not have to stay in childcare anymore.' (Mother 6)

#### 4.3.1.1.2 Scaling down on working hours

Ten out of twelve participant mothers, reduced working hours in order to combine work and family-life more easily.

Participant mothers who worked part time (50 %), about half of a fulltime work schedule, made this choice due to time pressure. Too little time was available besides their paid job to perform the required family-life activities. In other words, the combination of work-family life was challenging.

We had nice co-workers but the work pressure became too high and it was difficult to combine with my family-life. Then I decided to work half time (Mother 4).

When I have the time. When I work half time I do not mind driving to music school and waiting there twice for half an hour. I think, tomorrow I am home half of the day and then I can do this and that. While I was working fulltime, everything was so under pressure that when you had to wait 10 minutes in a traffic-jam you started thinking, I am not able to finish my household chores. This is too much. You became restless, your children react to it and this set the ball rolling. (Mother 3)

A part time job was also sought due to the extra care and support required for a child with special needs or due to a husband who worked abroad from time to time.

To make it feasible for everyone. This is my weak point. To make it feasible and supportable for everyone, I think that one half of my time is my job and the other half is my house and my family, as I need to organize everything through the autism spectrum disorder viewpoint (Mother 3).

Some families needed to support the aging grandparents in addition to responsibilities for the nuclear family. Reducing working hours to balance work and family-life was seen as a solution.

I never asked a babysitter to come. That is the reason why I have chosen to work part-time. The reason is because he (father 2) is often abroad, the extra care needed for our daughter, and because of my retired mother who still lives in her house not far from here. I go there twice a week to put her medicine in a pillbox and I arrange her administrative issues as well. Because I work half time, this is do-able (Mother 2).

One of the full-time working mothers received a lot of support from her extended family, making the combination of work and family life manageable as less time was needed to fulfil the remaining activities.

Then she (grandma) prepares the food. At 1 p.m. she brings the children back to school and does the ironing. That is also extra household help. At 4 p.m. she goes back to pick up the children. I said my mom is a very clean person, so she empties the dishwasher. She does the ironing; she sometimes puts the clothes away. She does a lot. In fact, I have a second household help because of her (besides the housekeeper) (Mother 12).

Families where the man was seen as the person that needed to work for the wife and children had fathers that took fewer responsibilities in the family-life activities. Those fathers did not really mention one of these activities but were strongly identified with the breadwinner's role.

What I feel good about is that my wife is well-dressed. That my children have a good life and are nicely dressed. That we can go to eat at a restaurant and that we from time to time can do something special (Father 7).

#### 4.3.1.2 Family – Life

In this study, the family-life area brought together all occupations needed to allow for a well-functioning family where parents and children experienced well-being. Throughout their family lives, parents need to arrange their household, take care of their children, and support them in their overall development.



#### 4.3.1.2.1 Household

Activities related to the household were mostly experienced by the participant mothers as occupations that needed to be done under a limited amount of time, which might give a feeling of pressure and stress.

Imagine that you can do this (ironing) during the daytime. When you have time, then the activity is not a problem. But when do you do this? Once you did everything. After cooking, after clearing, after homework (Mother 8).

I sometimes have the feeling that the week has passed, for me this is on Thursdays at noon. It is a rush. Like last Monday evening, we cleaned up the table around 9:30 p.m. On Monday, I was not able to do the household activities. I only have enough time during that little period when I am home from work and they (husband and children) still need to come home (Mother 9).

Both participant parents participated in family-life occupations within daily life. Household activities done by fathers varied between helping the wife when needed and being responsible for certain tasks. Different responsibilities and task division were influencing each other's balance.

The biggest amount of work in the household is for my wife. If you look at the percentage of it and compare it with an average family, she has a lot more. This is because I need to do a lot of telephone calls, answer emails, and leave (to sell the health drink) often for three to four hours (Father 1).

I participate in a bit of household activities such as the accounting and helping as for instance putting the dishes in the dishwasher (Father 5).

Once the children are at school I go to the grocery store and prepare the food in such a way that it is just heating up in the evening. Once that is finished I clear the household and vacuum. It depends on my working hours in the afternoon as they start at different hours (Father 6).

Two participant fathers went abroad from time to time for their jobs and were less involved in household activities. Both men had a wife working half-time meaning she had more time to compensate for their decreased levels of involvement. These fathers confirmed that they were less involved in household activities. Less participation of the fathers had the advantage that minimal changes needed to take place while they were abroad.

I manage by my-self .I am doing this already for 23 years (Mother 2). So she is used to it (Father2).

#### 4.3.1.2.2 Regular care and support

Caring and supporting activities are part of family life once you become a parent whether the child/ren have special needs or not.

Care and support activities towards children differed between participant parents and was strongly influenced by the working hours of both spouses. As an example, parents who left the house approximately at the same time divided tasks to maximize efficiency. This pattern in their morning routines was done in order to take care of the children and to get them ready for school at the necessary time. Those parents who left at different times needed to do their own morning routines with one doing it with the children's morning routine and one without.

I prepare the sandwiches for the children; prepare the lunch boxes by preparing some fruit and a biscuit then the oldest son is downstairs. You (wife) stay upstairs with the other son because if both children are together upstairs it does not work. So, one of us is upstairs and the other downstairs (Father 9).

My husband was working. I woke up around 7. Woke up the children, gave them breakfast, dressed them. My daddy is retired. He took the children to school yesterday (Mother 5).

Within this study, the activities of support performed depended on the needs and interests of the child/ren. Deciding which parent was responsible for this depended on the workflow of the individual parent.

Mary does ballet and Felix goes to swim at the same time, so we split up. (Mother 4) But the weekends are the most difficult (when the husband is abroad). In fact, the hobbies could be provided by one parent (Mother 4).

The children go to sports on Monday. I bring them home (when coming back from work) (Father 9).

#### 4.3.1.2.3 Supplemental care and support

Besides regular caring and supporting activities extra care and support was provided by the participant parents depending on the child's needs. These activities were included within both parents' occupational patterns but would differ in both the level and amount of care and support. Participant mothers were mostly involved in direct support while fathers supported their children rather indirectly.

For the vast majority of time, participant mothers brought their children to therapy as well as performing the extra therapy exercises with the child at home.

I have to go to school at 12:30 p.m. and bring her to therapy. She is ready around 3 p.m. Then I have to go back to school, because she wants to go to school again (Mother 1).

I join Lena during therapy. This became a habit and it is also because of my pedagogical diploma. I stay there with her (Mother 2).

Finally, it is me who is always going to therapy, to the doctors and to the other things with the two children (Mother 10).

One participant couple alternated the weekly visit to the therapist, however the home stimulation activities were almost exclusively carried out by the mother.

Therapy is fifty-fifty (Father 8). Yes (Mother 8). Homework is for you (wife), I think 90 percent of the time (Father 8). Yes (Mother 8). I do it each fourteen days on Tuesday and sometimes during the weekends. You do the follow ups much more than I do (Father 8).

Two participant fathers were more engaged in the stimulation of the children compared to their spouses. For the first father this was due to his wife's demanding job and for the other because of his profession. As a primary school teacher, he better understood how to handle the difficulties of the child.

Sometimes when I am home early on Tuesday evenings, I say 'I will go to therapy' because he (father) usually does this (Mother 12).

I am privileged that I have that job (primary school teacher). When you are a teacher, you know how to better support a child (Father 9).

Participant fathers who were less involved in direct support were often more engaged in indirect support of the child by doing extra household activities or by taking care of the other child(ren).

Wednesday afternoon, when I am home, I always prepare the food while you are taking the son to physiotherapy (Father 6).

Then I say: 'If you (husband) take care of Bob, I will do the homework with Susan' (Mother 5).

One participant father was not at all involved in the activities related to the special needs of the child.

In fact, when I have a late shift, you need to do this instead of me (Mother 1). Yes I should do this but I get up at 4 a.m. (Father 1).

### 4.3.1.3 Leisure

Leisure activities discussed were those activities carried out by participant parents with or without their children to solely enjoy life during their so-called free time. During this time, they were free to choose what to do.

#### 4.3.1.3.1 Family-Time

Family-time was the experienced available free time used by participant families for well-being and life satisfaction through chosen activities. These activities were mostly centred on the joy and well-being of children with parents' preferences being secondary. Leisure activities within

the family-unit were tailored to the children's interests and therefore waver on the intersection of the leisure and family-life area.

Sometimes we do a walk near 'De oude Kale' (Mother 12). Yes, we do this as well (Father 12). The children like this a lot. If the weather is nice, we try to do something outside (Mother 12).

If the weather is nice, we try to go to the playground with the children (Father 5).

#### 4.3.1.3.2 Me-Time

Me-time was the experienced available free time used by the individual participant parent to engage in personal well-being and life satisfaction while performing leisure activities.

Eight out of twelve participant mothers and six out of twelve participant fathers were lacking some me-time.

I have the impression that I have no me-time. Everything that I am doing is in favour of my children or my husband (Mother 1).

To take some time for yourself, just half an hour. This is never possible (Father 5).

Especially participant fathers found alternative ways to create me-time.

I am a social person, I like to be with other people but the travel (for work) is always lonely. That is also me-time for me. I am able to listen to my music, to read my own book. For me this is balance (father 2).

I think that my me-time is partly completed during the weekends. I like to drive my car, so this is an excellent moment for me to quiet down after work. I can also listen to the radio, listen to my music. So I am satisfied (Father 4).

Nine out of twelve participant mothers and six out of twelve participant fathers started me-time once the children were ready for or already in bed.

When I go to sport and they ask me to start at seven, I always say no, this is too early for the children. At 8 p.m. is okay (Mother 11).

You can start things for yourself after 9 or 9:30 p.m. (Father 3).

Participant couples alternated being at home with the children to give each other the opportunity for me-time.

We arranged it like that, so that we do not have to ask for a babysitter, we alternate our hobbies (Mother 8).

We alternate the evening routines and I go running when it is my wife's turn to do it (Father 12).

#### 4.3.1.3.3 We-Time

We-time was the experienced available free time used by the participant parental couple to engage in well-being and life satisfaction as a couple while performing joint leisure activities.

Ten out of twelve participant couples mentioned lacking we-time. It appeared difficult for most parents to ask someone to take care of the children to just enjoy life as a couple. The fact that some parents already receive considerable family-life support, makes it complicated for them to ask for child care support which would allow for we-time.

The problem is that we do not want to bother someone to take care of the children, so we don't do this often (Father 11). We prefer to ask them when there is a party (Mother 11). If it is really necessary, then we will ask them (Father 11).

When we go to work, my father comes in the morning and my mom picks up the children when she is free. We do not want them to come in on the weekend (Mother 5).

It appeared that a lack of we-time was the result of being forced to alternate activities in order to enjoy me-time.

Now it is always splitting up, we can't do things together (Father 10).

However, one participant couple has we-time on a regular basis.

We go out regularly for dinner (Father 12).

It has been a while but we used to go on city-trip twice a year without the children (Mother 12).

#### 4.3.1.4 Rest and Sleep

Activities used to quiet down were covered by the occupational area 'rest and sleep' as participant parents identified to need these activities to relax and recover.

One participant father enjoyed his commute home from his job to quiet down.

I am in the car for a long time but I like this. It is a moment to bring my working day to a close (Father 4).

One participant parental couple took intentional time to have a rest each Saturday in the early afternoon.

Saturday from 1:00 p.m. till 2 p.m. we take a rest on the couch. At that time, the children do not bother us (Mother 12).

One participant mom tried to take the time to rest but she was too tired by the time she was supposed to rest.

In fact, I go to bed later than I should because I take time to rest in the evening. This is at the cost of my sleep. Not so ideal. The sad thing is that I fall asleep during my time of rest (Mother 8).

Knowing that you need more rest but ignoring this need happened quite often. Some participant mothers rested by watching television but only when their household duties were finished so that they won't have to get up again once settled down.

We need more rest but we do not take these moments (Mother 10).

We want the table to be cleared off. However, when it is too late, we are afraid that we cannot get up anymore once we are sitting on the couch (Mother 9).

When I settle down, I almost always fall asleep. So, I keep going until I am ready with my household (Mother 11).

Some of the participant mothers are falling asleep after a long day at work. Two participant fathers mentioned this as well. One has a physically demanding job whereas the other recently got a new job with a lot of responsibilities.

You sleep (on the couch) three evenings out of five before the children go to bed (Mother 5). Yes, but when you have been working so hard for the day and in the winter, it is even worse as you are outside in the cold weather all the time (Father 5).

When the children are in bed, we both fall asleep on the couch (Father 9).

One participant parental couple used, from time to time, one hour of their sleeping time to create some extra time for themselves as a couple.

Sometimes we (spouses) wake up one hour earlier. Then we talk, otherwise we do not have time to talk (Father 10).

Two mothers were not able to have a restful sleep or lacked sleep due to stressful situations.

And now I am tired and I have to wake up (Mother 11).

The sorrows in my head keep me awake (Mother 10).

### 4.3.2 Theme 2: Occupational characteristics

A number of occupational characteristics were mentioned by the participant parents, which they had individually linked to their daily occupations. The assigned occupational characteristics were influenced by the person's experience while performing it. This experience might be related to the activity itself, to the emotions experienced and the circumstances in which this activity was performed, or through the acquired recognition of performing that activity.

Two immediate occupational characteristics related to the occupational balance of parents raising a child with special needs were derived from the data. The first one appeared to have a more important effect on the overall sense of occupational balance and related to experienced mental energy. A second influencing characteristic was social occupations. Parents talked only about social occupations if at least one person from outside the family unit was involved. Occupations performed within the family unit were not named as social occupations.

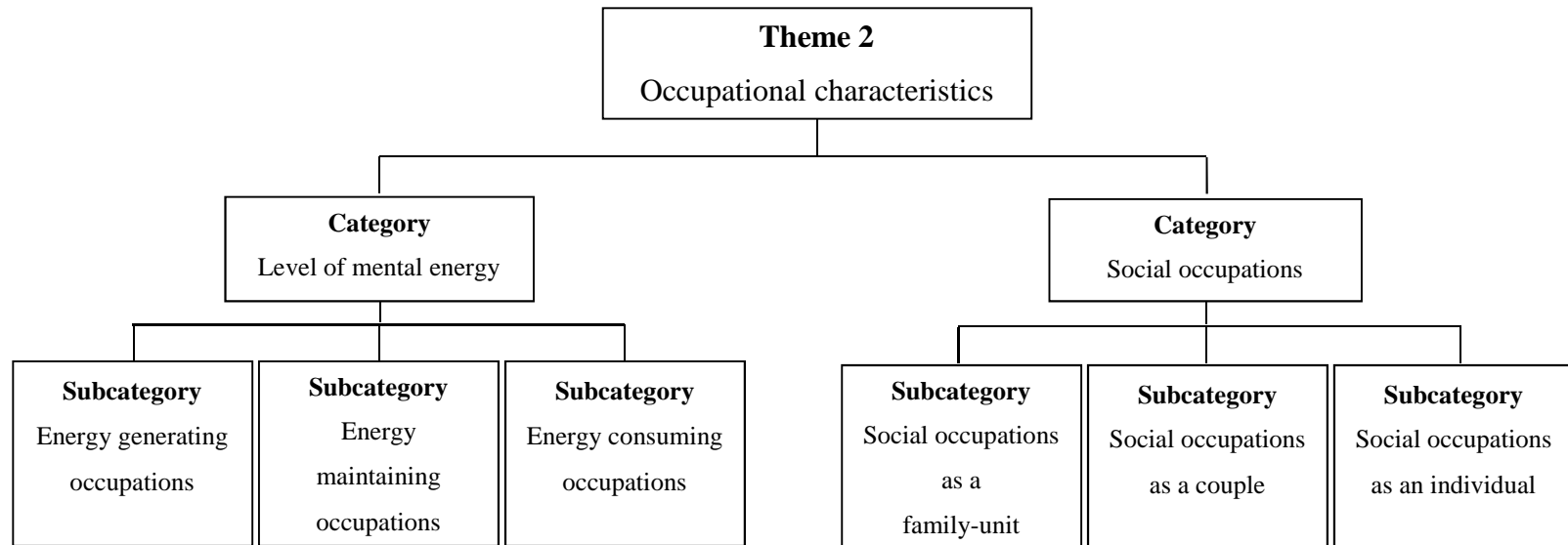


Figure 4.2 Occupational characteristics

### 4.3.2.1 Level of mental energy

The amount of mental energy obtained through a certain activity was affected by the degree of satisfaction as experienced by the participant parent during or after the activity. Levels of energy were divided into energy generating, energy maintaining and energy taking activities. Parents easily explained energy influencing occupations but had difficulties to mention activities that do not have such a clear effect on energy.

#### 4.3.2.1.1 Energy generating occupations

The energy generating occupations were those identified by the participant parents as ‘recharging the battery’ and are considerable sources to preserve occupational balance. Fathers and mothers create energy while doing something joyful together with their child(ren) as a family. Also one parent of the parental couple loved entertainment with the child(ren). Other influences such as preferred personal activities and those used to clear the mind seemed just as important.

Generally, participant mothers gained energy while performing activities together within the family unit. No participant father mentioned this spontaneously during the interview.

I just get energy when we're all together at home doing things together, I get a lot of energy (Mother1).

What gives me energy is the activities that we do together (Mother 12).

Energy could also be developed on a one-on-one basis with the child(ren). Individual activities with the children differed between mother and father. As an example, some participant mothers described enjoying watching television together while fathers preferred to do practical activities.

The brother is allowed to watch half an episode while the sister can watch it until the end. That gives me energy, watching ‘Family’ (soap series) together with them (Mother 1).

He (child) asks me, “How do I need to do this?” “We have to discuss it and he is very happy that he could work with his hands instead of being somewhere in a corner with a book. That gives me energy (Father 3).

Two participant fathers included their child within their preferred personal occupations.

I try to perform a part of my hobby (fishing) as much as possible. My son became interested in this hobby as well (Father 5).

I do this (judo) every Wednesday and Friday by myself. Every Sunday I coach my son and the other children of his team (Father 8).



Another energy generating occupation for both parents is experiencing their children enjoy an activity.

Going out with the children. When I see them having fun, I am enjoying that as well, it is charging my battery. If they tell you at the end, it was a nice afternoon, this satisfies you. You gather energy as well (Father 10).

Like football, when you see how they enjoy it, it stimulates you (Mother 5), yes it gives you energy (Father 5).

What gives me energy? Their hobbies. I like doing them. It seems crazy but when you are together in the car and they tell you what they did and how they have enjoyed it, I like it. Yes, those talks are enjoyable. (Mother 4).

Preferred personal activities gave the person satisfaction when they were done. Participant parents stated that they got energy from tangible activities. Some fathers could get it out of their job, like plastering or by selling healthy energy drinks.

My work (plastering) gives me energy, I love my job, if not I would have stopped it (Father 3).

Giving information related to my second job (selling a healthy energy drink). Not only because of the product but also because of my interest in other people, what they need, their total concept. This gives me energy (Father 1).

Others did it on their own time such as building a staircase or constructing furniture.

Creating things that are tangible. That's it for me, yes, it gives energy. So, I put energy into something that remains for a long time, I like that (Father 11).

Participant mothers also described tangible activities as creators of mental energy.

When I have finished ironing and I did one basket of laundry and everything is finished, I can get energy (Mother 1).

Mental energy boosts could also happen after doing an activity. The results of putting in a lot of work into something could inspire further action.

When I get my results (from a retraining course), and I succeeded, that gives me energy as well. (Mother 7)

Sometimes, I feel an urge so strong that I count till I reached the apex of curve (while biking). Yes 20 and then the following curve, 18. Yes and you stick to it, until you have it. (Father 10) This is the same for me. I always try to shorten my time (when running) (Mother 10).

Besides visible results and satisfaction for oneself, the recognition received by others produced energy. One participant mother described having prepared a well-received meal as giving her recognition further fuelling her energy.

When I have cooked something new and everybody likes it, this gives me energy (Mother 1).

Another important aspect of energy generating activities were those used to clear one's mind. This could be done in a variety of ways including such activities as clay pigeon shooting or sport activities.

As a matter of fact, I have to satisfy my anger through clay pigeon shooting. When I come home I feel resolved (Father 5).

I will not stop doing Judo, as this is medicine for me, it clears my mind. How should I say this, it keeps me balanced (Father 8).

Loudly expressing some frustrations was helpful also to refresh one's mood again.

Once the children are in school and my wife is at her work, I experience an oasis of peace. I can do my groceries. It is annoying when something is interfering with it. That happens as well. But it is indeed easier for me to respond to my personal needs. I can, like you (wife) were saying, open my throat (scream) when I am alone. No one will suffer (because of) it. I can without embarrassment and guilt say that I can curse for three to four minutes. Nobody will think what is going on with that one. But after doing this, how do you say that? You can clear your mind and you are able to go on (Father 6).

Everyday activities like doing the household chores could influence one's inner peace as well.

When I'm cleaning on Friday, I'm actually physically tired but I feel very different because I'm here alone. Even though I have to clean and to make sure our house is clean, I do not mind as I can clear my mind (Mother 9).

#### 4.3.2.1.2 Energy maintaining occupations

Energy maintaining occupations were those identified by participant parents as neutral, which kept the energy on an approximately unchanged level.

These were activities that took energy but were compensated for by the joy of doing the activity.

I'm so happy to go to work, I love it so much, but I have to say, it is a demanding job. It takes too much energy I would not do it anymore I suppose if it did not bring me joy. The joy definitely compensates for that (Father 4).

Household activities completed efficiently without being disturbed and without time constraints kept energy balanced.

When nobody is disturbing me, I can mop or iron efficiently (Mother 6).

An obligatory activity, once it has become part of the daily routine did not have an influence on the energy level.

With activities that I am obliged to do, I do not mind it anymore, once I can put these in my routines. I feel ok, as soon as that activity becomes a habit (Father 12).

#### 4.3.2.1.3 Energy consuming occupations

Energy consuming occupations were those identified by participant parents as activities consuming a lot of energy causing people to feel mentally tired during and after the activity.

One of these activities was negotiation with the child to do a requested activity such as homework, exercises for therapy, or daily activities.

Conversations like “Papa I do not want it”. Always that battle with its negotiations (Father 11).

Negotiating consumes energy. This is clear for me. It is really tiring to give him structure every time and to hope you can convince him to do what you want him to do (Mother 4).

Another example given by parents was a feeling of powerlessness about not knowing how to handle a situation while supporting the child or being concerned about the future.

What makes me feel tired is when the child does not understand what to do after many mathematical exercises or when she is not interested or when her attention is gone, she is playful and her mentality is still very young. Those are moments I might become angry and start shouting (Mother 2).

If it does not work out efficiently, I'll be pretty tired. On Saturday, she has been crying for over an hour because she had to do her sums. I became nervous. ‘How is it possible that you were able to do this and now, you cannot do it anymore?’ (Father 11).

The combination of work, caring and supporting activities limited the time to get things done at home, which also resulted in the depletion of energy.

I was not able to maintain my house anymore. I was crying because the house was not clean. It was too much for me as I am perfectionist (Mother 2).

I have no peace of mind, there are so many things I still want to do and arrange, but I am not able to do it, this makes me lose a lot of energy (Mother 11).

A tiring working day made caring and supporting activities more challenging and energy demanding.

My work makes me mentally tired. The pressure of making the inspections although I am shown kindness, there is always an atmosphere of enmity. If you do this a whole day long, you feel mentally tired. If you come home and need to discuss schoolwork, you think, is this really necessary (Father 8).

#### 4.3.2.2 Social occupations

During the parental interviews, activities performed together with different members of the nuclear family, without a person from outside the family, were not mentioned as being social occupations.

Some spouses within the participant couples expressed having differing social needs. Five mothers expressed wanting more social occupations whereas only one father mentioned this feeling of occupational imbalance.

Towards social life? I need more social contacts. You (wife) have fewer needs, isn't it so? (Father 9).

He meets his friends when he goes fishing, but I do not have this (meeting with friends) at all (Mother 5).

I would like to meet more people but I know that you (husband) do not have this need. On the other hand, I do not take some initiative either (Mother 8).

One participant mother described that on the one hand she liked social occupations but on the other hand she could not clear her mind completely as she did not stop thinking about her busy time schedule.

I like to go to parties but in my head, I am always busy. Tomorrow I have to do this and this and this (Mother 11).

##### 4.3.2.2.1 Social occupations as a family-unit

This subcategory appeared because all participant families had social occupations where the whole family-unit was involved mostly together with other families.

I have to admit, we have a nice group of friends, all have children around the same age. The children can play together, that is easy for them (Mother 11).

It could be limited to occupations with the broader family or just with a limited group of friends.

Now we mainly do activities with people who also appreciate him (child with special needs). That is something that has changed. Our social life is not limited. We have fewer people but actually do more

than before (Mother 3).

Every year, we go on holiday with my parents and my sister somewhere in the Ardennes in a big Chalet (Mother 5).

All participant families had these kinds of social occupations but the frequency differed among individual families.

We don't do this often, if we go to friends, the children join us (Mother 1).

It happens on Friday evenings, when the children are coming home from rope skipping, that they (the other family whose children are also at the rope-skipping come with their family to us or we go there. Even though it is already 8 o'clock in the evening. We come together and play board games (Father 9).

#### 4.3.2.2.2 Social occupations as a couple.

Social occupations as a couple were seen as the shared social activities of both parents with other people. Two participant couples did not mention having these kinds of social occupations.

We have a quiz group. (Father 4) We do this now since 2 or 3 years. (Mother 4)

Going to a concert with my wife and friends. I really enjoy that (Father 9).

#### 4.3.2.2.3 Social occupations as an individual.

Every participant parent is involved in social occupations without children or partner. Some parents have these social contacts rather sporadically.

I would go to have a drink with some of my ex-colleagues. How often would that be? Maybe once in four months (Mother 1).

These last years, we often play escape rooms. You are locked in a room and you have to solve riddles in order to open doors and to find your way out (Father 12).

My husband gives me the opportunity every year to spend a weekend with friends (Mother 6).

Going to work was expressed by one mother as being a social occupation as well.

I am very happy that I can go to work. To be together with other adults and to be able to chat a little bit (Mother 1).

### 4.3.3 Theme 3: Time Use

The availability of time a participant parent needed in order to perform one or more occupations, was defined as time use. Some activities needed to be performed in too short an amount of time and gave parents a feeling of having a lack of time to do certain activities properly. At other moments an adequate amount of time was available and during holidays for instance extra time was experienced.

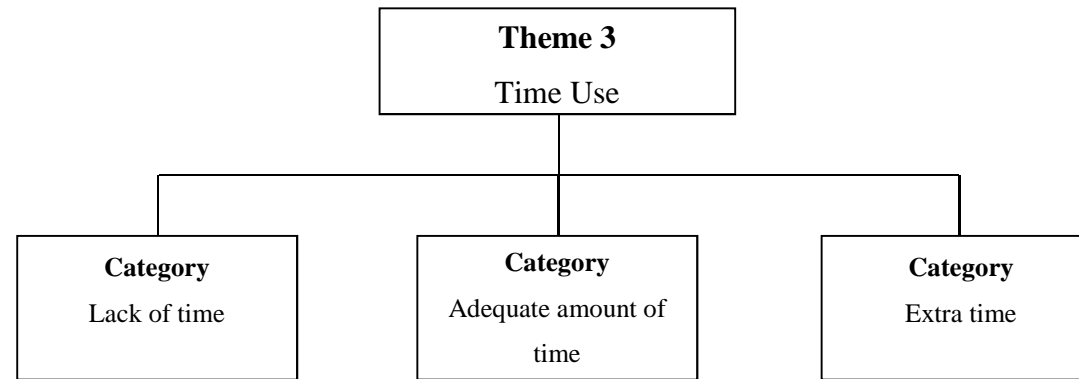


Figure 4.3 Time use

#### 4.3.3.1 Lack of time

Participant parents experienced some lack of time at moments that the available amount of time was not in relation to what had to be done. Parents experienced the impact of the availability of time on their lives but mentioned that they themselves organized their lives in such a tight timeframe.

I did not have this pressure in earlier days. I woke up and I was able to organize my work but now the children are there (Mother 11).

A human being is always lacking time. Why? Because you organize it like that (Father 10).

Like on Wednesday, my son goes to football, the eldest daughter goes to the baton twirling. In between we have to prepare dinner and we need to get the children. Hence, we make our life busy (Mother 1).

Being under time pressure during work was perceived by some participant parents as well.

I work for the government, so the political deadlines need to be achieved (Mother 6).

At work, more and more is expected from the same group of employees (Mother 5).

Participant parents were lacking time for extra special-needs related activities that were not scheduled weekly such as a visit to the doctor or parent talks at school.

The special parent talks at school are an attack on my holidays (Mother 6).

#### 4.3.3.2 Adequate amount of time

Participant parents expressed having an adequate amount of time at certain instances to do what they thought was needed, at a comfortable pace.

The four of us walk to school. We wait there until the latter group has entered. We stay for approximately 10 minutes at the school entrance to have a talk and to settle down (Mother 4).

On Monday, I arrive always home in time (Mother 12).

#### 4.3.3.3 Extra time

The availability of some extra time to do the activity properly felt comfortable for participant parents.

I have to be at work at 9 a.m. As I go to work by train I arrive at 8.25 a.m. In fact, I arrive 35 minutes early but I do not mind as this gives me the opportunity to gradually increase the pace (Mother 8).

Parents experienced this extra time on Sundays as they use this day to relax and get ready for the coming week.

I like Sunday, as this can be a pyjama-day, we can stay in our pyjamas until late in the morning (Mother 6).

Sunday evening, we keep it calm. From 7 p.m. onwards, we settle down to start the week again on Monday (Mother 3).

I am always happy when it is Sunday because it is calmer (Father 1).



### 4.3.4 Personal Factors

The overall theme of the personal needs of a participant parent and the available coping strategies they had were named personal factors. Within this study these personal factors shaped parents' occupations as well as linking subjective feelings to their different occupations.

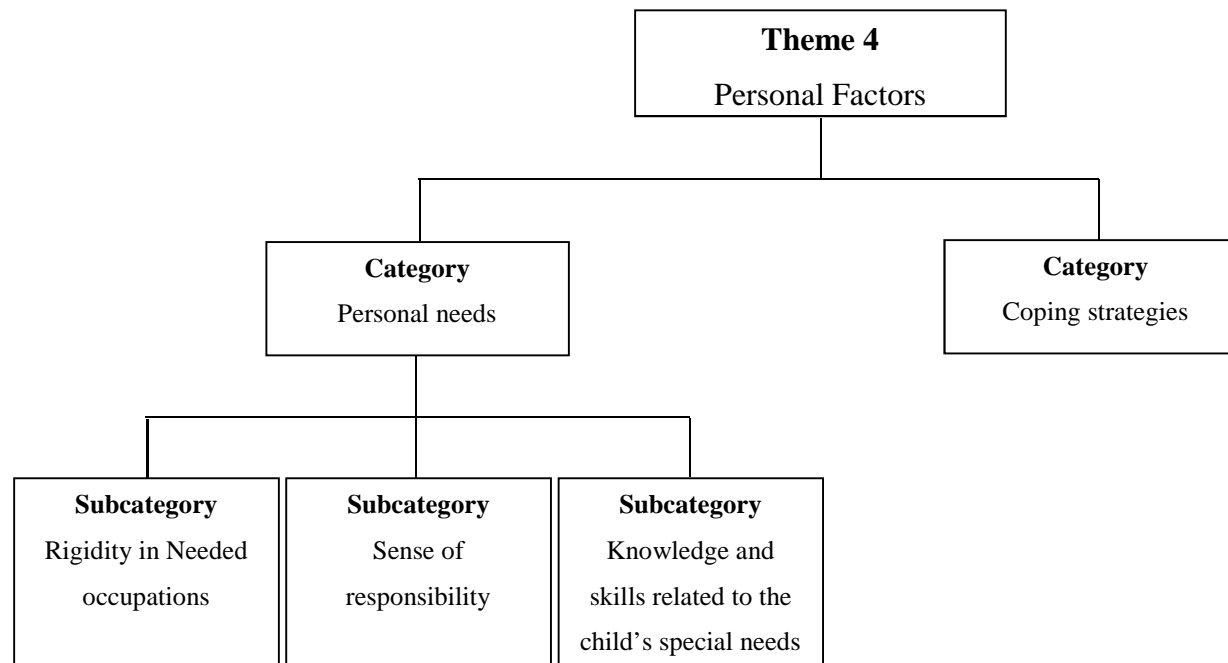


Figure 4.4 Personal factors

#### 4.3.4.1 Personal needs

Each parent had personal needs related to his or her life. These needs were influenced by the expectations he/she had towards the different occupations in life.

##### 4.3.4.1.1 Rigidity in needed occupations

Sometimes parents needed to do an activity in a certain way and at a certain time due to a personal need. Consequently these parents were guided to rigidity within their occupations, related to the household chores, such as clearing and cleaning the house. These participant mothers felt uncomfortable when they did not succeed in their foreseen occupations.

I do this (organizing papers) immediately, it has to be done otherwise I do not feel well (Mother 2).

The playroom has to be always clean (Father 9). Always is a big word (Mother 9). But I can say, it is a playroom, let it be. For you this is difficult (Father 9).

##### 4.3.4.1.2 Sense of responsibility

In this study the awareness of a parent that he or she should perform his/her parental duty properly, influenced the feeling of success in the parental role. The experienced negative feelings were influenced by the parent's sense of responsibility.

I have always said: I do this (stimulating and supporting the child/ren) as it is my responsibility (Mother 2).

We ask them (the eldest children) seldom to stay with the children. It was our choice to have children, we do not want to put this burden on them. They are children themselves (Father 10). It is not that we cannot ask this (to babysit) we do that rather rarely. It is the principle, that they are my children, it was my choice. They do not have to take care of one another (Mother 10).

Feelings of guilt were expressed by two participant mothers and two participant fathers. A feeling of failure was described by both mothers especially when something went wrong.

I feel guilty towards Susan (child with special needs) as I could give Bob (her brother) quality time and I was not able to give this to her (Father 5).

When everything goes well, when there is a decrease of weight (the child has a metabolic disorder and is on a strict diet) , yay, I did it well. When there is an increase of weight, I failed. Again, I did not do my best (Mother 5).

We also meet his barriers (what he is not able to do) when we are confronted with his autism. This makes me sad. I did not succeed. The feeling of having failed (Mother 6).

#### 4.3.4.1.3 Knowledge and skills related to the child's special needs

Knowledge and skills related to the child's special needs were seen in this study as the knowledge acquired due to the diagnoses and special needs of the child. This was in combination with skills to support and stimulate the child properly. Consequently these knowledge and skills were seen as personal needs of a parent to achieve competent parenting.

I am privileged that I have that job (primary school teacher). When you are a teacher, you know how to better support someone. When I sometimes see how she does this, I think "some parents have to suffer with their children" (Father 9).

We went to an information evening on Speech and Language Developmental Disorders. You understand your child better this way. But sometimes my wife needs to remind me: "What did you learn there?" (Father 10).

When a participant parent was lacking knowledge related to the special needs of his / her child, he/she felt powerless and became nervous.

When you work with her, you will need extra time as she is easily distracted. (Mother 11). On Saturday, she was crying for one hour. She had to do her exercises (math). I was finally so nervous. How is it possible that you could do this and that you are not able to do this anymore? How is this possible? (Father 11).

If you are in education yourself, you know much better how to perform. When I see her (wife) supporting our son (with special needs) I often think: 'there must be a lot of parents who have to struggle with their children' (Father 9).

#### 4.3.4.2 Coping strategies

Participant parents showed the ability to cope with the limitations of certain activities to ameliorate their occupational balance.

Some parents were able to adapt an activity or gave it a different meaning by transferring a certain activity into a joyful and meaningful occupation.

Because I was for years on the road, I learned 'between brackets' to enjoy traffic jams. It is a moment that I cannot change. Make a virtue of necessity. Enjoy that moment alone and the experienced rest (Father 1).

I used to go to football matches. I had a subscription but I have stopped it. I enjoy football from my couch. Why to spend that money on it? It is a whole engagement. You are always bound and now you are not bound anymore. They play at that time and you need to be there. Now I can record it and watch two hours later (Father 1).

One mother explained she was gaining me-time as she went to her job by train. This had some influence on her me-time at home as well.

It's been 2 or 3 years since I go to work by train. I can read 25 minutes in the morning and in the evening and I like that. Once you are in that book, you will try at home to steal some minutes to read further. If you need to start a book, you will not do this so quickly (Mother 8).

One parental couple was very inventive/innovative in creating some we-time. This was possible because their children could stay home alone for a while.

My husband likes to go with me to the shop in the neighbourhood. That is to buy a piece of chocolate for example. That is a moment that we can (Mother 6) talk with each other (Father 6).

If it is possible, together we bring our son to the dancing class. We do this to have one hour together, to talk. (Mother 6) Otherwise it is difficult (Father 6) You cannot text all the time (Mother 6).

### 4.3.5 Theme 5: External Factors of Support

The components of support that can be transmitted from one individual to another were considered as the external factors of support within this study. As support can be given and/or received the occupational pattern of each participant parent was affected and therefore had an impact on parent's experienced occupational balance.

Participant parents within the family-unit strived for the best in their parental roles. This means that they had to support each other to facilitate wellbeing of the individual child and parent. Consequently, the following categories appeared: giving support, receiving support and both parents providing mutual support.

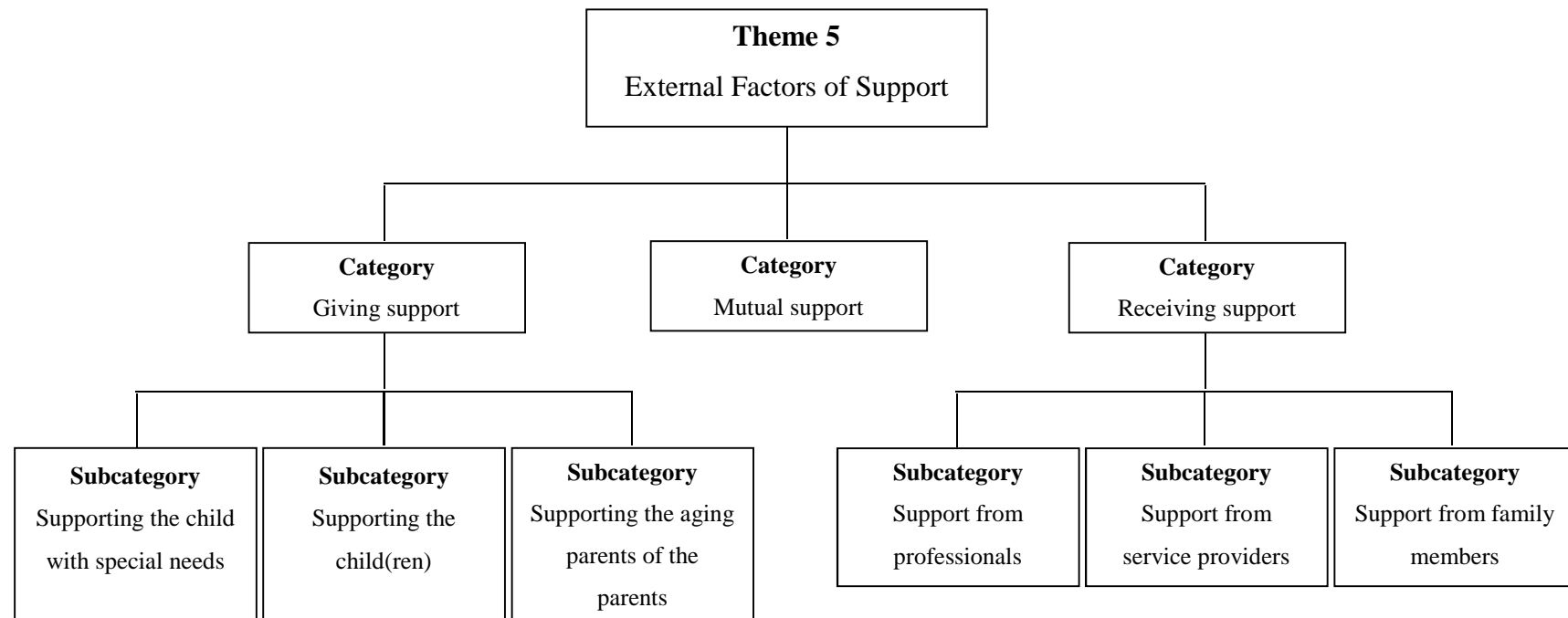


Figure 4.5 External factors of support

### 4.3.5.1 Giving support

The category of giving support involved expressing support to others around the participant parent such as children and their own parents.

#### 4.3.5.1.1 Supporting the child with special needs

Parents within the study needed to give different levels of support to the child depending on his or her special needs. Stimulating the child to accomplish tasks required a lot of direct (mostly given by mothers) or indirect (mostly given by fathers) support. Decreasing the developmental gap through teaching the child was a common task of all participant parents, except for one father. Components such as arranging, traveling to, attending, and completing homework for therapy were critical to the support of the child.

I stay there because Lena likes this and this engages her. I can see what the problems are and how the therapist is working with her. I stay there during that hour so that I can make notes (Mother 2).

I try to start with the homework of the child because after dinner it is often too late (Mother 8).

Parents had to arrange and acted as a bridge between the child and the environment.

Some schools where we went to look allow him to work with the computer and certain software to help him. Like in Word, when you type one letter, the whole word appears. He needs to be able to assimilate enough during the lesson. Otherwise he will only focus on the writing and not on the course content. So it is important to choose the best school for him (Father 10).

Organizing all kinds of supporting activities led the participant parents to the role of coordinator, as they had to keep an overview on all the necessary support needed by their child.

This endless organisation takes a lot of energy. Always planning and organizing (Father 11).

You have to plan constantly, this day this and that day that. Sometimes it is too much in one week because normally it is on Thursday the physiotherapist and on Friday the dietician (Mother 5).

#### 4.3.5.1.2 Supporting the child(ren)

The activities related to the child without special needs were a part of giving parental support. As a matter of fact, not all the assistance and stimulation towards a child with special needs was supplementary for the participant parents when compared to the support given to a child without special needs. Many of these activities were common within everyday life.

Serving the children a healthy meal is related to regular parenting.

On Tuesday and Thursday, the children come home at noon to have lunch (Mother 7).

Taking their children to their hobbies and school are assignments linked to parenting as well.

I bring them to the school at 8:15 a.m. and I go to work (Mother 2).

At 6:30 p.m. we had to leave for the dance school. That is the reason why the food had to be ready at 6 p.m. (Father 6).

Saturday afternoon Charlotte is going dancing. You (father) will take her most of the time (Mother 10).

Another example of providing support to children is preparing them for bed.

We have an evening routine to put the children in bed between 7 p.m. and 8 p.m. in the evening (Father 12).

#### 4.3.5.1.3 Supporting the aging parents of the parents

Some grandparents required additional support from their own children due to limited abilities.

The cause of the needed support ranged from not owning a car to having dementia.

I take her often home on Friday afternoon to drink a cup of coffee. She lives nearby. On Tuesday in the afternoon I go to visit her and keep her company (Mother 2).

My parents need me from time to time (Mother 6).

I went to Grandma yesterday because she didn't feel well (Father 10).

#### 4.3.5.2 Mutual support

In order to meet the needs of the children, participant spouses had to support one another. The occupational pattern of one spouse influenced the occupational pattern of the other in order to maximize the parental availability for the children.

In most participant families, the mother's occupational pattern showed more availability towards the children. It was common for a parent to accommodate their schedule to make job requirements possible and to provide me-time for the other parent. Mothers and fathers were both flexible in the support for me-time but in most of the cases it was the mother who adapted her schedule to the requirements of the father's job.

We arranged in such way that we are gone (for the hobby) during a different evening (Mother 8).

My husband makes it possible that I can do a trip with friends one weekend a year (Mother 6).

Then (when the husband has a late shift) I wake up at 5:45 a.m. and I leave at 6:40 a.m. (Mother 6) I left at 8:20 a.m. with Charles to the school (when the husband has an early shift) (Mother 6).

### 4.3.5.3 Receiving support

Receiving support was seen in this study as the transmission of support from the external environment to the individual. This was another aspect allowing the participant family to strive for well-being of each family member.

#### 4.3.5.3.1 Support from professionals

Children received support from professionals on a regular basis to lessen their developmental delay.

The therapist could give this encouragement at his or her practice, at home, or at school.

She (Speech and language therapist) comes to school and during the holidays to our house (Mother 1).

I go to the physiotherapist with the child (Mother 8).

Those participant parents who attended the therapy learned how to deal with the child's special needs and thus felt more supported.

You do not understand how this is possible and therefore the Speech and language therapist gives me a lot of support (to better handle the support) (Mother 2).

Sometimes the parents also needed to see a professional to better cope with their difficulties related to the child's special needs.

The psychologist supported us a lot. She told us how to react to certain situations (Father 5).

And because the conflicts with Jeff are most of the time with me I will go three times to the child psychiatrist (Mother 9).

#### 4.3.5.3.2 Support from service providers

Besides support related to the child's special needs, assistance to reduce the amount of household activities could be obtained from service providers.

Three participant families received some help from a professional cleaning lady in order to maintain their house.

Then we have decided to employ someone (cleaning lady) with service checks (Mother 2).

The cleaning lady comes on Monday (Mother 12)

Two families went out for dinner on a regular basis. One family does this every Friday evening. Children from two other families made use of the lunch facilities at school at least once a week. During that day, the parents did not have to cook at home.



On Friday evening, we do not cook. We go to a restaurant with the four of us (Mother 2).

We go to eat at a restaurant on a regular basis with the children (Mother 11).

On Monday and Friday, they eat a hot lunch at school (Mother 4).

One family used the facilities offered by the school to travel to the school and back home with the school bus.

At 8 a.m. the eldest son go to school with the bus (Mother 3).

#### 4.3.5.3.3 Support from family members

Support from participant family members was mostly given by the parents' parents. The activities done by these grandparents could be related to the child's special needs, to regular parental activities or to the household. In exceptional situations, a sibling of a parent or an older child of the family-unit could babysit during an evening or afternoon.

Seven families received support from the grandparents on a regular basis. This support was incorporated within the time schedule of the family in order to arrange the household, to go to work and to take care for the children's (special) needs.

Most of the grandparents assisted their children by taking care of their grandchildren before or after school.

When my wife has an early shift, my mother, my parents in fact come during the wintertime and during the summer time my wife's parents (Father 7).

Your parents pick up the children at school on Monday and Friday (Father8).

One grandmother brought her grandchild to the physiotherapist each week.

My mother goes to pick up the children every Thursday at a quarter to four because they have therapy (Mother 11).

Two brothers separately stayed overnight with the grandparents during the week to increase the well-being of all family members as the child with special needs behaved rigidly.

My parents have two grandchildren. The idea has grown to keep some balance in the family (well-being). Each child is, during the week, one evening a single child with the parents and one evening with the grandparents also (Mother 3)

One family had a lot of support from both grandmothers. Cooking, ironing and taking care of the children after school were activities of the wife's mother while the husband's mother

brought the children to the music school every week. When music school was closed, she to the cinema, to the sea, or undertook another joyful activity with the children.

Then she prepares the food. At 1 p.m. she brings the children back to school and does the ironing. That is also extra household help. At 4 p.m. she goes back to pick up the children. I said my mom is a very clean person, so she empties the dishwasher. She does the ironing, she sometimes puts the clothes away. She does a lot. In fact, I have a second household help because of her (besides the housekeeper) (Mother 12).

My mom was already home with the children. On Wednesday afternoons, my mom goes to the music school with the children (Father 12).

In the following chapter occupational balance will be viewed from different perspectives due to its layered nature of the concept. A schematic representation of the perceived occupational balance by parents raising a child with special needs will be discussed.

# Chapter 5: Discussion

## 5.1 Introduction

This study aimed to explore the occupational balance as experienced by mothers and fathers while raising a child with special needs. Similarities and differences within the occupational pattern and balance of both parents were part of the study as well.

Information was gathered through the central research question: ‘How do mothers and fathers of children with special needs perceive their occupational balance?’

The starting point of this study was the occupational balance concept as defined by Wagman, Håkansson and Björklund (2) who explained that occupational balance is perceived once the number and diversity of occupations lead to a personal balanced pattern (2). Within this study each parent has his/her personal occupational pattern, tailored to that of his/her spouse in order to make the essential job and family life related occupations possible in the first place. All parents have a personal and recognizable pattern in their daily lives in which the amount of and variation in occupations are recurring with a certain regularity.

As shown in Figure 5.1, the occupational pattern can be looked at from three different perspectives, interconnected with each other and finally leading to the perceived occupational (im)balance. Within the schematic representation of the concept, two dots are used to make this interconnectedness visible.

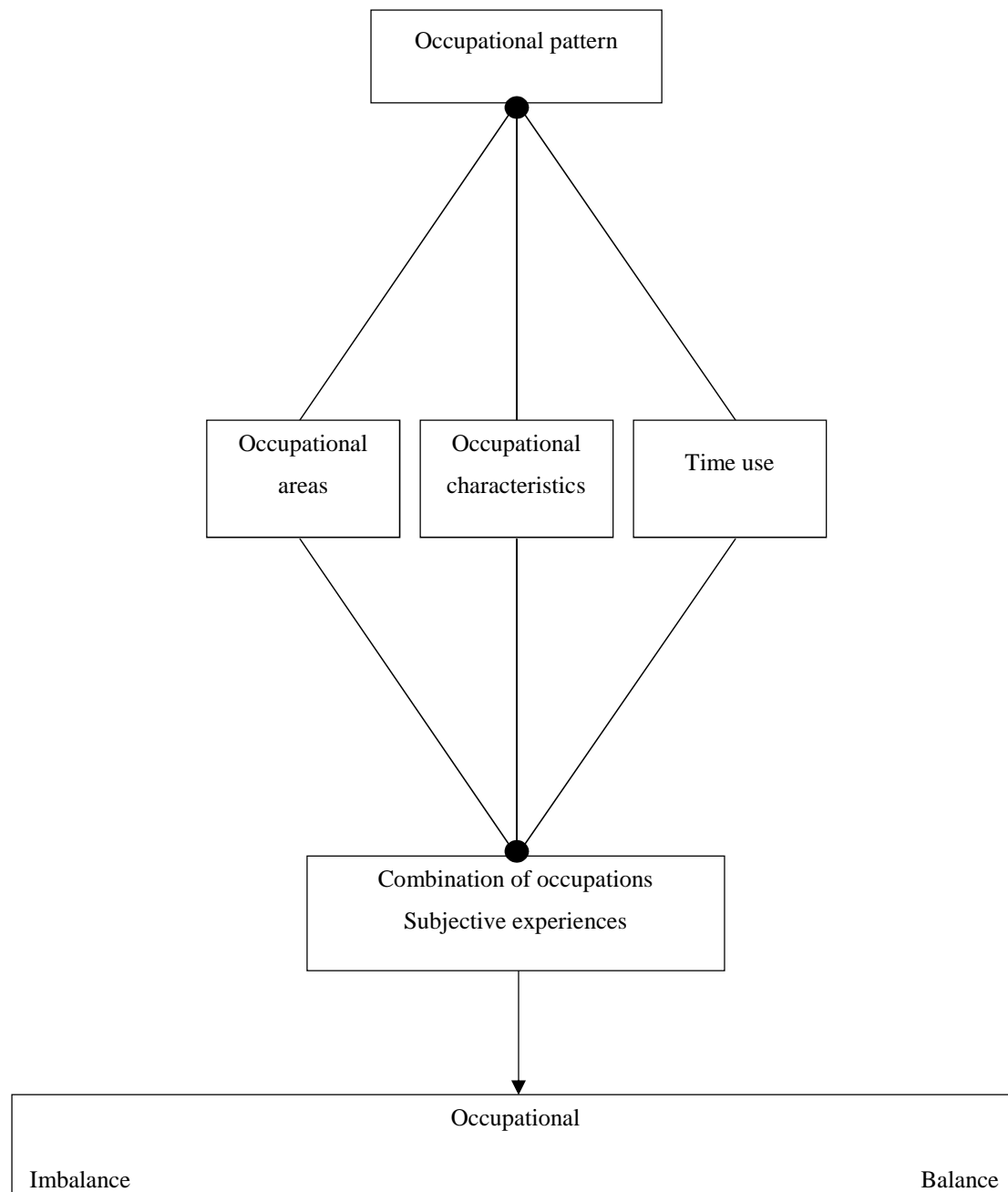


Figure 5.1 Schematic representation: concept of occupational balance as defined by Wagman, Håkansson and Björklund (2).

As mentioned in chapter 4, five themes emerged during the data analysis process namely: occupational areas, occupational characteristics, time use, personal factors and external factors of support.

In the discussion the researcher will present occupational balance from the intertwining of the different perspectives starting from the individual experience of each parent. Occupations related to work and family-life were seen as very important and therefore often prioritized within the occupational pattern. For this reason balancing work and family-life within the

occupational pattern will be discussed. Balancing family-life occupations in itself as well as leisure and rest and sleep occupations will be related to the occupational pattern. Finally findings of this study led to an adaptation of the occupational balance concept as described by Wagman, Håkansson and Björklund (2) when parents raising a child with special needs define their occupational balance.

## 5.2 Occupational balance viewed from different intertwined perspectives

It was evident from the interviews that an identical activity such as ironing could be experienced differently by individual parents, depending on the conditions of implementation and therefore influenced the perceived occupational balance. Did a person have enough time or must this activity be done in a rush? Did he/she experience it as an obligatory and energy taking activity or was it a tangible energy generating activity? Taking all these aspects into consideration meant that an activity, belonging to a certain family-life occupation such as household chores was intertwined with occupational characteristics and time use. Was ironing needed to be done immediately to experience peace of mind or could it be postponed? Was there some support from a spouse, a service provider or a grandparent? These questions indicate that besides the influence of occupational areas, characteristics and time uses other elements such as personal factors and/or external factors of support are affecting a parent's occupational balance.

Wagman, Håkansson and Björklund (2) confirmed that an individual person had to decide if he/she had an appropriate occupational pattern. The findings of this study indicated that this decision was influenced by personal needs or specific characteristics of each individual parent (personal factors). This could be linked to the stressful individual experiences of five mothers and two fathers who lacked knowledge and skills related to the special needs of their child. Insufficient knowledge of the diagnosis on the child's functioning while supporting the child with special needs had a negative effect on parental well-being. They felt frustrated, nervous and these supporting occupations were experienced as energy consuming. Therefore inadequate knowledge and skills on parenting a child with special needs were factors increasing the perception of occupational imbalance. Wilcock (8) emphasised this idea as she defined that occupational imbalance was determined by someone's personal capabilities, sense of responsibility and meaning. The influence of personal capabilities was emphasised by Jonsson and Persson (32) as too many challenging activities being part of one's occupational pattern would lead to occupational imbalance (32). One father expressed that his job was energy taking

during inspection days. Due to the faced challenges when inspecting different companies, the usual challenges at home were perceived as too much during those inspection-days.

Suzuki et al (15) indicated another influence of personal capabilities namely the link between, on the one hand, parental insecurity and incomprehension towards the child's special needs and, on the other hand, anxiety and nervousness (15). A lack of understanding of their child's special needs led to participant parents having expectations their child(ren) were not able to meet. Consequently low responsiveness on the child's (special) needs and high demandingness towards the child's performance were combined and resulted into parental stress. The imbalance between the parent's personal effort and the final result in their child's developmental progress was perceived as stressful and tiring. Vansteenkiste and Soenens (43) emphasized that the extent to which parents succeeded in harmonizing their children's needs influences their parenting styles as the combined level of responsiveness and demandingness leads to a certain parenting style (43). De Belie and Van Hove (14) named the above mentioned imbalance between striving for an outcome and the achieved result as 'parenting under stress' (14) and stated that this might influence the used parenting style.

Some participant parents make use of extra support to become better skilled in parenting their child with special needs. Others, especially mothers are attending therapy together with their child. According to this study parents who attend the therapy, knew better what to expect and how to stimulate their child. A competent feeling created less parental stress. Kvarme et al (66) confirmed that parental stress reduces once parents are skilled to raise their child with special needs (66).

In order to increase parental knowledge and skills to better support their child, findings from this study emphasised the need for extra available time. This time was often taken from another meaningful occupation, from the parent's personal interest, indicated in this study as me-time. Of the twenty-four participant parents, eight mothers and six fathers expressed lacking me-time within their occupational pattern. Wagman, Håkansson and Jonsson (83) confirmed that meaning and the availability of occupations for self-interest were indispensable to perceive occupational balance (83).

### 5.2.1 Balancing work and family life within the occupational pattern

Participants talked about their paid job while mentioning work. All participant fathers worked fulltime, while only two mothers had a fulltime job. The ten remaining mothers chose to work part-time. This was in line with decisions made by men and women on the Belgian labour

market where most working men worked fulltime and almost half of the working women preferred a part-time job (30). Having a child with special needs resulted for two participant mothers, in decreasing working hours. The other part-time working mothers declared that the harmonisation of work and family-life was an important reason to work part-time. McConnell (16) confirmed that parents reduced work-related activities as a solution to find on the one hand time for daily caring activities and on the other hand to improve family well-being (16).

Participant mothers and fathers both spent time on household, caring and supporting activities. Nevertheless, the mothers spent more time on household and caring activities compared to their spouses. Similar findings for Belgian women and men were released by Glorieux et al (37). Female participants of this study working part-time acted like other part-time working mothers in Belgium, using the released time to spread out household and caring activities (37). Participant mothers with more than fifty percent of a fulltime job experienced the combination work and family-life as overwhelming and stressful. Although the working time was reduced, the latter activities still needed to be done in a pressed amount of time. One mother did not share this experience but admitted that she received a lot of external support within the household chores. Three participant mothers working fifty percent of a fulltime job experienced a balanced work-family-life while the remaining seven participant part-time working moms did not share this feeling. Working more than fifty percent seemed to release too little extra time to suitably combine work and family-life and to feel balanced. Wada (84) reported also that when the combination work and family-life occupations did not fit, imbalance was experienced (84).

Although all participant fathers were conducting some household, caring and supporting activities, they all worked full-time and did not complain about the combination work and family-life. Apart from two of them who mentioned that the combination work and family – life was hectic. Participant fathers conducting a more traditional father role and identifying themselves as the responsible provider, hardly participated in household and direct caring activities. Despite the decreased differences occurring between the parental roles of mothers and fathers (59) the latter were still seen as the primary breadwinners (85).

Participant parents who had a job with flexible working hours used this flexibility to harmonize work and family-life. Attending a parent-talk or being able to pick up their child at school so that no aftercare was needed were examples given by the participant parents to strive for harmony and family well-being. Organizing working hours for family reasons without spending an official holiday or taking special measures was possible in Belgium for thirty-seven percent of all employees (86). Wada (84) confirmed the importance of a flexible working system as

being important to balance work and family life as both roles, employee and parent, are seen as important to be fully engaged in (84). The wish to harmonize family-life and to strive for the best was also expressed in the study of McConnell (17) and Wada et al (70).

### 5.2.2 Balancing family-life within the occupational pattern

Family life activities contained, for the participant parents, on the one hand household activities and on the other hand caring and supporting activities. Examples of household activities were cleaning the house, preparing healthy food and wearing nice washed clothes. Caring for and stimulating the children to develop their potential belonged to family-life occupations as well. The latter were divided into regular and supplemental caring and supporting activities. These activities were related to parenting a child while supplemental caring and supporting activities were extra activities due to the child's special needs. All these activities were seen as taking care of the family-unit to achieve a harmonised family life and a well-functioning family. This was endorsed by Wada (84) as she identified an intertwining between the parental perception of managing family life and Family Quality of Life (FQoL) (84).

Ten out of twelve mothers in this study were spending more time on extra caring and supporting activities such as therapy visits and stimulation of the child at home. Which is in line with the Belgian mothers who spent more time than their spouses on household, caring and supporting activities (37). Reasons for the participant mothers to take a bigger share on family-life occupations, were the chosen availability due to the part-time job, responsibility as a mother or the necessity for the individual to control these activities related to a specific characteristic such as being a perfectionist. Only one male participant was spending more time on household, caring and supporting activities due to a more suitable job as opposed to his wife. Another father was responsible for the caring and supporting activities of the child with special needs as he was better skilled as a primary school teacher. Although for most of these dual-income participant families parental roles became more or less similar, most mothers were more available to their children and especially to those with special needs. Those mothers saw it as their duty and were more accessible due to their part-time job. Fathers also felt responsible but the majority of them supported their child more often indirectly in the caring and supporting activities.

This study highlighted that the final responsibility of the household and caring activities was experienced strongly by all participating mothers and led more easily to a decrease in me-time. One mother perceived it differently as her full-time demanding job required a more or less



shared responsibility. She described her husband as a new man which meant that he was active in the household chores and took care of the children like a mother does in most Belgian families. Trifan et al (59) defined that although occupations of mothering and fathering had been intertwining more and more over the last 50 years, fathers were seen as an asset of support towards mothers in their caring roles (59).

Exceptions on the above mentioned task division were due to better knowledge on handling the child as a consequence of professional skills of the father. On the other hand better tuned working hours led to more availability. Nevertheless participant parents mentioned that tasks between fathers and mothers were clearly shared to maximize efficiency especially during the morning and evening routines. Bianchi et al in McGill (85) described the augmentation of childcare activities by fathers especially in routine tasks (85).

One could conclude that there was a shared intention and responsibility by the participant parents to care and support related occupations towards all their children. According to Wada (84) shared intentionality and responsibility are important to maintain a good partner relationship which is influencing balance of both individual partners (84). This was not the focus of this study. However participant parents indicated that they experienced a shortage of we-time which influenced the experienced occupational imbalance. Ten out of twelve participant parental couples expressed their desire to increase their we-time to achieve a better occupational balance.

Failure and guilt were experienced by nine participant mothers, due to their sense of responsibility. They experienced and/or did not allow themselves to have sufficient leisure time. Two participant fathers expressed feeling guilty as well. One of these fathers reduced leisure time to be more available for the children (with special needs). Another participant father who did not mention guilt, nevertheless reduced his leisure time. McConnel (16) stressed reducing leisure activities was one of the choices parents make to provide extra time for daily childcare and tasks related to the child's well-being (16).

### 5.2.3 Balancing leisure within the occupational pattern

Leisure was the third occupational area. These activities were performed during their so-called free time during which occupations to enjoy life could be chosen.

Me- and we-time were seen by parents as important sources to recharge and to increase the level of mental energy. Six fathers and eight mothers experienced insufficient me-time and

desired to find more time for oneself. Nevertheless, participant parents adapted their time schedule to make me-time possible for each other by alternating these activities in order to be available for the children. The fact that parents made the choice to facilitate me-time for each other, was at the expense of their joint we-time. Prioritizing me-time above we-time could probably be caused by a feeling of shared responsibility. As me- and we-time were important energy sources within the occupational balance, some participants within this study searched solutions to fill the gap. Starting me-time activities once the children were ready for or already in bed were answers used by nine mothers and six fathers. Adapting and/or giving a different meaning to a certain activity were coping strategies used by two mothers and four fathers to create some me- or we-time. One participant couple goes to the grocery shop in the neighbourhood, just to buy a piece of chocolate. This enables them to spend some time together and to discuss certain topics without the presence of their children. Being stuck in the traffic jam, gets a new meaning by one participant father who hardly has time to listen to his favourite music. The moments that previously would make him nervous due to a lack of time, have become meaningful as he starts listening to the music he enjoys. Lund et al (87) confirmed that if certain meaningful occupations could no longer be performed, adaptations to make these occupations possible again, even in a different way were important to experience occupational balance (87).

All participant parents mentioned not to spend less time with the siblings of their child(ren) with special needs. Ten out of twelve parental couples experienced a lack of time spending with each other as a couple. According to McConnell (16) parents raising a child with special needs were reducing leisure time to transfer to special needs related time and to the family-well-being. As a consequence less time would be spent for oneself and with the other family-members (16). These findings of McConnell (16) were partly supported by this study as the participant parents indicated that they did spend enough time with all their children (16).

Grandparents who still had the ability to support their children in their parenting tasks, were involved in some of the caring activities. One family was even supported in household activities. This engagement of the grandparents led to a hesitation of the parental couple to ask for supplementary support. Consequently we-time occupations were the first to be excluded although they were indicated as energy generating and led to occupational balance. Additionally Wada (84) described that the quality of relationship of the parents is a determining factor to experience occupational balance by both partners (84).

Families in this study who could not rely on the grandparents for some support experienced not only less help but they also had extra duties at the expense of their me- and we-time. The participant parents in this situation provided some needed assistance to the grandparents. Being part of the sandwich generation, another supplementary role emerged for those participant families. Besides the care and support for their children an additional task arose in providing care to their parents. This extra duty made those participant parents more vulnerable to experience occupational imbalance as more responsibilities were required within the same amount of time. Evans et al (88) identified that awareness on role balancing is essential if a care giving role towards for instance aging parents is required (88). According to Seghers (89) managing skills are indispensable to combine all needed and desired occupations if supplementary care is required as time is experienced as being limited (89). A different time schedule and prioritizing certain desires are advices given by Seghers (89) to compensate for the perceived time restrictions (89).

Social occupations with at least one person from outside the family were experienced as enjoyable and increased one's level of mental energy. During these activities, social contacts with the involvement of the entire family-unit were prioritized by participant parents above other social occupations. This was an opportunity to enjoy life with the entire family- unit. The experienced well-being of the different family members resulted in a positive feeling which generated energy for the parents.

All participant parents enjoyed time with others on an individual bases as well. Joint social occupations as a parental couple with at least one other person were rather sporadic in many participant families. Although every participant family had social occupations, more mothers than fathers mentioned the desire to increase them. Despite their longing towards more, no initiative was taken by these participant mothers. They experienced difficulties to be fully engaged within social occupations. Thinking of all the household chores that needed to be done was an important cause of neglecting their social needs. As a consequence those mothers could not fully enjoy the social occupation and continued to feel an imbalance. Wada (84) confirmed that full engagement is necessary to feel balanced (84).

#### 5.2.4 Balancing rest/sleep within the occupational pattern

Activities used to quiet down were covered by the occupational area rest and sleep. One participant mother was lacking time to take a rest and to relax, something she enjoyed before going to bed in order to clear her mind. For this reason, she postponed bed-time by using some

sleeping time to compensate for this shortage of time. This often resulted in falling asleep while relaxing on the couch. Two fathers had a similar experience, one due to a physically demanding job and the other because of a new job with more responsibilities. If parents worked in different shifts, an early shift resulted in less sleep during those days and took its toll overall. One parental couple even reduced sleeping time to provide some we-time by putting the alarm-clock one hour earlier, to have time to talk with each other.

Five mothers could not relax in the evening before their house was cleaned up. The feeling that all these caring and cleaning activities had to be finished in a pressed amount of time before being able to rest resulted in a feeling of imbalance. Wada et al (70) confirmed that many mothers feel that things needed to be done and consequently had to fit them in a strict time schedule (70). Accepting that super woman does not exist could be an important coping strategy to overcome this awkward situation according to Seghers (89).

Two participant mothers complained about a restless sleep due to experiencing stress. Both mothers worried about the future perspectives of their child, due to the developmental issues. This absence of sufficient sleep influenced their daily functioning as they felt tired. Lack of quality while sleeping was recognized by McBean and Schlosnagle (90). They described also that restless sleep had an effect on the well-being of the parent and on his/her retaining of information (90). Woodman (91) reported that parents of typically developing children experienced stress as well. The difference with parents raising a child with special needs was seen in the change of stress over the years from early childhood to middle childhood. Stress reduced once the children grew older for the first parental group while the level of stress increased for parents of children with developmental delays (91).

### 5.3 Parenting a child with special needs: schematic representation of occupational balance

Taking the findings and discussion of this study into account led to the expansion of Wagman, Håkansson and Björklund (2)'s concept of occupational balance as illustrated in Figure 5.2.

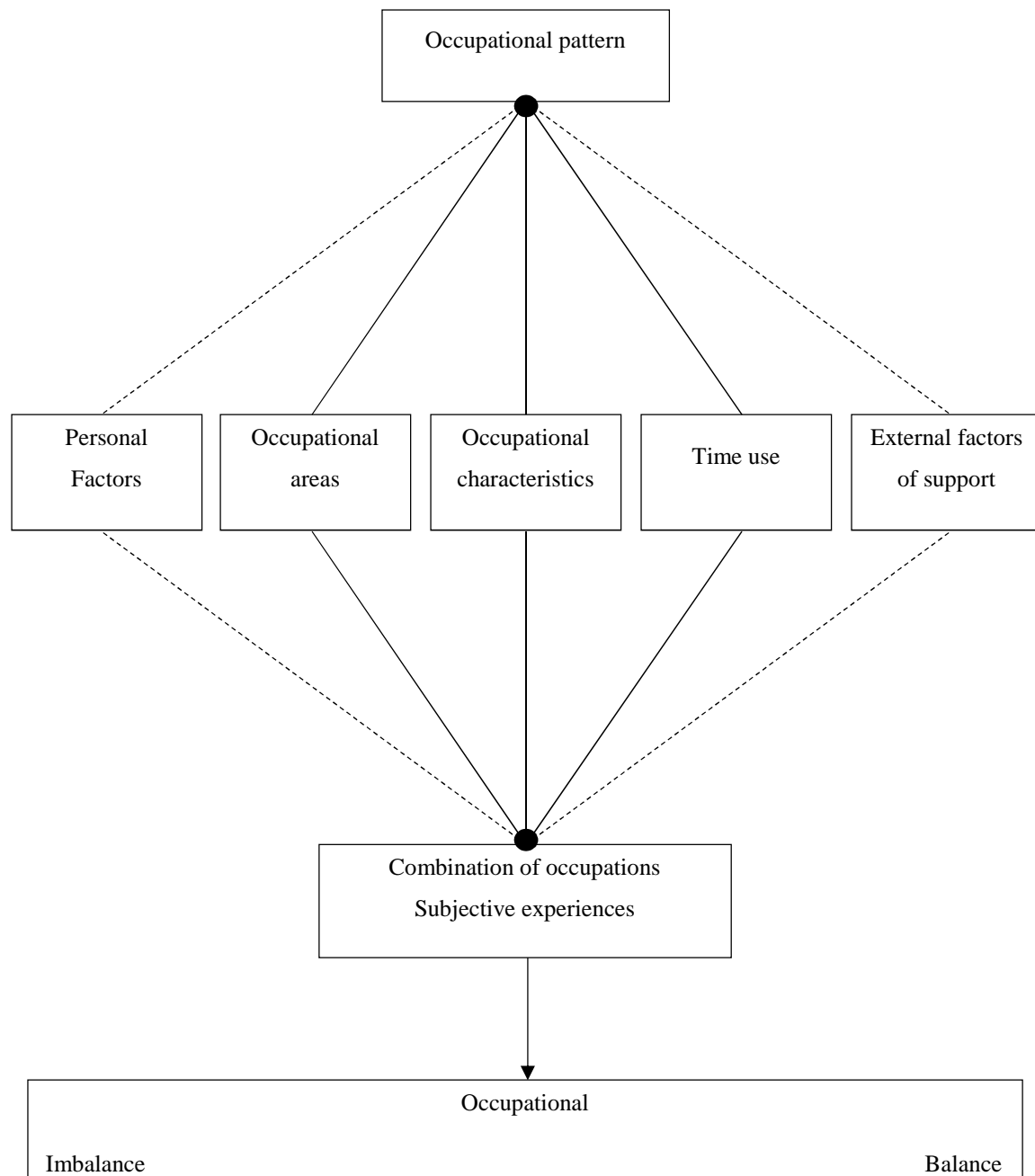


Figure 5.2 Adaptation of the Schematic representation: starting from the concept of occupational balance as defined by Wagman, Håkansson and Björklund (2).

The schematic representation, made in this study to visualise Wagman, Håkansson and Björklund's (2) concept was extended with additional influencing factors on the experienced occupational balance of parents raising a child with special needs. Wagman, Håkansson and Björklund (2) emphasized the importance of a subjectively correct amount of diverse occupations within the occupational pattern. Combining three different perspectives namely occupational areas, occupational characteristics and time use lead to the experienced occupational (im)balance. This concept fitted well within this study as it was very helpful for

participant mothers and fathers to express what they perceived concerning their occupational pattern and as a consequence their occupational (im)balance. Nevertheless, during the analysis of the gathered data of this study, it emerged that other additional influencing perspectives also determine one's perception of his/her occupational balance, namely: personal factors and external factors of support.

### 5.3.1 Two additional influencing perspectives

The first addition to the schematic representation of the concept of occupational balance as defined by Wagman, Håkansson and Björklund (2) was labelled as personal factors and were defined as specific characteristics possessed by an individual. As an example some participant parents said to be perfectionist and/or to feel very responsible towards all the things they do. These personal features led to certain occupational needs such as finishing household chores before taking a rest. Another personal need was the story of a participant mother who always wanted to do the stimulation activities with the child herself in order to keep an overview.

Every person has his/her own expectations and personal goals in life. These characteristics are reflected in what one does. In this study one participant father expressed his desire to have considerable material well-being. In order to achieve this goal, he worked very hard and proudly used his benefits to invest in real estate. A participant mother explained that although she had a less interesting job, her availability towards the family-unit was her primary objective in life. Both above mentioned parents experienced satisfaction through the realisation of one of their personally prioritised objectives.

Some personal needs can be conflicting. One participant father explained that if he is doing something, it needs to be done in a proper way. Due to his new demanding job, he had to work longer than before. This extra time was taken away from his personal leisure time and from his joint family-time early in the evening. Being available for his family, was an important aspect towards the satisfaction within his life. Not being able to conduct both occupations to the extent he would like, resulted in guilt and in a feeling of imbalance. Another example was given by a participant mother who expressed her wish of having a harmonized family-unit in which every member of the family experienced well-being. As she felt personally responsible for the achievement of this goal, she did her utmost to meet the required needs of her family members. Despite all her efforts and the decision to drop certain personal needs, she was not able to always meet her expectations towards family well-being. She also described a feeling of guilt, dissatisfaction and occupational imbalance.

Knowledge and skills regarding the support and stimulation of the child with special needs are indispensable personal factors influencing the feeling of parental competence. This (subjective) feeling was combined with an increase or decrease in the remaining level of mental energy. The perceived influence on the level of mental energy had an important effect on the experienced balance.

Another personal factor related to the experienced occupational balance is the ability to use strategies in order to cope with the limitation of certain meaningful occupations. One father reduced his feeling of guilt caused by a long working day by picking up his children from their sports activities when coming home from work.

The second addition towards the occupational balance concept is labelled external factors of support. The transmission of support happens from one individual to another and is inseparably connected with the occupational pattern of the one who gives and the one who receives.

Participant parents within this study provide support to their children with and without special needs, to each other and some of them to their aging parents. The level of support is depending on the different needs. Within the parental couple, mutual support is required to provide all the needed assistance. Subsequently, parents have to match their occupational pattern to each other's pattern. As an example, while a participant mother accompanies her child to the therapy, her husband cooks in order to have dinner all together once they arrive at home. In another participant family with two children, one child should better focus on her homework for therapy. Therefore the mother supports her daughter while the father plays with the sibling to avoid distraction. In this case it is always the father who plays with the sibling as the mother prefers to be in charge of all the stimulation.

Parents also support each other to conduct activities for oneself. Both parents within one family enjoyed doing sports on a regular basis. Although they both like to run and to cycle, they chose to alternate and postponed their intention to do sports together towards the future. For the time being while one parent was sporting, the other stayed home with the children.

Within this study, support was received by the parents from the external environment. Seven out of twelve families received support from the parents of one parent on a regular basis. Due to this support the occupational pattern of the parents changed as certain tasks could be skipped and extra time was released. As an example these seven families received support at least once in the week by picking the children up from school.

Besides support received from family members, service providers can take over certain household chores and free-up some time. Three of the twelve participant families received some assistance from a cleaning lady. Going to a restaurant on a regular basis resulted in an evening without cooking.

As all the participant parents raised at least one child with special needs attending therapy, professionals supported the parents in their stimulating task. Those parents who accompanied their child during the therapy session received additional knowledge and gained extra skills to better support their child. One parental couple went on to a psychologist a regular basis to improve their understanding of the child's problems. This received support led to more efficient parenting, to changes within the occupational pattern and finally to an improvement of the perceived occupational balance.

### 5.3.2 Intertwinement of the five perspectives

As described before, a person experiences occupational balance when the mix of the conducted quantity and diversity of occupations within the occupational pattern feels right (2). The occupational pattern from the participant parents was influenced by the three different perspectives as described by Wagman, Håkansson and Björklund (2) and by personal factors and external factors of support as highlighted in this study.

These five perspectives are intertwined and contribute to the subjective experience of the participant parent's occupational pattern and subsequently to their occupational balance. As an example one participant mother expressed her desire to ensure a harmonised family-life (*personal factor*). Due to her sense of responsibility (*personal factor*) she felt in charge to enable this harmony. Therefore she decided to work part-time (*occupational area*) and to free up some extra time (*time use*) in order to better combine work and family-life. Part of the liberated time is used to organise family-life from the perspective of autism (*give support / external factor of support*). The necessity to always take the autism-perspective and the need to consequently structure all activities for her son with special needs is experienced as tiring and energy consuming (*occupational characteristics*). Also the sibling expressed his need towards his parents to have sometimes a more flexible and spontaneous family-life. Therefore the grandparents supported their daughter to better harmonize her family-unit. Once a week, on Tuesday, the child with special needs stays overnight at the house of the grandparents. While the sibling does the same on Thursday (*Receiving support / external factor of support*). Because



of this support, more harmony was experienced by all family members and the occupational balance of the mother improved.

## 5.4 The overall perceived occupational balance

The type of mental energy was the predominant factor for the parent when disclosing the perception of their occupational balance and therefore determined their overall experience. Within the interviews some parents were surprised about the resulting overview of their occupational patterns. One mother and one father discovered that they had more me-time than originally thought. Another father was astonished by the monotony of his occupations but nevertheless, he preferred to keep this occupational pattern with a lot of working hours as material well-being was an important objective in his life. Occupations to obtain prosperity were energy generating occupations and kept him balanced.

Individual needs and characteristics of the participant parents had an important influence on the differences in the performed activities, on the way occupations were characterized and on the associated feeling before, during and after the performance. As a consequence personal factors had a determining effect on the experienced occupational balance. Gender related differences were limited. However, generally speaking for this study, mothers were less active in the open labour market but conducted more household and care and support activities than fathers. For special needs related activities gender differences were observed as mothers conducted direct care and support while fathers were more active in indirect care and support.

The required additional care and support related to the child's special needs was determined by the specific needs of the child. However the way of support was not only influenced by the child but also by the personal factors of the parent. As an example a lack of knowledge made support inefficient and caused a decrease in the level of mental energy. Besides the given support, the participant parents, also received some assistance. This amount of support given or received differed a lot in these families and was not always an indicator of the experienced occupational balance.

The variety within the occupational pattern and therefore the ratio between the occupational areas was important as well as the availability of time to perform the different activities. In conclusion, one could say that occupational imbalance was experienced if a parent could not answer his/her personal needs due to the necessity of other activities and as a consequence by an experienced lack of time.

This study indicates that most parents experience a shortage of time and voice that life is hectic. Nevertheless they succeed in supporting each other in their goal to achieve occupational balance.

The following chapter 6 will provide a conclusion of this study as well as implications for practice and recommendations for further studies.

# Chapter 6: Conclusions and recommendations

## 6.1 Introduction

This chapter contains a summary of the study as well as a description of its strengths and limitations. Thereafter implications for practice and recommendations for further studies are discussed. At the end an overall conclusion is provided.

## 6.2 Summary

The aim of this study was to explore the occupational balance of mothers and fathers rearing a child with special needs in Flanders. This study emphasised on the relation between the occupational pattern of an individual participant parent and on the perceived occupational balance. A subjective feeling of having a right composition of diverse occupations within this pattern leads to the ratio of the experienced occupational (im)balance. The weighting a parent made towards the combination of occupations within his/her occupational pattern and thus on the perceived occupational balance was viewed from the different perspectives, namely: occupational areas, occupational characteristics and time use as well as from two new perspectives: personal factors and external factors of support.

These two perspectives were added to the occupational balance conceptual framework as it contributed to the understanding of the participant parent's experience of occupational balance. Due to certain personal factors an individual parent decides voluntary or involuntary, which activity he/she will perform. How this will be done depends on the abilities and personal characteristics of the particular parent and on the circumstances such as the availability of time to bring this occupation to an end. Gender differences were limited. Mothers were more involved in direct care and support activities while fathers were mainly engaged in the indirect care and support. Each individual parent used a number of coping strategies which are also seen as personal factors, and were able to adapt and/or change the meaning of certain activities. Although it is not possible to create extra time, this adaptation or changed meaning diminished the feeling of time pressure nevertheless and contributed to the experience of occupational balance.

Providing extra time use for a certain occupation could on the one hand release the parent of time pressure but on the other hand exclude an occupation labelled by the occupational characteristic of energy generating. Often the time together as a couple (we-time) was reduced.

Time for one self, however, was preserved by the other parental partner. Subsequently, external factors of support which are about giving and receiving support influence the diversity and division of occupations within the occupational pattern and lead to changes within the other perspectives.

Mutual support of the parents towards the child(ren)'s (special) needs and towards the individual needs of mother and father are essential for both of them to strive for occupational balance. Therefore the occupational pattern of one parent, influences the pattern of the other as they both share responsibilities as parents and for each other's well-being and satisfaction in life. A dynamic interrelation exists between the occupational patterns within the parental couple and as a consequence their individual experience of occupational balance.

### 6.3 Strengths and limitations

- This study confirmed findings of previous studies on occupational balance while exploring the experienced occupational balance of mothers and fathers raising a child with special needs.
- Due to the focus on the occupational balance of both mothers and fathers, gender related information was obtained relating to the occupational pattern and balance of both individual parents.
- The findings of this study may be applicable to a broader scope of parents raising children with special needs in Flanders/Belgium, irrespective of the child's diagnosis.
- Allied health professionals using a family-centred approach may benefit from the findings of this study as parents went for therapy to at least one of the following professionals with their children, namely: a speech and language therapist, physiotherapist, occupational therapist or a psychotherapist.
- Parents of children, receiving therapy in government subsidized rehabilitation centres for children with special needs were overwhelmed with requests to participate in various studies. Therefore eleven parental couples out of twelve who participated within this study were recruited by private practitioners. As parents have to financially contribute more for therapy provided by a private practitioner, most of the children receiving therapy from those therapists, belong to parents who are able and willing to pay more for therapy.
- An equal group of three different educational levels was not obtained which led to a more homogeneous study sample. All families who voluntarily agreed to participate

within this study were dual-income families, which may have resulted in similar findings within this parental group.

## 6.4 Implications for practice

- Occupational therapists and other allied health professionals, using a family-centred approach, need to take into account that their therapy and advice towards the child have an influence on the occupational pattern of the parents. A change within the occupational pattern of a parent can lead to differently experienced occupational balance. Trying to apply the therapy homework with their child might be done at the expense of personal joyful activities. Nevertheless, it is important to support parents to obtain a right variety of occupations within their occupational pattern. This good mix results into occupational balance which influences the parental well-being and, by consequence, leads to well-being of the family-unit.
- Parents who attended the therapy session, became more familiar and better skilled to support their child with special needs at home. Therapists need to share the necessary knowledge and skills in a way convenient for the parents. Furthermore it is important to be aware of how the new knowledge and skills influence the occupational balance of the parents and therefore the family-unit well-being. This way therapists have a responsibility to assist parents to restore occupational balance despite the added activities. For occupational therapists this is their core business.
- Raising awareness through the Flemish occupational therapy association on the importance of occupational balance of parents raising a child with special needs within family centred practice for the well-being of the family-unit.

## 6.5 Recommendations for further studies

- Further research is needed to investigate to what extent the added perspectives within the occupational balance concept during this study, namely: personal factors and external factors of support are contributing to a better understanding of influencing factors towards occupational balance.
- In order to find out to which extent culture and spirituality can be regarded as personal factors influencing occupational balance, further research is needed.
- As a shortage of parental knowledge and skills leads to stressful parenting and is perceived as an energy consuming occupation, research could be done in order to

understand to what extent the lack of parental knowledge and skills related to the child's special needs is influencing the perception of occupational balance.

- Lack of understanding concerning the child's difficulties may lead towards less responsiveness and more demandingness. It needs to be investigated to what extent the parent's improved knowledge and skills towards the child's special needs will have an influence on the applied parenting style and how this relates to the perceived occupational balance.
- Further research is recommended to determine if there is any difference between the occupational pattern and balance of parents whose' child is attending therapy at a government subsidized rehabilitation centre for children with special needs and those who send their child to private practitioners.
- Research is recommended to explore the occupational balance of parents raising a child with special needs living in family structures that differ from a traditional nuclear family such as single parent families, co-parenthood or same sex parents.
- Further investigation is needed to better understand the correlation between the individual perception of occupational balance of a parental couple raising a child with special needs and the experienced family quality of life. An improved understanding of the extent to which occupational balance can contribute to the different domains of family quality of life may assist therapists to better support parents raising a child with special needs.

## 6.5 Conclusion

In conclusion one can say that occupational balance is a multi-layered and dynamic concept which starts with the occupational pattern of the person. Viewing that pattern from five different intertwined perspectives (occupational areas, occupational characteristics, time use, personal factors and external factors of support) leads to a certain subjective experience that will be named: occupational balance or imbalance.

Parents raising a child with special needs have to broaden their occupational pattern with supplementary caring and supporting activities. Therefore time needs to be created. How parents manage and perceive the subsequent changes within the pattern depends on their personal factors and on the external factors of support. Observed gender differences on the other hand are limited.

Although certain occupations were missing and life was often perceived as busy and demanding, thanks to the coping strategies, the mutual support of both parents and some extra received support, successful occupational balance can be perceived.

One could conclude that all participant parents lived what is expressed in the following quote:  
“Balance is not something you find, it’s something you create’ - Jana Kingsford

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# Appendix A 1:

## Approval from Health Research Ethics Committee Stellenbosch University



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

### Approval Notice New Application

11-Oct-2016  
Engelen, Anne-Marie A

**Ethics Reference #:** S16/09/172

**Title:** Occupational balance experienced by mothers and fathers of children with special needs in Flanders.

Dear Mrs Anne-Marie Engelen,

The New Application received on 26-Sep-2016, was reviewed by members of Health Research Ethics Committee 2 via Expedited review procedures on 11-Oct-2016 and was approved.

Please note the following information about your approved research protocol:

**Protocol Approval Period:** 11-Oct-2016 -10-Oct-2017

Please remember to use your **protocol number** (S16/09/172) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

#### After Ethical Review:

Please note a template of the progress report is obtainable on [www.sun.ac.za/ids](http://www.sun.ac.za/ids) and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

#### **Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Helene Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics

approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)

If you have any questions or need further assistance, please contact the HREC office at .

**Included Documents:**

Application form.pdf

Checklist.pdf

CV A Engelen.pdf

Consent form.pdf

Declaration A Sheik-Ismail.pdf

Declaration J Bester.pdf

Declaration A Engelen.pdf

Protocol.pdf

CV J Bester.pdf

CV A Sheik-Ismail.doc

Protocol Synopsis.pdf

Sincerely,

Francis Masiye

HREC Coordinator

Health Research Ethics Committee 2



## Appendix A 2:

### Approval Committee for Medical Ethics, University Hospital Ghent



Afz: Commissie voor Medische Ethiek

NKO  
Poliëniek 1 - 1ste Verdieping  
Prof. dr. Paul CORTHALS  
ALHIER

COMMISSIE VOOR MEDISCHE  
ETHIEK  
Voorzitter:  
Prof. Dr. D. Matthys  
Secretaris:  
Prof. Dr. J. Decruyenaere

CONTACT	TELEFOON	FAX	E-MAIL
Secretariaat	+32 (0)9 332 56 13	+32 (0)9 332 49 62	ethisch.comite@ugent.be
UN KENMERK	ONS KENMERK	DATUM	KOPIE
	2016/1173	17-06-16	Zie "OC"

#### BETREFT

Advies voor monocentrische studie met als titel:  
Handelingspatronen zoals ervaren door moeders en vaders van kinderen met specifieke ondersteuningsbehoeften in Vlaanderen  
- Scriptie Anne-Marie Engelen

Belgisch Registratienummer: BE03201629757

- \* Adviesaanvraagformulier: dd. 5/10/2016, (volledig ontvangen dd. 07/10/2016) versie 1
- \* Bevestigingsbrief: dd. 5/10/2016
- \* Durem: Interview richtlijnen (NL en E.)
- \* Antwoord onderzoeken: via mail ontv. dd. 10/10/2016 op opmerkingen EC dd. 10/10/2016
- \* (Publiek)informatie- en toestemmingsformulier + verklaring onderzoeker (N.) - aangepaste versie ontv. dd. 10/10/2016

Advies werd gevraagd door:

Prof. dr. P. CORTHALS: Hoofdonderzoeker

BOVENVERMELDE DOCUMENTEN WERDEN DOOR HET ETHISCH COMITÉ BEGOORDEELD.  
ER WERD EEN POSITIEF ADVIES OEGEVEN OVER DIT PROTOCOL OP 10/10/2016. INDIEN DE STUDIE NIET WORDT OPGESTART VOOR  
10/10/2017, VERVALT HET ADVIES EN MOET HET PROJECT TERUG INGEDIEND WORDEN.

Voorafzet het onderzoek te starten dient contact te worden genomen met Bimstra Clinica (09/332 95 95).

THE ABOVE MENTIONED DOCUMENTS HAVE BEEN REVIEWED BY THE ETHICS COMMITTEE.  
A POSITIVE ADVISE WAS GIVEN FOR THIS PROTOCOL ON 10/10/2016. IN CASE THIS STUDY IS NOT STARTED BY 10/10/2017, THIS  
ADVISE WILL BE NO LONGER VALID AND THE PROJECT MUST BE RESUBMITTED.

Before initiating the study, please contact Bimstra Clinica (09/332 95 95).

DIT ADVIES WORDT OPGENOMEN IN HET VERSLAG VAN DE VERGADERING VAN HET ETHISCH COMITÉ VAN 10/10/2016  
THIS ADVISE WILL APPEAR IN THE PROCEEDINGS OF THE MEETING OF THE ETHICS COMMITTEE OF 10/10/2016

- \* Het Ethisch Comité werkt volgens ICH Good Clinical Practice - regels
- \* Het Ethisch Comité beslist dat een goedgekeurd advies niet betekent dat het Comité de verantwoordelijkheid voor het onderzoek op zich neemt, bovendien dient U er over te weten dat Uw mening als onderzoeker wordt meegenomen in publicaties, rapporten voor de overheid enz., die het resultaat zijn van dit onderzoek.
- \* In het kader van Good Clinical Practice moet de mogelijkheid bestaan dat het farmaceutisch bedrijf en de autoriteiten inzage krijgen van de originele data, in dit verband dienen de onderzoekers ervoor te waken dat dit gebeurt zonder schending van de privacy van de proefpersonen.
- \* Het Ethisch Comité benadrukt dat het de promotor is die garant dient te staan voor de conformiteit van de onderstelde informatie- en toestemmingsformulieren met de Nederlandse wetgeving.
- \* Geen enkele onderzoeker betrokken bij deze studie is lid van het Ethisch Comité.
- \* Alle leden van het Ethisch Comité hebben dit project beoordeeld. (De ledenlijst is bijgevoegd)
- \* The Ethics Committee is organized and operates according to the ICH Good Clinical Practice rules.
- \* The Ethics Committee stresses that approval of a study does not mean that the Committee accepts responsibility for it. Moreover, please keep in mind that your opinion as investigator is presented in the publications, reports to the government, etc., that are a result of this research.
- \* In the framework of Good Clinical Practice, the pharmaceutical company and the authorities have the right to inspect the original data. The investigators have to assure that the privacy of the subjects is respected.
- \* The Ethics Committee stresses that it is the responsibility of the promotor to guarantee the conformity of the non-dutch informed consent forms with the dutch documents.
- \* None of the investigators involved in this study is a member of the Ethics Committee.
- \* All members of the Ethics Committee have reviewed this project. (The list of the members is enclosed)

Namens het Ethisch Comité / On behalf of the Ethics Committee

Prof. dr. D. MATTHYS  
Voorzitter / Chairman

OC: De heer T. VERSCHOORE - UZ Gent - Bimstra Clinica  
FAGG - Research & Development; Victor Hertaplein 40, postbus 40 1000 Brussel

Universitair Ziekenhuis Gent  
De Pintelaan 185, B-3000 Gent  
www.uzgent.be

Ann Haenebalcke  
09/332 22 66

# Appendix B 1:

## PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

**TITLE OF THE RESEARCH PROJECT:** Occupational balance experienced by mothers and fathers of children with special needs in Flanders.

**REFERENCE NUMBER:** S16 / 09 / 172

**PRINCIPAL INVESTIGATOR:** Anne-Marie Engelen

**ADDRESS:** Veldestraat 65b, 9850 Merendree, Belgium

**CONTACT NUMBER:** +32 496 49 13 87

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and by the **Health Research Ethics Committee at Ghent University** and will be conducted according to the ethical guidelines and principles of the international Declaration of

Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

Each person has a lot of daily occupations to fulfil in his/ her life such as cooking, reading, working, gardening, etc... These occupations are linked to different roles within a person's life, such as for example, a parental role, work related role, role as a husband or wife, as a child, as a sibling, as a friend. For a person's well-being, it is important to balance their different roles. If someone becomes a parent of a child with special needs, new and extra occupations need to be performed. Through the study the researcher would like to understand how fathers and mothers of a child with special needs experience the balance between their different occupations including the additional occupations associated with having a child with special needs. In other words, how satisfied are both parents with all the occupations they can do and have to do. By getting this information, health professionals can take this knowledge into consideration during family-centred interventions in order to provide better support to parents with respect to accommodating the additional occupations associated with looking after a child with special needs.

If you take part in this research, the researcher will interview you and your partner on both your experiences. A total of twelve couples will be interviewed. The researcher will come to your house to do the interview unless you prefer to come to the researcher's private practice or you find another place more convenient. The interview will take place at a time suitable for both of you. It is important that the researcher has a clear understanding of your experiences which means that she might need to listen several times to your answers. For this reason the interview will be tape-recorded. Before the end of the research, the researcher will discuss the findings with you, to check if everything was clearly understood.

### **Why have you been invited to participate?**

You have been invited to participate because you are raising a child with special needs. It is important that your child lives fully at home and has been receiving therapy for at least one year. Families who receive Budgets for Personalized Assistance or Personal Funding cannot be included in the study, as those parents are able to get funded assistance while other parents do not receive this extra funding.

**What will your responsibilities be?**

An appointment will be made at a time which is convenient for both of you and for the researcher. The interview will last approximately one and a half hours to two hours. The interviews will take place between 2016 December 1 and 2017 April 30. A second interview takes place to ensure if the given information was interpreted by the researcher as meant by you. If a topic that only appeared after interviewing several other parents, you will be asked to give your opinion on this new topic as well. If you would like to add something, this will be possible as well. At the end of the study, the researcher will contact you once again in order to discuss the findings with both of you together.

**Will you benefit from taking part in this research?**

There are no direct personal benefits for you but you might be able to understand how you can keep or improve the balance within all your different occupations. A secondary benefit might be experienced as other therapists will be informed in order to use the findings of this research while working with parents of children with special needs.

**Are there in risks involved in your taking part in this research?**

There are no risks involved for you when you take part within this research.

**If you do not agree to take part, what alternatives do you have?**

You are free to decide to take part in this research. If you decide not to take part, this will have no influence on the relationship with your therapist and the therapies for your child.

**Who will have access to your medical records?**

Your privacy will be protected by the researcher and the given information will be treated confidentially. Your name will not be mentioned to ensure anonymity. Only the research supervisors from the Stellenbosch University, the examiners of the study and, Benedicte De

Koker, researcher at University College Ghent will have access to all the collected information. The Belgian researcher will give feedback as the interviews will be held in Dutch/Flemish. The names of the parents will be changed within the research report in order to make everyone unrecognisable to readers.

**What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?**

No direct injuries, related to study are foreseen, as the researcher will only be talking with both parents.

**Will you be paid to take part in this study and are there any costs involved?**

There will be no costs involved for you if you do take part. Neither will you be paid to take part in the study. A little present to thank you for participating will be offered after the interview.

**Is there anything else that you should know or do?**

You can contact the researcher at 0496 49 13 87 if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 09 332 56 13 in Ghent or at 0027 21-938 9207 in Stellenbosch if you have any concerns or complaints that have not been adequately addressed by your researcher.

You will receive a copy of this information and consent form for your own records.

## Declaration by participant

**By signing below, I ..... agree to take part in a research study entitled** Occupational balance experienced by mothers and fathers of children with special needs in Flanders.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) .....

.....  
**Signature of participant**

.....  
**Signature of witness**

## Declaration by investigator

I *Anne-Marie Engelen* declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) ..... on (*date*) .....

.....  
**Signature of investigator**

.....  
**Signature of witness**

## Appendix B 2:

### INFORMATIEPAMFLET VOOR DE DEELNEMER EN TOESTEMMINGSFORMULIER

**TITTEL VAN HET ONDERZOEKSPROJECT:** Handelingsbalans zoals ervaren door moeders en vaders van kinderen met specifieke ondersteuningsbehoeften in Vlaanderen

**REFERENTIE NUMMER:** S16/09/172

**HOOFDONDERZOEKER:** Anne-Marie Engelen

**ADRES:** Veldestraat 65b, 9850 Merendree

**CONTACT:** +32 496 49 13 87

U wordt uitgenodigd om deel te nemen aan een onderzoeksproject. Neem a.u.b. voldoende tijd om de onderstaande informatie te lezen, aangezien het project gedetailleerd staat uitgelegd. Vraag verduidelijking aan de onderzoeker indien u bepaalde onderzoeksdelen onvoldoende begrijpt. Het is erg belangrijk dat u volledig begrijpt wat dit onderzoek inhoudt, dat u tevreden bent met het inhoudelijke en met de manier waarop u bij dit onderzoek zal betrokken worden. Uw medewerking is **volledig vrijwillig**. U heeft eveneens het recht om niet mee te werken aan deze studie wat in geen enkel geval negatieve gevolgen zal hebben voor u. U bent eveneens vrij om zich op ieder tijdstip uit deze studie terug te trekken, zelfs al gaat u akkoord om deel te nemen.

Deze studie is goedgekeurd door de **Ethische Commissie voor Gezondheidsonderzoek van de Universiteit van Stellenbosch** en de **Commissie voor Medische Ethiek van UZ Gent**. De studie zal worden uitgevoerd volgens de ethische richtlijnen en beginselen zoals voorgeschreven in de internationale verklaring van Helsinki, volgens de richtlijnen voor goede



klinische praktijk en volgens de richtlijnen van de Medische Onderzoeksraad, Ethische Richtlijnen voor Onderzoek.

### **Waarover gaat deze studie?**

Ieder persoon vervult heel wat dagelijkse handelingen in zijn /haar leven, zoals koken, lezen, werken, tuinieren, ... Deze handelingen zijn gelinkt aan verschillende rollen, zoals bijvoorbeeld, de rol van ouder, werk gerelateerde rollen, rol van man of vrouw, kind, broer of zus,... Het is belangrijk voor iemand zijn/haar welzijn, om een evenwicht te ervaren binnen die verschillende rollen. Wanneer iemand ouder wordt van een kind met bijzondere noden zullen extra handelingen moeten uitgevoerd worden. Via deze studie, wil de onderzoeker begrijpen hoe vaders en moeders van een kind met extra noden, het evenwicht tussen al deze verschillende handelingen en activiteiten ervaren. Met andere woorden, hoe tevreden zijn beide ouders met alle handelingen en activiteiten die ze moeten en willen vervullen? Paramedici en professionelen zullen in staat gesteld worden om de kennis die bekomen werd via dit onderzoek in de praktijk te gebruiken tijdens familie-gerichte interventies. Dit zal hen helpen om betere ondersteuning te bieden aan ouders, door rekening te houden met de bijkomende handelingen die eigen zijn aan de opvoeding van een kind met speciale noden.

Indien u bereid bent deel te nemen aan dit onderzoek, zal de onderzoeker u en uw partner interviewen over jullie ervaringen m.b.t. de handelingsbalans van beide. Er zullen in het totaal tussen de 10 en de 20 koppels deelnemen. De interviews kunnen, indien u dit wenst bij u thuis worden afgenomen, in het praktijklokaal van de onderzoeker of op een andere plaats. Ook het tijdstip wordt met u beide afgesproken. Het is belangrijk dat de onderzoeker een duidelijk beeld krijgt over uw ervaringen en bijgevolg zullen uw antwoorden verschillende keren moeten beluisterd worden. Om die reden zullen de interviews worden opgenomen. Voordat het onderzoek ten einde loopt, zal de onderzoeker de bevindingen aan u meedelen en checken of u goed werd begrepen en uw bijdrage werd geïnterpreteerd zoals u bedoelde. Dit om mogelijke misvattingen te vermijden.

### **Waarom werd u uitgenodigd om deel te nemen?**

U werd uitgenodigd om deel te nemen aan deze studie omdat u een kind met bijzondere noden opvoedt. Het is belangrijk dat uw kind volledig thuis woont en sinds minimum één jaar therapie volgt. Families met een persoonlijk assistentenbudget of persoonsgebonden budget kunnen niet

deelnemen aan deze studie. Deze ouders kunnen met dit budget extra ondersteuning betalen terwijl er ouders zijn die dit extra budget niet ontvangen.

### **Wat zullen uw verantwoordelijkheden zijn?**

Er zal een afspraak worden gemaakt op een tijdstip dat past voor zowel u beide als voor de onderzoeker. Het interview zal ongeveer anderhalf uur tot twee uren duren. De interviews vinden plaats tussen 1 december 2016 en 31 mei 2017. Om u te verzekeren dat de informatie die u gaf, werd geïnterpreteerd zoals bedoeld, zal een tweede interview georganiseerd worden. Indien er een nieuw belangrijk onderwerp aan bod kwam tijdens het interviewen van andere ouders zal jouw mening hierover ook worden bevraagd. Als u nog iets wil toevoegen kan dit eveneens.

Vooraleer de studie wordt afgesloten, zal u opnieuw gecontacteerd worden om de bevindingen met u beide te bespreken.

### **Haalt u voordeel uit dit onderzoek?**

U haalt geen persoonlijk voordeel uit de deelname aan dit onderzoek maar misschien ga je beter begrijpen hoe u de balans in uw verschillende handelingen kan behouden of verbeteren. Onrechtstreeks kunt u voordeel ondervinden, aangezien de bevindingen van deze studie zullen verspreid worden onder therapeuten / professionelen, die werken met ouders en kinderen met speciale ondersteuningsnoden.

### **Zijn er risico's verbonden door deel te nemen aan dit onderzoek?**

U ondervindt geen risico's door deel te nemen aan dit onderzoek.

### **Welke alternatieven heeft u, als u niet wenst deel te nemen ?**

U bent vrij om al dan niet deel te nemen aan deze studie. De relatie met uw therapeut noch de therapieën van uw kind zullen enige invloed ondervinden wanneer u niet wenst deel te nemen.

### **Wie zal er toegang hebben tot de medische documenten?**

De onderzoeker zal uw privacy beschermen en de informatie die u deelt vertrouwelijk behandelen. Uw naam zal niet vermeld worden zodat anonimiteit verzekerd wordt. Enkel de onderzoeksbegeleiders van de Universiteit van Stellenbosch en Benedicte De Koker, onderzoeker aan HoGent, zullen toegang hebben tot de verzamelde gegevens. De Belgische onderzoeker zal feedback geven, aangezien de interviews in het Nederlands/Vlaams worden afgenomen. Iedere deelnemer wordt onherkenbaar gemaakt voor de lezer van het onderzoeksrapport door fictieve namen te gebruiken.

### **Wat zal er gebeuren wanneer u, als direct gevolg van dit onderzoek, gewond geraakt?**

Er worden geen, aan deze studie gerelateerde verwondingen verwacht, aangezien er enkel een gesprek plaatsvindt tussen de onderzoeker en beide ouders.

### **Zal u betaald worden om aan deze studie deel te nemen en zijn er kosten verbonden aan dit onderzoek?**

Er zijn voor u geen kosten noch vergoedingen, verbonden aan dit onderzoek. Na het interview, zal er een geschenkje worden aangeboden als dank voor uw medewerking.

### **Is er iets anders dat u moet weten of doen?**

Indien u verdere vragen of twijfels heeft, of indien u op bepaalde problemen stuit, kan u de onderzoeker contacteren op het volgende telefoonnummer: 0496 49 13 87

U kunt contact opnemen met het Ethisch Comité voor gezondheidsonderzoek van de Universiteit van Gent en / of Stellenbosch, op het nummer 09 332 56 13 (Gent) of 0027 21-938 9207 (Stellenbosch) als u zich zorgen maakt of klachten heeft over zaken die onvoldoende door de onderzoeker werden aangepakt.

U ontvangt een kopie van deze informatie en van het toestemmingsformulier, voor uw eigen administratie.

## Verklaring door de deelnemer

Door onderstaand formulier te ondertekenen, verklaar ik ..... mij akkoord om aan de studie met als titel Handelingsbalans zoals ervaren door moeders en vaders van kinderen met specifieke ondersteuningsbehoeften **deel te nemen**.

Ik verklaar dat:

- ik de informatie, die in een voor mij vloeiende en begrijpelijke taal geschreven is, gelezen heb of dat deze werd voorgelezen.
- ik de kans kreeg om vragen te stellen en al mijn vragen duidelijk werden beantwoord.
- ik op de hoogte ben van het feit dat deelname aan deze studie volledig **vrijwillig** is en dat ik niet onder druk werd gezet om deel te nemen.
- ik indien ik dit verkies, op elk moment uit het onderzoek kan stappen zonder enige vorm van boete of veroordeling.
- ik kan gevraagd worden om mijn deelname aan deze studie vroegtijdig te beëindigen, indien de doctor of de onderzoeker van oordeel zijn dat stopzetting noodzakelijk is voor mijn eigen bestwil of omdat ik de voordien gemaakte afspraken niet volg.

Getekend te (*plaats*) ..... op (*datum*) .....

.....  
Handtekening van de deelnemer

.....  
Handtekening van de getuige

## Verklaring door de onderzoeker

Ik *Anne-Marie Engelen* verklaar dat:

- ik de informatie uit dit document heb uitgelegd aan .....
- ik hem/haar heb aangemoedigd om vragen te stellen en de nodige tijd nam om hierop duidelijk te antwoorden.
- ik ben tevreden met het feit dat hij/zij alle aspecten van het onderzoek, zoals besproken hierboven, duidelijk begrepen zijn.
- ik werkte / niet werkte met een tolk.

Getekend te (*plaats*) ..... op (*datum*) .....

.....

**Handtekening van de onderzoeker**

.....

**Handtekening van de getuige**

# Appendix C 1:

## Interview guide

### Main questions

- Can you describe for me in as much detail as possible what you did yesterday?
- Can you describe for me in as much detail as possible what you did last weekend?
- What do you think about today? Is it a typical day if you compare it with the other regular days?
- What do you think about? last weekend? Was it a typical weekend if you compare it with other weekends?
- What is your perception when you look to the amount of occupations you are doing and what is your perception concerning the variation within these occupations?

### Probing questions

Probing questions will be based on the 13 items of the occupational balance questionnaire as developed by Wagman and Håkansson (73).

#### Content

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Balance between doing things for others/for oneself  
 Perceiving one's occupations as meaningful  
 Time for doing things wanted  
 Balance between work, home, family, leisure, rest, and sleep  
 Balance between doing things alone/with others  
 Having sufficient to do during a regular week  
 Have sufficient time for doing obligatory occupations  
 Balance between physical, social, mental, and restful occupations  
 Satisfaction with how time is spent in everyday life  
 Satisfaction with the number of activities during a regular week  
 Balance between obligatory/voluntary occupations  
 Balance between energy-giving/energy-taking activities  
 Satisfaction with time spent in rest, recovery, and sleep

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(73).

- Can you explain which occupations are meaningful for you and which you would really like to keep doing as they are so important for you?

- Which of your performed occupations feel as though they take less time than they actually do?
- Which of your performed occupations feel as though they take longer than they actually do?
- Which of your performed occupations makes you tired, cost you energy?
- Which of your performed occupations give you energy?
- Which occupations are important for you to be able to achieve your personal goals?
- What is the ideal balance for you in doing occupations alone or with others?
- Do you experience enough personal time?

# Appendix C 2:

## Interview richtlijnen

Voor het interview plaats vindt zal uitgelegd worden wat binnen de ergotherapie bedoeld wordt met activiteiten en handelingen.

- Ieder persoon vervult heel wat dagelijkse activiteiten en handelingen in zijn/haar leven. Alles wat een mens doet om zich bezig te houden bedoelen we wanneer we spreken over activiteiten en handelingen. Het gaat over zorg dragen voor jezelf en anderen, over vrije tijd en over het productief zijn binnen de samenleving (92).

### Hoofdvragen

- Kan je zo gedetailleerd mogelijk beschrijven welke activiteiten en handelingen je gisteren allemaal hebt gedaan?
- Wat denk je over deze dag? Zien je andere weekdays er meestal ongeveer hetzelfde uit?
- Kan je zo gedetailleerd mogelijk beschrijven welke activiteiten en handelingen je vorig weekend allemaal hebt gedaan?
- Wat denk je over dit weekend? Zien je andere weekends er meestal ongeveer hetzelfde uit?
- Wat is je gevoel, wanneer je naar het aantal activiteiten en handelingen kijkt die jij op één dag uitvoert?
- Wat is je gevoel, wanneer je naar de variatie binnen deze activiteiten en handelingen kijkt?

### Verdiepende vragen:

- De verdiepende vragen zijn gebaseerd op de 13 items uit de “occupational balance questionnaire” ontwikkeld door Wagman and Håkansson (73)



## Content

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Balance between doing things for others/for oneself  
 Perceiving one's occupations as meaningful  
 Time for doing things wanted  
 Balance between work, home, family, leisure, rest, and sleep  
 Balance between doing things alone/with others  
 Having sufficient to do during a regular week  
 Have sufficient time for doing obligatory occupations  
 Balance between physical, social, mental, and restful occupations  
 Satisfaction with how time is spent in everyday life  
 Satisfaction with the number of activities during a regular week  
 Balance between obligatory/voluntary occupations  
 Balance between energy-giving/energy-taking activities  
 Satisfaction with time spent in rest, recovery, and sleep

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(73).

- Kan je uitleggen welke activiteiten en handelingen betekenisvol zijn voor jou en deze bijgevolg zeker wil blijven uitvoeren?
- Welke activiteiten, handelingen geven jou het gevoel dat ze minder lang duren dan ze in werkelijkheid doen?
- Welke activiteiten, handelingen geven jou het gevoel dat ze langer duren dan ze in werkelijkheid doen?
- Welke activiteiten en handelingen vragen veel energie en maken je moe?
- Welke activiteiten en handelingen geven je energie?
- Welke activiteiten en handelingen zijn belangrijk en heb je nodig om je persoonlijke doelen te verwezenlijken?
- Wanneer vind jij dat er een evenwicht is tussen activiteiten en handelingen die je alleen uitvoert of die je samen met anderen doet?
- Heb je voldoende tijd voor jezelf?