

**EXPLORING PARENTAL AND OCCUPATIONAL THERAPISTS'  
PERCEPTIONS OF THE UTILISATION OF THE OCCUPATIONAL  
THERAPY SERVICE AT THREE PAEDIATRIC OUTPATIENT UNITS IN  
THE WESTERN CAPE PROVINCE, SOUTH AFRICA.**

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Mini thesis submitted in partial fulfilment of the requirements for the degree of  
Masters in Public Health in the School of Community and Health Sciences,  
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**KEYWORDS:**

- Occupational therapy
- Paediatric outpatient service
- Parental perceptions
- OT perceptions
- Parental health seeking behaviour
- Child Health
- Explorative studies in Occupational Therapy
- Paediatric Occupational Therapy
- Poor utilisation of health services



## ABSTRACT

**Background:** The Western Cape’s Comprehensive Service Plan (CSP) is committed to “treating the right patient at the right level right, with the right skills and at the right cost” (Page 1, Tygerberg Hospital Annual Report, 2007). Occupational therapy (OT) Managers in the Metro District, Western Cape Province are in the process of aligning the OT services to the new CSP document. A major problem is the high default rate (non attendance) and irregular attendance (patient attends but skips sessions) amongst paediatric out-patients. In order to properly improve the OT paediatric services, it is vital for the OT managers to know the reasons for the poor utilisation of the OT services at the paediatric out-patient units.

**Purpose of study:** The irregular attendance and high default rates (where patients stop attending the OT sessions completely) among children are a major problem at three OT out-patient units in Cape Town, Western Cape Province. The occupational therapists who work at these units are adamant that this impacts negatively on the child’s progress. This study sought to explore the factors influencing the utilisation of the OT service in these three OT paediatric out-patient units in the hope of providing relevant information to the OT managers of these units in order to rethink the current service and make appropriate changes to improve adherence and treatment progress.

**Study design:** This was an exploratory study using qualitative research methods. In-depth interviews were conducted with ten parents of children who have to attend the OT out-patient services. One group discussion was conducted with the occupational therapists that provide the services at the out-patient units.

**Sampling:** Purposive sampling methods were employed to select four occupational therapists (at least one from each unit) and ten parents (at least three from each unit, with at least two who attended poorly and one that attended regularly).

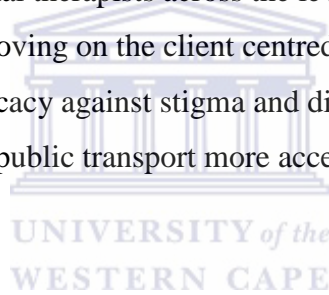
**Analysis:** Thematic analysis was used to interpret the data. The data was coded and categorised according to themes that emerged during data analysis.

**Results:** The results of this study revealed that the factors that impact the utilisation of the OT service at the three OT units is complex. Factors that influenced the utilisation of the OT services in this study were related to the OT service such as staff attitude, relationship between the occupational therapist and the mothers as well as their child, communication between the mother and the occupational therapist,

treatment progress, parent involvement in the OT programme and access to the OT service. Other factors such as the mothers' perception of the severity of the child's health condition, family support, work factors and family support were important factors related to the mother. The findings also revealed that environmental factors namely stigma, discrimination and travelling to the OT units impacted utilisation of the OT service. The participants made recommendations on how to improve the service.

**Conclusion:** This study describes the complexity of what impacted the utilisation of the OT services and how closely interlinked these different factors are. It is evident from the findings of this study that a comprehensive, client centred approach is required to properly deal with the factors that negatively impact the utilisation of this service.

**Recommendations:** A multi-faceted approach is required. Important issues to address are the shortage of occupational therapists across the levels of health care in the Western Cape Province; improving on the client centred approach in OT intervention programmes; advancing advocacy against stigma and discrimination against children with disabilities; and making public transport more accessible to children and their mothers.



## DECLARATION

I declare that **Exploring parental and occupational therapists' perceptions of the utilisation of the occupational therapy service at three paediatric outpatient units in the Western Cape Province, South Africa** is my own work. It has not been submitted for any degree or examination in any university. All the sources that I have used or quoted have been indicated and acknowledged by complete references.

Fatima Peters



Date: November 2011

Signature: \_\_\_\_\_

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## CHAPTER ONE

### 1. INTRODUCTION

#### 1.1 Background to the study

An estimated 10 % of the world's population is disabled, that is approximately 650 million people of which 200 million are children (WHO, 2008). In South Africa 5% of the total population have some form of disability of which 2% are children (Statistics South Africa, 2001). According to the 2001 Census report, a significant limitation of its study was the stigma attached to being disabled. This may have resulted in people not answering truthfully and hence a lower figure portrayed than what the reality actually is.

Children with disabilities often have “a slow start to life” and have less opportunity to develop to their full potential and to partake in societal activities (Unicef, 2007). A major problem area for these children is access to school or vocational training (Unicef, 2007). Dowrick (2003) states that academic failure linked with physical, mental and/or learning disabilities may lead to a dislike of school, frustration, depression and social isolation because of lack of achievements. This and the subsequent ridicule by peers could result in premature drop out of school (Dowrick, 2003). Zabel and Nigro (1999) conducted a study at a juvenile detention facility and found a relationship between learning disabilities, poor performance at school and behavioural problems and assert that proper intervention that addresses the learning problems would improve productivity in adulthood. Furthermore, long standing disabilities may reduce productivity and cause an inability to sufficiently produce an income without a supplementary state subsidised income (Taylor & Barusch, 2004).

Occupational therapy (OT) plays a major role in enabling people with disabilities to participate in the activities of everyday life such as work, the ability to perform personal self-care activities and socialising (Wilcock, 2006). There are two important occupations for children that occupational therapists focus on, namely social engagement and schooling. Occupational therapists are concerned with making sure

that there is understanding of, and that a child's skills and abilities match the expectations placed upon him/her (Whalen, 2002). Whalen (2002) explains that direct intervention is often required to improve, restore, maintain or prevent deterioration in the necessary skills for coping at school. The direct intervention may be therapy to develop various skills such as motor co-ordination, visual perceptual skills and/or visual-motor skills (Whalen, 2002). This author reminds us that important activities, such as reading, writing, mathematics, manipulation of tools, physical activity, self-care activities and social integration are dependent on the child's ability to perform motor co-ordination (gross and fine), visual-motor integration and visual-perceptual skills. Therefore, when children with disabilities are identified with physical, learning and behaviour problems, occupational therapy plays a vital role in early intervention and appropriate school-based support to minimise long term problems (Edwards, Millard, Praskac & Wiseniewski, 2003; Hermes, 2007).

## **1.2 Research Problem**

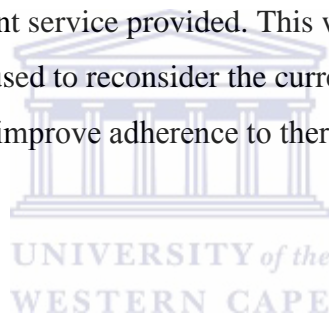
The Western Cape Province's Healthcare 2010 and Comprehensive Service Plan (CSP) prescribe restructuring and transformation across all levels of healthcare and all disciplines within the Department of Health (Comprehensive Service Plan for the Implementation of Healthcare, 2010). The CSP is committed to "treating the right patient at the right level right, with the right skills and at the right cost" (Page 1, Tygerberg Hospital Annual Report, 2007). OT managers in the Metro District, Western Cape Province are in the process of aligning the OT services to the new CSP document.

In a personal communication with two Chief Occupational Therapists of Paediatric units on 14 April 2008, the major problem at the three OT outpatient units in Cape Town was identified as irregular attendance and high default rates (patients stop attending therapy completely) of children with disabilities that result in their expected outcomes of treatment not being realised. They are convinced that successful interventions when treating a child with a physical, mental or learning problem depend significantly on regular, consistent attendance of OT sessions. The high default rate is evident by the attendance statistics for one paediatric outpatient unit. During 2007, that particular OT unit booked 1032 outpatients and 315 (30.5%)

patients did not attend. In 2008, 1202 patients were booked and 347 (28.8 %) patients did not attend one or more sessions (OT Annual Reports, Tygerberg Hospital for 2008 & 2009).

### **1.3 Rationale**

Understanding parental perceptions of health and related services may improve compliance strategies and service delivery and ultimately health outcomes (Beller, Colditz & Pritchard, 2008; Clark, Hedges, Magaret, Magnusson & Warden, 2002; Gerdes & Sphar, 1997; Jessee & Strittmatter, 1999 and Friesen, Jivanjee, Kruzich & Robinson, 2003). This study therefore sought to explore the utilisation of the OT services to determine the reasons for the irregular and non attendance of the children treated at the three tertiary hospitals from the parents' and Occupational Therapists' points of view. It is hoped that the study will not only highlight limitations or barriers but also strengths of the current service provided. This will present the OT managers with information that can be used to reconsider the current service and make appropriate changes that will improve adherence to therapy and improve the child's progress.



### **1.4 Study Setting**

This study took place at the OT outpatient units of three urban tertiary, teaching hospitals based in Cape Town. Two hospitals are general children's hospitals; one being a part of a large central academic hospital. The third outpatient department is based at a psychiatric hospital in Cape Town. These hospitals cater for a diverse patient population from all over the Western Cape Province. The majority of the patients seen at these specific outpatient units are from poverty-stricken backgrounds, from both rural and urban settings, from diverse cultural backgrounds, have parents with high unemployment rates, low income brackets, low level of education and are medically uninsured (OT Annual Reports, Tygerberg Academic Hospital and Red Cross Memorial Children's Hospital, Western Cape Province, 2008 & 2009).

According to two chief occupational therapists working in the paediatric units at the large teaching hospitals, approximately 70% of the children treated there are coloured, about 20 % black and approximately 10% are white. Children seen at the units are

between the ages of 0 and 12 years old (Personal communication, E.Laminette and M.Pursad, 05 May 2010).

### **1.5 Researcher's Personal Stance**

The researcher manages one of the occupational therapy units included in the study. She is responsible for the management of the overall occupational therapy clinical services which includes the out-patient occupational therapy services to children. She also manages all resources (physical and human) in the occupational therapy department. The researcher's personal role is solely in management, so she has no direct clinical involvement in any of the occupational therapy services.

The researcher, as the manager of the OT department, has always been concerned when patients do not attend the OT sessions without prior notification. This results in loss of productivity for the occupational therapists who at times have waited for half an hour for the patient to arrive and is left with limited time to make alternative arrangements such as going to see an inpatient or writing a patient report. In addition, the occupational therapists reported regularly to the researcher that they are troubled about the high default rate amongst their patients as well as when patients attend irregularly because it impacts the child's progress. These occupational therapists have also shared during meetings that they felt discouraged by this because they perceived the non-attendance and irregular attendance as disinterest from the parents. The researcher has observed how some of the younger, inexperienced occupational therapists "reprimand" or "speak down" to mothers who have skipped a session or arrived late for a session. The researcher discussed this problem with the managers of the other OT departments and they confirmed that they experienced the same dilemma. The new health care plan for the Western Cape then prompted the researcher to use this as a topic for her mini thesis because she felt it would benefit all the OT units in Cape Town if it was known why mothers do not attend regularly.

## CHAPTER TWO

### 2. LITERATURE REVIEW

The literature review reports on studies that explored general parental and patient perception of healthcare services and presents factors that influence health seeking behaviour both from an individual point of view but also in relation to a parent on behalf of his/her child. In searching for relevant literature it was found that literature pertaining to parental health seeking behaviour in relation to occupational therapy as in the proposed study was scarce. Two main categories of factors have been identified from the literature: service related factors and parent related factors. Two theories are briefly presented that assists in understanding health seeking behaviour.

#### 2.1 Service related factors

Service related factors describe the interaction with health care professionals, parent enablement and accessibility.



##### 2.1.1 Interaction between healthcare provider and parent/patient

Parents' interaction with healthcare professionals significantly influence their perception of health care services and would thus be an important factor when exploring reasons for poor attendance and high defaulting in relation to the current study (Clark, Hedges, Nathan, Magnusson & Warden, 2002). Improved patient satisfaction linked with positive patient-therapist interaction also boosts job satisfaction of the healthcare professional which in turn improves the overall work environment (Clark et al, 2002). Gerdes and Spahr (1997) found from their ten year patient satisfaction surveys done at a large multispecialty group practice that the better the interaction with the physician was, the more satisfied the patient was. They established that patients who were dissatisfied with the interaction simply stayed away or found alternative help.

Results from a qualitative study with teachers, parents and occupational therapists suggest that good relationships are an effective tool to good practice (Nelson & Allison, 2007). The study aimed to explore what forms a socially and culturally

appropriate OT service for urban indigenous Australian families. From the study it emerged that the more technical aspects of OT (therapy techniques and tools) were less important than the therapist's approach to the patient and the interaction between the occupational therapist and the patient. Friesen, Kruzich, Jivanjee and Robidson's (2003) study on the child's out-of-home mental health care treatment found that communication between staff members as well as positive attitudes amongst staff members were notable factors in parental satisfaction. Another influencing factor that emerged from this study was parental language. Parents value a health care provider who is able to communicate with them in their native language and who understands their beliefs and practices (Bauchner, Feinstein, Flores & Nguyen, 1991; Krauss & Weinick, 2000).

When children have to see more than one healthcare professional, an intangible factor such as communication between staff either verbally or via the patient folder about the child's progress, was perceived by parents to be an enabler to the health service (Friesen et al, 2003). Reasons for this are not indicated in the findings of this quantitative study because parents were presented with a list of possible barriers or supports to participation in the out-of-home treatment which they simply had to check if applicable.

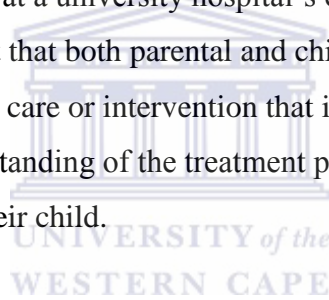
### **2.1.2 Enablement of parent**

Families should be enabled to cope with their sick children in every way (Deloian & Gottesman, 2008). Parents feel enabled when there is a collaborative partnership between themselves and healthcare professionals that actively includes the parents' input during the child's treatment (Deloian & Gottesman, 2008). A study by Beller, Coditz & Pritchard (2008) had a similar finding when they explored parental experiences and preferences which encourage subsequent use of outpatient health services for their children. Parents in their study suggested that a collaborative approach where their specific needs and thoughts regarding their child's treatment are considered would result in a better understanding of their child's problems.

Beller, Colditz and Pritchard (2008) found that the reuse of services increased where self-efficacy of the parent was encouraged. In their study parents shared the belief that a family centred approach would ensure that clinicians plan interventions that

consider the family environment more broadly. This they feel would make instructions more relevant and thus easier to understand, creating a sense of confidence and reassurance in parental ability to competently take care of their child (Beller, Colditz & Pritchard, 2008). Their study supports the findings of Deloian & Gottesman (2008) that parents favour a service where they are empowered by being involved in the decision making process of their child's treatment, are further enabled by being educated about the child's medical condition and are taught to manage their children born with difficulties (Beller, Colditz & Pritchard, 2008). The results of the study also revealed that parents acknowledged that sharing of information such as leaflets containing information regarding their child's health and developmental needs was an enabler of health care services (Beller, Colditz & Pritchard, 2008).

Similarly, Clark et al (2002) assessed both parents' and children's views in a patient satisfaction survey conducted at a university hospital's emergency department. Their study reinforced the argument that both parental and child satisfaction increased when staff adequately explained the care or intervention that is provided to children, thus increasing the parent's understanding of the treatment process and their ability to use this information to care for their child.



### **2.1.3 Access to the service**

Inaccessibility and ignorance of available services are seen as important reasons why health care services especially rehabilitation services, are under- utilised (Saloojee, Phohole, Saloojee & IJsselmuiden, 2007).

Unaffordable cost of transportation and far distance from the service has been found often to be a deterrent to attending therapy (Friesen et al, 2003). Beller, Colditz & Pritchard (2008) found that more decentralised (not only hospital based but at community level as well) health services improved access for most parents. Their study revealed that primary health care (which is community based) is more accessible and is appropriately placed to provide early intervention, referral and to monitor the patient.

Long waiting lists and long waiting times are also seen as factors limiting access (Beller, Colditz and Pritchard, 2008; Jesse & Strittmatter, 1999). Specialist services



such as disability and special education services were often found to be difficult to attend because of rigid appointment times and long waiting lists (Beller, Colditz & Prichard, 2008). Jesse and Strittmatter (1999) found that the longer a patient had to wait the less satisfied they were and the less likely they were to return.

In Beller, Colditz & Pritchard's (2008) study, parents indicated that where staff was more accommodating in terms of appointment time, attendance and improved adherence was facilitated.

## **2.2 Parent related factors**

Health-seeking behaviour is reliant not only on the availability of health services but also on the motivation and ability of the patient to seek health care (Philips & Teerawichitchainan, 2007).

Parental education was found to be a major parent related factor (Bauchner, Feinstein, Flores & Nguyen, 1991; Hayes, Kelleher, Stevens & Ward-Estes, 2006; Philips & Teerawichitchainan, 2007). It is claimed that mothers who have at least a primary school education will seek healthcare more readily than those without any education (Phillips & Teerawichitchainan, 2007; Bird et al 2001). Bauchner, Feinstein, Flores and Nguyen (1991) looked at the impact of amongst others, family income and parental education on children's health and the use of health services. They found that the least healthy children came from the poorest families and had the least educated parents.

In their analysis of the 2001-2 Vietnam National Health Survey (VNHS), Philips & Teerawichitchainan (2007) argue that parental perception of the severity of the illness is an important factor in parental health-seeking behaviour. The authors claim that the more severe the illness (as perceived by the parent), the more likely the parent will seek health care and the more compliant they will be. This claim however is not based on actual information from parents in relation to this factor but merely an assumption based on findings in the literature as well as data from the VNHS where a large percentage of parents reported to have sought health care for moderate to severe illnesses. Hayes, Kelleher, Stevens and Ward-Estes (2006) reported that low perceived relevance of treatment will negatively impact utilisation of treatment.

From the data they analysed from the VNHS, Philips and Teerawichitchainan (2007) hypothesise that the age of the sick or disabled child played a role. Parents with children under one year reported more consistently in the survey that they obtained help than those with children older than one year. It is also assumed that parents with more than one child were less fervent to get health care assistance especially amongst the poorer families (Philips & Teerawichitchainan, 2007). The data revealed that parents with more than one child seldom sought health care from a professional health care provider (Philips & Teerawichitchainan, 2007). Parents in this study would use cheaper options such as home remedies or purchase “over the counter” medication without consulting a health care provider. The authors explain this could be as a result of these parents having difficulty in dividing resources (money and time) amongst their children.

## **2.3 Theories that explain health seeking behaviour**

### **2.3.1 Health Belief Model**

The Health Belief Model (HBM) can be used to explain various health related behaviour, in this instance health seeking behaviour of parents with children who have health problems. According to the HBM, an individual’s action is motivated by perceived susceptibility, perceived severity, perceived benefits, perceived barriers and cost involved in carrying out the behaviour and cues to take action and self-efficacy (Croyle, 2005). Each of these perceptions can either individually or in combination be used to explain health related behaviour. It is believed that by understanding the relationship between a person’s beliefs and their behavior, a health care provider can gain meaningful insight into how well or poorly a patient will behave in relation to their health or ongoing health care programmes (Croyle, 2005). If, for example, a parent believes that their child’s health problem is very serious or severe, they will be more motivated to seek healthcare or if they felt sufficiently enabled or empowered, they would also more readily seek healthcare for their child.

The HBM however does not address the issue of environmental and social factors such as unemployment, poor social support or high public transport costs (Croyle, 2005).

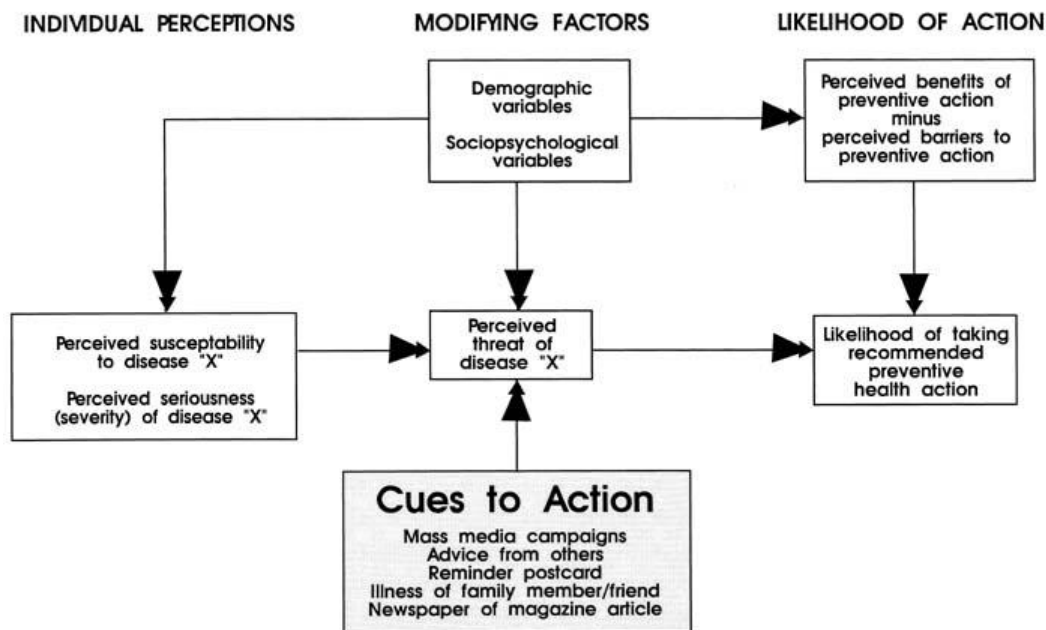


Figure 1: Diagrammatic illustration of the major elements of the HBM  
Source: Ashford & Blinkhorn (1999)

### 2.3.2 Person Environment Occupation Model

The Person Environment Occupation Model goes beyond the individual and describes a transactional relationship between the person, the environment and occupation (Law, Cooper, Strong, Stewart, Rigby & Letts, 1996). This dynamic relationship between the person, their environment (where people work, live and play) and their occupations results in occupational performance. This model is explained further below.

The model has four main constructs:

- **Person (P):** The person is defined as a unique being who takes on different dynamic roles concurrently (Law et al, 1996). Law et al (1996) goes on to explain that these roles change over time, over context, in significance and duration. These authors describe the person in a holistic manner and view individuals as having various intrinsic factors (psychological, cognitive, physiological, spiritual and neuro-behavioural) that make up an individual's skills and abilities. The authors also remind us that each person also brings a set of personal attributes (such as being confident and assertive) and life

experiences (such as being an unemployed, single mother) to the occupational performance transaction of person-environment-occupation.

- **Environment (E):** Participation is always influenced by the extrinsic factors (built, natural, cultural, social interaction, societal, economic) of the environment in which it takes place.
- **Occupation (O):** The model suggests that activity, task and occupation share a very close bond. An activity is described as a basic unit of a task where there is a single quest to participate in daily occupational performance such as a mother feeding their child. A task is described as the engagement in several purposeful activities such as shopping for ingredients, cooking the meal and then feeding the child. Occupation is the pursuit of many meaningful groups of functional activities and tasks over a lifespan. The idea of an occupation can be illustrated by a parent who has to perform several different child caring activities and tasks on a daily basis. Occupations (such as working, schooling, playing, socialising and personal management) are defined as those groups of activities and tasks in which the person engages in order to satisfy his/her inherent needs for self-maintenance, expression and fulfilment (Law et al, 1996).
- **Occupational Performance:** Occupational performance is the result of the transaction between the person (such a child or adult), their environment (where they work, live and play) and their occupations (such as being a student or a mother) (Law et al, 1996). Law et al (1996) describes occupational performance (such as the child's school performance or the mother's parenting performance) as the dynamic experience of the person engaged in purposeful activities and tasks within their environment.

The interaction of the person's intrinsic factors, the environment (extrinsic factors), and one's chosen activity leads to occupational performance and participation (Law et al, 1996). The model assumes that the three major constructs (person, environment and occupation) interact on a continuous basis over time in ways that either boosts or lessens their congruency (Law et al, 1996). The more secure the compatibility between the three components, the more harmonious the interaction, which results in

better occupational performance and participation. In the case of a parent of a child with a disability or health problem; if a parent's intrinsic (individual) factors fit well within their specific environment, and they are able to attend more sessions (occupations such as ability to travel to hospital, ability to take care of the child/children, ability to negotiate/communicate time off from work) it will lead to better overall health seeking behaviour and adherence to the treatment programme (occupational performance and participation). Incongruence between the parent's factors, his/her environment and occupation will lead to poor occupational performance and participation meaning poor health seeking behaviour.

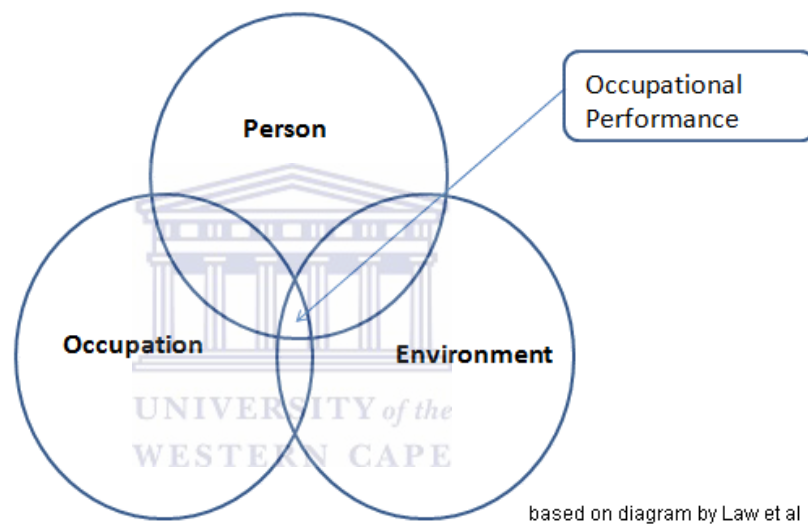


Figure 2: Diagrammatic illustration of PEO

Source: Law, Cooper, Strong, Stewart, Rigby & Letts (1996) in Ramafikeng (2009).

### Chapter Summary

In this chapter the researcher captured what literature says about utilisation of health services in general. Research in terms of the utilisation of OT services is limited. Adding to this gap, research about OT services as well as general health services in the South African context is scarce.

## CHAPTER THREE

### 3. RESEARCH DESIGN AND METHODOLOGY

#### 3.1 Aim of this study

The aim of this study was to explore the factors that influence the use of the current OT services provided to children at three urban tertiary, teaching hospitals in Cape Town from the perspectives of the parents and occupational therapists.

#### 3.2 Objectives

- To explore parents' and occupational therapists' perceptions of the factors that influence the use of the current OT services provided at the three selected OT outpatient units.
- To identify the barriers and enablers experienced by parents which influence the use of the current OT service provided at the three outpatient units.
- To explore the occupational therapists' perceptions on the barriers and facilitators to the OT services at the three OT outpatient units.
- To describe the participants' recommendations for better uptake and attendance of OT services.

#### 3.3 Study design

An exploratory and descriptive qualitative study design was chosen to highlight the enablers and barriers of the current OT services in order to make improvements in service delivery which would hopefully improve patient attendance. Qualitative studies provide good explanations and insight of situations or behaviour by unearthing participants' personal opinions and experiences (Green & Thorogood, 2004). The proposed study aimed to explore the experiences of parents and occupational therapists regarding the utilization of the current service and therefore a qualitative design was deemed appropriate.

### **3.4 Study population and sampling**

The study population consisted of two groups. The one group included parents of children with physical, mental or learning problems attending the paediatric outpatient OT units at the three tertiary hospitals in Cape Town. The second group was occupational therapists working at these institutions. Purposive sampling was employed to ensure that the researcher could select participants who possessed the specific characteristics or lived in circumstances that were relevant to the study (Mays & Pope, 1995). The inclusion criteria were:

#### **3.4.1 Parents**

- The child required at least four-six OT sessions as it would be difficult to see a default or poor attendance pattern if the treatment programme consisted of less than four sessions.
- Parents were either English or Afrikaans speaking as the researcher who collected the data is fluent only in these two languages.
- Parents who had missed two or more appointments. The researcher wanted to interview parents where there is a pattern of missed appointments to establish barriers to the utilization of the OT services.
- In addition parents were selected who regularly attend sessions to gain an understanding of the enablers to the utilization of the OT services.

#### **3.4.2 Occupational Therapists**

For the inclusion criteria it was intended that all occupational therapist participants had to be permanently employed with two years or more working experience in the field of paediatrics in public service and currently working in one of the OT paediatric out-patient units. The researcher hoped that the more experience the occupational therapist has the better their insight and the “richer” and “thicker” the information they would be able to provide.

Three of the participants met this criteria, however at one out patient OT unit, the only occupational therapist working there was temporarily employed (she was completing her compulsory community service) and had only eight months relevant experience. The researcher decided to deviate from the criteria because this was the only out-



patient unit at a mental health care facility whereas the other two out-patient units were based at general hospital facilities. The researcher felt that it would be important to get the perspective from the two different clinical fields.

### **3.5 Sampling procedure**

#### **3.5.1 Occupational therapists**

Three occupational therapists were selected for the group discussion by asking the OT departmental managers to each recommend one occupational therapist from each unit who met the criteria to participate in this study. The researcher then contacted each potential participant via email requesting their willingness to participate. Once the participants were recruited a date and venue was agreed to that was suitable for all three participants.

A day before the group discussion, one of the participants fell ill and an alternative occupational therapist was selected. However on the day of the group discussion, the original occupational therapist arrived for the group discussion. The researcher decided to let both sit in on the group because they were both very keen to participate.

#### **3.5.2 Parents**

The researcher recruited the parents on recommendation by staff working in the selected OT paediatric outpatient units. The researcher made her final choice by gathering further information from the patients' hospital records such as contact numbers and addresses. She called the parents on the list and explained the purpose of the study and enquired if they would be willing to participate in her study. If they agreed, a date, time and venue was agreed on that was convenient for them.

The researcher intended to recruit three parents from each hospital, however, half of the data of the first interview was lost because the interview was interrupted and the voice recorder was subsequently not switched on again resulting in the latter part of the interview not being recorded. Hence a tenth parent was recruited to compensate for the lost data although the researcher still used the data that had been collected from that participant. The tenth parent was recruited from a different hospital to where the first interviewee was from because the occupational therapist that assisted in the



recruitment of parents had left and the new occupational therapist was unfamiliar with the patients at that particular hospital at the time. All the potential parents on the list agreed to participate. However, two parents who agreed to participate did not arrive on the day of the interview, one parent being a father. The researcher followed up with the two parents after they did not arrive for the appointment. She contacted them telephonically but was unable to reach the father but reached the second parent. This particular parent had two subsequent appointments that she did not keep either. She had great difficulty attending due to work commitments. She also personally had to attend health services so could not take more time off from work. However, she also did not want to make the appointment over a weekend or meet at her place of work. After the third time the researcher did not call her again. Two other parents were then recruited from the selection list. All parents who came in for the interview were reimbursed for their transport costs.

### **3.6 Brief description of each occupational therapist**

The occupational therapists are identified by numbers as they featured during the group discussion.



#### **3.6.1 OT 1**

OT 1 is a black female who has been working in the area of paediatrics for eight years.

#### **3.6.2 OT 2**

OT 2 is a white female who has only been qualified for eight months at the time of the study. The eight months of experience has been in the field of paediatrics. She was completing her one year compulsory public service at one of the hospitals.

#### **3.6.3 OT 3**

OT 3 is a white female who has been working in the field of paediatrics for 15 years. She has been working in her current post, at one of the hospitals in this study, for eight years as well.

### **3.6.4 OT 4**

OT 4 is a coloured female who has been working in the field of paediatrics for two years.

### **3.7 Brief description of each parent participant**

When asked how parents would prefer to be identified in the study (choose a pseudonym) they either left the decision up to the researcher or had no issue with being called on their real names. The researcher then decided to call them “Mom” and number them as they were interviewed. The researcher has given each child a pseudonym. A very brief description of each parent and their child (who receives OT treatment) follows.

#### **3.7.1 Mom 1**

Mom 1 is a 24 year old black, single mother. Her highest level of education is grade 12 and she also mentioned that she has a driver’s licence. She is currently unemployed. She previously worked as a Law Enforcement Officer during the 2010 soccer world cup tournament. She was employed on a contract basis only. She is Xhosa speaking but also quite fluent in English. Her seven year old son, Andile, was referred for OT in 2010 due to severe behavioural problems and scholastic problems. He has a working diagnosis of Attention Deficit Hyperactive Disorder (ADHD). He is in Grade 1. Mom 1 shared that her son’s father is also unemployed and so is not able to provide financial support but has regular contact with his son. She has only the one child and they live with her mother, her brother and three nieces and one nephew. Mom 1 has missed some sessions and has also had to reschedule sessions. The occupational therapist recommended her as a parent who attended irregularly.

#### **3.7.2 Mom 2**

Mom 2 is a 24 year old married, coloured woman. Her highest level of education is Grade 8. She is a housewife. Her husband has completed grade 12 and currently works as a security officer. They are both Afrikaans speaking. They have two children. Aiden receives the OT treatment. He is a 4 year old boy who has a diagnosis of spastic quadriplegia with controlled epilepsy. He uses a buggy (wheelchair for children). The other child is a seven year old boy. Mom 2 shared that they are very religious and are very devout Christians. They live in a Wendy House erected in the

backyard of another family. She has missed some sessions and has had to reschedule many appointments. She was recommended as a parent who attends irregularly.

### **3.7.3 Mom 3**

Mom 3 is a 30 year old, married, coloured woman. Her highest level of education is grade 12. She has a diploma qualification obtained at a technical college. She is English speaking. Her husband is 32 years and is employed as a floor manager in a retail store. She is a housewife. She feels that she cannot work because she has no-one who can care for her children especially the child with the special needs. They have three children. Yusuf, their eldest child, receives the OT treatment. He is a six year old boy who was referred to OT because of his behavioural and scholastic problems. He has a diagnosis of autism. The other two children are a three year old boy and a one year old girl. They live in a rented house. Mom 3 was recommended for the study as a parent who attends irregularly. According to her, she missed several sessions because it was cancelled by the occupational therapist and there were many problems rescheduling these cancelled appointments.

### **3.7.4 Mom 4**

Mom 4 is a 41 year old, coloured woman. She is a single mom and currently unemployed. She has had several jobs on a casual basis at various factories, a catering company and a charity organisation. She has a grade 9 level of education. She has three children aged 17, 15 and 6. Her youngest daughter, Emma has autism and is receiving OT treatment. She shared that her children have no contact with their father. They live with her 78 year old mother. She says that it is difficult for her to work because she has no-one who can take care of her daughter and that it is extremely difficult to get her daughter into a school. Mom 4 has missed and rescheduled sessions. She was recommended for the study because she attended irregularly.

### **3.7.5 Mom 5**

Mom 5 is a 36 year old coloured, married woman. She has a grade 7 education. She is currently unemployed but used to work as a cleaner. Her husband is however employed. She is Afrikaans speaking. She has two children, Andrew who is seen at OT and is just over a year old and a 14 year old boy. Andrew receives OT due to having been born with his skull not completely formed and therefore receives a

special “helmet” to protect his head but also to encourage the correct skull development. This child also has bad eczema for which he receives treatment at a community clinic.

Mom 5 attends regularly but has had to reschedule some sessions.

### **3.7.6 Mom 6**

Mom 6 is a 40 year old coloured, married woman who is a housewife. She has a grade 8 level of education. She is Afrikaans speaking. Mom 6 says that she used to work but then her mother became ill and she had to quit her job to care for her sick mother. She has not worked since. Her husband is also 40 years old, also has a grade 8 level of education and works as a general assistant for the Department of Health. They have four children, a girl who has completed grade 12, a child who is grade 9, one who is 10 years old and Lily, the child receiving OT who is two years old. Lily is receiving OT treatment for scar management (pressure therapy) for burn wounds to her face and chest. They attend regularly but have had to reschedule at times.

### **3.7.7 Mom 7**

Mom 7 is a 41 year old coloured female. She is a single mom. She has high school education (no specific grade was mentioned during the interview) and has done some extra courses at tertiary institutions. She is employed as a data administrator at a research company. She is English speaking. She has only the one child, Ryan, aged four. Her son has no contact with his father and she receives no financial support from him either. They live with her mother and her sister. Her son has autism and was referred for OT because of a marked developmental delay.

She was the only parent interviewed at her work place. She has had to reschedule several times and has missed some sessions.

### **3.7.8 Mom 8**

Mom 8 is a 26 year old coloured woman. She has a grade 10 level of education. She is currently employed as a cleaner at a hotel on a casual basis. She works 3 days a week. She is Afrikaans speaking. She has only the one child, James, who is eight years old. He has a diagnosis of Post Traumatic Stress Disorder due to having been the victim of violent sexual assault when he was four years old. He was referred to OT because of scholastic and behavioural problems. Mom 8 is unmarried but has been in a

relationship with her son's father for 11 years. Her son has regular contact with his father. The father is also unemployed. She and her son live with her parents, two sisters, two nieces (aged 12 & 14) and one nephew (aged two).

Mom 8 has not attended regularly at all and has missed most sessions.

### **3.7.9 Mom 9**

Mom 9 is a 26 year old coloured woman. She has a grade 12 level of education and works at a call centre. She has done some further studies in the United States of America in hospitality but never pursued a career as a chef because she found it exceptionally difficult to find a job. At the time of her return from the USA, the only job she could find was that of a driver. Mom 9 is English speaking. She is currently separated from her husband. They are however working on reconciliation. They have two sons, aged five and three. The eldest child, Logan, is the one receiving OT treatment. He has Attention Deficit Hyperactivity Disorder (ADHD). He was referred for OT due to his behavioural and scholastic problems. He is in grade R. Mom 9's husband is 26 years old and unemployed. He does not assist her financially but has regular contact with his sons. His highest level of education is grade 10. Mom 9 lives with her children, her grandmother and cousin. Mom 9 attends sessions regularly and has only rescheduled minimally.

### **3.7.10 Mom 10**

Mom 10 is a 30 year old coloured woman. She is a single mother with an educational level of grade 10. She is currently unemployed but says that she has only ever held temporary positions. She is Afrikaans speaking. She has three children aged eleven, six and a baby who is about nine months old. The baby attended the interview with Mom 10 as she had no one to look after him. Her son, Samuel, (six years old) is the child receiving OT treatment. He was referred for OT because of a marked developmental delay. He was born prematurely (at 33 weeks) and now suffers from growth retardation. The father of her children has no contact with them nor does he support them financially. Mom 10 and her three children live with her parents who support them financially. However, she lives in a house that she inherited from her grandmother. She was recommended for the study because she attends irregularly. She has missed sessions.

### **3.8 Data collection**

Data for this study were collected through individual interviews and a group discussion.

#### **3.8.1 Individual interviews**

The ten individual interviews were conducted with the mothers lasting between half hour to one hour and one group discussion with the occupational therapists that lasted for an hour and twenty minutes. The data collection took place between October 2010 and July 2011. The researcher conducted all the interviews herself. She designed an interview guide for the interviews with the mothers (See Appendix 1 & 2). The mothers were asked very generally in the beginning about their experiences with a disabled child. According to Robson (1993), the flexibility and adaptability of interviews are a definite advantage for collecting information rich data. Robson (1993) goes on to say that conducting personal interviews presents the researcher with the opportunity to alter the line of questions or probing, allows the researcher to follow-up worthy responses, observe non-verbal responses and explore core motives that cannot be done using self-reporting questionnaires. The mothers were inclined to make statements without elaborating or being clear as to what they meant such as that they were happy to attend the OT services or that everything was nice. The researcher would then asking probing questions such as “What about the service is nice?” or “Will you tell me what you mean by nice?” or “What about the service makes you happy?” This was very useful in gaining more specific and richer detail. The researcher also responded to non verbal cues such as facial expressions or changes in tone for example, a frown or angry tone of voice.

Venue options for the interviews were the nearest healthcare facility to the patient, the hospital where they were currently being seen, their homes or their work places. All ten parents interviewed were the mothers of the children. Nine interviews took place at the hospitals where their children were being treated and one interview took place at the parent’s work place. Parents preferred not to meet at their homes. Some of the reasons provided were: their houses were too noisy and overcrowded, the areas they lived in were too dangerous for the researcher to come to or the child who is the OT patient will be too distracting during the interview.

### **3.8.2 Group discussion**

The researcher facilitated the group discussion with four occupational therapists in August 2010. The occupational therapists all work in similar contexts. The occupational therapists were very comfortable with one another because they knew each other except for the occupational therapist currently doing her community service. The researcher developed an interview guide for the group discussion (See appendix 3). The broad topics in the interview guide covered a description of the occupational therapists work as well as their perceptions of the negative and positive factors that influenced the utilisation of the OT services. The group setting allowed them to share their perceptions, interpretations and beliefs about working with children and this provided an in-depth understanding about the topic (Ezzy & Liamputtong, 2005). The group discussion allowed the participants to go into greater detail through the group participation process which provided an opportunity for participants to explore and clarify their points of view as the discussion progressed (Ezzy & Liamputtong, 2005).

The interviews and group discussion were audio taped. The researcher also took notes during the data collection process to note down any non verbal responses and other observations such as group dynamics.

### **3.9 Data Analysis**

Using thematic analysis the researcher sought to find recurring themes and sub-themes that emerged from the data (Ezzy & Liamputtong, 2005). Key themes and sub-themes were coded and categorised, using colour codes according to the main, broad themes/categories that emerged from the literature and then rechecked for contradictions, inconsistencies or over-or-under-interpretations (Durrheim, Painter and Terre Blanche, 2006). The researcher used the two broad themes of “service” and “parent” that emerged from the literature review as an initial start to making sense of the data collected. From this exercise a third broad theme emerged from the data, namely “environment”. Further key and sub-themes were then identified still using the literature review themes as an initial framework but also checking for new themes that emerged from the present study. One key theme that emerged was “interaction



between the parent and their child with the occupational therapist” and sub themes such as “communication” and “staff attitude” were further indentified. The final main themes were summarised and discussed and used direct quotes from the transcribed data to further illustrate the themes. For the purpose of this study all Afrikaans quotes were translated to English.

### **3.10 Rigour**

To ensure that no data was lost, all interviews as well as the group discussion were audio taped and transcribed verbatim by external sources and then rechecked by the researcher. The researcher compared the audio tape recordings with the typed transcripts of at least three quarters of each interview. This was to ensure correctness and thus increase validity of each document as the researcher was familiar with the data because she did all the interviews herself.

To further achieve credibility, Sandelowski (1986) suggests methods such as triangulation and through confirmation from the participants themselves. Rigour was strengthened by triangulation methods using different data sources (parents and occupational therapists) and using different methods (interviews and group discussion). Rigour was also improved through member checking. The researcher summarised the key discussion points at the end of each interview and group discussion and shared it with participants to verify that her understanding of their opinions, beliefs and views was a reflection of what had been said. The researcher noted any suggested changes. Credibility of this study was also increased by describing the setting, the participants and the themes in thick, rich detail (Creswell & Miller, 2000). By doing so the researcher hopes that the deep, dense description allows the reader a feeling of personally having experienced the events being described (Creswell & Miller, 2000).

The researcher also kept a journal to reflect on and monitor her own thoughts and feelings throughout the study. As advised by Rice & Ezzy (1999) this process is particularly important for transparency as the researcher herself is an occupational therapist who manages one of the selected OT units and who selected one of the occupational therapists participants. All assumptions, beliefs and biases that affected



this investigation was recorded in the researchers' journal and reported under limitations of the study (Creswell & Miller, 2000). An audit trail was created by keeping a fieldwork diary that was used to note, in chronological order, all research decisions and activities (Creswell & Miller, 2000). The researcher has used this to reflect on and report on the process followed and decisions made throughout this paper. It is hoped that this will improve conformability of the study.

Peer debriefing was employed, to an extent to further enhance credibility of this study. The data and research process of this study was reviewed by an appointed research supervisor from the School of Public Health (University of the Western Cape). Although the research supervisor was outside the context of the study and was appointed as a "superior" in this situation, she provided support, scrutiny and interrogation of the data and research process and asked clarifying questions (Creswell & Miller, 2000).

### **3.11 Limitations of the study**

The researcher has partial bilateral hearing loss due to Meniere's disease. This had some impact on her ability to conduct the interviews, as at times she had to ask parents to repeat themselves for her clarity. This may have affected the flow of the interviews although all parents were more than willing to accommodate her. The researcher may also, due to her impairment, have lost out on information during the interview on which to follow up on or prompt for more information. The researcher however tried to compensate for this by telling the parent upfront about her hearing loss as well as summarising key points continually during the interview.

The researcher's hearing impairment also prevented her from being able to transcribe the interviews herself. She did however, check for reliability of the transcriptions by comparing the audio recording with the transcript. She was also able to follow most of the transcription because she was familiar with the content but had difficulty with some parts. However, from the bulk of what she could hear, she had enough confidence that the transcriptions were an accurate reflection of what was said during the interviews.

The researcher is an occupational therapist who manages one of the OT departments where one of the out-patient units in the study is based. She was concerned of possible bias and so tended to push harder for the participants from her hospital to share the “negative” factors namely, barriers, concerns and recommendations to improve the service so as not to appear as if she was pushing for a positive review. The researcher also recruited one of the occupational therapist participants from the OT unit that she manages. The researcher is this occupational therapists direct supervisor and therefore was concerned that the occupational therapist would feel pressurised to participate or feel uncomfortable to share her feelings or opinions openly during the group discussion. To overcome any bias, she reassured the occupational therapist that her participation was completely voluntary, that nothing she shared would count against her, that she was free to withdraw at any point and that her input would be most valuable for the department’s development which was the intention of the study. However, the researcher’s concerns were unfounded because this occupational therapist was very keen to participate.

Given the nature of the research, some parents felt uncomfortable admitting that they missed appointments possibly due to feeling ashamed or embarrassed about non attendance. The researcher made the utmost effort to reassure parents that the study was exclusively for the purpose of improving the OT service and not in any way judging them as parents. The researcher also never asked directly if they missed appointments. She emphasised that she was only interested in what made it easy or difficult to attend the OT sessions in order to improve the service.

Another limitation of the study is that the researcher was restricted to interviewing parents who spoke English or Afrikaans which meant that the other language parents were excluded from the study. This meant that important information from their perspective could have been missed.

### **3.12 Ethical Considerations**

Participation in the research study was voluntary for all parents and occupational therapists. Participants were informed that they could withdraw from the study at any time and that it would not impact negatively on their work (for the occupational

therapists) or to their child's treatment (for the parents). Each participant received an information sheet in the language of their choice (see appendix 4 & 5) detailing the study, requesting their participation and ensuring confidentiality. Each participant signed a consent form once again in their language of preference (see appendix 6 & 7) before commencement of the interview. The information sheet and consent forms were in English and in Afrikaans to accommodate the participants of this study.

One mother whose son was sexually abused became very tearful during the interview. The researcher referred her to the occupational therapist that sees her son, for counselling. It was arranged that if she required further psychological intervention, the occupational therapist would refer her to a psychologist.

Permission to conduct this study was sought from the individual hospital boards and the research proposal was approved by the University of the Western Cape's Research and Ethics Committee.



## CHAPTER FOUR

### 4. RESULTS

This chapter presents the findings of the group discussion with the four occupational therapists as well as the interviews held with the mothers. The results are presented using three main headings, namely service related factors, parent related factors and environmental factors.

#### 4.1 Service Related Factors

Service related factors describe the factors relating to the OT service (building, staff, OT intervention) that had a direct and indirect impact of the utilisation of the service. The mothers mentioned that their interaction and/or their child's interaction with the occupational therapists, treatment progress, their involvement in the treatment programme, accessibility, OT treatment sessions and facility environment influenced their perceptions of the OT service.

##### 4.1.1 Interaction between the parent and/or child and the occupational therapist

###### 4.1.1.1 Staff attitude

There was agreement amongst the mothers that staff attitude impacts on their satisfaction of the OT services in the out-patient units. The mothers viewed the occupational therapists that were friendly, warm, empathetic and sincere as a positive factor to the service as illustrated by the following quotes:

*“ people is friendly here with us so, you understand. So, I don't have a problem at all coming here.”*

*“ .....she's a very chirpy person [laughs]....the way she interacts, you could warm up to someone”*

*“ the way they [occupational therapy staff] deal with children like these it’s not pretence, its real ...um um there’s not, there’s no pretence about her [occupational therapist], what you see is what you get.”*

*“.....and makes you feel that you are not alone because they are also there to help and they feel it with you.”*

Mom 7 was very encouraged when the occupational therapist showed interest and excitement in her child’s progress. She said that the occupational therapist:

*“was over excited when Ryan start counting.....because for the first time she said that she could see the things that she taught him.”*

She also said that when her son achieved something during an OT session, the occupational therapist would offer words of encouragement such as:

*“Well done! He’s done something!”* or positive reinforcement such as *“it’s a high 5”* [gesturing the high 5 hand shake] *“it’s a star here”* [pointing to her forehead].

However, not all the mothers had positive interactions with the occupational therapists. One mother was dissatisfied with the occupational therapist that treated her son. She criticised the occupational therapist for showing no interest in her job and said she lacked the necessary enthusiasm and energy required to deal with children particularly those with special needs. She gave her opinion about how an occupational therapist is supposed to be:

*“... you must be vibrant and you must really love what you are doing.....even if it’s a front that you are putting up, then do it for the child.”*

She explained that then:

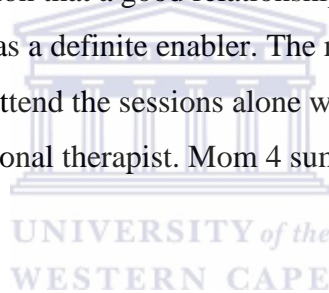
*“the child also starts feeling like, ‘yes, I feel like doing this’ and you get the child going.”*

From the occupational therapists perspective, there were reasons for the negative attitudes. Most children are only seen once a month at the OT out-patient units and for this reason parents are given a home programme with specific activities that parents should do at home with their child. One of the occupational therapists admits that she would display quite a negative attitude towards parents if they did not implement the home programme.

*“if they don’t even attempt to do something, I am quite miserable with them.”*

#### 4.1.1.2 Relationship between the child and the occupational therapist and between the occupational therapist and the mother

The mothers were of the opinion that a good relationship between their child and the occupational therapist staff was a definite enabler. The mothers felt that it was easier for them to let their children attend the sessions alone when their child was happy and comfortable with the occupational therapist. Mom 4 summed it up aptly when she said:



*“ ....uhm if my child is happy with [occupational therapist] then I’m happy.”*

One mother said that she struggles to get her daughter to participate in the home programme activities but her daughter gives her full co-operation during the OT sessions because she is so fond of the occupational therapist. Her daughter is very excited to attend the OT sessions. This was the case for some of the other mothers as well. Mom 1 shared that Andile would be the one to remind her of his OT sessions and was tearful when he heard that the occupational therapist seeing him, was leaving at the end of that year. Another case is that of Andrew, the youngest child (11 months old at the time of the interview) in the study. When the researcher commented that at times the younger children cry when they see the occupational therapist, Mom 5 replied:

*“but he does not cry....he laughs before the time when he sees her [referring to the occupational therapist] because he knows her already.”*

She goes on to explain:

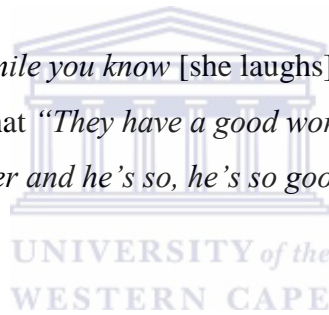
*“And when she is busy with him, she plays with him first before she starts to work on his head.”*

She ends off with:

*“I am very satisfied with this.”*

Mom 7 stated that a major reason that she tried her best to get her autistic son for his OT treatment is based on the positive reaction from her son when he arrives at the OT unit.

*“you should see the smile you know [she laughs], it lights up.....”* She continues to explain that *“They have a good working relationship and they do understand one another and he’s so, he’s so good, he goes on cue what she does.”*



On the other hand, Mom 3 expressed that a bad relationship between her son and his occupational therapist was a barrier in the utilisation of the OT service. She said that her son was not enthusiastic to attend the OT sessions and that he seemed bored during the sessions. She attributes their poor relationship partly to the fact that the occupational therapist never provided any positive reinforcement during the OT sessions.

*“And you know how children work on praise and you know that type of thing...”*

The occupational therapists confirmed that a therapeutic relationship between them and the child is important. They added that a good relationship with the parents is as necessary and agreed that sound relationships with the parent and the child resulted in better attendance. One occupational therapist confirmed that her patients *“look forward”* to attend her sessions. The occupational therapists identified some key

factors to establishing a good relationship with the child as well as with the parent. Factors identified were empathy and patience especially with children who display the worst behaviour.

#### 4.1.1.3 Continuity of occupational therapist

The mothers expressed a definite preference for the same occupational therapist to see their child as far as possible. As presented above, parents valued a good relationship between their child and the child's occupational therapist and therefore, found staff changes a barrier to their utilisation of the OT service because it interrupted the therapeutic relationship that was developed.

Mom 4 compared the OT service with another service her child receives at the hospital in relation to the continuity of the occupational therapy staff. Her daughter has only been seen by one specific occupational therapist but has been seen by several different service providers from the other discipline. She is unhappy that her daughter has to become used to a different service provider so often and shares that her daughter is extremely reluctant to enter that discipline's building. This is confirmed by Mom 7 and Mom 8. Mom 7 says:

*“I would prefer the same person.....They need to familiarise themselves. With autistic children they come into the room, the first thing they would they would look at their surroundings and they want to see something that's familiar. So he's familiar with ...[occupational therapist name] he's familiar with her methods, the way she teaches. Now he's having about-this is the fourth ... [refers to other discipline] he has.....going through the same routine again, him needing to warm up to this person... they don't develop their full you know, because they only have that ... [therapist] for a couple of months then someone else come in to take over it it change their whole routine whereas with ...[the occupational therapist] he has a certain routine. He's comfortable with her... [occupational therapist name] has been his, his occupational therapist no one else.”*



Mom 8 explained that when her son started with the OT service, they saw one occupational therapist twice and because the occupational therapist only had a one year contract, she left. Her son was also being seen by another discipline at a different facility and there he was also being seen by different health care providers and it had a negative impact on him. She did not want him to have the same experience with the occupational therapist. This was a significant reason that she never scheduled an OT appointment for her son with the new occupational therapist.

Mom 7 and Mom 9 stated that when their child's occupational therapist is not available to see their child, they prefer to cancel or reschedule the appointment but will not agree for the child to be seen by someone else.

*“ If, uhm, there was someone else, one of the other OT's that was going to be with him it might not have been the same, so I'm not sure if because I would say ok fine uhm service wise get him another OT, you know, but at the end of the day it's his personally liasing with her and she gives me feedback because she knows the case....I feel for uhm the process to really have the effect that it has, he's got the one person he goes to.” (Mom 9)*

#### 4.1.1.4 Communication with parent and amongst staff

Another positive aspect for some mothers was clear and adequate communication between themselves and the occupational therapists. Most mothers appreciated the time occupational therapists took to discuss their child's condition, treatment, progress and the home programmes (the activities the mothers must do at home) in specific detail by giving them feedback, explaining treatment concepts or answering questions.

In contrast, Mom 4 found the language used unfamiliar and the information vague and not specific to her needs. She says:

*“Yes, they did explain it to me um but I mean I wanted more. Because sometimes the hospital gives you information but it doesn't sink in.” “I thought ‘what's this doctor talking about?! That's a big word!’”*

The occupational therapists confirmed this. They agree that differences in language pose a problem when trying to educate the parents regarding their child's condition, or explaining the role of occupational therapy and their child's progress.

*“...especially if they're not English or Afrikaans speaking, especially if they're Xhosa speaking patients, I often find that our services are very difficult to define and to help them understand....”*

The mothers felt that when the occupational therapists do not communicate properly with other staff about their child or their appointments, it negatively affects the service provided and their interaction with the staff. For example, Mom 6 expressed dissatisfaction and disappointment because when she arrived for her child's last appointment, she was told by the clerk that her child's name was not on the occupational therapists' appointment schedule for that day. The clerk told her to wait at reception to see if the occupational therapist would be able to see her child that day. She said that her husband had called to the OT unit to reschedule a prior appointment, and the occupational therapist had booked her child for an appointment but had not communicated with the clerk.

#### **4.1.2 Treatment progress**

The mothers mentioned that seeing progress in their child's condition was a positive factor of the OT service which encouraged them to utilise the service. Mom 4 explained that when she implements the home programme that the occupational therapist gives her, she can see the progress in her child's functional performance. Mom 5's son, Andrew was born with a physical condition where the bones in his skull did not fully close and so requires a device from OT (helmet) to facilitate normal growth of the skull. She attended regularly sharing that there was a definite improvement in her son and that this was part of the reason she never skipped a session unless absolutely necessary.

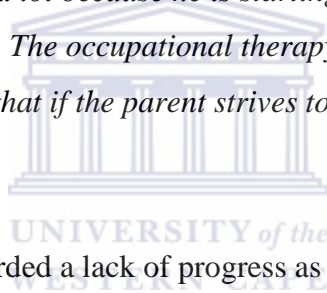
Mom 8 said that her son has severe behavioural problems and that she is unable to manage his behaviour and felt quite despondent about her son's behaviour. He tends to scream very loudly and at any time, no matter where they are. At the OT sessions,

he was taught basic behaviour management skills such as to shout into a pillow when he had this urge. She was reluctant to attend OT because of staff changes and her son had to attend another service from a different discipline, at a different facility. She therefore had difficulty taking her child to attend both and initially chose to take him to the other discipline. She shared that she could not see any progress with the other discipline and seeing her son actually implementing something he was taught during his previous OT, made her reconsider the OT service.

Mom 9 shared a similar experience where her son's behaviour has improved significantly since he has been attending the OT sessions.

Mom 10 was very excited and encouraged by her son's progress. She said:

*“....it also helped him a lot because he is starting to count nicely and read and he is doing everything. The occupational therapy helped him nicely.....That is why I will always say that if the parent strives to get the therapy for the child, it benefits the child.”*



Some mothers, however, regarded a lack of progress as a negative aspect to the OT service and this discouraged them from bringing their child for subsequent sessions.

Mom 1 who did not attend regularly with her son was concerned that she did not see progress in his schoolwork even though he enjoyed the OT sessions. Mom 3 said that she could not see any progress in her son's functioning and that she therefore could not see any need in taking her son for the sessions. She felt that she did more with her son at home.

The occupational therapists confirmed that parents attend more regularly when they see progress. They agreed that many parents however become impatient at the beginning when the child is being assessed. They expect an immediate improvement and when they do not see this, they tend to stay away.

#### 4.1.3 Parent involvement in their child's occupational therapy treatment

The mothers preferred being involved in their child's OT sessions in different ways: either by sitting in on their child's treatment sessions where they could see directly what the treatment entails and how their child is progressing; by being included in the child's treatment either by being asked for their input or by being allowed to participate during the treatment sessions and by receiving home programmes (booklets or pages) with exercises and activities that they could do with their child. The mothers agreed that being involved in their child's OT resulted in them gaining more knowledge about their child's condition and made it easier for them to deal with their children at home. It even helped some of the mothers with the management of their other children as well. One mother confirmed that the home programme encouraged her to spend more time with her son and since they have been participating in the home programme, their relationship has improved. Moreover, even the mothers who did not attend regularly appreciated being included in their child's treatment.

Mom 4 found sitting in on her daughter's sessions very useful, especially after she tried something new at home and it worked. She shares that:

*“That, that actually surprised me yes, the way they worked with her and, and I didn't actually expect that she will do that at home, if I must do it with her.”*

Mom 9 says that the occupational therapist treating her son really made her feel like she was part of the team treating her son. She felt very comfortable with her and felt that she could open up to her about all matters pertaining to her son. She felt that the occupational therapist and she managed to deal with all her son's problems together.

Another positive aspect that was mentioned was parent sessions where a group of parents were called together to share their experiences as well as be taught various coping strategies to deal with their child. This was a highlight for Mom 8.

*“With the parenting skills that we attended, we learnt a lot. There we were taught not to hit the child.”*

However, Mom 3's experience was in contrast to the above. She sat in on her son's sessions but she was never involved in any way, and she was never given any sort of home programme for her son. This was a definite barrier to the utilisation for her.

*"No! I would just sit there and then they do their thing!"* When asked about any home programmes she said, *"Uhhh, this place, no, not that I know of...No, huh uh."*

Some mothers stated that at times it was difficult to implement the home programmes because of their home circumstances or lack of suitable equipment.

Mom 2 shared that she received a home programme:

*"... but there are a few that you cannot do because it is not the same"*

She referred to a particular exercise where her son has to stand up against a table of a specific height. She says that she does not own a table so tried to use her bench and her bed but neither was appropriate. There are some activities that require her son to be in his wheelchair (buggy) but the buggy cannot fit through their door so it stands outside in front of their two roomed wooden structured home.

#### **4.1.4 Accessibility in terms of the service**

The mothers raised issues around appointment times, rescheduling appointments and waiting times. Attendance was improved when appointments were scheduled to accommodate them and they were happier when they did not have to wait long for their child to be seen. Many of the children in the study have multiple health problems and therefore needed to be seen by more than one discipline, occupational therapy being one of three or four different service providers at times. Parents preferred that all their child's appointments be made on the same day to avoid having to visit the hospital three to four times a month, sometimes even more. Parents disclosed that they have skipped OT sessions when the occupational therapist cannot accommodate them on the same day as the other disciplines.

Mom 3 said that she prefers having all her son's appointment on one day because he is the eldest of three children and when she takes him for his sessions she has to travel by herself with all three of her children, using public transport. The occupational therapists emphasised that they try very hard to accommodate these parents but felt that parents should take the initiative to make suitable arrangements with all respective service providers. There are times when they are unable to meet these requests primarily due to shortages of staff. The occupational therapists however felt that having the child see all disciplines on one day is not always a good idea because if they are the child's last appointment, they tend to find the child less co-operative and they assume this is because the child is tired or over stimulated. However, the occupational therapist at the mental health facility did not experience this problem. The occupational therapists confirmed that the nature of the OT intervention at the mental health care facility is less active and therefore, having several sessions on one day do not have the same impact on the OT service there.

Some mothers felt that they wanted their child's sessions after school to ensure that their children did not miss out on school, while others, especially those with children not school going yet, preferred that their children be seen earlier in the day when they are most active and alert. Mom 9 shared that a definite enabler for her was being able to be accommodated as far as possible regarding her son's appointment times due to her work commitments.

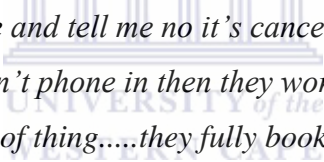
*"...we negotiate even more now that I'm working... I try and make it early in the morning and they accommodate me. If I, if I can't like now ....[names occupational therapist] has got sessions in the morning, which where she can only see me at 11h30, now I make my arrangement at work."*

Mom 2 shared that appointments early in the morning was a barrier for her as she travels by public transport with her child.

*"The trains are really inconvenient. Unless they make my appointment at 12, 1 o'clock, then it will be fine. Then I can come with the train....But they usually make my appointments at 8, 9 o'clock. The trains are full at that time of the morning."*

She however praised the OT staff because they accommodated her at a later time if she asked. The occupational therapists confirmed being willing to accommodate parents but only as far as they could manage with the number of staff they have on duty. The occupational therapists mentioned that it is very difficult to always accommodate parents who want all their child's appointments on one day and insist on being accommodated in terms of specific times. They feel that parents lack understanding of their work rosters and long waiting lists. One occupational therapist mentioned that she was completely booked for the following two months. Therefore, if a mother now tried to book an appointment with her for that time, she would not be able to accommodate her.

In contrast, not all mothers found it easy to reschedule their child's appointments. Mom 3 says this was the main reason that they did not utilise the OT service as prescribed.



*“They would phone me and tell me no it's cancelled then he skips four months of OT. And then if I don't phone in then they won't give me another appointment, that type of thing.....they fully booked and another thing is there's only two therapists available and this one resigned and that one didn't write it in the book. It's always something, you know. That made me very angry.”*

Although the mothers found the waiting times were not that bad, it was a negative factor because of the impact it has on their children. They agreed that children become restless and more difficult to manage and when they have waited for too long, they are less co-operative during the OT sessions. Mom 7 showed understanding that the occupational therapist had to see inpatients as well as out-patients and so would at times run late but she was concerned that this would have a negative impact on the OT session. She gave an example:

*“She was a bit late and because she had uhm, after hospital she said she had just come from there, she was tired and then you know sometimes if you are tired you can be a bit irritated and the fact because he, he was tired as well he*

*was irritated as well waiting a long time. So he didn't want to do the things instead he was kicking the ball all over the ball even against her because he wasn't happy."*

#### **4.1.5 Quality of service**

The mothers commented on the frequency of the sessions, the duration of an individual session as well the relevance of the treatment provided. Most of the children receive the OT service once a month. Moms 3 and 8 stated that they felt this was inadequate. Mom 3 felt that because she does not work, she could attend more often. She was concerned that her son was not exposed to enough stimulation. She said that her son is only seen once a month, and she has to travel very far to get to the sessions and so expects a meaningful session to be longer than 25 minutes.

*" Ya but the OT went so quick also.....it's only like about twenty minutes, twenty five minutes and they just busy with puzzles and putting beads things on here and then its again finished."*

Mom 3 also raised a concern that the OT sessions were repetitive and she was unable to understand the relevance of the activities done.

*" It's like....say you give him this to do.....put the puzzles together and stuff then maybe next time you give him something more of a challenge.....Don't every time give him the same thing to do or whatever....."*

Mom 4, however was very satisfied because her daughter's OT sessions were different each time and the occupational therapist explains to her what they are doing and why.

The occupational therapists also refer to the quality of their services. They state that they try their utmost to render the best services possible within resource constrictions. According to the occupational therapists, shortage of occupational therapists as well as limited budgets impacts on the quality of the OT service.



#### 4.1.6 Indirect Factors

##### 4.1.6.1 Facility environment

The mothers mentioned various details about the hospital environment that influenced their opinion of the OT service in an indirectly. .

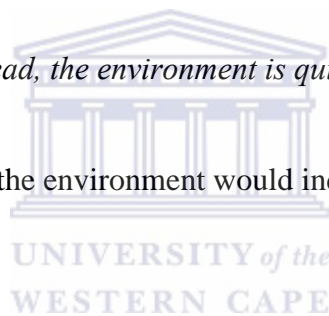
Parents valued a clean environment. Parents mention dirty toilets as a deterring factor.

*“You go to the toilet, there’s no soap, but it’s a hospital.....with no hand towel or no thingy to dry your hands, no toilet paper and no soap so you’ll come here to get a disease, it’s terrible! Because here you pick up a lot of germs, I mean it’s all over the show!”*

Mom 9 specifically referred to the mental health facility as:

*“This place is quite dead, the environment is quite dead you know...”*

She mentioned that changing the environment would indirectly help patients get better.



Mom 9 also shared a concern about the absence of a proper reception area at the OT unit. There is a reception area but no specific person assigned as a receptionist. So, there is no one that patients can report to, or to address any enquiries to.

Mom 2 said that being familiar with the environment at the current hospital as well as knowing her way around in the hospital was a positive factor in utilising the OT service.

*“I feel very at home here.”*

She goes on to explain that the community health clinics are closer for her but she prefers to attend the bigger, central hospital because she is more familiar with it.

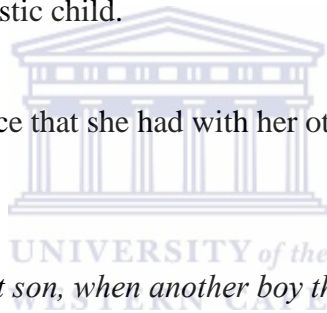
*“.....but I don’t know the area.....I am not familiar with Belhar, I am not familiar with travelling to Delft. I have never been to those places. That is why*

*I say that it is easier here because I familiar with the place, I know which floors to go to. I know where .....[names hospital] is.....how to travel to [names hospital] and so on. That is why I am comfortable at ....[names hospital].*

#### **4.1.6.2 Poor district health services**

Although the community health clinics and district hospitals are closer for mothers to attend, many of them prefer to travel the further distance to the larger, central hospitals where the OT units in this study are situated. This is because of poor services that either they or their family have received at the district level services. Mom 4 says that there are some clinics and district hospitals that render unsatisfactory services. She has a health problem for which she has to attend a community health clinic but she lied about her address because she refuses to attend the clinic in her area because of the rude staff and very long waiting times. She felt that this environment would be negative for her autistic child.

Mom 2 described an experience that she had with her other child at their nearest district hospital.



*“Once I took my eldest son, when another boy threw a spade here [points to the side of her leg]. It was open. The ambulance took us in the morning already. It’s 7 o’ clock already, and we’re still sitting, not even called up yet. So, I took a lift home with someone. So, I doctored my child’s leg myself. The people don’t like.....[names district hospital]. I have all my stuff sorted out here [names tertiary hospital child is being seen at] yes, if they want to refer me, truly I tell them....[names tertiary hospital again] is my closest hospital.”*

The occupational therapists agreed that access in general would be improved if patients attended the OT services at the community health clinics or district hospitals. They mention though that a few parents still miss their appointments at the closer facilities.

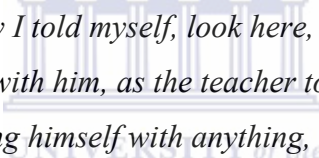
## 4.2 Parent Related Factors

The mothers' personal circumstances were a key factor that impacted on the utilisation of the OT service. These include severity of the child's problem, support network, parental beliefs and work.

### 4.2.1 Severity of the child's problem

The mothers had many concerns about their child's condition especially developmental delays, scholastic and behavioural problems. Some of the mothers expressed a sense of hopelessness and desperation with regards to their child's problems. They shared that this was a reason to seek help, the OT service being one option and at times the last resort or only option.

Mom 9 recalls how bad things were with her son and why she attends the OT sessions regularly.



*“The real problem why I told myself, look here, I need help with Logan, at the rate things was going with him, as the teacher told me he's not completing work, he's not bothering himself with anything, and I just told myself look he's gonna be in school, what's gonna happen if he's in grade one? The teachers don't have the time, and if my child is not gonna listen or focus at the end of the day they gonna push him to the back of the class.....So at this point in time Logan is concentrating more....he is with all the activities that we've been given from .... [names OT unit].....Uhm that was my main priority, I can't let Logan fall through the way side.”*

Lily was being seen at the OT unit for a burn wound, Mom 6 was very concerned about the legal consequences of not attending the OT sessions regularly which would be construed as neglect.

*“And if I don't come [referring to OT sessions] and she gets hurt, then I'll go to jail. If my child must get hurt again, or the people [social services] will take her away from me because I am neglecting her and not able to care for her.”*

The occupational therapists shared this view that the more severe the parents perceived the child's problem to be, the more likely they were to utilise the OT service. One occupational therapist defined severe as:

*"...it's physical,...it's a CP (cerebral palsy), or it's a severe behavioural problem, like they can see that it's an autistic child."*

During the discussion about parents who do not attend, especially during school holidays, this occupational therapist said:

*"...but if you are seeing more like the severe cases, they make a plan to come just for the severe, but otherwise, if it is a mild developmental delay, they won't pitch."*

#### **4.2.2 Family support**

The support (financial, providing a place to stay or helping with the children) that mothers got from their families helped them with the challenges of caring for their child with special needs. It directly and indirectly enabled their being able to attend the OT services. The mothers relied on support from their spouses (those who were married), parents as well as siblings to assist with taking the child for their OT sessions, providing transport money for the hospital, or care for their other children while the mother took the child with special needs to the hospital. As one mother testified:

*"I have a good support system. I not only have a sister that loves him so, grandmother too...their love is unconditional so he doesn't have to feel that even thus he's out of place he, he, he is being loved so, that's the most important."*

Another mother says:

*"I am still dependent on my parents.....they support us financially, me and Samuel.....My sisters also assist us, when he needs stuff. They also assist with medication."*

Mom 9 said that when she was unable to take her child for the OT session her parents would take him. This ensured that he very seldom missed OT sessions.

On the other hand, Mom 3 shared that she has no one who can assist her with her other children when she needs to bring Yusuf for his sessions (OT and other). This has not resulted in her missing sessions but has made it very difficult for her to attend the sessions.

#### 4.2.2.1 Support from the child's father

Most of the mothers who participated in this study shared that caring for their child with special needs was very tiring and time consuming. This led to them not attending some sessions or not implementing the home programmes. The mothers mentioned that they received very little actual support from the fathers with child rearing activities that includes taking the child for their OT sessions and implementing the home programmes provided. Even the married mothers mentioned that the fathers mainly contributed indirectly by giving transport money or making phone calls to the hospitals to cancel or reschedule appointments. The single mothers had full responsibility for their children.

Mom 3's husband is employed but works long hours so the primary child care responsibility is with her. Mom 10, a single mother, shared that her child's father lives in a different province to them but does support his child financially. Mom 8 has been in a relationship with her son's father for 11 years but they are not married and do not live together. He assists with all child care responsibilities except financial support. She shares:

*"His [referring to her child] father is unemployed at the moment. His father and I attended [the parenting skills session]. We came here together"*

Referring to her son's relationship with his father she says:

*"Ooooh, he is crazy about his father! They have a very good relationship."*

On the contrary, when asked about Andile's father, Mom 1 (single mother) says:

*“ He doesn't help with anything. He doesn't. But he sees Andile once in a while.....he would come and pick him up and then bring him back after a while. He doesn't contribute on anything.”*

Mom 9 (separated from her husband) commented on the father's involvement with her son:

*“...uhm if ....[names occupational therapist] know when they go to their father, when they've been a weekend by their father uhm it is not, it is just she knows how to, how Logan would be when he is with me and Logan would be when he comes back from his father.....I've been giving it [the OT home treatment programme] to him as well, we've been doing, working through it together. At the end of the day I told him it doesn't matter I do it at home and you don't practice it by you. Logan is more interactive with his father as well, which last year those things weren't taking place.”*

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Mom 4 and Mom 7 have complete responsibility for their children. Mom 7 says that Ryan's father abandoned him when he discovered Ryan was autistic. Mom 4 is frustrated because she has followed the legal procedure to gain financial support from her children's father but she has been unsuccessful.

#### **4.2.3 Work factors**

The mothers shared that being able to take time off from work to attend the OT services was an important contributing factor. They relied on supportive employers. Mom 7 and Mom 9 were permanently employed. They shared that they had to make special arrangements around their work schedules and honour certain work employer expectations. They had to control the amount of time away from work and had to consider the amount of leave (vacation and family responsibility leave) due to them. This was confirmed by one of the occupational therapists:

*“Then , the other problem is that most parents are working, so they cannot continue like they do, to ask for a day off, or in fact family responsibility is not a lot of days to bring their kids here.”*

They booked all their child’s treatment sessions from various disciplines, on one day and scheduled the appointments at specific times of the day so as to cause the least disruption to their work schedules.

*“...because I can’t take off more than one day a month.” (Mom7)*

Mom 7 has to inform her supervisor at least one week prior to her son’s appointment. Both had supportive employers which made attending the OT sessions easier.

*“... my line manager and even the CEO, the doctors that I’ve worked with, everyone knows the situation of Ryan and everyone have been supportive thus far uhm, knowing there are times that I have to be out of work.”*

Mom 9 has to provide proof of attendance to the OT session, to her employer which the occupational therapist provides. One occupational therapist confirms this:

*“....they come and they say, ‘please make sure that you write extra things on the sick note.....say that we were here from this time until this time, not just a general note, because work gives us problems.”*

#### **4.2.4 Parental beliefs**

Some mothers raised religious beliefs as a factor affecting their utilising of the OT service. Mom 2 missed more than two OT sessions and often called in to reschedule sessions. She said that she and her husband were very devout Christians and that they valued God’s will significantly and viewed God’s will as the ultimate solution to their children’s problems. Both her sons have physical problems but only one is being seen at the OT unit. She disclosed that they discontinued her eldest son’s treatment because they believed medical care was no longer required. She does not admit that this is a reason for missing the OT sessions but when asked about what influences her child’s

progress, she emphasised that it was God’s will and that the OT service featured to a much lesser extent.

*“If God wants him to walk, then he will walk. But if it is not from God, it won’t be from God.”*

#### **4.2.5 Treatment Fatigue**

Most of the children in this study must be seen on a monthly basis and at times, twice a month. The mothers described a feeling of fatigue in relation to attending these sessions every month and sometimes twice a month. Mom 2 disclosed by saying:

*“ Yes, sometimes I become so tired of coming to hospital every month....I am just so tired that I do not feel like attending....”*

The occupational therapists agree that the mothers at times feel treatment fatigue as illustrated by the following quote:

*“....you get her [the mother] for a month or two where she just goes through a bad patch.....we do cut the slack, because you get mothers that for their whole life, every single day have to deal with that child and plus we giving them extra work [referring to the monthly appointments and home programmes] to do with the child as well and it’s hard.”*

Another case was that of Mom 8 who expressed difficulty in attending the OT service because her son attended simultaneous interventions from different service providers at different facilities. Her son was sexually assaulted and had to attend the other sessions to prepare him for the court case. It was tough to manage her time and energy between her job, her son’s school and the two sessions he had to attend. This was a barrier to the utilisation of the OT service.

#### **4.2.6 Parental education**

The occupational therapists agreed that parental education impacted the utilisation and adherence to the OT service. They felt that the lower the parent’s educational level was, the less they were able to understand their child’s health condition and the



treatment required to assist the child. This lack of understanding then resulted in parents not bringing the child because they lacked insight as to the importance of the OT service or the parents simply did not get involved in the OT service nor did they implement the home programme activities with the child. One of the occupational therapists explained how lack of education can result in poor attendance at OT sessions:

*”Adding to that it is the parents’ own level of education. Even though we try to explain to them in simple language why it is necessary to bring the child in, sometimes it’s as if you struggle to get that message across and they don’t see the importance in terms of why...”*

### **4.3 Environmental Factors**

Mothers noted stigma and discrimination as well as travelling to the health service as key environmental factors that impacted the utilisation of the OT service.

#### **4.3.1 Stigma and discrimination**

The mothers viewed stigma and discrimination as an indirect barrier to the utilisation of the OT service. They experienced stigmatisation and discrimination from the community through abandonment, gossiping, name calling, and laughing at their children’s disabilities. They do not directly admit that this resulted in them not attending the out-patient OT services but share that it deterred them from leaving the house.

Some of the comments by the mothers are:

*“...if you are walking in the street, the children laugh at his chair and say ‘look at that child’s pram!’”*

*“This child acts like a stupid monkey’....they used to make fun of him....I was scared to go out....”*

*“When they say that he is mad, it make me very angry....”*

*“...like in my case....the father finds out the child has special needs, they leave, they abandon them...”*

Mom 9 mentioned that she delayed her attendance of the mental health care facility due to the stigma attached. She continued saying that people fail to see the value of these facilities and call this hospital where her child is being seen:

*“...the mad hospital unfortunately.”*

#### **4.3.2 Travelling**

The factors related to travelling were mainly as a result of financial constraints. Most of the mothers travelled to the hospitals with public transport. The mothers and occupational therapists confirmed that travelling was exhausting and very demanding for them due to transport costs, travelling with a disabled child, the distance they had to travel and some of the mothers had to travel with other children. Other factors that impacted their travelling were bad weather, transport system strikes and gang violence. However, Mom 9 had no difficulty travelling to the hospital because she had her own car and travelled directly to and from the hospital.

Eight of the ten parents who participated in this study were unemployed. Lack of finances to pay for transport was a major barrier to utilising the OT service. Parents would have to pay for themselves, the child attending the OT service and at times, also their other children and people who travel with to assist them with their disabled child. Many of the parents also needed to use two or more forms of transport because of the far distance between their homes and the hospital. They would for example have to take a taxi to the nearest station or take two or more taxis to reach the hospital. Most mothers who made use of public transport had to walk long distances from their homes or the hospital to arrive at nearest train station or taxi rank. The occupational therapists confirm that transport costs are a major barrier to the utilisation of the service. Parents were forced to miss appointments when they did not have money. Some parents would borrow money but then end up with debts that they could not repay because of a lack of a steady income.

One occupational therapist says:

*“...they can't actually afford money for transport....it actually does cost to come here.”*

The mothers had to manage their financial resources carefully especially when they have more than one child. They have to consider their expenses carefully and share their finances appropriately. Taking their child for their OT session is not a priority for these families, when they have to buy food, toiletries such as nappies or pay for transport to work. Mom 6 says that only her husband works in their household and they have four children so they do not always have transport money to attend the OT sessions.

*“He is the only one working and he has to pay for the house, buy food and some months there is no money to buy clothes of other stuff.”*

This is confirmed by the occupational therapists. An example given by one occupational therapist:

*“...they have to choose between that (OT session) and putting food a meal on the table, then obviously OT will stand second in line.”*

In addition, Mom 2 added that it is very difficult for her to travel with her disabled child because of his wheelchair (buggy). This is confirmed by the occupational therapists who add that some mothers have great difficulty travelling by taxi because the taxi drivers become impatient with them when they take long to get into the taxi and at times will not stop for them due to this.

The weather also played a role in the utilisation of OT services. The mothers did not attend sessions on very rainy, cold, windy or hot days. They found that their children become ill when exposed to severe weather conditions. The occupational therapists verify this. One occupational therapist says:

*“As soon as it rains, they default their appointments, so in winter the statistics just drop....”*

Mom 4 recalls that the gang violence in her area as well as neighbouring areas impacted her travelling. She had to change her mode of transport to avoid the gang violence. Instead of taking a taxi that she catches in the gang invested areas and that drive through those areas, she had to take a bus which is more expensive. Another environmental negative factor that occupational therapists confirmed was transport system strikes such as the taxi strike.

#### **4.4 Recommendations to Improve the Utilisation of the OT Service**

The following are the recommendations that were made by the mothers and occupational therapists in this study:

- The mothers felt strongly that the staff at the community health clinics and district hospitals should be better informed regarding services rendered at the higher levels of care namely the specialised and tertiary hospitals. This will result in them being able to direct the mothers and other patients better as to where to go for the necessary help they require. Some of the mothers said that it took them months to be referred appropriately after seeking assistance at the community health clinics and most times, they sourced the required information themselves either from a private doctor or from family or friends.
- The mothers asserted that all OT units must have a proper reception area where there is a designated person where patients can report and where they can make enquiries when they arrive, especially parents who attend for the first time.
- One mother requested that each unit have a toy library where parents, like her, who cannot afford toys can access the necessary toys required to implement the home programmes. She was very happy to take responsibility for the toy and suggested that each parent bring it back when they have their child's next appointment.
- To improve access, it was also suggested by both the mothers as well as the occupational therapists that their children rather be seen at the district hospitals and community health clinics unless there is an improvement in the

quality of the services there and that OT services must be available at all levels of care.

- The mothers appealed for parent groups that will provide relevant education and support.
- It was also recommended that children and their caregivers be subsidised with transport money. Although, it was not specified who should sponsor the money.
- The mothers appealed for assistance from the OT units to enrol their children into special and if possible, mainstream schools.
- All the study participants strongly recommended that each OT unit acquire more occupational therapists.
- The mothers felt strongly that each OT unit must have adequate toilet facilities. Important aspects that were requested were toilet paper and soap. It was suggested that toilets be locked or that the toilet paper and soap be handed out as individuals go to the bathrooms to prevent misuse.
- For patients who are school-going (even crèche), the occupational therapists proposed a stronger link between the occupational therapists at the health care facilities and the teachers.
- The occupational therapists advised that they must make extra effort to build adequate therapeutic relationships with the mothers and their children.
- Lastly, the occupational therapists suggested that special means of transport should be available for disabled children. However, no suggestions were made as to who would take responsibility to initiate and sustain such an endeavour.

### **Chapter Summary**

This chapter presents the various factors that influenced the utilisation of the OT service at the three paediatric out-patient units as well as the recommendations from the study participants as to how the OT services can be improved. From the findings put forward it is apparent that there were enablers to utilisation as well as barriers to the service. It is evident that the factors are related to the OT service, to the mothers and to the environment in which the mothers and their children exist and these factors impact on one another.

## CHAPTER FIVE

### 5. DISCUSSION

This chapter discusses the key findings of the current study and places these findings in the literature. The Health Belief (HBM) Model (Croyle, 2005) and the Person Environment Occupation (PEO) Model (Law et al, 1996) forms the theoretical framework of this discussion.

Key findings are discussed with reference to the HBM (Croyle, 2005) and using the PEO Model (Law et al, 1996) as an organising framework.

#### 5.1 Person (P)

The person (intrinsic) factors of the mothers in this study were the mother's perception of the severity of her child's health condition, her perception of treatment progress, her religious and personal beliefs and lastly a feeling of fatigue in relation to OT attendance.

##### 5.1.1 Severity of the child's health condition

The HBM (Croyle, 2005) helps us understand what motivates people (in this study, mothers on their child's behalf) to seek health care. According to the HBM, a parent will more readily seek help for their child if there is a perception that the child's illness or health condition is severe (Rebhan, undated). The findings of the present study, is in keeping with the theory of the HBM. All the participants agreed that the more severe the mother perceived her child's health condition was, the more likely they were to attend the OT sessions.

##### 5.1.2 Patient satisfaction in relation to improved health status

Patient satisfaction in relation to treatment progress (or health outcomes) is not well researched in rehabilitation services where the treatment process is of a longer period than medical services (Keith, 1998). Keith (1998) reports, after extensively reviewing the available literature, that patient satisfaction in general was higher when there was an improvement in a patient's health status after receiving the service. Moreover, this author found that patient satisfaction is positively related to the utilisation of health

services. This finding was evident in the current study, where improved health outcomes were found to be a major factor that influenced the utilisation of the OT service. The mothers expressed increased satisfaction with the OT services because they could see visible improvements such as improved behaviour, better social interaction and improved developmental functioning (such as gross and fine motor activities). As explained by the HBM, the mothers who believed that their child was progressing in their health status were more inclined to utilise the OT service continually despite the huge costs of travelling to reach the OT units (Rebhan, undated). However, occupational therapists should not consider this factor in isolation as a measure of how effective the actual OT intervention is because when a patient receives more than one intervention, as in the current study, it is difficult to tell how much influence a particular service has on a patient's health status (Keith, 1998). This is because patients tend to be satisfied with any health service when they are experiencing better health outcomes irrespective of the actual effectiveness of the service (Keith, 1998).

### **5.1.3 Parent Beliefs**

A parent's traditional religious beliefs can negatively influence treatment adherence (Mekonnen & Mekonnen, 2002). This was the case in the current study where one mother stated that she and her husband value God's will and intervention as the primary source of help for their disabled child. They believe that the OT services, as well as other health services, are far less important or required for their child to progress. Stone, Bronkesh, Gerbarg & Wood (1998) recommends that to overcome this adherence dilemma, health care providers must provide treatment from the patient's perspective. These authors assert that by working within the patient's belief system, where you agree on treatment that makes sense in the context of their lives, it will improve their utilisation of the health service.

### **5.1.4 Treatment Fatigue**

The participants in this study described having to attend the OT sessions once to twice a month difficult, tiring and very time consuming. At times, they experienced a sense of fatigue and say that when they felt this way, it was difficult to attend the OT sessions or implement the OT treatment home programmes. Literature supporting this finding was scarce. The researcher was unable to find any literature of treatment

fatigue in relation to utilisation of a service. Some studies however have discovered that patients who have to take chronic medication such as anti-retroviral medication often yearn for a break in taking the tablets (WHO, 2006). Even though the two situations are totally different, the mothers in the current study's experiences can be compared to those of the people on chronic medication because their child's treatment is something that they cannot take a break from easily.

## **5.2 Environment (E)**

Participation in occupational performance (in this study referring to health seeking behaviour) is impacted by the extrinsic factors (built, natural, cultural, social interaction, societal, economic) of the environment in which the action takes place (Law et al, 1996). Several environmental factors were raised in the present study as factors influencing the utilisation of the OT service.

### **5.2.1 Quality of Care**

Several factors related to quality of care were identified in the current study. Developing a workable and dynamic relationship with a patient is a vital part of an occupational therapists job (Richardson, 2009). Tickle-Degnen (2002) supports this viewpoint and refers to this workable and dynamic relationship as a therapeutic alliance which is related to better occupational therapy intervention. This author explains that a therapeutic alliance relies on the development of two general types of relationships: rapport and a working alliance. Rapport is developed as the patient and therapist develops a mutual liking for one another as well as when each individual experiences the other as respectful, genuinely warm and understanding (Tickle-Degnen, 2002). The working alliance develops as individuals collaborate with one another to structure common goals and as they develop a sense of shared responsibility for working on tasks that are involved in achieving those goals (Tickle-Degnen, 2002). Given that occupational therapy is very dependent on a patient's cooperation, utmost effort to establish a sound, therapeutic relationship is suggested as a most effective approach to encouraging patient cooperation (Richardson, 2009). A notable factor that influenced the utilisation of the OT service, in the present study was the interaction between the occupational therapist and the parent as well as her perception of her child's interaction with the occupational therapist.



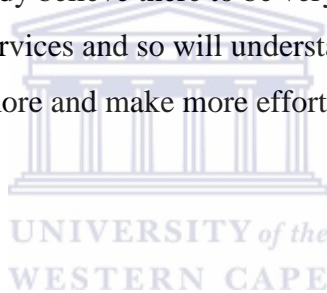
The findings of the present study reveal that a warm, friendly, caring, empathetic, sincere, patient nature from the occupational therapists were seen by the mothers as positive factors. This is in keeping with the findings of a literature review dealing with patient satisfaction, in particular, rehabilitation services (Keith, 1998). Leading from the fact that mothers in the current study valued good relationships with the occupational therapist, another factor eminent was the continuity of care by the occupational therapist. The dilemma of heavy patient loads and shortages of occupational therapists makes it difficult to provide continuity of care at these OT units. The findings of this study is in accordance with the literature where continuity of care has been found to be an important aspect for both patients as well as health care providers, particularly general practitioners (Hjortdah, 2001; Sayal, Tischler, Coope, Robotham, Ashworth, Day, Tylee & Simonoff 2010). Patients value a long term, trusting relationship with their health care provider (Sayal et al, 2010). However, patients will have to be prepared to wait to see their preferred health care provider as alluded to in the current study (Freeman & Richards, 1993). Hjortdah (2001) supports this and describes continuity of care as a vital tool to quality patient care. He warns that there has to be a balance between providing continuity of care and ensuring access to the particular service as demonstrated in the current study where access to the service became limited when the children's usual occupational therapist was unavailable to see the child.

Another important factor impacting on quality of care that was evident from the present study was good communication between the occupational therapist and the mother. This finding corroborates Keith's (1998) and Tickle-Degnen's (2002) findings where they cited that optimal communication are core to developing a functional relationship between occupational therapists and their patients. In the present study the occupational therapists did this by taking their time to provide clear, understandable, thorough information to most mothers.

Furthermore, the findings in the present study suggests that the mothers have varying needs, according to their personal circumstances, regarding the frequency of the OT sessions, how long each session should be and what should be provided during the sessions and included in the home programmes. Health care providers are urged to accommodate patients by communicating with them to reach an agreement that respects the patient's values and needs (Stone et al, 1998). This is also in keeping with

the view of establishing a working alliance between the occupational therapist and the patient (Tickle-Degnen, 2002).

The mothers in the present study stated that poor quality of services at the district health services are a definite barrier to the utilisation of OT services there. They refuse to attend the community health clinics and the district hospital services because they feel they receive better care at the tertiary hospital OT units. Dissatisfaction with district health (primary level care) services lead many patients to prefer higher level hospitals for primary care, resulting in major inefficiencies and loss of control over efficacy and quality of services at the higher levels of care due to the influx of patients (Shaikh & Hatcher, 2004). This is the predicament for the OT units in this study because they are inundated with patients and cannot cope due to shortage of occupational therapists. The HBM can be used to explain this behaviour (Croyle, 2005). The mothers in this study believe there to be very little perceived benefits in attending the district health services and so will understandably not utilise these services and thus rather pay more and make more effort to attend the OT services at the tertiary hospitals.



### **5.2.2 Access**

Access to services is an important enabling factor of any health service (Saloojee, Phohole, Saloojee & IJsselmuiden, 2007). Treatment adherence is definitely improved where health care providers can accommodate parents in terms of appointment times (Beller, Colditz & Pritchard, 2008; Stewart, O'Connor, MacRae, Brignell & Bianchet, 2006). Stewart et al (2006) talk about the conflict between work and the health care service in their parental satisfaction survey of a speech therapy service. This was the case in the present study where the employed mothers had to arrange specific appointment times so as not to affect their jobs negatively. Similarly though, the unemployed mothers also requested specific times, preferring specific days or particular times of the day depending on their or their child's needs. However, a clear obstacle to accommodating the mothers' requests was once again the shortage of occupational therapists.

Another factor which impacted on access was transport. Access was limited in this study due to high transportation costs and far distances to travel with public transport

as was found in Freisen et al's study (2003). Travelling long distances by public transport was further exacerbated in this study by socioeconomic and environmental conditions such as transport system strike action, gang violence and bad weather conditions. This further contributed to mothers missing appointments or cancelling at the last minute. The researcher found literature that only speaks to access in relation to transport costs and distance but does not speak to the exacerbating environmental factors revealed in this study.

### **5.2.3 Family Support**

The social environment of a person (mother and child in this study) is an important determinant of that person's health (WHO, 2011). Family support which is a positive part of an individual's social environment was found in the present study to be an integral part of the mothers' social environment and a major factor that positively influenced their utilisation of the OT services. The mothers who had less support from the child's father and the mothers' extended families, struggled to attend the OT sessions or missed their appointments completely.

### **5.2.4 Work factors**

According to the WHO (2003) the social organisation of work places, the management styles and social interaction at work all impact on a person's (in this case the parent and indirectly the child's) health and their subsequent utilisation of health services. Leka, Griffiths & Cox (2003) have identified specific attributes of a stressful working environment. They identified factors such as strict and inflexible working hours, employees having no or very little say about their working conditions such as negotiating time off, conflicting demands of work and home circumstances and inconsiderate and unsupportive supervisors. However, the employed mothers in this study were allowed to negotiate their time away from work to attend the OT sessions, provided that they followed specific work regulations and procedures. They found the requests from their employers reasonable and described their employers as very supportive which facilitated utilisation of the OT services.

### **5.2.5 Stigma and discrimination**

The stigma of a disability, especially a mental health disorder (such as Autism, Attention Hyperactivity Deficit Disorder, or Post Traumatic Stress Disorder) for

children can be a significant drawback and can have a direct impact on a parents' health seeking behaviour on behalf of their child (Oatis, undated). In the present study, stigma and discrimination resulted in one mother delaying her son's treatment and others missing sessions because they would at times not leave their homes to avoid coming into contact with others. The WHO (2003) confirms that social exclusion or isolation is a universal problem because of stigma and discrimination which negatively impacts on the health of individuals and families.

### **5.3 Occupation (O)**

The occupations (broadly referring to abilities, activities and tasks as well for the sake of this study) were parent involvement in OT treatment, communication, parental education and travelling to the OT service.

#### **5.3.1 Parent involvement in OT treatment**

Active involvement of the patient in their treatment is a key factor to improving patient satisfaction leading to better utilisation of health services (Keith, 1998; Stone, Bronkesh, Gerbarg & Wood, 1998). The mothers in the current study who were actively involved in their child's OT treatment were very satisfied and felt encouraged by this as alluded to earlier. The present study found that participating actively in their child's OT treatment improved their ability to deal with their disabled child and their other children. Stewart et al ((2006) have the same opinion as the mothers in the present study and further say that parents play a vital role in their child's treatment plan and that the benefits of the treatment plan can be vastly improved when parents are equipped on how to promote specific skills such as developmental play or fine motor manipulation. A number of strategies together work well to encourage parental participation as found in the present study and in Steward et al's (2006) study. Some of the strategies mentioned in their study are parent information sessions, parent training through participation in sessions, home programmes and homework assignments many of which were strategies in the current study as well.

#### **5.3.2 Mother's ability to effectively communicate**

The findings of this study show the importance of the mother's ability to communicate her needs on behalf of herself and her child. The mothers had to articulate their needs in relation to arranging time off from work, negotiating

appropriate appointment times for their children, as well as ask questions when she was unsure of something regarding her child's health condition or OT treatment. A barrier for the mothers was that at times the treatment was not appropriate to their personal living circumstances because they did not assert their needs and/or because the occupational therapist overlooked this aspect. This means that the mothers' communication skills have to be improved. Stone et al (1998) found in their study looking at how to improve patient compliance, that communication is vital in a "doctor-patient" relationship. They refer to the ability of the health care provider to listen adequately to their patients, thus implying that patients must be in a position to sufficiently communicate their needs to the health care provider.

### **5.3.3 Mother's level of Education**

Parent education was mentioned by the occupational therapists to be a notable factor that influenced the utilisation of the OT service, including the execution of the home programmes. They believe that when parents are less educated, it affects their understanding of the child's health condition, the importance of the OT service and limits their involvement in the child's OT programme. The findings of several other studies confirm that education affects utilisation of health services and that the lower the parents' (or adult patient, in the case of other studies) level of education, the less likely they are to seek healthcare or actively participate in the specific treatment plan or process (Philips & Teerawichitchainan, 2007; Bird et al, 2001; Mekonnen & Mekonnen 2002). No schooling or less than primary school level of schooling results in very poor utilisation of health services (Oanh, 2009). In a study that looked at the utilisation of maternal health care services in Ethiopia, it was found that women with at least secondary school level of education were four times more likely to utilise the maternal health services (Mekonnen & Mekonnen, 2002). However, the mothers in the present study all had secondary school level education yet some mothers attended more regularly than others making it evident that other factors influenced their utilisation of the OT services.

### **5.3.4 Travelling**

In the present study, the mothers' ability to travel to the OT units was challenging. A particular problem for some of the mothers was travelling to hospital with their very disabled child and at times with their other small children as well. The findings fit in

with the HBM's balance between the perceived benefits and barriers where the mothers felt that the effort of travelling was worth it because of the perceived benefits of the OT service, and that the perceived barrier can either be endured or managed by paying for a family or community member to accompany them to hospital and assist with their children (Croyle, 2005).

By contrast, for one mother, travelling to the OT unit was remarkably easier owing to her well established individual lifestyle factors. She owned a car, so travelled to and from the OT unit with minimal hassles, and was employed which meant she could afford the costs of travelling by car. This contrast demonstrates the inequity that still exists in our country.

#### **5.4 Illustration of interrelation between Person, Environment and Occupation**

It is clear from the discussion that the various factors that impacted the utilisation of the OT service are strongly related. This interrelation between the person (P), their environment (E) and their occupations (O) highlights the complexity of the mothers' situations. This is illustrated below based on the individual circumstances of two mothers from the present study. Mom 9's case shows a maximum fit between person, environment and occupation (see Figure 3) while Mom 3's case show a minimum fit between the factors (see Figure 4). The stronger the link between the factors, the greater the congruency resulting in maximum utilisation of the OT services (occupational performance) while a weak link will result in minimum utilisation of the OT services (Law et al, 1996).

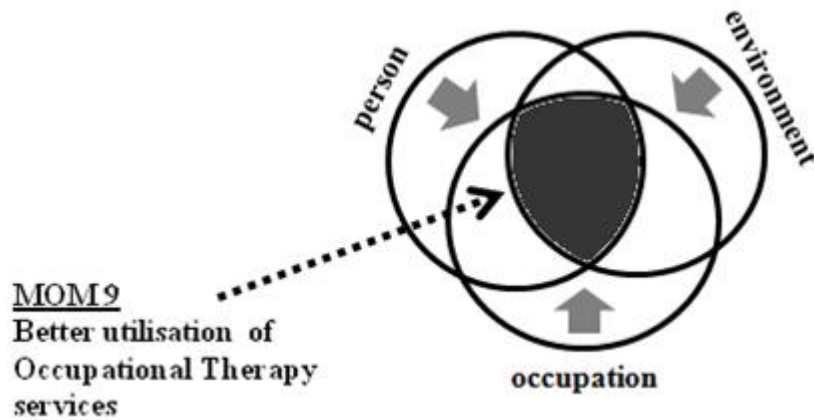


Figure 3

<b>Factors for Mom 9 (regular attendance) Age =28</b>	
<b>POSTIVE</b>	<b>NEGATIVE</b>
<b>PERSON FACTORS</b>	
<ul style="list-style-type: none"> <li>• Perception of the severity of child's condition</li> <li>• Treatment progress</li> </ul>	
<b>ENVIRONMENT FACTORS</b>	
<ul style="list-style-type: none"> <li>• Good quality of services in all respects such as adequate communication with OT, continuity of care, therapeutic relationship with OT etc</li> <li>• Good family support</li> </ul>	<ul style="list-style-type: none"> <li>• Poor service at DHS (District Health Services)</li> <li>• Stigma and discrimination</li> </ul>
<b>OCCUPATION FACTORS</b>	
<ul style="list-style-type: none"> <li>• Employed</li> <li>• Has a drivers licence</li> <li>• Owns a car</li> <li>• Has a matric qualification with additional tertiary education</li> <li>• Ability to communicate her and her child's needs effectively</li> </ul>	



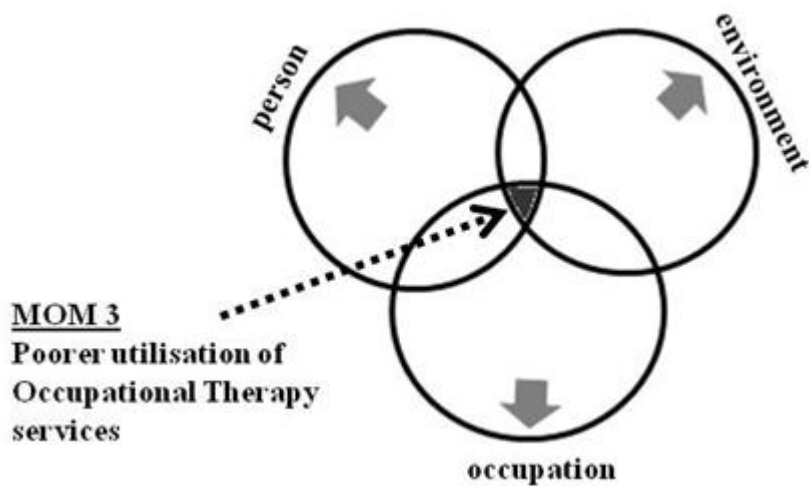


Figure 4

<b>Factors for Mom 3 (poor attendance) Age =30</b>	
<b>POSITIVE</b>	<b>NEGATIVE</b>
<b>PERSON FACTORS</b>	
<ul style="list-style-type: none"> <li>• Perception of the severity of child's condition</li> </ul>	<ul style="list-style-type: none"> <li>• No treatment progress observed</li> </ul>
<b>ENVIRONMENT FACTORS</b>	
	<ul style="list-style-type: none"> <li>• Poor service at DHS (District Health Services)</li> <li>• Very poor quality of service - decreased understanding of OT intervention, poor communication with OT, no parent involvement, bad staff attitude, bad relationship with the child etc</li> <li>• Poor family support and support from husband with regards to child care</li> <li>• Stigma and discrimination</li> </ul>
<b>OCCUPATION FACTORS</b>	
<ul style="list-style-type: none"> <li>• She has a matric qualification and a diploma in office management</li> <li>• Ability to adequately communicate her needs</li> </ul>	<ul style="list-style-type: none"> <li>• Unemployed</li> <li>• Difficulty travelling due to far distance</li> <li>• Mother of 3 aged 6 (patient), 3 and 1-she has to travel with all 3 by public transport to attend</li> </ul>



## CHAPTER SIX

### 6. CONCLUSION AND RECOMMENDATIONS

#### 6.1 Conclusion

This study explored and presented the factors that influenced the utilisation of the OT service at the OT out-patient units of three teaching, tertiary hospitals based on the perceptions of mothers who attended these units with their children as well as the perceptions of the occupational therapists who work at the units.

The utilisation of the OT services is impacted by complex issues that no single intervention can resolve. A comprehensive approach that is client centred is needed that deals with the person factors as well as the factors pertaining to the environment and improvement of the mothers' ability to perform optimally in their daily occupations.

A critical factor that emerged from the study was continuity of care. Although there is agreement from the occupational therapists and support from the literature, this appeal from the mothers poses a challenge for the occupational therapists because of the gross shortages of occupational therapists at all levels of care in Cape Town where the study took place. Another vital factor that was presented is the paramount importance of a therapeutic relationship between the occupational therapist and the mother and her child. Of particular significance was adequate communication between the parties. Occupational therapists must make every effort to ensure that the mothers understand completely what the OT service entails as well as be available to answer any questions that the mother may have. It was evident from this study that inadequate interpersonal communication between the mother and the occupational therapist resulted in poor attendance.

Stigma and discrimination indirectly affected the utilisation of the OT services by resulting in social isolation where the mothers avoided leaving their homes due to the teasing, labelling and name calling they suffered from community members. This is a

universal problem as pointed out by the WHO (2003). The researcher herself is aware of countless advocacy groups who campaign against discrimination against people with disabilities. However, these endeavours are relatively removed from what happens inside the hospitals in this study and as revealed by this study has not “reached” these mothers so remains a considerable problem. The researcher feels that an empowering approach towards the mothers will be a useful where the mothers are adequately educated about their child’s condition, taught how to cope optimally with their disabled child and can gain support on how to manage stigma and discrimination. The researcher is of the opinion that the occupational therapists, the mothers and their families should play an active role towards eradication of the stigma and discrimination against children with disabilities.

Access to health care services in relation to transport is frequently mentioned in the literature reviewed for this study. Further investigation is required to explore access to OT and other health services with regards to travelling with public transport in a developing country context. Current literature, as well as this study, points out difficulties patients have due to high transport costs and the far distances they have to travel. This study however highlights the negative impact socio-economic factors have on health seeking behaviour. The occurrences of taxi strikes, transport company strikes (affects train and bus transport systems) and gang violence had a notable impact on the mothers’ ability to use public transport to the hospitals.

This study revealed implicitly the need for managers of the various OT units in this study to design a comprehensive, client centred OT service for the children who attend these units. In order to improve the utilisation of the OT services and also maximise health outcomes, occupational therapists must recognise that the mothers (and their children) are individuals with specific backgrounds, life circumstances and needs and their approach towards their patients and their parents should be geared towards their clients specific context.

Lastly, it is very evident from this study that a research gap is present in relation to the actual effectiveness of Occupational Therapy in public service in South Africa.

## 6.2 Recommendations

The recommendations for this study are based on the findings of this study as well as the recommendations that were shared by the mothers and occupational therapists who participated in the study.

- The OT treatment programmes must be more client centred. This implies that the occupational therapist must plan the OT intervention in collaboration with the parents of the child. If a parent is unable to articulate their specific needs the occupational therapist must still consider the cultural, ethical and personal living circumstances of her patient when planning for therapy. The occupational therapist must as far as possible only facilitate the treatment process while the parents drive it on behalf of their child. Occupational therapists claim to already implement a client centred approach but the findings of this study clearly show that this can improved.
- Attempts should be made to increase the OT budgets at these units to be able to render optimal services as well as initiate projects that can assist the parent to utilise the service better and also participate more actively. Two examples are to establish a toy library where parents can borrow toys that is required to execute the OT home programmes and to create a transport fund that can be sourced from the budget and charity groups and organisations.
- Improve on the environment of the OT units by making sure that there is an adequate reception and waiting area for patients and by providing basic hygienic measures in the toilet facilities.
- Introduce parent support groups to educate, support and empower parents with the necessary knowledge, skills and abilities to deal with their disabled child and to advocate against stigma and discrimination against children with disabilities.
- Establish joint initiatives between occupational therapists and the parents to fight stigma and discrimination against children with disabilities.
- Advocate for specific means of transport for health users and for access to be improved within the public transport system.
- Further research to be conducted to explore the actual effectiveness of the OT service provided to children attending state facilities.

- Further research on the same topic needs to be conducted taking the perspectives of other language speakers apart from English and Afrikaans as they are also users of the OT services.



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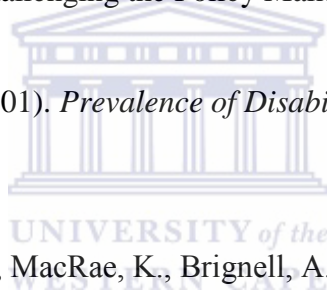
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## **APPENDIX 1: Interview Guide - English**

### **1. The researcher will provide a general overview.**

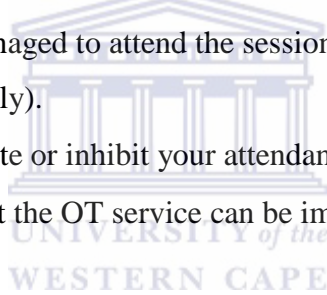
- Purpose: Interview forms part of study towards researcher's completion of her MPH.
- Background: Aim of study is to provide recommendations to improve OT outpatient service to children.

### **2. The interview will be around following themes:**

- Describe your experience with your disabled child.
- Describe your experience of the OT unit?
- How have you managed to attend the sessions regularly? (For patients who attend regularly only).
- Factors that promote or inhibit your attendance?
- How you think that the OT service can be improved.

### **3. Closure:**

- Thank parent for their participation.



## **APPENDIX 2: Interview Guide - Afrikaans**

### **1. Die navorser sal 'n algemene oorsig gee.**

- Doel: Onderhoud is deel van die studie met benadering tot die navorser se voltooiing van haar MPH.
- Agtergrond: Doel van studie is om rekomendasies voor te lê vir die verbetering van AT buitepasient dienste vir kinders.

### **2. Die onderhoud sal die volgende bevat:**

- Hoe dit voel om 'n kind met 'n gestremdheid te hê?
- Wat is jou ondervinding van die arbeidsterapie departement
- Hoe het jy daarin geslaag om die terapie gereeld by te woon? (aan ouers wat wel daarin geslaag het om dit gereeld by te woon)
- Noem faktore wat jou bywoning bevorder of teenwerk.
- Hoe kan ons die dienste verbeter?

### **3. Sluiting**

- Bedank die ouers vir hulle deelname.

### **APPENDIX 3: Discussion Group guide for occupational therapists**

#### **1. The researcher will provide a general introduction.**

- Purpose: Group forms part of study towards researcher's completion of her MPH.
- Background: Aim of study is to provide recommendations to improve OT outpatient service to children.

#### **2. Group discussion will be around following themes:**

- Describe your work in the paediatric outpatient units.
- Describe factors that you think may inhibit or promote your patients' utilisation of the OT services.
- How you think that the utilisation of the OT service can be improved.

#### **3. Closure:**

- Thank occupational therapists for their participation.

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### **APPENDIX 4: Participant Information Sheet English**

May 2010

Dear Participant,

Thank you for allowing me to inform you of this research. What follows is an explanation of the research as well as your potential involvement. The research is being done as part of a mini thesis. I am completing my Masters Degree in Public Health at The University of The Western Cape and it is a requirement for me to do a research study. I will answer any questions you may have so please feel free to ask me anything you are unclear of or concerned about. My contact details, as well as those of my supervisor are included below.

#### **Title of Research**

Exploring parents' and occupational therapists' perceptions on the utilisation of the Occupational Therapy (OT) service at three paediatric outpatient units in the Western Cape

#### **Purpose of the Study**

This study is trying to understand the factors that influence the utilisation of the outpatient OT services for children treated at three tertiary hospitals from the parents' and occupational therapists' points of view. It is hoped that the study will highlight limitations or barriers as well as strengths of the current service provided and will present the OT managers with information that can be used to reconsider the current service and make appropriate changes that will improve adherence to therapy and improve the child's progress.

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### **Description of the Study and Your Involvement**

The study will involve conducting personal interviews with parents of children who are patients at the OT outpatient units as well as one focus group discussion with the occupational therapists who work in those units. You will be asked about your experience either as an occupational therapist in this unit or as a parent of a child who must attend the OT service at the unit.

### **Confidentiality**

Your identity will remain confidential at all times. All records as well as consent forms (that you will be required to complete should you agree to participate in this study) will be locked away and will be destroyed at a later date.

### **Voluntary Participation and Withdrawal**

Your participation is completely voluntary so you do not have to partake if you do not wish to. If you decide to participate, you may withdraw at any time without any detrimental consequences. You may also refuse to answer or discuss certain questions or matters pertaining to you during the study.

### **Benefits and Costs**

There are no direct benefits in participating in this study but the information gathered may help to improve the OT service at the various outpatient units. There are no costs involved in participating except the time that it takes to do the interview with you.

### **Informed Consent**

I require your signed consent before I may interview you. Please find one attached for you to review.

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Website: [www.uwc.ac.za/publichealth](http://www.uwc.ac.za/publichealth)

### Questions

Please feel free to contact me should you have any queries regarding this study or wish to know more.

Fatima Peters

Student Number: 9083168

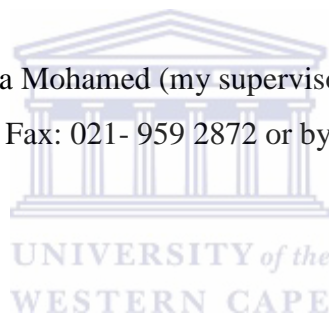
Cell phone: 0824106997

Email: [fabra@pgwc.gov.za](mailto:fabra@pgwc.gov.za)

Work: 021 9385962 | Fax: 021 9386545

I am accountable to Ms Suraya Mohamed (my supervisor at UWC) who is contactable at 021-959 2809 or c/o SOPH Fax: 021- 959 2872 or by e-mail at

[sumohamed@uwc.ac.za](mailto:sumohamed@uwc.ac.za)



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### **APPENDIX 5: Participant Information Sheet - Afrikaans**

May 2010

Beste Deelnemer,

Baie dankie dat ek die geleentheid gegun word om aan jou die inligting van my voorgenome studie te verskaf. Die inligting behels agtergronds-inligting van my studies sowel as inligting oor wat jou betrokkeheid sal behels. Die navorsing is deel van 'n mini-tesis. Ek is besig met my Meestersgraad in Openbare Gesondheid by die Universiteit Wes Kaap. Ek sal enige vrae wat u mag hê beantwoord en daarom moet u asseblief vra indien u enigsins meer duidelikheid verlang. Ek sowel as my toesighouer se kontakbesonderhede is hieronder beskikbaar.

#### **Titel van die Studie**

'n Ondersoek na beide die ouers en arbeidsterapeute se persepsie oor die benutting van die Arbeidsterapie dienste in drie pediatriese buitepatiënt eenhede in die Wes Kaap.

#### **Doel van die studie**

Deur middel van die studie word gepoog om die faktore wat 'n invloed het op die benutting van buitepatiënt arbeidsterapie dienste wat kinders behandel by 3 tersiêre hospitale vanuit die perspektief van beide die ouers en arbeidsterapeute te verstaan. Hopelik sal die studie beide die beperkinge en struikelblokke sowel as die sterk punte van die huidige dienste uitlig en die arbeidsterapie bestuur van die nodige inligting verskaf sodat die nodige veranderinge aangebring kan word wat volgehoue samewerking met terapie sal verseker om sodoende die nodige vordering van die kind se toestand te verseker.

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Website: [www.uwc.ac.za/publichealth](http://www.uwc.ac.za/publichealth)

Die studie behels persoonlike onderhoude met die ouers van kinders wat behandeling ontvang by die genoemde eenhede. Dit behels ook 'n fokusgroep bespreking met die arbeidsterapeute wat in die betrokke eenhede werk. Die vrae sal handel oor jou ervaring as ouer of arbeidsterapeut wat betrokke is by die dienste by die betrokke eenhede.

### **Vertroulikheid**

Jou identiteit sal ten alle tye vertroulik gehou word. Al die rekords asook die toestemmings vorms (wat jy sal invul indien jy toestem om aan die studie deel te neem) sal weg gesluit word en na die studie vernietig word.

### **Vrywillige deelname aan en onttrekking van die studie**

Jou deelname aan die studie is heeltemal vrywillig. Jy is dus onder geen verpligting om deel te neem nie en, indien jy sou besluit om wel deel te neem, kan jy op enige stadium onttrek sonder enige gevolge/nawerking/nadraai. Jy mag ook wyer om tydens die verloop van die studie sekere vrae te beantwoord of deel te neem aan besprekings.

### **Voordele en Koste**

Buiten dat die inligting mag lei tot die verbetering van die arbeidsterapie dienste by die genoemde eenhede sal jou deelname nie tot verdere direkte voordeel wees nie. Daar is nie onkoste aan die deelname aan die studie gekoppel nie behalwe die tyd wat jy sal afstaan om aan die onderhoud deel te neem.

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### Ingeligte toestemming

Ek benodig 'n getekende toestemming van jou voordat ek die onderhoud met jou mag voer. Die dokument is aangeheg vir jou kennisname.

### Vrae

Kontak my gerus indien jy enge verdere vrae het of meer inligting verlang oor die studie.

Fatima Peters

Studentenommer: 9083168

Selfoon: 0824106997

Email: [fabra@pgwc.gov.za](mailto:fabra@pgwc.gov.za)

Werk: 021 9385962

Fax: 021 9386545



Ek is aanspreeklik aan Me. Suraya Mohamed (my toesighouer by UWK) wie kontakbaar is by die voldgende: 021-959 2809 of, SOPH Fax: 021- 959 2872 of e-pos [sumohamed@uwc.ac.za](mailto:sumohamed@uwc.ac.za)

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### APPENDIX 6: Informed consent - English

Date:

Interviewer's name: Fatima Peters

UWC Student no: 9083168

Tel: 0824106997

E-mail: [fabra@pgwc.gov.za](mailto:fabra@pgwc.gov.za)

Institution: School of Public Health, University of the Western Cape

Interviewee's pseudonym:

Place at which the interview took place:

Dear Participant

Thank you for agreeing to allow me to interview you. What follows is an explanation of the purpose and process of this interview. You are asked to give your consent for me to conduct an in-depth interview with you and to use this data for my research project at School of Public Health, UWC.

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### **Title of Research**

Exploring parents' and occupational therapists' perceptions on the utilisation of the Occupational Therapy (OT) service at three paediatric outpatient units in the Western Cape

### **1. Information about the interviewer**

I am Fatima Peters, a student at the School of Public Health, UWC. As part of my Masters in Public Health, I am required to conduct a mini research project. I intend to gather data for my research by interviewing parents whose children attend an outpatient OT unit and occupational therapists working at these units. I am accountable to Ms Suraya Mohamed who is contactable at 021-959 2809 or c/o SOPH Fax: 021- 959 2872 or by e-mail at [sumohamed@uwc.ac.za](mailto:sumohamed@uwc.ac.za)

### **2. The purpose and contents of the interview**

This interview serves as a means to gather relevant data for my research project. My project looks at the experiences of parents whose children require OT intervention and explores possible factors that influence (impact) the utilisation of the OT out-patient service to children. It is hoped that with this information, we would be better able to plan our service and influence health policies that deal with the health care of children within the public service. The interview will focus on the experiences you have had towards ensuring OT services for your child.

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### 3. The interview process

The interview will take place at a venue that you choose. It should last between 40-60min. The interview will be conducted in either English or Afrikaans. You may choose your language of preference. The interview focus is on your experience as a parent in relation to your child who required healthcare at a public service facility or as an occupational therapist working in a paediatric OT out-patient unit.

### 4. Anonymity of contributors

At all times, I will keep the source of the information confidential and refer to you or your words by a pseudonym or invented name which I would like you to choose. I shall keep any other records of your participation locked away at all times, and destroy them after the study has been completed.

### 5. Things that may affect your willingness to participate

The interview may touch on issues which are private and sensitive issues for you. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question or speak about a specific topic. I would appreciate your guidance should I ask anything which you might see as intrusive.

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### 6. Agreement

#### Interviewee's agreement

I, ..... agree to participate in this interview as explained by the interviewer, Fatima Peters, in the language of my choice. I fully understand what the procedure entails and am willing to be interviewed by Fatima Peters towards completing her research study.

#### Interviewer's agreement

I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred to above, but may also be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you.

Signed (Interviewer):

Signed (Participant):

Date:

Place:

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### APPENDIX 7: Informed consent - Afrikaans

**Deelnemer se skuilnaam:**

**Plek waar onderhoud plaasgevind het:**

Beste Deelnemer

Baie dankie vir die geleentheid om die onderhoud met jou te voer. Hier volg 'n verduideliking van die doel en die verloop van die onderhoud. Ek benodig jou toestemming om 'n in-diepte onderhoud met jou te voer en om dan die inligting uit die onderhoud te gebruik vir my studie by die "School of Public Health, UWC.

#### **Titel van die Studie**

'n Onderrsoek na beide die ouers en arbeidsterapeute se persepsie oor die benutting van die Arbeidsterapie dienste in drie pediatriese buitepasiënt eenhede in die Wes Kaap.

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## School of Public Health

### 1. Inligting oor die onderhoud voerder

My naam is Fatima Peters. Ek is 'n student by die School of Public Health, UWC. As deel van my meestersgraad word van my verwag om 'n mini-tesis te voltooi. Ek gaan die data vir my studie verkry deur onderhoude te voer met die ouers van kinders wat terapie ontvang by buitepatiënt arbeidsterapie eenhede asook met die arbeidsterapeute wat by die eenhede werk. My toesighouer is Me Suraya Mohamed. Sy kan gekontak word by (021) 959 2809..... Haar faks nommer is (021) 959 2872 en haar e-pos adres is [sumohamed@uwc.ac.za](mailto:sumohamed@uwc.ac.za)

### 2. Die doel en inhoud van die onderhoud

Die onderhoud is die metode waardeur ek die nodige inligting vir my studie gaan bekom. My studie ondersoek die ervarings van ouers wie se kinders arbeidsterapie benodig asook faktore wat 'n invloed mag hê op hul benutting van die arbeidsterapie buitepatiënt dienste. Ek glo dat die inligting sal bydra om die huidige dienste te verbeter en ook aangewend sal kan word om die gesondheidsbeleide wat 'n impak op die gesondheid van ons kinders het, aan te pas. Die onderhoud sal fokus op die ervarings wat jy gehad het om jou kind se arbeidsterapie te verseker.

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# FACULTY OF COMMUNITY AND HEALTH SCIENCES

## School of Public Health

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### 3. Die onderhoudsproses

Die onderhoud sal plaasvind by 'n plek wat jou sal pas. Dit sal tussen 40 en 60 minute duur. Die onderhoud kan in beide Afrikaans of Engels gevoer word. Jy kan die taal kies waarin jy die gemaklikste kan kommunikeer. Die onderhoud fokus op jou ervaringe as 'n ouer wie se kind arbeidsterapie dienste in die staat se gesondheid sisteem benodig of as 'n arbeidsterapeut wat in die buitepasiënt dienste in die sisteem verskaf.

### 4. Anonimiteit van deelname

Ek sal ten alle tye die bronne asook die inligting vertroulik hanteer en na wat jy sê/ jou naam fiktief hanteer. Alle rekord van jou deelname sal weg gesluit bly en na afloop van die studie vernietig word.

### 5. Aspekte wat jou gewilligheid tot deelname mag beïnvloed

Indien die onderhoud enigsins aspekte wat vir jou te privaat of sensitief is aanraak, moet jy dit asseblief as sodanig aandui. Indien jy dit nie verder wil bespreek nie sal jou versoek, sonder enige verdere gevolge, gerespekteer word.

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### 6. Ooreenkoms

#### Deelnemer se ooreenkoms

Ek ..... stem hiermee in tot die onderhoud wat met my gevoer gaan word deur Fatima Peters in die taal van my eie keuse. Ek verstaan wat die proses behels en is bereid dat Fatima Peters as deel van haar studies die onderhoud met my voer.

#### Onderhoudvoerder se ooreenkoms

Ek sal die inhoud van die navorsings onderhoud vertroulik hanteer en die bogenoemde pseudoniem in al my dokumente wat na die onderhoud verwys, gebruik. Die inhoud sal vir bogenoemde rede gebruik word, maar mag ook in die toekoms vir gepubliseerde of ongepubliseerde navorsing gebruik word sonder verdere toestemming van jou. Enige veranderinge in die toestemming sal eers met jou ooreengekom word.

Geteken (Interviewer):

Naam:

Geteken (interviewee):

Naam:

Datum:

Plek

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