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PARENT/CARE GIVERS' PERCEPTION OF THE EFFICACY OF A STUDENT BASED OCCUPATIONAL THERAPY SERVICE WITH AUTISTIC SPECTRUM DISORDER CHILDREN

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of

Master of Science in Occupational Therapy

DECLARATION

I, Rebecca Bale, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

.....RLBale.....

.....22nd..... day of .....May.....20..09

ABSTRACT

This qualitative study explores the perceptions of parents/caregivers of the efficacy of a student based occupational therapy service with children with autistic spectrum disorders (ASD). Key informant interviews were conducted with ten randomly selected parents/caregivers of children with ASD receiving occupational therapy from final year students of the University of the Witwatersrand. Data analysis generated six themes: Understanding of Occupational Therapy; Limitations of students as therapists; Lack of partnership; Inadequate structure of the program; Inefficacy of the service and, Desperate need of help. The study showed that the student based occupational therapy service was not effective because students were not in a position to provide a comprehensive treatment programme for the children. The findings highlight the need for the provision of a full time occupational therapy service at the CDC. A follow up study to explore experiences of students in the management of ASD is recommended.

ACKNOWLEDGEMENTS

To my family and friends, thank you for supporting me during the entire time of my studies. Your support kept me sane.

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To my husband, Outule Bale and our boys, Katlego, Wetsho and Bogolo, thank you for putting up with my absence while I was pursuing this course.

To my supervisor, Mrs. Denise Franzsen, your patience, hard work, and expertise you brought into this study can not be over emphasized. Thank you very much.

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NOMENCLATURE

ADLs – Activities of daily living

CDC - Children's Disability Centre

CMI – Children's Memorial Institute

OT – Occupational Therapy

OT-SI - Occupational therapy with sensory integration

SI – Sensory Integration

SMD – Sensory modulation dysfunction

SPD - Sensory processing dysfunction

Wits – University of the Witwatersrand

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CHAPTER 1
INTRODUCTION

1.0 Background

Research tells us that autistic spectrum disorders (ASD) are on the rise, with the latest international research implying that one in every 158 children under the age of 10 are affected (Autism, South Africa, 2007). These statistics suggest that ASD have become an epidemic.

In the Diagnostic Statistical Manual (DSM IV, 1994), ASD includes conditions like autism, Asperger's disorder and "Pervasive Developmental Disorder not otherwise specified (PDDNOS)". Aetiology is still unknown but genetic and environmental factors have been implicated (Bailey, LeCouteur, Gottesman, Bolton, Simonoff, Yuzda, & Rutter, 1995).

The common characteristics of ASD as described by Charman (2008) are a triad of symptoms: impaired social interaction, communication problems and unusual, repetitive behaviours, activities and interests. Difficulties with social interactions may include little awareness of other people, preference to play alone and difficulty forming relationships. Communication problems may include delayed, absent or abnormal development of speech, expressionless faces and difficulties understanding and using non verbal speech. Unusual repetitive behaviours can present as following the same routine, spinning around, rocking or flapping, etc. In addition, these children may display lack of imaginative play, temper tantrums, self injurious behaviour and sensory processing difficulties. The extent to which a child can be affected differs, ranging from mild to severe. Children with severe autism have no functional means of communication and they also have some degree of mental retardation (Roan, 2004).

Parents of children with ASD are usually the first to notice signs of dysfunction from their children long before a clinical diagnosis is made (DeGiacomo & Fombonne, 1998). And according to Green, Pituch, Itchon, Choi, A., O'Reilly &

Sigafoos (2006), parents seek all types of interventions, those that have and those that do not have scientific evidence for efficacy. To this extent, parents make use of many treatments and therapies at the same time (Green *et al.,* 2006; Goin-Kochel, Myers. & Mackintosh*,* 2007; Ruble & McGrew, 2007).

Despite the numerous treatments and therapies utilized by parents, the hallmark of effective intervention for ASD is much behavioural rather than pharmacological, with the primary goal of intervention being to maximize functional independence, improve quality of life and alleviate family distress by minimizing the core features of ASD and associated deficits (Myers & Johnson, 2007; Filipek, Steinberg-Epstein, & Book, 2006).

Occupational therapy is almost always among the numerous treatments utilized by children with ASD. According to Case-Smith (2005) the purpose of occupational therapy in the management of ASD is to improve the children's ability to function in everyday context. The aim is to remedy deficits in areas of occupational performance: play/leisure, self-management and productivity /school. The goals of therapy being to improve social skills, increase engagement in developmentally appropriate activities, improve fine and gross motor skills, improve organizational skills, as well as to change distractive behaviours to developmentally appropriate behaviours.

Because of evidence that suggest that children with ASD have sensory processing difficulties, the focus in occupational therapy has shifted towards understanding how and when a child is reacting to sensory experience and structuring the environment to accommodate or minimize such reactions to enhance occupational performance (Law, 2006). In fact research tells us that in the management of ASD, the use of a sensory integration approach (OT-SI) has been shown to have an effect on undesirable behaviour and engagement in activities (Case-Smith & Bryan, 1999; Linderman & Steward, 1999).

The aim of sensory integration is to improve the ability of the child to process and integrate sensory information for effective use in occupational performance (Bundy, Lane & Murray, 1999) and not to teach specific skills or behaviours. The goal is to remediate deficits in neurologic processing and integration of sensory information so that the child can interact with the environment in a more adaptive manner (Bundy *et al*., 1999).

However the use of OT-SI is limited to occupational therapists with a post graduate qualification in sensory integration. Undergraduate students in fieldwork practices and other occupational therapists use traditional occupational therapy when managing children with ASD. According to Myers & Johnson (2007) traditional occupational therapy provides opportunities for functional participation in meaningful activities to remedy dysfunction and promote development in areas of self-care (dressing, feeding, personal hygiene), productivity/academic (cutting with scissors, writing) and leisure (play skills and interaction with other children). It also looks at modification of the environment (home or classroom) and establishment of routines to allow for optimal occupational performance.

However, for some children with ASD and their families, accessing occupational therapy services is difficult for a number of reasons, be either inadequate family resources to enable access to these services or lack of professionals within their catchment areas to provide these services. In some instances, student based services are the only services available for these children.

This study, therefore, explores parents/caregivers perceptions of the efficacy of a student based occupational therapy with ASD children provided by the final year occupational therapy students of the University of the Witwatersrand which, for most of these children, is the only occupational therapy service they receive. The service provided by the students is purely for learning purposes and is provided free of charge. The clients/children are from the Children's Disability Centre (CDC) in Johannesburg, where the Occupational Therapy Clinic is sub-letting space.

The use of parents/caregivers to evaluate this service was informed and motivated by Ruble & Gallagher (2004) who contended that although there are many scientifically proven methods of evaluating a service, parental ratings are the most effective as parents are the service users and are therefore better placed to evaluate it.

1.1 Statement of the problem

The student based occupational therapy offered to children with ASD by the final year OT students of the University of the Witwatersrand is the only occupational therapy service most of the children at the CDC are receiving. However, this service has never been evaluated. Secondly, although several studies have been conducted to evaluate the efficacy of occupational therapy with children with ASD, these studies were concerned with the evaluation of OT-SI techniques with only a few evaluating traditional occupational therapy. The studies that evaluated traditional occupational therapy lack a comprehensive view of the occupational therapy service and the perceived effect it has on the everyday functioning of the children. There is need, therefore, to evaluate the efficacy of student based occupational therapy for children with ASD through the eyes of the parents/care givers in a qualitative manner.

1.2 Purpose of the study

The purpose of this study is to explore parents/caregivers' perceptions of the efficacy of occupational therapy service provided to their children with ASD by the final year occupational therapy students of the University of the Witwatersrand. This will be done by determining parents and caregivers' level of understanding of occupational therapy and the value they feel occupational therapy has in improving the areas in which their children are dysfunctional.

1.3 Aim of the Study

The aim of this study is to establish the parent/caregiver's perception of the efficacy of the Wits student based occupational therapy service offered to their children with ASD.

1.4 Objectives

1. To establish parents/caregivers' understanding of occupational therapy
2. To establish parents/care givers' perception of the functional changes that they have observed in their children with ASD, which they attribute to the student based occupational therapy service.
3. To establish how these factors relate to parents/caregivers perception of the efficacy of the occupational therapy treatment.

1.5 Justification for the study

This study will be used to determine from a parent/caregivers' perspective whether there is need for full time occupational therapy service at the Children's Disability Centre which currently has a student based service available for teaching purposes only on Tuesday and Wednesdays afternoons.

1.6 Structure and organisation of the report

This report is structured and organized into six chapters as follows:

Table 1.1 Structure and organisation of the report.

Title	Parent/care givers' perception of the efficacy of a student based occupational therapy service with autistic spectrum disorder children.
Chapter 1	**The introduction** provides a background about ASD, statement of the problem, the purpose, aim, objectives and justification for the study.
Chapter 2	**A review of the literature** critically evaluates underpinning concepts, theories, frameworks and previous studies on ASD.
Chapter 3	**Methodology** describes the processes undertaken during the study: the research design; the context; the research population, sampling techniques; ethical considerations; research procedure; data collection and analysis and validation of the study.
Chapter 4	**Findings of the study** are reported.
Chapter 5	**The discussion** relates the results of the study with previous studies. It outlines the researcher's opinions as well as strengths and limitation of the study.
Chapter 6	**The conclusion** summarizes the main outcomes of the study. Recommendations are reported.

CHAPTER 2
A REVIEW OF THE LITERATURE

2.0 Introduction

When evaluating services provided for children with ASD, Ruble & Gallagher (2004) contended that parental ratings are the most effective method to use. Hence, this study explores the perceptions of parents/caregivers of the efficacy of the occupational therapy service provided to their children with ASD by the final year occupational therapy students at the University of the Witwatersrand. This chapter, therefore, seeks to provide a critical review of literature with the focus on: characteristics of ASD; ASD and the family and the services utilised by families of children with ASD. The generic principles of managing children with ASD are outlined. The management of ASD in occupational therapy and efficacy thereof will also be reviewed. Finally, the perception of parents in terms of outcomes of treatment and factors determining their satisfaction with the services is also included.

2.1 Characteristics of Autistic Spectrum Disorders

Autistic spectrum disorders (ASD) are among the most disabling chronic conditions of childhood. Despite rigorous interventions, most children remain in the spectrum and in institutionalised care for the rest of their lives (Myers & Johnson, 2005). Among the most disturbing features of ASD are behavioural and communication problems which make it difficult for the children to interact and have meaningful relationships with other people. Depending on the severity of the condition children also present with difficulties with activities of daily living (ADL). They often have difficulties with feeding, dressing, toileting etc (Case-Smith, 2005), making them dependent on their parents and other family members for care.

In addition, most children with ASD have sensory processing difficulties (Charman, 2008). They may present with under or over responsiveness to sensory stimuli also known as sensory modulation dysfunction (SMD). This view is supported by Kern *et al.,* (2007) in a cross-sectional study that examined sensory modulation in 103 individuals with autism and/or pervasive developmental disorders (PDD), aged between three and forty-three years of age compared to 103 community controls of the same ages. They examined the following sensory modulation items from the sensory profile: modulation related to body position and movement; modulation of movement affecting activity level; modulation of sensory input affecting emotional responses and modulation of visual input affecting emotional responses and activity level. They found that the ability of individuals with autism to modulate sensory input in areas that affect emotional responses, activity level and movement was significantly different from those in the control groups. They concluded that sensory modulation is different in individuals with autism.

Sensory modulation dysfunction (SMD) is found to affect behaviour and all aspects of daily life. According to Dunn (1997) the behaviours of children with SMD maybe in accordance or counteracting the sensory stimuli they receive. For example, a child who is under responsive to sensory stimuli might run around, bashing and crushing in order to maximize the amount sensory input he receives. Another child who is also under responsive to sensory stimuli might appear to be lethargic and disinterested in the world because they do not register adequate sensory stimuli for them to be actively engaged. On the other hand children who are over responsive to sensory stimuli may appear lethargic and disinterested in the world in an attempt to avoid sensory input as it is uncomfortable to them. Some children who are over responsive to sensory stimuli may appear over active and disorganised in response to high levels of sensory input as they fail to screen background information. They may even be aggressive to those providing the sensory input as a defence mechanism.

When the children's activity level is high, they are said to be in a high state of arousal and when it is low they are said to be in a low state of arousal. According to Wilbarger & Wilbarger in Bundy *et al.,* (1999), in these states, the children's concentration and attention levels are inadequate to effectively engage in activities.

These theories are supported by Pfeiffer, Kinnealey, Reed, & Herzberg, (2005) who examined the relationship between sensory modulation dysfunction and affective disorders in children and adolescents with Asperger's disorder aged between six and seventeen years old. The study found a strong correlation between sensory defensiveness and anxiety (r=476, p=.000) as well as between depression and hyposensitivity (r=214, p=.05). Pfeiffer *et al.* also established that, individual who are sensory sensitivity have low levels of activities related to community use and social skills (interaction with others and the environment). The same relationship was found between hyposensitivity and community use and social skills.

In another study by Bundy *et al.* (2007), it was established that sensory processing dysfunction (SPD) affected play in children. For instance, the Test of Playfulness (ToP) score of typically developing children was higher than those of children with SPD.

2.2 Autistic Spectrum Disorders and the Family

Studies have shown that autistic spectrum disorders (ASD) like other chronic conditions of childhood do not only affect the child but those that are responsible for the child as well (Gray, 1997; Case-Smith, 2004; DeGrace, 2004; Nuutila & Salantera, 2006). As Chen, Alsop, & Minor (2000) observed, parents and siblings of children with chronic conditions experience considerable distress and emotional pain at the time of the diagnosis and throughout their lives unless they

receive the support required to meet their needs. This view point supports that of Gray (1997) and it is also supported by Gupta & Singhal (2005) and Benderix & Sivberg (2007).

Gray (1997) explored the construction of family life of families with high functioning autistic children. He found that of the two parents, mothers were the ones who were much more affected emotionally. For mothers with adolescent children, Gray found major family problems such as decreased coping ability in their social lives, psychological stability and self-esteem. But most significantly parents of children with chronic conditions hurt: for themselves, for the child they have 'lost' and the future of themselves and the child (Frainberg, 1997).

According to Gupta & Singhal (2005), the presence of a child with ASD in the family also affects the siblings emotionally. Siblings may have feelings of bitterness and resentment as they feel that their parents always put their needs secondary to that of the affected child in view of the fact that the parents spend less time with them than they do with the affected child. Another study by Benderix & Sivberg (2007) found that siblings feel sorry for the autistic child; they feel responsible for taking care of the child and assume parental roles in the absence of adults. Their relationships with friends are also negatively affected. Siblings also feel anxious, frightened and unsafe due to the child's unpredictable and dangerous behaviours.

In terms of family life, Gray (1999) found that unlike the fathers, the mothers' careers were significant affected as they often missed work and some even went on part time employment. Mothers were also found to be held responsible for the child's behaviour. He concluded that normal family life was an illusion for families with autistic children. Case-Smith (2004) and DeGrace (2004) support these findings. Case-Smith (2004) investigated experiences of parenting a child with chronic medical condition. Parents reported that they needed to be with the child at all times and some were forced to change their careers in order to

accommodate the needs of the child. Engaging in activities outside the home was described as close to impossible. In addition parents found themselves in a dilemma which caused them high levels of anxiety when faced with making difficult medical decisions.

DeGrace (2004) investigated everyday occupations of five families with children with severe autism. She found that the families had difficulties in engaging in every day activities that are part of family life. For instance, they described their lives as revolving around autism leaving them feeling robbed of a normal family life. Parents also felt that they spent most of their time occupying and pacifying the affected child. A normal family life was described as fleeting moments, where, sometimes, for a short while, the child gives them a break.

Further more parents and primary caregivers of children with ASD are faced with other challenges such as dealing with unfavorable prognosis, the chronicity of care, financial difficulties, negative attitudes of the public as well as inadequate social support (Coyne, 1997).

The extent to which the family is affected by the presence of a child with ASD is worrisome. It is, therefore, imperative that services that are offered to these children can provide some relief to families hence the importance of evaluating the efficacy of the student based occupational therapy service provided to children with ASD at the Children's Disability Centre.

2.3 Services utilized by children with autistic spectrum disorders and their families.

In a bid to find help for the children, studies mostly in the United States of America (USA), tell us that parents make use of many treatments and therapies at the same time. A study by Goin-Kochel *et al.* (2007) examined and analysed

the use of treatments by children according to the different diagnosis of ASD. The results showed that depending on the type of ASD, families had used between seven and nine different therapies in the past and were at the time using between four and six services. In another study, Green *et al.* (2006) found that parents of children with autism were using an average of seven different treatments. The number of treatments varied with the age and severity of the condition, the most severely affected and the younger children received many treatments.

The results of these two studies were supported by the findings of Ruble & McGrew (2007). These authors found that parents/caregivers used a mean average of 3.5 different therapies at any one point in time and had used as many as nine types of services in the prior six months. The credibility of these studies seems satisfactory as they used internet surveys which attracted a high number of participants and thus allowing wide ranging representation.

The use of so many therapies may indicate that parents are desperate to find help for their children and are willing to try any treatment available on the market.

From all these treatments and therapies, Green *et al.* (2006) established that the top most commonly used by families of children with ASD are speech therapy (70%), visual schedules (43%), sensory integration (38%), applied behavioural analysis (36%) and social stories (36%). On the other hand, Meyers *et al.* (2005), found that the most commonly used interventions by parents of children with ASD social skills training 42%, positive behaviour support and drug treatment (41%), sensory integration (37%), the applied behaviour analysis (32%) and the picture exchange communication system (PECS) (32%).

However, in the school setting treatments used for children with ASD differed significantly from those determined by Smith & Antolovich (2000) and Green *et al.* (2006). Using an internet survey that examined services that were used by children with autistic spectrum disorders in public schools in Georgia, USA, Hess,

Morrier, Heflin, & Ivey (2008) established that the top five most frequently used treatments and services were gentle teaching, sensory integration, cognitive behavioural modification, assistive technology and social stories.

When treatments and therapies were analysed according to the different diagnosis of ASD, children with autism and PDDNOS were found to have a higher frequency usage of the following services: ABA, early Intervention Services, Floor time, Music Therapy, Occupational Therapy, Picture exchange system, Physical Therapy, Sensory integration and Speech Therapy. Children with Aspergers Syndrome used medical treatment and participated in Social Skills Training and Social Stories the most (Goin-Kochel *et al.*, 2007).

Despite the wide range of treatments and therapies utilized by children with ASD, it is clear from these studies that sensory integration (SI) and speech therapy are always an option for parents in the treatment of their children with ASD.

According to Green (2007), parents get information about available services and treatments for children with ASD from the internet, recommendation from other parents and health professionals such as occupational therapists.

2.3 Management of autistic spectrum disorders

Autistic spectrum disorders (ASD) are simply quite difficult to manage and one reason is that aetiology is not known (Gupta & Signhal, 2005). As a result, the focus of intervention is to minimize the core features and associated deficits rather than treat the cause (Myers & Johnson, 2007). To effectively manage ASD, generic principles and strategies guide all professionals who are involved in the treatment of the children (Myers & Johnson, 2007).

First of all because children with ASD have global deficits, effective management requires a well coordinated multidisciplinary team (Myers & Johnson, 2007). The following are some of the services considered necessary in the management of ASD: Educational programmes; speech & language therapy, occupational therapy, parent training, medical treatments, individual therapy, in-home behaviour therapy and social skills training (Ruble & Gallagher, 2004).

Secondly, because the brain is said to be highly plastic at a very young age, intervention should begin as soon as an ASD diagnosis is seriously considered while the child is still very young rather than waiting for a definitive diagnosis to be made (Myers & Johnson, 2007). In this case the prognosis is said to be favourable because intervention effect change at a neurological level. The WITS Occupational Therapy Clinic, seem to have taken this view on board as the children who are treated by the students are all younger than ten years of age.

Thirdly, a family-centred approach has been adopted for use with children with ASD (Gupta & Signhal, 2005; Myers & Johnson, 2007). A family-centred approach has been defined by Brewer, McPherson, Margrab & Hutchins (1989) cited in O'Neil, Palisamo, & Westcott (2001) as,

> 'a philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special needs…[in which] families should be supported in the natural caregiving and decision making roles…[in which] parents and professionals are seen as equal in a partnership committed to the development of optimal quality in the delivery of all levels of health care', p1413.

Within this approach, parents are trained to set up their own treatment goals as well as strategies of handling and managing the children at home. According to Becker-Cottrill, McFarland, & Anderson (2003) parents are increasingly being taught how to implement treatment programmes through modelling and rehearsal and by practicing the programme with the feedback from the experts. In a briefing

to the Senate Standing Committee on Social Affairs, Science and Technology, Law (2006) emphasized the importance of a family-centred approach, stating that health professionals should develop supports for families to enable them to participate in satisfying shared occupations to ensure the well-being of the family.

In reiteration, Singer, Goldberg, Peckham-Hardin, Barry & Santarelli (2001), stated that three activities that could improve services for autistic children with severe behavioural problems are:

1. Educating professionals to form collaborative partnerships with the families
2. Developing and implementing family-centred, home based positive behavioural support interventions
3. Interventions that are extended to focus on family routines

Other principles and strategies that are recommended for intervention with children with autistic spectrum disorders as adopted from Myers & Johnson (2007) include:

- provision of intensive intervention, with active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate educational activities designed to address identified objectives;
- low student-to-teacher ratio to allow sufficient amounts of 1-on-1 time and small-group instruction to meet specific individualized goals;
- incorporation of a high degree of structure through elements such as predictable routine, visual activity schedules, and clear physical boundaries to minimize distractions;
- implementation of strategies to apply learned skills to new environments and situations (generalization) and to maintain functional use of these skills; and
- use of assessment-based curricula that address: functional, spontaneous communication; social skills, including joint attention,

imitation, reciprocal interaction, initiation, and self-management; functional adaptive skills that prepare the child for increased responsibility and independence; reduction of disruptive or maladaptive behaviour by using empirically supported strategies, including functional assessment;

- cognitive skills, such as symbolic play and perspective taking; and traditional readiness skills and academic skills as developmentally indicated.

2.5 Occupational Therapy with Autistic Spectrum Disorders

2.5.1 Management of children with Autistic Spectrum Disorders in Occupational Therapy

In the management of children of ASD, studies show that occupational therapists generally employ a holistic approach. They use different frames of reference in order to address all areas of difficulties identified from the child. For example, if a child has behaviour, social and sensory processing difficulties, the frames of reference of choice will be the behavioural, psychosocial and sensory integration respectively.

Watling *et al.* (1999), examined current practice patterns of occupational therapists who were considered to be experienced in treating children with ASD. They found that occupational therapists typically provide a one-to-one intervention and the most commonly used techniques are sensory integration (99%) and positive reinforcement (93%). Theoretical approaches used included sensory integration (99%), developmental (88%), and behavioural (73%). Non-standardized tools and clinical observations were the evaluation tools of choice. The skill areas addressed being praxis, self regulation, language and communication, oral motor/feeding and interaction style. Educational methods which were identified by occupational therapists as most helpful were weekend workshops (56%) and on-the-job training (52%).

Case-Smith & Miller (1999) also examined occupational therapy practices with children with Pervasive Developmental Disorder (PDD). The results of this study differed with those of Watling, Deitz, Kanny & McLaughlin (1999) except on the sensory integration approach. They found that occupational therapists mostly used sensory integration and environmental modification approaches in the treatment of children with PDD. Therapists were sometimes found to use child-centred play in the treatment of children with PDD.

It is clear from these two studies that OT-SI is almost always a choice for occupational therapists treating children with ASD. According to the key informants of the WITS Occupational therapy department, in the WITS Occupational Therapy Clinic, the fourth years use traditional occupational therapy, where the children are engaged in purposeful activities to remedy identified dysfunctions. The Behavioural and Developmental frames of Reference are used to correct undesirable behaviours and develop age appropriate skills respectively. The approaches/frames of reference are in accordance with the findings of Watling *et al.* (1999) with the exception of sensory integration.

2.5.2 The use of sensory integration for children in the management of autistic spectrum disorders

Sensory integration therapy as described by Bundy *et al.* (1999) seeks to improve the ability of the child to process and integrate sensory information for effective use in occupational performance. The goal is to remediate deficits in neurologic processing and integration of sensory information so that the child can interact with the environment in a more adaptive manner and not to teach specific skills or behaviours. Therapy addresses both altering the input and interpretation of the sensation as well as changing and structuring the environment to address such reactions (Law, 2006). For example, if a child finds certain textures of clothes unbearable recommendations are made for a less or more acceptable

texture for the child. In addition treatment is provided to normalize the sensory modulation.

However, there is varying empirical evidence to support OT-SI. Despite this, occupational therapists have shifted their intervention from traditional occupational therapy to understanding how and when a child with ASD is reacting inappropriately to sensory input (Law, 2006). This is based on the evidence that children with ASD have sensory processing difficulties and that OT-SI is effective in treating these children.

In a single case-study, Linderman & Steward (1999) evaluated the efficacy of occupational therapy using a sensory integration approach on two three year old boys diagnosed with pervasive developmental disorder (PDD). One subject received intervention for seven weeks and the other for eleven. The results of the study supported the use of sensory integration as an effective approach in the treatment of children with PDD. They found that both children had significantly improved, the frequency and duration of their disruptive behaviours had decreased (e.g., high activity levels, aggressive behaviours), they had increased functional behaviours, such as spontaneous speech, purposeful play, and they were able to pay attention to activities and conversations. They concluded that although their study supports the use of OT-SI, further research is needed to replicate the findings by isolating other concurrent interventions that the children receive (e.g. speech therapy, preschool) as these may be confounding the results.

In another single subject study design, Case-Smith & Bryan (1999) determined the effects of occupational therapy using a sensory integration approach with five preschool children with autism. A baseline of three weeks was established over a period of three weeks where non-engagement, mastery play, and interaction were measured using videotapes during free play in the preschool. Therapy was then provided in one- on- one sessions and consultation to teachers for 10

weeks. The results showed that all four children demonstrated decreased frequency on non-engaged behaviour, and three demonstrated increased frequency of mastery (goal-directed) play. Improvements in frequency of interaction were minimal.

However although the results of these studies support OT-SI, they both could not be generalized due to very small sample size.

On the other hand, studies on the use of OT-SI with children with ASD did not arrive at definite conclusions. In a study that reviewed the literature on the prevalence of sensory and motor abnormalities in children with autism and the effectiveness of sensory integration, traditional occupational therapy and auditory integration training in addressing these difficulties, Dawson & Watling (2000) found only four objective outcome studies of OT-SI. They concluded that the scale was too small to make any firm conclusions regarding the efficacy of OT-SI. In another study which reviewed the literature, Hodgetts & Hodgetts (2007) reported lack of empirical evidence and suggested that when these interventions are used, they should be evaluated systematically.

However the use of literature reviews is not an effective method of evaluating a service. Ruble & Gallagher (2004) contend that although there are many scientifically proven methods of evaluating a service, parental ratings are the most effective as parents are the service users and are therefore better placed to evaluate it.

In contrast, Prizant & Rubin (1999) do not support the use of sensory integration on its own. These authors argue that sensory integration is a supportive intervention, and thus it need not interfere with time spent in child engagement. They suggest that SI may occur in activities that require engagement and may serve to foster engagement when they support a child's ability to modulate level of arousal and thus maintain a calm and intentional state.

2.5.3 The use of traditional occupational therapy in the management ASD.

Studies in the use of traditional occupational therapy in the management of ASD are lacking. In a literature review by Dawson & Watling (2000), no empirical studies to support the efficacy of traditional occupational therapy with ASD children were found. They concluded that empirical studies are required to support the use of this intervention. Another literature review by Myers & Johnson (2007) did not find any studies on the efficacy of traditional occupational therapy with ASD either. They concluded that research regarding the efficacy of occupational therapy with ASD is lacking.

2.5.4 Parents and caregivers perspective on the outcomes of occupational therapy services with autistic spectrum disorder

Cohn (2001) explored parents' opinions regarding their children's participation in occupational therapy using a sensory integration approach. The parents' perceptions were that therapy was beneficial to the children and themselves. On the part of the children, parents felt that therapy improved the children's abilities, activities, and reconstruction of self-worth. On their part parents valued understanding their children's behaviour from a different perspective. This perspective facilitated a change in their expectations for themselves and their children. Parents also felt that their parenting experience was validated as they realized that the children's behaviours were not due to their poor parenting skills. They also felt that OT-SI helped them to be able to support and advocate for their children.

Ruble & Gallagher (2004) carried out a study in which they solicited parents' views on the outcomes of different therapies which were used by their autistic children. On a scale of 1 to 5, 5 being the best, parents evaluated occupational therapy as follows: the child was better at home (3.6), better at school (3.6), better behaviour (3.3), better communication (3.2), better social skills (3.4) and

better in problem solving (3.3). The study also established that therapy had a positive effect on the family: less stress on the care giver (3.2), less overall family stress (2.2) and less financial worry (2.9).

However, this study used pre-determined answers for participants to choose from hence limiting participants from fully expressing their opinions. In addition the study did not elaborate on the areas of function, it did not qualify the ways in which the children were better when at home or school or in what ways the children's behaviours were different. The study did not specify what type of occupational therapy was being used by the parents, whether it was OT-SI or traditional OT.

In a follow up of the above study, Ruble & McGrew (2007) compared the effectiveness of the different services utilized by families and children with ASD. Outcomes which were evaluated were: improvement of the child at home, improvement at school, improvement in behaviour, improvement in communication, improvement in social skills, improvement in problem solving, less stress on caregiver, less stress on family and less financial worry. Services which were evaluated were in-service hospitalization, family counselling and training, individual therapy, in-home behaviour therapy, Speech and language therapy, occupational therapy, case management and respite care. They found that occupational therapy was rated as the most effective in helping children improve in problem solving skills.

However this study did not make it clear as to who provided services termed inpatient hospitalization, family counselling and training, individual therapy and in-home behaviour therapy. Occupational therapy is also provided in the above manner such that the results might not be a correct representation of the effectiveness of the occupational therapy service. This study also did not make it clear as to what type of occupational therapy was received by the children.

2.6 Factors that determine parental satisfaction with services for children with autistic spectrum disorder

According to Gupta & Singhal (2005) when seeking help for their children, parents usually consult paediatricians first while other professional are consulted later. These authors continue to say that parents feel that early referrals to other professionals would be helpful to their children and argued that paediatricians should be made aware of these services. Parents are more concerned about addressing problematic behaviours and specific skill deficits as these can be an impediment to academic and social learning (Doughty, 2004). On the other hand, according to Gupta & Singhal (2005) intervention priorities emphasized by the Association of Parents' of Children with Autism are creation of specialized diagnostic and home-training services, classrooms for children and adolescents, living and working facilities for adults, crisis intervention centres and weekend devoted to developing social skills.

Once the children are enrolled in these services, several factors determine parental satisfaction with the services. A study by Nuutila & Salantera (2006) explored parents' experiences of care for children with long term illnesses. Eleven parents were interviewed and the results revealed that during the diagnosis process, parents needed to be given consistent information empathetically. In the intervention phase where parents engage in the process of exchanging information with the professionals, mutual trust was paramount. Parents expressed that is as much as they trusted professionals to do the best for their children, professionals should also trust them to do what is best in the care of their children. The study also showed that where there was lack of a permanent relationship with health professionals, parents lacked confidence in the professionals' knowledge of the condition and care of their child. They concluded that health professionals needed to lay the ground work for partnership with parents where both parties will acknowledge each other's competencies.

In a follow up study with two subjects who indicated the most dissatisfaction with services provided for their autistic children in a previous study, Roger, *et al.,* (2008) examined their satisfaction with the use of home programmes for children with ASD. They found that decreased satisfaction of these parents with the services were related to the child's lack of improvement; parental stress, decrease parenting competencies; decreased performance post intervention; decreased perceptions of family-centredness of the service and difficulties in forming collaborations with professionals. The study concluded that building strong relationships was of particular importance in the management of ASD.

These studies clearly indicate that working in collaboration with the clients is important when managing children with ASD. However, despite this knowledge, professionals do not necessarily adhered to this approach of care. This was proven in a systematic review of the literature by Legare`, Ratte, Gravel, & Graham Legare`, F., Ratte, S., Gravel, K. & Graham (2008) who found that time constraints was found to be the number one barrier into practicing joint decision making with the patients. Professionals felt that these consultations are simply time consuming. Disagreement with the applicability of shared decision making based on the characteristic of a patient was found to be the second major barrier. The third barrier was disagreement with the applicability of shared decision-making based on the clinical situation.

Factors that were found to encourage health workers to implement shared decision-making included motivation of health professionals, professionals' perceptions that implementing shared decision-making will lead to better clinical outcomes and perceptions that implementing shared decision-making will lead to improved health process (Legare` *et al.*, 2008).

On the other hand, when examining parental experiences with treatment for autism that have varying degrees of empirical evidence (sensory integration, Applied Behavioural Analysis (ABA) and a combination of vitamin A and

magnesium) Green (2007), found that continued use of these treatments was influenced by the following factors: ease of implementation, time commitment and perceived effectiveness.

2.7 Summary

A review of the literature has shown that children with ASD present with behavioural, communication and sensory processing difficulties which interfere with their occupational performance. As a result, the children depended on their families for care. Families of children with ASD have emotional and financial problems as well as difficulties in engaging in fulfilling everyday activities that are considered normal in family life. In a bid to find help for their children, parents make use of many treatments and therapies, between three and seven, at the same time. They also make use of treatments that have and those that do not have empirical evidence for efficacy. Among the top five treatments of ASD, sensory integration is almost always a choice by both parents and therapists as the treatment of choice.

Early intervention, multi-disciplinary team, family-centred approach, structured environment with fewer distractions and interventions that allow for generalisation of skills are some of the principles that are recommended when managing children with ASD. Occupational therapists generally use OT-SI which has also been shown to have effect on behaviour and engagement in activity. Parents of children with ASD also support the use of OT-SI in the treatment of their children. Studies on the use of traditional occupational therapy with ASD are lacking, literature reviews yielded no results and recommend research.

Factors that determine parental dissatisfaction with services utilized by their children with ASD include lack of improvement; parental stress, decrease parenting competencies; decreased performance post intervention; decreased

perceptions of family-centredness and difficulties in forming collaborations with health workers. Collaboration with health care workers was found to be a very important factor in determining parental satisfaction. However, professionals do not necessary adhere to forming collaborations with patients citing reasons such as time constraints. Consultations with patients was found to be facilitated by motivation of health professionals, professionals' perceptions that implementing shared decision making will lead to better clinical outcomes and perceptions that implementing shared decision-making will lead to improved health process. Factors that influenced continued use of treatments are ease of implementation, time commitment and perceived effectiveness.

CHAPTER 3
METHODOLOGY

3.0 Introduction

This chapter will describe the research process undertaken for this study. It aims to provide a comprehensive framework for the research. As Leedy & Ormrod (2005) noted, the research methodology will help explain what the nature of the data collected is and what methods were used to process data and arrive at the conclusion. The chapter details the research design; the context at which the research was conducted and how access was negotiated to carry out the study in the research context. The research population is described as well as the sampling techniques. Ethical considerations which directed the study are also outlined. Finally research procedures are explained pertaining to data collection, data analysis and data validation.

3.1 Research Methodology

Saunders, Lewis, & Thornhill (2003) noted that most researchers present research as a multi-stage process that must be followed in order to undertake and complete research project. This process guides the project from its conception through the final analysis, recommendation, ultimate action (Kumar, Aaker, & Day, 1999). Leedy (1993) discussed two broad generic types of methodology; quantitative and qualitative research, within each having sub-methodologies. The framework he uses is shown in Figure 3.1 on the next page.

Figure 3.1: *Framework by Leedy (1993) depicting two broad generic methodologies*.

Although Leedy's framework above appears simplistic and not comprehensive to give guidance on the research processes it, however, provides an-easy to understand basis for this research. The framework does not show the methods of data collection, research philosophy and approaches and the time scales. Guidance on these is derived from the works of authors such as Bush & Burns (2003); Hucker (2001), LeCombe (2000), Holloway (1997) and Saunders *et al.* (2003).

3.2 Research Design

A qualitative research design was employed in this study. Qualitative research involves collecting, analyzing, and interpreting data by observing what people do and say (Bush & Burns, 2003). Observations and statements are in a qualitative or non-standardized form. When using qualitative methods the researchers intend to understand and to gain a new perspective on things about which little is known and to collect in-depth information that may be difficult to assess quantitatively. Since the efficacy of the University of the Witwatersrand student based occupational therapy service with ASD children has never been evaluated, the researcher intended to explore this new phenomena qualitatively.

Qualitative researchers have a choice of the following research designs: case study, ethnography, phenomenological study, grounded theory study and content analysis.

A phenomenological design was used in this study. This design is concerned with the lived experiences of the people (Holloway, 1997) involved, or who were involved, with the issue that is being researched. Leedy & Ormrod (2005)

describe a phenomenological study as one which attempts to understand people's perceptions, perspectives and understanding of a particular situation. It is

> '*interested in people's attitudes, opinions and thoughts on issues'* (Hucker, 2001, pg.10).

This type of design was found to be appropriate in this study because the aim was to establish or find out parents/caregivers' opinions and feelings about the student based occupational therapy service offered to their children.

3.3 The Research Context

3.3.1 The WITS Student Occupational Therapy Service

This study was carried out at the Wits Occupational Therapy Clinic. According to the Key informants of the Occupational Therapy Department, the clinic is a University of the Witwatersrand - occupational therapy service learning project. The clinic is sub-letting space from the Children's Disability Centre (CDC) which is housed in the Children's Memorial Institute (CMI), Johannesburg. The clinic consists of three rooms: the bigger room is used as a therapy room by all the students while the other two small rooms are used as storerooms for equipment.

The CDC provides educational services for children with visual impairment and ASD and these are the clients for the OT students. Other clients are from the Children's Homes in Johannesburg. The service is for teaching purposes only for both the fourth years and the post graduate students and is free of charge. The clinic also provides services for some private patients at R30.00 per session.

For the fourth years, the clinic runs every Tuesday and Wednesday afternoons. Each day has a different group of about 20 to 25 students with each student having one or two children per session. The students are placed at the clinic for

the whole academic year to offer therapy to the children. During the year the students get to go for other placements in different settings and in their absence, the remaining students take over their cases. Before the students leave, they write handover reports to the student who will be taking over the treatment of the child. This strategy is put in place to ensure continuity of therapy.

3.3.2 The referral system

Before the children are enrolled in the students' programme, there is collaboration between the students, their lecturer and the teachers at the CDC school to identify the children who will benefit from occupational therapy. After the children have been identified, the students send information forms home by putting them in the children's bags for the parents to fill and sign. The forms form part of the comprehensive assessment of the children. Parents are called in for interviews if more information is required to complete the assessment.

3.3.3 The Occupational Therapy Treatment Sessions

The treatment sessions for each child is once a week in a 45 minutes session. During these sessions the students are under the supervision of their lecturer and two other tutors. The sessions begin with students submitting their treatment plans for the day. This is followed by a treatment demonstration for gross motor skills by two or three selected students. The demonstrated treatment is used by all the students for the treatment of gross motor skills. However, students are free to adapt the treatment to suit the needs of their clients. For those children who are easily distracted or have difficulties functioning in a group environment, students make use of other unoccupied rooms and corridors in the CDC to treat the children. For the treatment of fine motor skills, the students rely exclusively on their own treatment plans.

3.3.4 Negotiating access to the service

The researcher was a post graduate student of the University of the Witwatersrand at the time of the study and was attached to the WITS OT clinic. The researcher got to know about the students' service during this attachment. However, the researcher was not involved with the fourth year's programme. Access to carry out the study was gained from the coordinator of the WITS occupational therapy clinic (Appendix B). The researcher approached her supervisor about her interest in carrying out the study at the clinic who in turn discussed the issue with the coordinator of the clinic.

3.4 Research population

About fifty parents/caregivers of children who are diagnosed with ASD who were receiving student based occupational therapy from the final year occupational therapy students at the Wits OT clinic constituted the research population.

3.4.1 Sampling

Random sampling was used to select participants. In random sampling participants are selected randomly such that everyone has an equal chance of being chosen (Hucker, 2001; Leedy & Ormrod, 2005). A computer generated programme was used to randomly select ten participants from the research population.

A sample size of ten participants was adequate in this type of study. Patton (2002) argues that in qualitative research the sample size is ideal if sampling has been done to the point of redundancy or saturation. Lincoln & Guba (1985, pg. 202) also argue that

> '…the sampling is terminated when no new information is forth coming from new sample units; thus *redundancy* is the primary criterion'

and that the sample can be changed if information emerges that indicate the value of a change.

In this study a sample size of ten participants constituted the initial sample and all participants were interviewed. And since no new information was forth coming the sample size was not increased as a point of redundancy was reached.

3.4.2 Inclusion criteria

All participants who took part in the study were:

- Parent/care-giver of a child diagnosed with ASD
- Staying with the child at home
- Aged between 25 and 50 because this age group is considered mature enough and would have cared for the child for at least 3-10 years to be able to give detailed information about their experiences with the occupational therapy service, and
- Their child was receiving occupational therapy intervention at WITS clinic from the final year OT students.

3.4.3. Exclusion Criteria

- Parents/care givers whose children were relatively new (less than 3 months) at the Wits clinic because the effects of therapy may not be visible by that time.

3.5 Ethical Consideration

The following were employed to ensure that this study conformed to ethical standards:

- Approval from the University of the Witwatersrand Ethics Committee was obtained. Certificate number M080541 is in Appendix A.
- Approval from the Coordinator of the WITS OT clinic to carry out the study at the clinic was obtained. (Appendix B)
- The researcher ensured informed consent by sending home information sheet (Appendix C) for the participants to read. This, detailed information about the purpose of the study and how data was going to be collected. It was emphasized that participation was voluntary and the participant could withdraw at any stage. It was also made clear that refusal to participate or withdrawal at any stage was not going to be detrimental to them and the child in any way. This information was also verbally given to the participants to ensure understanding. Before the interviews the researcher went over the purpose of the study and also emphasized to the participants their right not to participate and to withdraw at anytime.
- Signed consent forms for participation and audio recording of interviews were obtained from the participants (Appendix D and E respectively)
- To ensure confidentiality, all names were coded and are not mentioned in the study.
- The tapes are stored in a locked cupboard which is only accessed by the researcher.
- Feedback was offered to participants on request

3.6 Research Procedure

3.6.1 First Stage

1. During the first contact, letters were sent home with the children of the parents/caregivers who were randomly select to take part in the study. Information included what the study was about, how the study would be conducted and ethical considerations as detailed in the information sheet (Appendix C) together with consent forms for both participation and recording of interviews.
2. Six parents/caregivers responded positively and subsequent telephonic follow ups were made to acknowledge receipt of the consent forms and confirm their responses.
3. The other four parents/caregivers did not respond and therefore telephonic follow ups were made to confirm whether they had received the information. Three parents/participants responded positively while one declined to participate.
4. One more parent was randomly selected from the research population to substitute for the one who could not participate and the same process was repeated. This parent responded positively.

3.6.2 Second Stage

After all the signed consent forms were received from the participants, each participant was telephoned again to set an interview date and time that was convenient for the participant.

3.6.3 Third Stage

Participants were reminded telephonically about the interview a day before. Interviews were conducted as per schedule. All interviews were done at the Wits OT clinic in the therapy.

3.7 Data Collection

According to Cresswell (2003) qualitative research seeks the involvement of the participants in collecting data and the researchers themselves are the primary tools in collecting data. Qualitative researchers rely on four methods for gathering information: (1) participation in the setting, (2) direct observation, (3) in depth interviews, and (4) analysis of documents and materials.

3.7.1 Techniques

This study made use of face-to-face in-depth semi-structured interviews in collecting data with the researcher being the interviewer. A list of questions that the researcher wanted to explore during each interview was developed as an interview guide or "schedule" (see Appendix F2). Using an interview guide ensured good use of limited interview time; while making the interviews more systematic and comprehensive. Having prepared questions helps to keep the researcher focused (Lofland, & Lofland, 1984).

Interviews also allow the researcher to have ‘control over the line of questioning’ (Cresswell, 2003, pg 187) and collection of detailed information (Hucker, 2001). Semi-structured interviews help the researcher to cover all areas that need to be covered and they allow for consistency with all the interviewees (Cresswell, 2003). Most questions were open ended so as not to limit the interviewees on expressing their feelings and opinions. There were no predetermined responses, and during the interviews the researcher was free to probe and explore further using follow up questions for more information whenever necessary.

The following were the main questions:

1. Describe to me your understanding of occupational therapy?

2. How would you describe your child in terms of his/her functional abilities and behaviour.
3. Has there been any change in his/her behaviour or functional abilities in the past year?
4. If yes, describe for me those changes that you have noticed and what you think has contributed to the changes?
5. Describe the challenges that you and the family are faced with due to the child having difficulties?
6. Have these challenges always been the same or has there been a change along the way?
7. Describe to me what you think occupational therapy has done for your family and your child?
8. Is there anything else you would like to add about the OT service that your child is receiving?

This list of questions was drafted by the researcher based on the literature review and the research objectives. The first question was considered important as it would give a clear picture that the participants understood the service they were evaluating. The rest of the questions were informed by the expected outcomes of occupational therapy intervention.

The structure of the interview guide was maintained during the course of the interviews.

The procedures used to keep track of the research process were recorded and became part of the audit trail. These included process notes on day to day activities, methodology and decisions made about procedures, changes to questions and information recorded straight after each interview. The interview notes included impressions of the participant, their reactions, motivation and experiences. (Appendix H). This formed the second source of information.

The third source of information for this study involved the analysis of documentation from the children's occupational therapy records at the WITS OT clinic service to supplement and compare data gained through interviews.

3.7.2 Recording Data

The interviews generally took half an hour each and were recorded on a dictaphone. All tapes are stored in a locked cupboard by the researcher where no one has access to. The researcher also took notes during the interviews as an audit for the researcher to capture the reactions and impressions of the participants. Data was colleted until data saturation was reached. An extra 15 minutes was spared at the end of the interview for questions, comments and queries that the participants might had.

Each interview begun with an introduction by the researcher and some time was spent putting the participant at ease before the interview began to make the participant more relaxed. This was achieved by making small talk and clarifying issues that participants needed clarity on. The participants' characteristics were also gained from this introductory part of the interview.

The interviews were carried out in the therapy room at the clinic at the times when the students were not at the clinic. This ensured privacy and no disruptions during the interviews.

3.7.3 Duration of data collection

Interviews took place over a period of two months.

3.8 Data analysis

Data was analysed using a strategy by LeCompte (2000) of analyzing qualitative data. The first step involved the researcher transcribing the tapes word for word. After the tapes were transcribed, the researcher listened to the tapes again to ensure the accuracy of the transcription. The second step entailed reading and re-reading each of the transcripts in detail to identify items that were relevant to the research questions. Identifying these items involved a:

> '*systematic process of looking at the frequency, omission and declaration of items'* (LeCompte, 2000, pg. 150).

After the items were identified the third step involved grouping together those items that were similar or even slightly different to build taxonomies or codes. This was done primarily by comparing and contrasting items. The fourth step involved further analysis of the taxonomies/ codes, those that went together were clumped to form patterns/categories. The final step involved assembling together the patterns/categories to form themes or structures.

3.9 Validation of the study

To ensure accuracy and credibility of the findings the researcher employed the following strategies described by Cresswell (2003):

1. Member-checking – After identifying items in the initial stage of the analysis, a summary of the identified items was sent back to the participants to determine if the report had captured their perceptions.
2. Data Triangulation is the use of multiple sources of data. Information about the child's progress from occupational therapy progress reports from the Wits clinic were used for triangulation.
3. Audit trail – the researcher kept a research journal throughout the study where impressions and ideas were recorded. Information that arose from the interviews like the emotive component was considered in the light of the participants' responses to the questions asked and prompts for further

interviews. This assisted with the "confirmability" of the research (Lincoln & Guba, 1985) and consisted of the raw data; analysis notes; synthesis products; process notes; personal notes; and initial developmental information.

4. Data Saturation – by generating the same information from the participants, credibility of the data was ensured.
5. Bracketing – the researcher was not involved in the management of the Wits OT clinic or training of the students. Time was spent discussing any preconceived ideas of how the research might prevent this interfering with the interpretation of the results. The interpretation was confirmed with an external auditor.
6. External auditor – an external auditor who was totally new to the research and the researcher and also experienced in qualitative research was asked to review the entire project at the conclusion of the study.

CHAPTER 4
FINDINGS OF THE STUDY

4.0 Introduction

This chapter reports on the findings of the study and has been divided into three sections as follows: Section A describes both the participants and children's characteristics. Section B reports on the themes and categories generated during data analysis. Section C reports on the information gathered from the children's occupational therapy files.

4.1 SECTION A

4.1.1 Participants' characteristics

Information about the participants' characteristics was purposefully excluded from the structured questionnaire as the researcher wanted to use gathering of this information as an ice breaker just before the interview. This was the researcher's strategy for the researcher and the participant to get to know each other in order to build trust and have the participants relaxed so that they can give information freely. The information was not recorded on the dictaphone but it was captured in the researcher's field notes.

- Ten participants took part in the study, eight mothers, a father and a maternal grand mother.
- Participants were aged between 25 and 54 years.
- Nine were Black and one was Indian.
- All female participants raised the children with ASD from birth and at the time of the study lived with the children at home. One participant (father)

raised the child from the age of one. The child lived with the mother prior to that.

Participants were divided into two groups according to their educational level as from the researcher's field notes it was evident that they viewed the situation differently and their ability and confidence in the key informant interviews differed markedly. It was felt, therefore, that some of the information gained from the two distinct groups could not be combined.

Six participants had primary school education of whom four did voluntary work while two were unemployed. These participants were also from a low-socio economic class. This group is referred to during the entire report as Group A. Other characteristics of this group, which also presented as limitations to the study were:

- This group was very cautious of what they said and often the researcher felt they did not express their opinion fully. They needed assurance before the beginning of the interviews that their identity will not be known and confidentiality would be ensured.
- English was not their first language and coupled with their educational level they had some difficulties expressing themselves in English. The researcher was not familiar with their vernacular language. This might have affected the richness of the data collected.

Four participants had tertiary education and had formal employment. These participants constituted the working class and were more free and coherent in their responses. They are referred to as Group B in the report. Table 4.1 on the next page shows details of these characteristics.

Table 4.1: Participants' demography

Group	Participants	Age	Occupation	Relationship with the child	Education level
Group A	A1	50	Voluntary work	Mother	Primary
	A2	28	Unemployed	Mother	Primary
	A3	54	Voluntary work	Grandmother	Primary
	A4	37	Voluntary work	Mother	Primary
	A5	35	Unemployed	Mother	Primary
	A6	26	Voluntary work	Mother	Primary
Group B	B1	44	Self employed	Mother	Tertiary
	B2	37	Auditor	Father	Tertiary
	B3	38	Teacher	Mother	Tertiary
	B4	40	Works for an NGO	Mother	Tertiary

4.1.2 Characteristics of the Participants' Children

Parents were asked to provide children's characteristics before the interview by filling in a biographical questionnaire, (Appendix F).

- All the 10 children had severe forms of ASD
- All the children were attending the Children's Disability Centre (CDC), Johannesburg, a school of children with special needs.
- The children were aged between four and nine years
- Eight of the children were boys and two girls.

- Two of the children had received OT before being enrolled at the WITS OT student clinic, the rest were receiving occupational therapy for the first time.
- The children had been receiving therapy from the clinic for a period of eight months or more.
- Two of the children were at the time also receiving sensory integration therapy (OT-SI) from an occupational therapist who provided community work for the children at R20.00 per session once a week.
- Eight of the children were also receiving speech and language therapy.
- No other therapies were received by the children.

4.2 SECTION B

This section reports on the themes and categories generated during data analysis. Direct quotes are italicized. The first theme of understanding of occupational therapy was taken directly from the first question of the questionnaire. The rest of the data analysis generated the following themes: inefficacy of therapy, lack of partnership, lack of students' confidence, inadequate structure of the program and desperate need of help. Table 4.2 on the next page shows a summary of the themes and categories generated.

Table 4.2: Themes and categories generated during the analysis

THEMES	CATEGORIES
Understanding of Occupational Therapy	Understanding of occupational therapy
Inefficacy of the service	Effectiveness of therapy
	The effects of therapy
Limitations of students as therapist	Understanding autistic spectrum disorders
	Handling and managing the children
Lack of partnership	Parental involvement
	Feedback and carry over
Inadequate structure of the program	Change of students
	Duration of therapy
	The nature of the service
Desperate need of help	Hope and the need to cooperate

4.2.1 THEME 1: UNDERSTANDING OF OCCUPATIONAL THERAPY

This theme describes the participants' understanding of occupational therapy and the services occupational therapists offer their children. Understanding of occupational therapy was crucial, this was so because the participants would be better positioned to evaluate the service. The same was true for the researcher in

respect of determining the credibility of information given by participants regarding occupational therapy. The category of understanding of occupational therapy made this theme.

4.2.1.1 Understanding of occupational therapy

In general participants in Group A did not have an understanding of occupational therapy. Despite some of the participants having watched the children during therapy, they still did not know what it was and what its purpose was. One participant even confused occupational therapy with speech and language therapy.

> *'I don't know, I don't know what occupational therapy is and I don't .. even know the kind of things they do with my son.'* A2

> *'Wow, I… I can't tell you, I don't want to lie, I can't tell you.'* A4

> *'I don't know much but I think they stimulate the child to help them speak…'* A6

Participants in Group B had a better understanding of occupational therapy and the services offered by occupational therapists. They generally described occupational therapy as one that helps the children to improve their skills (functional and social) and helping the children to lead a balanced life.

> *'To me occupational therapy is basically helping the child with improving their skills like tying their shoe laces…'* B3

> *'is basically monitoring a child in terms of his development, the way he interacts um..his skills..'* B1

4.2.2 THEME 2: INEFFICACY OF THE SERVICE

This theme describes how participants view the students' abilities as therapists. On the whole, participants felt that the students were not competent enough to be able to handle children with autistic spectrum disorders, especially those with severe forms of autism.

This theme describes the participants' perception of the efficacy of student based occupational therapy in treating their children with ASD. On the whole, participants felt that therapy was inefficient. Two categories made this theme: effectiveness of therapy and the effects of therapy.

Two categories made this theme: effectiveness of therapy and the effects of therapy.

4.2.2.1 The effectiveness of therapy

This category describes the participants' perception of the value they feel occupational therapy has in their children's lives. Three participants from Group A felt that occupational therapy was helpful in improving the children's functional skills and behaviours. However their responses were rejected and not reported under this theme because one of these participants confused occupational therapy with speech and language therapy, one was not aware that her child was receiving occupational therapy and the other did not know what occupational therapy was and what type of services the child was receiving. Therefore it was felt that their responses were contradictory.

On the whole, the rest of the participants from both groups felt that therapy was not valuable as it did not effect change on the children.

Group A

'I am not satisfied a lot about the students…but the students are not the same….some can be good….' A3

Group B

'To be honest with you, for me I don't see any effect of OT on my child' B3

For participants, whose children were receiving sensory integration therapy (OT-SI) and those who had received occupational therapy from qualified occupational therapists prior to being enrolled in the student based service felt that therapy was effective. They reported improvements mainly in the children's behaviours, stating that children were much calmer at home and that they slept throughout the night.

Group A

'In terms of sensory integration, yes he was doing well but with the students I don't know what he is doing here. Anyway last year he was better, this year is worse. A1

Group B

'I mean last year she was seeing a qualified OT at TMI and I could see the difference. She gave him things to use to calm himself down but since he was taken over by the students, there is no difference'. B3

In addition to improvement that participants attributed to OT-SI, participants reported some improvements from the children during the time that they were attending WITS student occupational therapy programme which they attributed to the school's intervention. Improvements were mainly noted in the children's behaviours, communication and activities of daily living (ADLs). Refer to Table 4.2.2 below.

'The way the teachers work with him. Before he used to … scream, laugh and clap hands for no reason but now he is controlled since coming to school' A3

'I think it is the environment [school environment] and also seeing other kids in the class. And by teachers encouraging them to play together' B3

Table 4.3 Children's areas of improvement attributed to the school's intervention.

Area of improvement	Descriptive information
Behaviour	Less distractive at home
	Can attend parties without getting very excited
	Sit and eat independently with out being distracted
	Interacts well with other children
Communication	Follow simple instructions
	Can indicate if needs food or toilet
Participation in activities	Put on shoes
	Put on and take off loose T-shirts

4.2.2.2 The effects of therapy

This category describes what the participants perceived as the effect of therapy. Both groups felt it was not really therapeutic. For participants who have watched the children in therapy, they described therapy time as a stressful time for them, the children and even the students themselves. Some participants felt that therapy itself had negative effects on the children, they reported that after therapy sessions the children are exhausted and irritable.

'When he first attended OT, I used to attend with him and it was a serious problem for me because um…. I don't remember the girl's name..um.. but she was not handling it very well. …..so this girl, there was a day where she just burst out crying and she left the room.' B2. This participant was describing a student who found it difficult to handle the child to a point where she cried as the child was not cooperative.

'the only time I have trouble with 'Masa' after school is on Wednesdays when she has had OT, I have even started bringing food to keep her busy while I drive, otherwise it's a fight all the way. I don't know what they do to these kids in there. . . I see the stress on the OTs side as well'. B3

'they [students] stress me as if its my fault' A1. This particular participant was not happy, saying most of the time she was expected to sit in therapy sessions to help control her son whom the student could not manage on her own.

4.2.3 THEME 3: LIMITATIONS OF STUDENTS AS THERAPISTS

This theme describes how the participants perceived the students' capabilities as therapists. In general both groups of participants felt that the students had limitations in terms of their theoretical knowledge and skills to effectively manage and treat their children. They felt that these limitations resulted in therapy being ineffective.

'One wonders if they are doing justice to their child by letting him be seen by students' B2

Two categories formed this theme: understanding autistic spectrum disorders and handling and managing the children.

4.2.3.1 Understanding autistic spectrum disorders

This category describes the perceptions of participants regarding the students' understanding of ASD. Both groups of participants had a strong conviction that the students did not have the theoretical knowledge of ASD. They also implied that the students were learning about ASD for the first time by working with their children.

> *'the students who come to attend to our kids need to be clued up in autism, they should have knowledge before actually attending to our kids. They should know what autism is really about…until they do that, is when they will get positive results.'* B3

> *'If there is a way that the students can know about autism or if they can be briefed about autism.'* A3

4.2.3.2 Handling and managing the children

This category describes the participants' perceptions on the students' capabilities to handle and manage the children. Participants felt that the lack of theoretical knowledge of ASD on the students' part made it difficult for them to know how to handle and manage the children especially when the children displayed problematic behaviours. This meant that the students spent a lot of therapy time trying to no avail to deal with these behaviours leaving no time for therapy resulting in therapy being ineffective.

> *'they [students] always complain that 'Thabang' is not doing well, that he is always running around, I don't know what they want me to do with his running around. Aren't they suppose to be able to contain him as therapists, what do they want me to do?'* A3

*'One day I went to OT to watch how 'Kgosi' was doing in therapy and when I got there the student was just chasing 'Kgosi' around the room'.*A1.

'They should know how to handle our kids because some of these kids have difficult behaviours…' B3

4.2.4 THEME 4: LACK OF PARTNERSHIP

This theme describes the relationship between the students and the participants. Participants from both groups felt that there was lack of partnership between themselves and the students. They felt that the lack of partnership affected the efficacy of therapy because there was no continuity of therapy at home as the students did not provide home programmes for the children and parent education on the general day to day care of the children. Two categories formed this theme: parental involvement and feedback and carryover.

4.2.4.1 Parental involvement

Both groups of participants felt that they were not involved in their children's therapy and expressed that they would love to be involved. One of the participants did not know that her child was receiving occupational therapy, one did not know how the child was involved or referred to occupational therapy while some felt they did not know what exactly happens during therapy.

'I didn't know that he was receiving OT until you send me the um..the.. thing from you the letter…' The participant was referring to the letter that was requesting her participation in the study. A2

'How are these children chosen to attend OT? I mean what criteria do you guys use?' B3. This participant asked this question with feelings that had she been approached she would not have consented to therapy.

'The only time I talked to the therapist was in the beginning when she asked me to come for the interview, that's all. …. I would like to be involved in what they do with my child..' A5

4.2.4.2 Feedback and carry over

On the whole, participants expressed concern that there was lack of feedback and carry over/continuity of therapy at home for the children and this negatively affected the efficacy of therapy. They reported that the students did not provide feedback regarding their children's progress in therapy. Some felt that feedback was adequate in the past years as compared to now, as the students used to document in the children's communication books that the school uses to communicate with parents, something that they would like to see happening again. Only one participant was satisfied with the feedback she was getting from the student who was treating her child. However this participant was not satisfied with feedback from the previous years saying it was not adequate.

'..but the lack of feedback from the therapists has made it difficult for me to pin point exactly where OT has helped' B3

'I think the reporting part of it….one would like to see this is the progress, this is what he did today and these are the suggestions for home……..I would like to see that happen'. B2

Participants expressed concern about lack of carry over or continuity of therapy at home as the students did not provide home programmes for the children nor

do they provide parental education to assist parents in day-to-day care of the children.

'.I.. um.. would like to learn how to deal with him from what I would have learnt from the therapists. Right now I don't know what they do with him and how I can continue at home' A2

4.2.5. THEME 5: INADEQUATE STRUCTURE OF THE PROGRAM

This theme describes participants' perceptions on the structure of the program. The structure determined how, when and the extent to which therapy was delivered to the children. Participants described the structure of the programme as inadequate for children with autistic spectrum disorders which led to inefficacy of therapy. Four categories made this theme: change of students, duration of therapy, structure of therapy sessions and the nature of the service.

4.2.5.1 Change of students

Participants who were familiar with how the programme operated felt that the change of students every year and during the year was not benefiting the children. They felt that the children needed to get used to a regular person whom they can build a relationship with. Once the relationship is formed the children would be in a better position to work and cooperate with that person during therapy.

'My biggest concern is the frequent change of students, these kids take time to get used to one person but just before they do, a new student comes in. They are bound to be confused. So they spend time in OT getting used to new faces and they have no time for therapy'. B3

'My son is not good with strangers, it takes him time to get used to people' B2

'I don't know …. they change the students for them… but this year was worse' A3

4.2.5.2 Duration of therapy

Both groups of participants felt that the period of time that the children were receiving therapy was inadequate to effect change on the children. They felt that therapy once a week for 45 minutes was not enough and as a result was not effective.

'Ya I mean he attends OT but for how long, once a week for 30 minutes or so'. B2

'I think if they see the kids maybe twice a week or something…' A3

4.2.5.3 The structure of the sessions

Participants who have watched the children in therapy described the structure of the session as not optimal for children with autistic spectrum disorders. Participants felt that having many students and children in one room was not therapeutic, especially when the children were not working together. They felt that the environment that the children were treated in was also facilitating the children's problematic behaviours.

'You have a room full of autistic kids running around, full of students. Autistic kids need quiet space'. B2

‘ I was simply… um horrified when I saw a room full of people each doing their own thing…if they were doing it together it would have been ok I guess’ B2

4.2.5.4 The nature of the service

Participants’ perceptions were that the nature of the service affected the outcome of therapy. They felt that the free nature of the service made it less effective.

‘Considering that it is a free service I guess maybe I’m expecting too much’ B2

They also felt that the purpose of the programme (student training) meant that the best interest was on the students and not the children per se.

‘I think the whole thing is for the students to learn about autism’

‘Sometimes the students wake the children from sleep to attend OT which is not good. Even when the child is in a bad mood they still have to go to OT’ A3

4.2.6 THEME 6: DESPERATE NEED OF HELP

Despite what participants perceived as an inefficient service, they continued with therapy citing different reasons which the researcher felt that it indicated a desperate need for help. A category of hope and the need to cooperate made this theme.

4.2.6.1 Hope and the need to co-operate

Participants from Group A continued with therapy mainly because they did not want to be viewed as uncooperative with the students' learning programme. Some felt that withdrawing the children from therapy might disadvantage them in the future. Participants also kept going with therapy because they were hopeful that maybe in the future the situation will change and the children will get an improved service.

> '*You see, I'm not sure, if I pull him out he will be disadvantaged if say they get qualified OTs. They might say I refused therapy before…'* A3

> *'I don't know, sometimes I feel like they should just leave him alone but I can't because they will say I'm not cooperative'* A1

> *'You see these students are not the same, like I said last year the therapist who was treating him was good, she taught him how to wash his face, how to put on a T-shirt. May be next year he will get a good one hopefully.'* A3

Group B participants on the other hand felt that since therapy was free they will continue with it because taking the children to other schools would be very expensive. Beside, the children were making progress from the school.

> *'Considering that the school is cheaper I guess we just be hopeful that one day they will provide qualified staff like in other autism schools'* B2

4.3 SECTION C

This section reports on the children's progress in therapy. This information was gathered from the children's files kept by the students. The information was used for triangulation purposes.

In general the students' aims of therapy were to:

- Improve concentration and attention skills
- Build concepts (colour, shapes, body)
- Improve bilateral integration
- Improve dissociation of body parts
- Improve gross skills
- Improve fine motor skills
- Play skills

The frames of references used by students were mainly the developmental and behavioural frames of reference.

Information gathered indicated that children were improving although improvements were not that significant. Improvement was noted in the following areas:

- Concepts (colour, shapes, body)
- Interaction with the therapist
- Gross motor skills
- Fine motor skills

4.4 Summary

The findings indicate that participants with low educational level and of low socio-economic class have little or no understanding of occupational therapy and the

services provided by occupational therapists as compared to those with tertiary education and constituents of the working class.

The findings also indicate that participants perceive the student based occupational therapy service with their children with ASD as ineffective. They did not attribute the improvements they observed in the children to occupational therapy but to the school. They also felt that the service was stressful for them, the children and the students. Several factors influenced this perception:

1. Students working as therapists: Participants felt that students lacked the theoretical knowledge of ASD and hence they found it difficult to handle and manage the children.
2. Lack of partnership: participants reported that there were not involved in their children's therapy. They also felt that the students did not provide parental education, home programmes and feedback on the children's progress.
3. Inadequate structure of the programme: participants felt that the change of students, duration of therapy and the structure of therapy sessions were inadequate for children with ASD. They also felt that the service benefits the students more than it does the children.

On the contrary, information from the students' files indicates that the children were improving. Areas of improvement were noted in gross and fine motor skills, concentration, interaction with the therapist and in building of concepts.

Despite what participants perceived as an inefficient service, they continued using the service with the hope that it will improve in future as well as indicating the need to cooperate with the students' programme while some felt that since the service is free they have nothing to loose as the children were improving from the school's intervention.

CHAPTER 5
DISCUSSION

This chapter discusses the implications of the findings under the themes identified in chapter 4 as well as indicate their inter-relationship. The findings are also discussed in relation to the existing literature. Limitations of the study are also presented.

The aim of this study was to establish parent/caregivers perception of the value of the student based occupational therapy service offered to their children with ASD attending the CDC. The first objective of the study was to establish parents/caregivers understanding of occupational therapy. The study established that participants from group B, who had tertiary education and constituents of the working class had a better understanding of occupational therapy and the type of services occupational therapists offer as compared to participants from group A, who had level of primary education and constituted a lower socio-economic class.

This constituted one of the limitations of the study, as it would be difficult to get rich data if the participants do not know much about the topic that is being studied, thus occupational therapy.

Ten parents/caregivers of children with severe forms of ASD from the CDC and also receiving occupational therapy from the final year WITS occupational therapy students participated in this study. The limitation of this sample size can not be over-looked, it was too small to allow for generalization of the findings to other contexts. Thus the findings of this study represent the thoughts and opinions of the participants and not all the parents and caregivers of the children with ASD at the CDC. Data saturation, however, was achieved in this particular setting.

One common characteristic of all the participants, which was also a limitation of the study, was that they often expressed their inner most feelings once the interview was over and the dictaphone switched off. Therefore some of the information and other direct quotes were captured in the researcher's field notes. The researcher often felt that the participants did not trust the way the information was going to be used and were concerned about confidentiality when being recorded. This could have affected the richness of the data that was collected. There was no opportunity for second interviews where participants may have felt more comfortable and trusting, thus comments made which were not recorded were used from field notes as this added to the richness of data.

The second objective was to establish parents/care givers perception of the functional changes that they have observed in their children with ASD, which they attribute to the student based occupational therapy intervention received at CDC. The study adequately answered this objective. Participants did not observe any functional changes in their children that they could attribute to the student based occupational therapy intervention.

Participants felt that the primary issue was the **limitations of students as therapists.** They felt that in terms of knowledge and ability to handle and manage children with ASD, students were not competent enough. When this lack of competence is carried forward to the implementation of therapy where, the **structure of the program is inadequate** coupled with the **lack of partnership** with the parents/caregivers, the results are **inefficacy of the service.** However, because the participants are in **desperate need of help** for their children, they continue with therapy with the hope that the situation will change for the better in the future, fear of victimization and the need to cooperate with the students' programme. Refer to Figure 1 below for a diagrammatic presentation of the relationship between some of the themes that depict participants' perception of therapy.

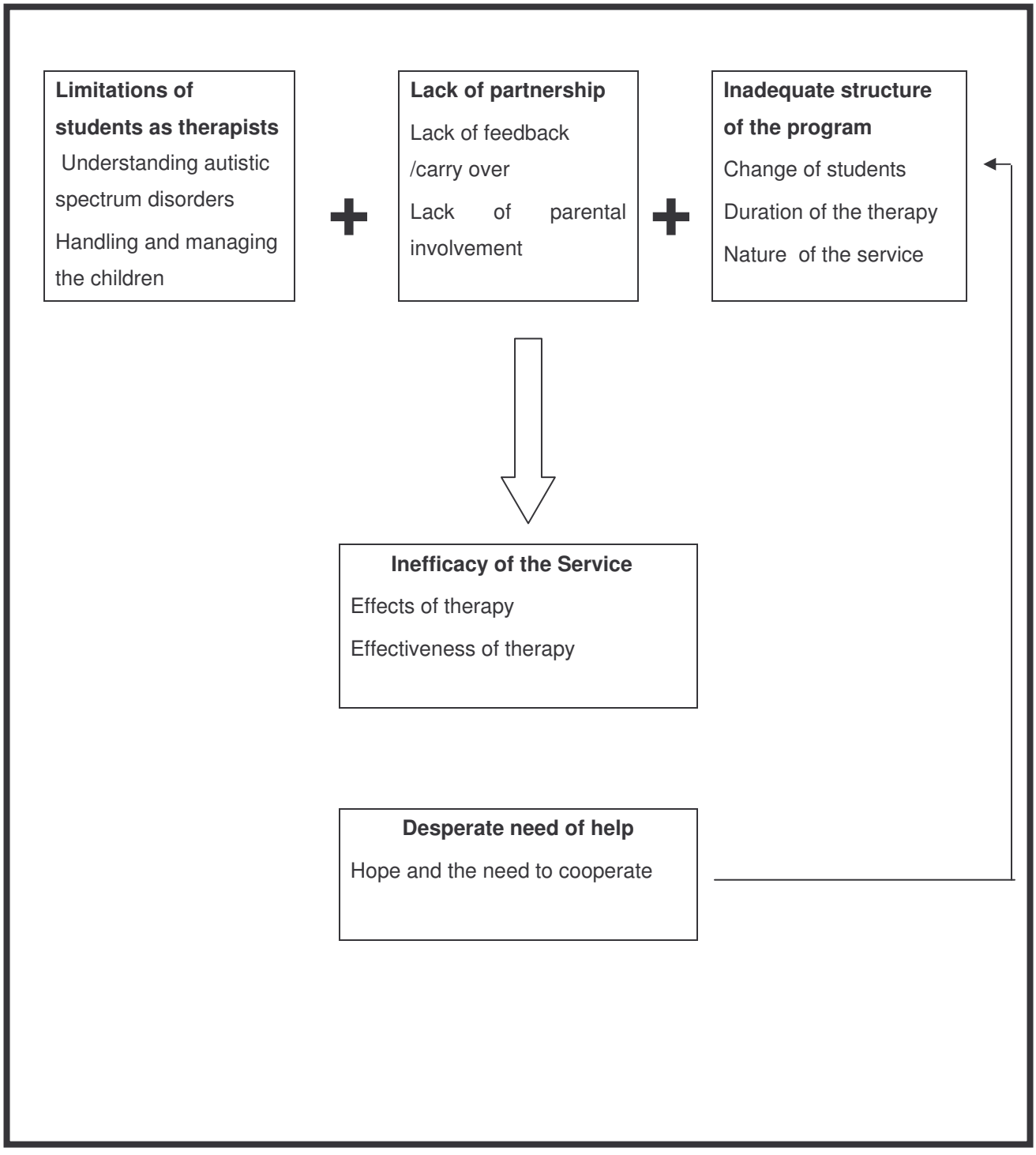

Figure 5.1: The relationship between the themes that depict the participants' perception of the service

5.1 Inefficacy of the service

The theme, Inefficacy of the service emerged as the end product of the participants' perception of the value of the Wits student based occupational therapy service offered to their children with ASD. Participants felt that the service was inefficient in treating their children. The use of traditional occupational therapy could have affected the efficacy of this service suggesting that traditional occupational therapy is ineffective in managing treating children with ASD. The literature shows that occupational therapists generally use specialised techniques of OT-SI when managing ASD (Case-Smith & Miller, 1999 and Watling *et al.,* 1999); OT-SI has effect on undesirable behaviour and engagement in activity (Linderman & Steward, 1999; Case-Smith & Bryan, 1999) and parents support the use of OT-SI in the management of their children with ASD (Cohn, 2001). The findings of this study also showed that participants whose children were also receiving OT-SI, felt that it was effective as compared to the student based service, further supporting the use OT-SI in the treatment of ASD.

However, the fact that this service is offered by students can not be overlooked. The students are still learning and their lack of experience in effectively treating or managing any condition is a factor that might have affected the efficacy of the service. Therefore, the results of this study can not conclusively discount the use of traditional occupation therapy in the treatment of ASD. This supports Dawson & Watling (2000) and Myers & Johnson (2007) opinion that, empirical studies regarding the efficacy of traditional OT with ASD is lacking and studies are required to support the use of this intervention.

The service was deemed inefficient as participants did not observe any functional changes in the children that they could attribute to the student based occupational therapy service. The observed changes which fall under the categories of behaviour, communication and participation in activities were

attributed exclusively to the school's intervention. On the contrary, the review of the children's occupational therapy files indicated that the children were improving. Areas of improvement were observed in the children's ability to identify basic concepts, improved concentration in activities, bilateral integration, gross and fine motor skills as well as interaction with their respective therapist. When considering the skills that the students feel the children improved on, it clearly indicates that the students were concentrating more on building foundation skills that support occupational performance. For example, improved concentration will enable a child engage in an activity for longer periods of time. A child with improved bilateral integration will be able to dress himself. It is therefore possible that because the skills addressed by students may not have been obvious to parents. These skills are addressed through participation in functional activities, e.g using scissors, buttoning their shirts ect.

Participants reported lack of communication between themselves and students and this could be a contributing factor in parents failing to attribute any improvements to the OT clinic. For example, in terms of improved concepts (colour, shapes, body parts) it is easy to attribute those to the school. Therefore it is important for students to communicate, educate and give feedback to parents about the service they offer the children in order for the parents to appreciate and recognize their efforts. In addition, those participants who have watched their children in therapy at one point reported that students found it difficult to control the children. It is, therefore, possible that they hold the perception that this happens all the time during therapy and hence there could be no improvement.

Participants also felt that therapy was not therapeutic as it was stressful for them, the children and even the students themselves. This indicates a major problem in the service as therapy is supposed to relieve stress not induce it. On the children's part, some participants felt that after therapy the children are fatigued and irritable which indicates that therapy was not fulfilling the goals of occupational therapy should achieve with children with ASD. These goals are to:

improve social skills, increase engagement in developmentally appropriate activities, improve fine and gross motor skills, improve organizational skills, as well as change distractive behaviours to developmentally appropriate behaviours (Myers & Johnson, 2007)

The stress on the participants is also quiet disturbing and is in contrary to the finding of Ruble & Gallagher (2004) who found that parents of children with ASD who where receiving occupational therapy reported less stress on the care giver, less overall family stress and less financial worry. Therapy cannot afford to induce stress especially to an already stressed person. Research indicates that parents of children with ASD experience considerable stress and emotional pain at the time of the diagnosis and throughout their lives unless they receive the support required to meet their needs (Chen *et al.,* 2000; Nuutila & Salantera, 2006). One of the primary goals of intervention is to alleviate family distress by minimizing the core features of ASD and associated deficits (Myers & Johnson, 2007). The results of the current study indicate that students are not achieving this in the current situation. This may be due to both poor communication with parents and their inexperience in dealing with family concerns and not just an individual patient in isolation from the family.

The stress on the students' part was another concern from the participants. They reported that the students get stressed when treating the children to a point where some of them succumb to tears. The students' reaction might actually be a 'cry for help', an indication that 'this is too much, I don't know what else to do here'. This is supported by the literature which indicates that postgraduate specialized techniques may be more effective with these children. The students are being expected to manage cases for which the do not have adequate skills. The stress endured by the students has a potential of inducing feelings of job dissatisfaction and may negatively affect their future decisions in working with children with severe ASD. However, the emotional reactions displayed by the students could be exacerbated by the fact that the students are being marked

during these times and the fear of making mistakes might be getting the better of them as the mark form part of their continual assessment towards their degree.

Despite the difficulties faced by the students, being watched by a parent in a state of total loss of control does not reflect professionalism and well on the students' part. Costa, Burkhardt & Royeen (2003) states that one of the goals of fieldwork practice is for students to practice and apply academic knowledge through supervised intervention and professional role modelling with clients, their families, significant others and other health professionals. For a parent whose hopes and dreams have been shattered by the child condition and who now hopes to resurrect those dreams through therapy, a therapist breaking down might be the last thing they want to see. A service is supposed to inspire confidence in the service users and not to leave the users feeling sorry for service provider. This clearly raises the question, are undergraduate students positioned to deal with ASD in this context. The supervision needed to achieve fieldwork goals is not available to result in a positive experience for the participants, the children and the students due to a high ratio of students to supervisors.

5.2 Limitations of students as therapists

One major reason that participants raised as contributing to the inefficiency of the service was due to limitations of students as therapists. Participants perceived students' as lacking the theoretical knowledge of autistic spectrum disorders and as a result they found it difficult to handle and manage the children especially when they displayed problematic behaviours such as running around. It seemed though that this perception was due to the participants' lack of understanding of the purpose of fieldwork placements as they implied that the students were learning about ASD for the first time by working with their children. Field work placements are used for the students to apply the theoretical knowledge through

supervised interventions (Royeen, 1996). Before field work practices, students are taught both the theoretical aspect of the conditions that they will encounter during their filed work practices as well as their management. It can be assumed, therefore, that the students have some theoretical knowledge of ASD and thus lack of theoretical knowledge might not be the reason they find it difficult to handle and manage the children. Fieldwork should allow the students to apply the theory under guidance, which participants did not experience.

Participants came across as simply not having faith in the students' abilities as therapists. This perception came out strongly from most of the participants and could have had a major contribution on how the participants viewed the service.

The lack of partnership between the students and the parents/caregivers could also have influence this perception. A study by Nuutila & Salantera (2006) showed that where there was lack of a permanent relationship with the health professionals, parents lacked confidence in the professionals' knowledge of the condition and the ability to care for their child.

On the issue of students being unable to handle and manage the children's problematic behaviours, the lack of knowledge on the students' part in using specialized techniques in treating sensory processing dysfunction (SPD) could be a major contributing factor. Because most children with ASD have SPD (Charman, 2008), which influence behaviour (Bundy *et al.*, 1999;), it therefore suffices that the problematic behaviours displayed by the children could be a result of SPD. It would therefore mean that before engaging the children in activities, their arousal levels should be brought to a calm-alert-state to enable them to maintain optimal levels of concentration and attention (Bundy *et at,* 1999). However, treatment of sensory processing dysfunctions is not taught at an under-graduation level, it is a post-graduation qualification. As a result, the students find themselves in a situation where they have to engage children in purposeful activities while their state of arousal does not allow. This, results in

students being unable to apply appropriate techniques required to handle and manage these problematic behaviours. These findings may then suggest that it is unrealistic to expect undergraduates to effectively manage children with ASD because of a lack of adequate theoretical knowledge at this stage on their training.

5.3 Lack of partnership

The lack of partnership between the participants and the students was also cited as affecting the efficacy of therapy. Participants indicated that the students did not provide feedback on the children's progress in therapy and there was no continuity of therapy at home as the students did not provide home programmes for the children. There was also lack of parental education on the general day-to-day care of the children as well as lack of parental involvement the therapy.

The lack of partnership indicates that the students were not using a family-centred approach. This is contrary to Myers & Johnson (2007); Law, (2006); Singer *et al.* (2001) who state that, effective *management* of ASD should include collaboration with families. However, students, unlike qualified staff may lack the resources to fulfil the demands of a family-centred approach. The first one is the resource of time, which according to Legare` *et al.* (2008) is one of the barriers to implementing shared decision making with patients. This was a result of the context in which the Wits OT clinic manages the treatment sessions. First of all, in addition to the fieldwork practice at the WITS OT clinic, students have to contend with other academic obligations such as attending classes, assignments, exams etc. Further, students work with the children within the stipulated times, between 2:00 pm and 2:45 pm once a week. Everything that the students do with the children has to be done within these times because this is the only time that supervision is available. Even if the students could afford extra time, they can not provide therapy without supervision.

The second is the resource of finances. A family-centred approach demands regular contact with the family, physically and sometimes telephonically, an exercise that can be very expensive for a student. Considering that one of the goals of occupational therapy with children with ASD is modification of the environment (home or school) in order to maximise occupational performance (Myers & Johnson, 2007), this would mean that students would have to carry out home visits. However this would not be feasible for supervisors and since students can only provide intervention under supervision, this exercise is not expected for students. These findings reiterate the opinion that in this context with limited staff, it is unrealistic to expect students to effectively manage children with ASD and provide a family based practice. Although the ratio of supervisor to students during fieldwork practices depends on the context (Aiken, Menaker &Barsky, 2001), in this case, the high ratio of supervisor to students may not be ideal considering the difficult clients that students are dealing with. This is despite the fact that supervisors have no other clinical duties to perform other than supervision.

The lack of partnership could also have influenced the participants' perception that therapy was not effective. A study by Nuutila & Salantera (2006) found that decreased perceptions of family-centredness in service delivery and difficulties in forming collaborations with professionals decreased parents' satisfaction with the service.

The other issue of concern was that of lack of participants' involvement in their children's therapy, as one participant expressed that she did not know how the child was referred to occupational therapy while one did not know that their child was receiving occupational therapy. Interestingly, before the children are enrolled in the students' programme, there is collaboration between the students, their lecturer and the teachers at the CDC school to identify the children who will benefit from therapy. After the children are identified, information forms are then sent home, by putting the forms in the children's school bags, requiring

parents/caregivers to fill in and sign because the information forms part of the comprehensive assessment of the child. When more information is required parents are called in for further interviews.

It therefore suffices to suggest that the referral procedures to the WITS OT clinic are not clear to the parents. This is seemingly a problem which could be a result of lack of understanding of the purpose and importance of these forms resulting in the forms not being completed as a result of the level of literacy. Whatever, the reason, the findings suggest that communication is inadequate and a system need to be put in place to address this problem.

By extension, the clinic needs to consider ethical implications of treating minors without the consent of the parent/caregiver. Ethically, the right to consent to treatment usually rests with the parent and the legal guardian (Richards & Rathbun, 1996). Diaz, Neal, Nucci, Ludmer, Bitterman, & Edwards (2004) recommend that in treating children people should always investigate into the feasibility of involving parents and caregivers, so that they might be involved in the care. In addition Royeen, (1996) states that during fieldwork practices students are expected to uphold the values and beliefs of the profession that guide ethical practice.

Poor communication was further seen in the lack of feedback. Participants expressed that there was lack of feedback on the children's progress in therapy. Feedback is important as one participant has clearly pointed out that without it, it is difficult to pinpoint exactly where OT has helped her child. However, beside the annual progress report that is sent to parents, there is a system in place (the school's communication book) that the students are free to use to communicate feedback to the parents. It seems, however, that the students do not adequately utilize it which indicates some limitations. This, therefore, suggests that other means of giving parents feedback should be put in place.

The lack of carry over/continuity of therapy at home was also seen to be affecting the efficacy of therapy as the students did not provide home programs for the children. Home programmes are an integral part of occupational therapy with children with ASD (Bundy *et al.*, 1999). Home programmes may include activities that parents can do with the children at home or modification of the environment to accommodate the needs of the child. As indicated earlier, the students are not in a position to carry out home visits.

There was also the issue of lack of parental education on the day-to-day handling of the children which would definitely affect the implementation of home programs if they were provided. This is contrary to findings Becker-Cottrill *et al.* (2003) who found that in the management of ASD, parents are increasingly being taught how to implement treatment programmes through modelling and rehearsal and by practicing the programme with the feedback from the experts.

The lack of parental education and continuity of therapy relates to the context of this study which discourages a family-centred approach indicated in the management of ASD. It appears to be as a direct consequence of the manner through which the service is provided. The service runs during school hours and parents pick their children after school when the students are finished. In addition, most of the children are not picked by their parents but by arranged transportation. This leaves little or no time for students to make educational contact with parents.

5.4 Inadequate structure of the programme

The other major reason that the participants indicated as affecting the efficacy of therapy was the structure of the program which they felt was inadequate. Participants felt that the change of students every year and during the year was not ideal for the children. Due to other fieldwork commitments and some training

blocks having to be run outside of Johannesburg, there is often a change in the student treating the children throughout the year. The change of students is not so frequent as in the whole year, a child is treated by at most four different students. By extension, the children need to learn to transfer learned skills to other contexts (Myers & Johnson, 2007). For example, if the children have learnt to interact with one student, they need to transfer the skill to other people. The challenge in this case would be for the students to assist the children to gradually get to know the other student before they leave.

Considering that the children in this study have severe forms of ASD, change of students appear to be disorganizing to the children, totally agreeing with the literature that children with ASD prefer to follow a certain routine. Myers & Johnson (2007) state that for effective management of ASD treatment should incorporate a high degree of structure through elements such as predictable routine, visual activity schedules, and clear physical boundaries to minimize distractions Therefore, the change of students disrupts the children's routine. Although the students write handover reports for the next student, detailing what the child likes and how the child should be handled, this appear not be adequate. The new student might not necessarily follow the same routine to the letter and a new face might just be enough to disorganize the child.

Participants also felt that the duration of therapy was inadequate to effect change on the children. The WITS OT clinic provides therapy to each child once a week in a 45 minutes session. This practice is in accordance with the general practice of occupational therapists, who provide therapy to clients within a period of one hour once a week. The results indicate that this practice might be ineffective especially with children with severe chronic conditions like ASD and this therefore might need to be revised accordingly especially in view of the lack of home programmes normally provided to reinforce therapy.

The structure of the sessions was also viewed negatively by participants. During fine motor activities the students make use of secluded areas that affords a one-to-one intervention. This part of intervention is in accordance with findings by Watling *et al.* (1999) that occupational therapist generally use a one-to-one approach with children with ASD. However, during gross motor skills the students make use of one room and corridors to provide treatment. Although each student has one client, at most two, there is a lot of activity going on that is enough to disorganize a child especially if the child has sensory modulation dysfunction (SMD) which contrast the recommendations that effective management of children with ASD. Treatment should incorporate clear physical boundaries to minimize distractions (Myers & Johnson, 2007). The use of one room and corridors is necessitated by space constraints and the need to accommodate 20 to 25 students at the same time. The structure of the sessions is reliant on the facilities available to the Wits OT Dept and CDC**.**

The nature of the programme run at WITS OT clinic also came under scrutiny. The fact that the participants are not charged for the student service meant they may hold a common belief that what is free can not be good. There was also a belief that the programme benefits the students more than it does the children. This also reflects the lack of family based programme and goal setting with participants so they can identify concerns for the students to address which will be seen as beneficial to the children.

Despite what the participants perceive as an inefficient service, they continued with therapy. Group A participants continued with therapy because they did want to be viewed as uncooperative with the students learning programme. These findings add another dimension to the reasons that parents continue with therapies in addition to those established by Green (2007): perceived effectiveness, time commitment and ease of implementation.

Participants also felt that withdrawing their children from therapy will disadvantage them in the future should the situation change for the better. Participants maybe continuing with therapy due to lack of confidence to initiate the termination of the service. Thus, it calls for health care workers to educate service users on the options that are available for them which include, termination of a service if they feel it is not helpful to them.

Participants also felt that they continued with therapy because they hoped that the situation will change in the future. These findings support Ruble & Gallagher (2004) who found that parents access many different therapies at one point in time. In this case parents lack the financial resources to access different therapies and instead of them moving from one therapy to the other, they stick to the one that they perceive as inefficient in the hope that it will improve.

5.5 Understanding of Occupational Therapy

While some participants were aware that their children were receiving occupational therapy intervention, it was interesting to realise that participants with low educational background did not know what OT was and the type of services it occupational therapists offered their children. Occupational therapists can not afford in this era to have their profession misunderstood, especially by people whom they offer services to. Occupational therapists and OT students have a duty to educate the service users and the public at large about the services they offer.

The lack of understanding of occupational therapy by service users has negative implications on the profession. It limits the growth of the profession. A study by Green (2007) showed that one way in which parents get information about available treatments for their children was through recommendation from other

parents. Thus, if the service users do not have an understanding of occupational therapy there will be in no position to pass information to other people.

The results also indicate that information about OT does not reach the lower socio economic class as only participants in Group A were the ones without knowledge of what occupational therapy was. Therefore there is need for occupational therapists to intensity education to those who do not have the background and the ability to find information about services offered to children with ASD.

However, for the students to educate parents, parents need to be available for the education. As discussed earlier, the children are at school all day and some parents do not bring and fetch them which limits educational contact with the students. Even when they fetch the children this is not with in the students therapy time suggesting that there is need to improve communication with parents either through the teachers as they have regular contact with some parents or the clinic should put a system in place to make this possible.

The following were the strengths of the study:

- Participants in this study were aged between 25 and 55 years. This age group is considered mature enough to give relevant and reliable information. Participants also raised the children from a tender age and were staying with them at home during the time of study which put them in a better position to notice any changes in the children.
- The use of a randomized sample minimized chances of bias

Most of the limitations of this study were integrated in the throughout the study. Some which the researcher acknowledges as they have impacted of the findings are:

- The sample represented mostly of one race, nine out of ten participants were black while one was Indian.
- Depth of information may have been affected by participants' lack of knowledge about aspects being started.
- The use of one interview meant that development of trust and willingness to speak especially when being recorded may have affected the depth of the data collected.

5.6 Summary

All the themes indicate limitations in the service offered by the Wits OT students in the treatment of children with ASD at CDC. This is due to the structure of the clinic, referral procedure and inadequate supervision at the clinic. The students lack the experience with children with ASD and their inability to provide therapy based on specialized techniques used with ASD also impacts on the participants' perception of the efficacy of the therapy their children receive.

Lack of communication resulting from lack of partnership with parents and inadequate guidelines and policies on giving parents feedback appears to be one of the greatest factors impacting on participants' perceptions.

Participants appear to continue with therapy even though they feel it is not effective in a hope that it may improve.

CHAPTER 6
CONCLUSIONS

6.1 Final conclusions

This study aimed to establish parent/caregiver's perception of the value of the student based occupational therapy service offered to their children with ASD by establishing parents/caregivers understanding of occupational therapy and functional changes that they have observed from their children which they attribute to occupational therapy intervention.

The educational level of participants influenced their understanding of what OT is. Participants with low educational background had little or no understanding occupational therapy and the services occupational therapists offered their children while those with tertiary education had a better understanding of occupational therapy.

Results indicate that participants did not believe the student based occupational therapy service was effective in treating their children with ASD. They did not observe any changes on the children that they could attribute to occupational therapy. Where improvement was observed, participants attributed it directly to the school's intervention as well as to the occupational therapist offering sensory integration.

This appears to be due to the negative perception of the student service. Limitations of students as therapists were cited by participants as some of the reasons the service was not effective. Students were described as lacking theoretical knowledge of ASD which made it difficult for them to effectively handle and manage the children. In the contrary the students do have the theoretical knowledge of ASD but lack the skills to manage SMD. Most children with ASD have SMD (Charman, 2008) which affect behaviour and all aspect of daily life

(Bundy *et al.,* 1999; Pfeiffer *et al.,* 2005). However, treatment of SPD is not taught at undergraduate level, it is a post graduate qualification.

Lack of partnership with the students was another reason cited as affecting the efficacy of therapy. Participants felt that they were not involved in their children's therapy; the students did not provide parental education, home programmes for continuity of therapy nor feedback on the children's progress. Lack of partnership with the students indicated that the students did not adopt a family-centred approach which is indicated in the treatment of the children with ASD (Myers & Johnson, 2007). However students do not have the resources (time and finances) to adopt a family-centred approach. In addition, their intervention time is limited to times that supervision is available, an exercise that is not feasible for home visits.

The perception that the service was inefficient was explained in part by the structure of the programme. Participants felt that the change of students in the middle and at the end of the year was disruptive as the children are unable to form permanent relationships with therapists. However, this is unavoidable as during the year, students have other fieldwork commitments and other training blocks are run outside Johannesburg. The structure of the sessions was thought to be distractive to the children as some students share one room and at times make use of corridors to treat the children. This is in contrast with some principles of managing ASD as stated by Myers & Johnson (2007) that there should be a high degree of structure with minimal distractions when managing children with ASD. However, the arrangement is due to limited space at the clinic. Supervision in terms of monitoring the students is also marked by the staff/student ratio.

The duration of the treatment sessions and the structure of therapy was also thought to be inadequate as children were seen once a week in a 45 minutes session. Participants also felt that the service was benefiting the students more

that it did the children and that because the service was provided free of charge, it could not offer the best of service.

However despite the ineffectiveness of the service, participants continued using it because they were desperate for help, they hoped that the situation will change for the better in the future. They also felt the need to cooperate with the students' programme but most importantly they felt that their children will be disadvantaged in the future should the situation improve. For some, the free nature of the service contributed to them not withdrawing the children from therapy.

Considering the fact that management of ASD need specialized care in structured environments with the use of family-centred approach (Myers & Johnson, 2007), it is convincing that indeed the student based occupational therapy service is not effective in treating children with ASD. Because most children with ASD have sensory processing difficulties (Charman, 2008), the lack of students' knowledge in managing these difficulties, further suggest the same.

This study, therefore, concludes that the student based occupational therapy service is inefficient in treating children with ASD because the students are not in a position to deliver a comprehensive treatment programme for the children.

6.2 RECOMMENDATIONS

The following recommendations were informed by the results of the study.

- The study has established, from the participants' perspective, that Wits student based occupational therapy service is ineffective in treating their children with ASD. Children with severe forms of ASD should be managed by qualified staff. Because of evidence that most children with ASD have sensory processing dysfunction, the therapist should be qualified to offer OT-SI. Perhaps children with severe ASD are not suitable patients for the clinic, and a consideration should be given into referring them to other facilities.

- Occupational therapy students need clinical exposure to every condition that they will encounter in the work place after completion of their studies, including ASD. Since delivering a family-centred approach is not feasible for the students, during fieldwork placements, they should be placed in areas where there are full time qualified occupational therapists to assist and supervise them in learning to handle this condition.

- Due to space constraints at the clinic, students should be divided in small groups of ten. This will reduce the amount of activity going on around the children.

- Before students leave for other fieldwork placements, the student who will take over the treatment of the child should be identified in advance so that the two can work together in a group to allow for smooth transition of the child to the other student. The programme should be re-structured so that the students do not leave Johannesburg during the attachment at the

clinic, the change over should be mid year so that there is only one change during the year.

- A system should be put in place at the clinic for students to provide parents/caregivers with feedback on their children's progress.

- The referral system to the OT clinic should be made clear to the parents

- Children with severe ASD are perhaps not suitable patients for the clinic.

Implications for further research

- The study established from the participants perspective that the students experience stress when managing children with ASD. There is need, therefore, for a follow up study to explore the students' experiences on the treatment of ASD at the WITS OT clinic.

- There is need to explore experiences of entry level occupational therapists in the treatment of children with ASD. It is important for occupational therapy as a profession to look at this problem as the incidence of ASD is on the increase and services being offered by occupational therapists trained in OT-SI is predominantly in the private sector and expensive.

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APPENDICES

Appendix A

ETHICAL CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Bale

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M080541**
PROJECT	Parent/Care Giver perspective on the efficacy of occupational therapy with autistic spectrum disorder
INVESTIGATORS	Ms R Bale
DEPARTMENT	Occupational Therapy
DATE CONSIDERED	08.05.30
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 08.06.11 **CHAIRPERSON** .....

(Professor P E Cleaton Jone

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Ms D Franzsen

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B
LETTER FROM THE COORDINATOR OF THE WITS OT CLINIC

Occupational Therapy

School of Therapeutic Sciences • Faculty of Health Sciences • 7 York Road, Parktown 2192, South Africa
Tel: +27 11 717-3701 • Fax: +27 11 717-3709 • E-mail: denise.franzsen@wits.ac.za

25 April 2008

Dear Mrs Rebecca Bale

RE: Request for participation in research

The supervisors of the University of the Witwatersrand, Perception Clinic, at The Memorial Institute for Child Health and Development have considered your request to conduct research at the facility. We hereby give consent to distribute your information sheet and consent forms to the parents of children attending our clinic, and are willing to provide you with space to conduct interviews on those parents who consent to participation in your study.

We wish you luck in your research.

Regards

Paula Barnard-Ashton
Co-ordinator of Perception Clinic
Paediatric Occupational Therapy Lecturer

Appendix C

INFORMATION SHEET

Dear parent/care giver

I am Rebecca Bale, an occupational therapist completing my masters degree in the Department of Occupational therapy at the University of the Witwatersrand. One of the requirements for completion of the course is to carry out a research relevant to the area of study. My interest is to find out how parents and caregivers view the occupational therapy service rendered to their children who are diagnosed with ASD or autism. I would be grateful if you could consider participating in this study.

Please note that participation in the study is completely voluntary and that you can withdraw at anytime once the study has commenced. If you don't wish to participate or wish to withdraw from the study after commencement please note that this will not in anyway be detrimental to you and your child in terms of the occupational therapy intervention that you are receiving.

Confidentiality will be maintained at all times as no names will be used. Names will be coded and the identity of participants will only be known to the researcher and will not be mentioned anywhere in the study.

Participation will involve sitting in a 30-45 minutes interview regarding occupational therapy intervention that your child has received. Please note that I will like to record the interviews for easy reference as I continue with the study and your permission to do so is hereby sort.

The results of the study will be made available to you on request.

If you need more information please do not hesitate to contact me at 0730939874.

Appendix D

CONSENT FORM

I have read and understood the information provided in the information sheet and I agree to take part in the study

Name…….

Signature…….

Date…….

……

Appendix E

CONSENT TO RECORD THE INTERVIEW

I have read and understood the information regarding the recording of the interview and I agree that the interview can be recorded. I understand that all tapes will be stored in a locked cupboard by the researcher and will not be accessible to any other persons.

Name…….....

Signature……

Date…….

Appendix F

Biographical questionnaire

If you consent to taking part in the study, please complete this section and return with the consent forms. Note that the child's identity will remain confidential and will not be mentioned in the study.

1. Code ……
2. Age: ……
3. Diagnosis: ……
4. Has your child received OT before coming to CDC? Yes …../ No…..
5. If yes for how long …….
6. When did your child start therapy at CDC…….
7. What other therapies is your child receiving?
    - Speech therapy Yes…../ No……
    - Physiotherapy Yes…../ No……
    - Remedial Yes…../ No……
    - Other (please specify) ……..

Appendix F2

Semi-structured interview questions

Introductions of self and purpose. A bit of conversation to break the ice.
'Thank you for agreeing to take part in the study. Without taking anymore of your time let us start.

9. Describe to me your understanding of occupational therapy?
   Prompts – What do you think occupational therapy can do for your child?

10. How would you describe your child in terms of his/her functional abilities and behaviour.
    Prompts: What is it that he/she is able to do for himself/herself and what is it that he/she is not able to do.
    What behaviour does he/she have that worries you?

11. Has there been any change in his/her behaviour or functional abilities in the past year? If there has been a change, describe for me the change and what you think has lead to the change?
11. Describe to me what you think occupational therapy has done for your family and your child?
12.
    Prompts: Are there any changes in his/her behaviour
    Can he/she do more for him/herself?
    Have any of the behaviours that worry you improved?

13. If yes, describe for me those changes that you have noticed and what you think has contributed to the changes?
    If no – Why do you think he/she is not getting better?

14. Describe the challenges that you and the family are faced with due to the child having difficulties?

Prompt : Are there any difficulties you find in managing him/her?
How does he/she affect your family life?

15. Did his/her improvement have any effect on those challenges and in what way?
    Prompts Are there any changes that you have noticed since starting OT,
    Did OT help you achieve anything?
    What effect has OT had on you and your family.
    Would you recommend it to anybody in a similar situation?

16. Is there anything else you would like to add about the OT service that your child is receiving?

'Thank you very much for your time. If you have any additional comments or questions please feel free to ask. And remember a copy of this study will be made available to you on your request. Thank you again, have a nice day'.

Appendix G

AUDIT TRIAL

The following provide the steps which the researcher undertook during data analysis.

1. The researcher transcribed all the tapes.
2. The researcher listened to the tapes again to ensure accuracy of the transcription.
3. The researcher read each transcript and the field notes to identify the items that were relevant to the research questions. The items were highlighted in the script using one colour.
4. The transcripts and the field notes were re-read to ensure that all the items were identified.
5. The identified items of each script and field notes were compiled
6. Five randomly selected participants were given copies of the compiled items from their scripts to check if the researcher captured their views accurately. All the five participants agreed that their views were correctly captured.
7. From each compiled transcript, similar and or related items were identified by highlighting them with the same colour. All items highlighted with the same colour were recorded in a different card and each card represented a code or taxonomy. The cards were colour coded the same as the highlighted items.
8. Eighteen code/taxonomies were identified
9. From each card, the codes which were related were identified by highlighting them with same colours.
10. All codes/taxonomies highlighted with same colours were transferred to another card and these formed categories. The cards were colour coded the same as the taxonomies.

11. Eleven categories were identified
12. All categories that went together were highlighted with the same colour and were transferred to another card that was coded the same and these formed the themes.
13. Six themes were identified.
14. The children's records were reviewed looking at the assessment and the annual reports. These were compared to the participants' views of the children's progress.
15. An individual who was new to the research and knowledgeable in qualitative research reviewed the study after it was completed