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Exploring the sensory compatibility of ten children with autism and their mothers

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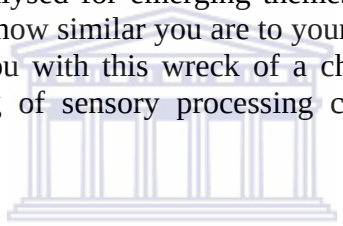
Abstract

Children with autism typically present with sensory processing difficulties that affect their ability to relate to people. This qualitative study focused on exploring the sensory processing of children with autism and their mothers, using a frame of reference of sensory integration theory. The purpose of the study was to help mothers gain knowledge and understanding into their own sensory processing so that they could develop a better understanding of their child's sensory processing in order to facilitate better mother-child relationships. An evaluation tool, the Sensory Profiles by Dunn (1999) and the Adolescent/Adult Sensory Profile by Brown & Dunn (2002) was used as the instrument for gathering information on sensory processing. The population consisted of ten sets of mothers and their children with autism who attend Vera School for Learners with Autism. The Sensory Profiles was completed to investigate the phenomenological issues regarding the sensory modulation aspects of the parent-child relationship. Each mother received individual feedback on their own and their child's sensory processing. Two focus groups were then conducted with the mothers to determine the value of the information gained from the profiles. Data consisted of two audio taped feedback from the focus group. Data was analysed for emerging themes. The three major themes that emerged were, (a) You realize how similar you are to your child, (b) I also have needs (c) They walk away and leave you with this wreck of a child. The findings of the study suggest that an understanding of sensory processing can influence the mother-child relationship positively.



Declaration:

I declare that *Exploring the sensory compatibility of ten children with autism and their mothers*, is my own work, that it has not been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Full name……Date……..

Signed……

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Exploring the sensory compatibility of ten children with autism and their mothers

CHAPTER 1

1.1. Introduction

Children with autism experience sensory processing difficulties that affect their ability to relate to people (American Psychiatric Association, 1994) and consequently leads to difficulties in the parent-child relationship (Mailloux, 2001). Reflection on one's own sensory processing could result in a deeper understanding of sensory processing aspects of behaviour that influence relationships. In this study, I explored whether mothers of children with autism could benefit by developing deeper understanding of their own and their child's sensory processing traits and that the deeper understanding would improve the mother-child relationship. A sensory processing evaluation tool for children, the Sensory Profile (Dunn, 1999), was used by mothers of the children with autism to evaluate and understand the sensory processing traits of their children. A similar evaluation tool for adults, the Adolescent/Adult Sensory Profile (Brown & Dunn, 2002), was used by the mothers to understand their own sensory processing with the aim of alleviating the challenges posed by potentially conflicting sensory processing difficulties in their own and their child's behaviour.

1.2. Background

The National Institute of Child Health and Human Development (2004) describe autism as a complex, biological disorder of development. It is a life-long condition that impacts on mainly three areas of development; social interaction, communication and behaviour.

Kane (2003) reports on epidemiological data that suggest a significant increase in the incidence of autism. According to Kane previous studies indicated that autism was reported in 4-5 per 10, 000 children, however more current studies shows that the incidence has increased to 1 per 500 children in the United States of America. Information on the incidence of autism in South Africa is not readily available.

Vera School for Learners with Autism is one of six schools for children with autism in South Africa and is situated in Cape Town. Parent participation and collaboration in the management of their children with autism is encouraged at Vera School for Learners with Autism. As the occupational therapist at Vera School, I have become aware of the extent to which sensory processing difficulties affect children with autism. Parents of children with autism often express the need to understand their children better and to improve their relationship with their child. The broad focus of this study is to contribute to the alleviation of the challenges posed by the sensory processing difficulties experienced by children with autism and the influence thereof on family relationships.

Mailloux (2001) states that children on the autistic spectrum characteristically present with sensory processing difficulties. Evidence from clinical studies (O'Neil & Jones, 1997) suggests that the most children with autism display unusual responses to sensory information and that these unusual responses manifest early in the child's development. There has been a recent increase worldwide in the use of a sensory integration approach in the treatment of children with autism (Murry-Slutsky & Paris, 2000). Cohen, Miller & Tickle-Degnen (2000:36) report on parent testimonials that occupational therapy with a

sensory integration approach has positive consequences for the quality of their family lives.

1.3. Rationale and significance

Sensory integration theory (Ayres, 1980; Fisher, Murray & Bundy 1991:4) is a neurobehavioral approach that attempts to theorize the relationship between neural functioning and behaviour. The use of a sensory integrative approach in the treatment of children with autism offers the opportunity to parents to understand the neurological basis of behaviour of their child (Anderson, 1998). In keeping with the international shift in health care towards a client-centered approach and in the case of children towards a family-centered approach, a sensory integration approach can involve parents more in decision making, in the therapeutic process and in assuming a greater role in their child's management. Anderson (1998:viii) suggests that parents can play a big role in the sensory intervention programme for their child with autism. She states that "*caregivers who investigate negative behaviours as a clue to what the sensory need is can avoid power struggles and pursue solutions*".

Cohen, Miller & Tickle-Degnen (2000) in reporting a study that investigated parent's hopes for occupational therapy outcomes, found that the use of a sensory integrative approach helped parents in understanding their children's behaviour. Mailloux (2001) states that methods of evaluation such as the Sensory Profile is useful in enlightening parents about the underlying reasons for many of the behaviours that they observe in their children.

According to Dunn (1999:3) one of the benefits of the Sensory Profile is the therapeutic benefits it has for the caregiver. Items on the profile are familiar and descriptive of the "*idiosyncratic*" behaviours displayed by the child with autism. According to Dunn the Sensory Profile "*provides validation that there is something real about their family's struggle and suggests that there may be some ways to deal with it*".

From the above, the focus of my study was therefore informed by sensory integration theory to explain the sensory processing difficulties experienced by children with autism and the impact there-of on the mother-child relationship. The study focused on exploring the sensory processing characteristics of children with autism as well as those of their mothers, to facilitate the mothers' understanding of underlying sensory processes that influence both her and her child's behaviour and in turn, foster a better mother-child relationship.

1.4. Aim and Objectives

The aim of the study was to explore the nature of sensory processing in children with autism and the nature of sensory processing of their mothers. The purpose was to help mothers gain knowledge and understanding into their own sensory processing traits so that they can, on reflection, develop a better understanding of their child's sensory processing traits in order to facilitate better mother-child relationships.

The objectives were:

- To evaluate sensory processing of ten sets of mothers and their autistic children by completing ten Sensory Profile questionnaires for children and ten Adolescent/Adult Sensory Profile questionnaires for the mothers.
- To analyse the sensory profiles and provide feedback to the mothers of the analyzed results.
- To facilitate the development of knowledge and understanding in the mothers through discussion and education, by explaining the sensory processing of their children and themselves and how it impacts on their relationship.
- To evaluate the impact of the newly acquired information by means of focus groups with the mothers, to determine to what extent the information that they received from the sensory profiles informed their understanding of their own and their children's sensory processing and if it had an impact on the mother-child relationship.

1.5. Research Question

Could mothers' knowledge of their own sensory processing traits and the sensory processing traits of their child with autism contribute to better understanding of their own and their child's behaviour, and in turn positively influence the mother-child relationship?

1.6. Definition of key terms

1. Sensory integration theory: is a theory developed by Dr. A. Jean Ayers to explain the relationship between neural functioning and behaviour. The theory aims to explain the relationship between *"(a) deficits in interpreting sensory information from the body and the environment, and (b) deficits in academic or neuromotor "learning"* in some children who appeared clumsy or were thought to have learning difficulties (Fisher, Murray and Bundy, 1991:4).

2. Sensory integration dysfunction: occurs when an individual has deficits in the processing and integrating of sensory input that result in deficits in planning and producing behaviour which interfere with conceptual and motor learning (Fisher, Murray and Bundy, 1991).

3. Sensory modulation: is the nervous system's ability to "*regulate, organize and prioritize incoming sensory information*" while simultaneously inhibiting or suppressing irrelevant information thus enabling the individual to focus on the necessary information (Murray-Slutsky and Paris, 2000:108).

4. Sensory Profile: is a "*judgment-based caregiver questionnaire*" that provides a standard method of measurement of the sensory processing abilities of children. Professionals can use the profile to characterize children's behaviours and performance in relation to sensory processing (Dunn, 1999:1).

5. Adolescent/Adult Sensory Profile: is designed to self evaluate behavioural responses to everyday sensory experiences in a self-report questionnaire (Brown and Dunn, 2002:1).

6. Neurological threshold: is the amount of stimuli required for a neuron or neuron system to respond. Thresholds at one end of the continuum are very high therefore it would take a lot of stimuli to meet the threshold and to fire the neuron. On the other end of the continuum thresholds are very low and it would take very little stimuli to meet the threshold and fire the neurons (Dunn, 1999).

7. Low Registration: behaviour consistent with low registration corresponds with a "*high neurological threshold and a tendency to act in accordance with the threshold*". It is hypothesized that inadequate neural activation in individuals with low registration results in the individual's subsequent inability to support sustained performance and therefore may miss important cues in the context (Dunn, 1999:33).

8. Sensation Seeking: sensation seeking behaviour represents a "*high neurological thresholds with a tendency to act to counteract these thresholds*". It is hypothesized that sensation seekers have inadequate neural activation, and are therefore instinctively create opportunities to increase input to meet their high threshold (Dunn, 1999:36).

9. Sensory Sensitive: sensory sensitivity is represented by "*low neurological thresholds and a tendency to act in accordance with those thresholds*". It is hypothesized that overreactive neural systems in individuals with sensory sensitivities is responsible for making the individual aware of every stimulus available therefore making it difficult for the individual to habituate these stimuli (Dunn, 1999:35).

10. Sensation Avoiding: behaviour consistent with sensation avoiding represents "*low neurological thresholds with a tendency to act to counteract these thresholds*". It is hypothesized that meeting thresholds occur too frequently resulting in discomfort or fear in the individual (Dunn, 1999:37).

CHAPTER 2

Literature review

In this chapter I review the literature on sensory integration and sensory integration dysfunction to provide a theoretical framework; I describe the historical and current theories on autism and discuss the sensory processing traits of children with autism.

2.1. Sensory integration and sensory integration dysfunction

2.1.1. Sensory integration theory:

Sensory integration theory emanates from a body of work initiated and developed by Dr. Jean Ayres (1980), an occupational therapist and researcher in the United States of America. Research in the area of sensory integration has flourished over the past three decades and is viewed as one of the most researched theories of the occupational therapy profession (Barnard, 2004). Ayres (1989) describes sensory integration as information processing and explains:

> *Sensory integration is the neurological process that organizes sensations from one's own body and from the environment and makes it possible to use the body effectively within the environment. The spatial and temporal aspects of inputs from different sensory modalities are interpreted, associated, and unified* (Ayers, 1989:11).

Schaaf and Miller (2005:143) explain that Ayers developed the theory of sensory integration to explain the possible relationship of the neural processes that take place when *receiving, modulating* and *integrating* sensory input and consequential output of an

adaptive response. Sensory integration theory assumes that adaptive behaviour is reliant on adequate processing and integration of sensory information.

Sensory integration is therefore "*both a neurological process and a theory of the relationship between the neurological process and behaviour*" (Fisher, Murray & Bundy, 1991:3).

Ayers' theory is founded on principles from other disciplines including neuroscience, developmental psychology, education and occupational therapy. These principles are summarized by Schaaf and Miller (2005) who argue that sensorimotor development is important for learning. The interaction of the individual with the environment influences the development of the central nervous system. The central nervous systems characteristic of neural plasticity implies that the brain is capable of change.

It is postulated that meaningful sensory-motor experiences could be powerful mediators of neural plasticity. Ayres (1980:1) states that sensory integration "*results in perception and other types of synthesis of sensory data*". Information about one's body and the world is gathered through the sensory systems, namely, the tactile, visual, auditory, olfactory, gustatory, vestibular and proprioceptive systems. Ayers (2005) explains this process:

> *Sensory integration is the organization of sensations for use. Our senses give us information about the physical condition of our body and the environment around us. Sensations flow into the brain like streams flowing into a lake. Countless bits of sensory information enter our brain at every moment, not only from our eyes and ears but from every place in our body. We have special senses that detect the pull of gravity and movements of our body in relation to the earth* (Ayers, 2005:5).

Dunn (1997) states that it is important to consider the function of the central nervous system in its capacity to process and modulate sensory information as well as the child's environment and the sensory experiences available to the child, as both of these factors influence the child's performance in daily life activities. Kapes (2002:1) describes the normal progression in the development of sensory integration. She states that this process starts in the prenatal stages and continues throughout the individual's lifetime. According to Kapes the greater part of sensory integration takes place before adolescence. Sensory integration becomes more "*refined and effective*" with maturity as it is the foundation that determines how well emotional stability, speech and motor skills develop.

Although sensory integration focuses on all sensory stimulation; visual, auditory, gustatory and olfactory sensations, there is marked emphasis on three senses, the tactile sense, the vestibular sense and the proprioceptive sense. The tactile system has nerves under the skin's surface that transmit information about light touch, pressure, pain and temperature to the brain. The proprioceptive system is comprised of muscles, joints and tendons and provides an individual with a subconscious awareness of body position. The vestibular system includes structures within the inner ear that detect changes in head position and movement. The interconnections of these senses start developing in the pre-natal stages and continue to develop throughout life with maturity and the individuals continued interaction with the environment. The tactile, proprioceptive and vestibular systems are connected to each other and are also linked to other systems in the central nervous system. These three senses are not as familiar as the auditory and visual senses however they play a crucial role in an individual's survival (Hatch-Rasmussen, 1995).

Occupational therapists have in the past produced substantial information on sensory processing and continue to produce information about how individuals process sensory information and the influence of those processes on the individual's choices. Dunn (2001:609) states that these choices influence an individual's ability to "*live a satisfying life*". She argues that occupational therapists are in an ideal position to develop the concept of the significant involvement of sensory processing to the "*understanding of the human experience*".

Inamura (1998) agrees with Dunn (2001) and states that the ability to integrate sensory input adequately has an effect on all areas of development and that understanding normal development and the impact of sensory processing on this process provides a basis for evaluation and treatment. Inamura (1998) maintains that integration of sensory information allows one to derive meaning from the world and it is through the senses that children learn about the world and how to function in it.

Dunn (2001:608) states that "*the experience of being human is imbedded in the sensory events of everyday life*" and that people often describe their experiences from a sensory point of view. Dunn (2001) explains that sensory experiences are so intimate and personal that they define a person's individuality.

> *We describe the difference between one person and another in relation to those persons' interests in, tolerance for, and pleasure with sensations. Because of our personal experiences with sensations, it is sometimes hard or even inconceivable to imagine another persons' experience with an object or event or context. We want to frame the sensory experience within our own parameters; we think of another persons' description as "same," "somewhat similar," or "very different" from our own (Dunn, 2001:608).*

Inamura (1998) considers the impact of the environment on a child's development as it is governed by the integration of sensory experiences made available to them. She states that even though nature supplies the basis for development, it is the environment provides the stimuli that make this development possible. She asserts that it is the child's active participation in their environment and their ability to process sensory information adequately that facilitates learning and development. Baranek (2002) agrees with Inamura that the assumption of sensory experiences having an impact on learning is widely recognized.

2.1.2. Sensory modulation:

Sensory modulation is considered to be a key neurological process in the integration of sensory stimuli. Murray-Slutsky and Paris (2000:108) explain sensory modulation as the ability of the nervous system to *regulate, organize* and *prioritize* incoming sensory information while inhibiting or suppressing information that is irrelevant at the time. Sensory information is prioritized during modulation to help the individual focus on relevant information. Murray Slutsky and Paris (2000) state that when the nervous system is well modulated it is able to adjust to changes in the environment, it has appropriate levels of attention and arousal for tasks, it tunes out irrelevant information while focusing on only the relevant stimulation and responds appropriately to the input.

Despite a variety of definitions and theory on sensory modulation by such authors as Fisher, Murray and Bundy (1991), Murry-Slutsky and Paris (2000), Schaaf and Miller (2005) and others, I quote extensively from the work of Dunn (2001) and Brown and Dunn (2002), as they are the key theorists on modulation in children with autism.

The actual process of integrating sensory information is discussed in both neuroscience and sensory integration literature. Neuroscience literature (Ayers, 1979, Fischer, Murray & Bundy, 1991) considers modulation of input to be crucial to the functioning of the central nervous system. Modulation refers to the ability of the central nervous system to *monitor* and to *regulate* incoming information in order to produce an appropriate response (Brown and Dunn, 2002:7). The functioning of the nervous system is based on excitation and inhibition of neurons. Excitation occurs when neurons are activated and inhibition occurs when responses are decreased or blocked. Dunn (1999:7) defines modulation as "*the brain's regulation of neural messages by balancing facilitation or inhibition of responses*". According to Dunn, modulation and the neurological threshold continuum is considered synonymous. On one end of the neurological threshold continuum is habituation and on the other end is sensitization. Modulation occurs by regulating habituation (when the central nervous system identifies stimuli as being familiar and decreases transmission among cells) and sensitization (when sensory information is perceived as being new and-or potentially harmful the central nervous system generates a sharper response). Both sensitization and habituation are considered to be an important component of learning in the central nervous system (Brown & Dunn, 2002).

Dunn (2001) explains that varying thresholds for perceiving, responding to and becoming irritated with sensations exist among individuals. These thresholds have an affect on an individual's mood, temperament and daily choices.

2.1.2.1. Key constructs of sensory processing: Dunn's model of sensory processing

Dunn (2001) developed a model of sensory of processing based on her work. The main feature of this model considers an individual's neurological threshold, the individual's response or self regulation strategies and the interaction between the thresholds and the responding strategies used. Dunn explains that thresholds and responding strategies represent a continuum and that a persons response to daily sensory events can fall anywhere on the continuum. High neurological thresholds are on one end of the continuum low thresholds are on the opposite end. An individual with a high neurological threshold requires a lot of sensory input in order to respond and an individual with a low neurological threshold registers sensory input quicker than others. A high threshold with a passive response is called low registration and a high threshold with an active response is called sensory seeking. A low threshold with a passive response is called sensory sensitivity and a low threshold with an active response is called sensory avoiding.

In an attempt to understand human nature, researchers have studied and generated a wealth of information on personality, temperament, self regulation and responsiveness traits. Dunn (2001) reports on various studies of temperament characteristics in infants and young children, children of school going age and adults. Temperament features that were identified across the different groups were surgency which indicates a positive affect and activity level; fear, irritability and anger; and persistence. Dunn (2001) hypothesized that there is a relationship between the Model of Sensory Processing and an individual's temperament. She paralleled the four categories of sensory processing

(sensory seeking, sensory avoiding, sensory sensitive and low registration) with the features reported in temperament literature. According to Dunn (2001) sensation seeking is associated with a positive affect and both sensory and temperament theories reflect an individual's pleasure with sensation and events. Sensation avoiding is associated with a negative affect and manifests as an individual's need to stay away from events and limit experiences. Sensory sensitivity is associated with irritability and the individual's vigilance when noticing stimuli in the environment. Low registration is associated with conscientiousness. Brown and Dunn (2002) state that although both of these paradigms address the individual's ability to stay on task, low registration addresses a lack of noticing and conscientiousness addresses the suppressing of sensory input to accomplish task performance.

An important aspect of modulation is the development of thresholds for responding to information (Dunn, 1999). According to Dunn genetic endowment and the individuals personal life experiences establish the central nervous systems thresholds. People with atypical sensory processing may display exceedingly high thresholds such as habituation or hyposensitivity; or exceedingly low thresholds, such as sensitization or hypersensitivity. Dunn asserts that when thresholds are too high, the individual's responses and reactions to stimuli are slower and the individual appears lethargic. Conversely, the individual reactions to stimuli are quick and frequent and they appear excitable or hyperactive when thresholds are too low.

According to a sensory integrative perspective, learning occurs when accurate sensory information is received, processed, and used to organize an individual's behaviours.

Dunn (1999) explains that appropriate responses are disrupted when a person receives inaccurate or unreliable sensory input. The individual is unable to process the information and create appropriate responses (Brown & Dunn, 2002).

2.1.3. Sensory integration dysfunction:

Ayers (1972) hypothesized that some children with learning disorders had deficits in processing and integrating sensory information and this consequently had an impact on their learning and behaviour. She theorized that behaviour and learning difficulties were partly the result of dysfunctional integration of sensory information and the inability of higher brain centers to modulate and regulate the lower brain sensory centers.

Fisher, Murray and Bundy (1991) explain that sensory integration dysfunction occurs when an individual has inadequate processing and integration of sensory input that result in deficits in planning and executing behaviour. This consequently interferes with the individual's conceptual and motor learning. Kranowitz (2003) states that sensory integration dysfunction manifests differently in each individual. It can vary in its frequency and intensity making it inconsistent by nature.

Kranowitz (1998) suggests that all individuals experience some difficulty with sensory processing on occasion. Too much or too little sensory stimulation results in confusion and temporary discomfort. Factors like illness, fatigue and stress can also contribute to difficulties in processing sensory information. Kranowitz (1998) further states that feelings of discomfort owing to poor sensory processing and occasional disorganizing experiences are normal phenomena. According to Kranowitz (1998) it is only when the

central nervous system disorganization is so extensive that the individual is unable to function optimally in daily routines that the individual is diagnosed as having a sensory integration disorder or dysfunction.

Kapes (2002:1) asserts that a person with sensory integration dysfunction cannot respond to sensory information that is necessary for planning and organizing behaviour in a manner that is automatic and appropriate to the situation. Therefore primitive survival strategies such as the "*fright, flight, or fight*" responses are employed. Often these responses appear "*extreme and inappropriate*" in context when a person has sensory integration dysfunction.

Kapes (2002) explains that there are three possible explanations for the neurological disorganization that result in sensory integration dysfunction. Firstly disconnections in the neuron cells may interfere with the brains ability to receive sensory information. Secondly, sensory messages may be received erratically and thirdly, messages may be received consistently, but are possibly not connecting correctly with other sensory messages. When the nervous system processes sensory information poorly the consequences are efficient motor, language, or emotional output.

Dunn (1997) examined the impact of sensory processing in the daily lives on infants and young children and states that when the central nervous system processes sensory information poorly it interferes with the child's learning about their environment and the child appears clumsy an unresponsive.

Inamura (1998) states that in children with sensory processing difficulties, the problem is observed earlier in life however it is often not identified as sensory integration dysfunction. These difficulties are more apparent when the child attends school and shows evidence of resulting motor, social-emotional, cognitive and academic difficulties. According to Inamura (1998) these children may compensate for their difficulties by avoiding situations that challenge them.

Mailloux (2004:19) shares experiences of parents who describe sensory integrative problems in their children without knowing what sensory integration is. She states that these problems are often "*mislabeled, misunderstood, or missed entirely*".

Ayers (2005) suggests that problems underlying difficulties with learning and poor behaviour are often the result of dysfunctional sensory integration within the child's brain and are often less obvious and less recognized than other childhood conditions although they occur among many children throughout the world. Sensory integration dysfunction is often overlooked by those who are not trained to identify these problems.

Sensory integration dysfunction is diagnosed and treated by occupational therapists with specific postgraduate training in the field of sensory integration. Baranek (2002:406) explains that a key feature of a pure sensory integration approach includes a child-centered approach that provides what is termed a '*just-right challenge*' in order to facilitate an increasingly '*sophisticated*' adaptive response and engaging the child in more meaningful and appropriate interactions. Kapes (2002) agrees that occupational therapists can play a vital role in providing the necessary sensory information and

experiences through sensory integration therapy. This in turn enables the individual to learn and mature.

2.2. Autism

2.2.1. Historical theories of autism:

The most famous of the early cases of probable autism widely reported. Victor was referred to as the '*the wild boy of Aveyron*'. In 1799, Victor was discovered naked in the woods of France. He was approximately eleven years old. He was covered in dirt and scars. He was mute and behaved like a '*wild animal*'. He was put in the care of a physician from the institute for deaf mutes, Dr Jean Itard. Dr Itards description of the boy demonstrated many of the characteristic features of autism including poor eye contact and a lack of interest in toys. According to DeMyer (1979), one of the more striking observations of Victor was his extraordinary memory. He was able to remember the exact position of different objects in his room and he was resistant to any adjustments or modifications to these objects.

DeMyer (1979) states that the word "autism" was initially used in 1919 by Blueler. It was used to describe the '*withdrawal from the outside world*' that was seen in adults with schizophrenia. Although this term applied to people with schizophrenia and was quite different from the syndrome of autism, both have the similarity of an apparent preference for an inner world rather than external reality.

In his earliest description of early infantile autism syndrome in 1943, Dr. Leo Kanner described children who appeared to have a "*remarkable lack of interest in other people*". Dr. Kanner also observed a number of unusual behaviours and developmental features in these children including a "*marked resistance to change*", "*stereotyped and self-stimulatory movements*", and "*occasional areas of isolated interest or proficiency*". Language was absent or delayed and often if it did develop, it was of an unusual nature (Volkmar, Klin, Marans and McDougle, 1996:129).

According to Volkmar et al. (1996), Kanner's original description of autism remains as a valuable contribution to psychiatry as it has had immense influenced on the work of several generations of professionals since its publication in 1943. However, certain features of Kanner's original works proved to be misleading for researchers. Several of the earlier researchers and clinicians assumed that there was a continuum between autism and schizophrenia however almost 30 years later Rutter revealed that the clinical features of these two disorders were significantly different.

2.2.2. Current theories of autism:

Autism is currently viewed as *"a severely incapacitating lifelong developmental disability that typically appears in the first three years of life"* (Murry-Slutsky and Paris, 2000:1). Autism is one of the pervasive developmental disorders. Both categorical and dimensional approaches have been employed to define and diagnose autism. The Diagnostic and Statistical Manual of Mental Disorders, 4th edition, (DSM IV) by the American Psychiatric Association (1994) is widely used in diagnosing autism. It categorically describes the key features of autism as characterized by the presence of a

"*markedly abnormal or impaired development in social interaction and* communication and a *markedly restricted repertoire* of activities and interests (American Psychiatric Association, 1994:66).

2.2.2.1. Impairment in social interaction

The DSM IV's (American Psychiatric Association, 1994:66) description of the classification of autism is summarized as (a) an impairment reciprocal social interaction that is gross and sustained; (b) multiple nonverbal behaviours that are typically used to regulate social interaction and communication may be impaired; (c) there may be a failure to develop peer relationships appropriate to the child's developmental age; (d) the child may not spontaneously share enjoyment, interests or achievements with others and the (e) child may lack social and emotional reciprocity. The individual may prefer solitary activities and there is a decreased awareness of other people.

2.2.2.2. Impairment in communication

The impairment in communication is "*marked and sustained"* and has an impact on both verbal and non-verbal communication. Often there is a delay in language and at other times there is a total lack of language. The individual may experience difficulties in initiating or sustaining a conversation. There may also be a "*stereotyped and repetitive use of language or idiosyncratic language*". Abnormalities in the pitch, intonation, rate, rhythm, or stress of speech may be present (American Psychiatric Association, 1994:66)

2.2.2.3. Restricted, repetitive and stereotyped patterns of behaviour, interests and activities

The description of criteria in this category is summarized as follows: "*restricted, repetitive and stereotyped patterns of behaviour, interests, and activities*" are present in individuals with autism. The individual could have an "*encompassing preoccupation with one or more stereotyped and restricted patterns of interests"* that may be atypical in focus and intensity. They may adhere inflexibly *to* "*specific, nonfunctional routines or rituals*" and "*stereotyped and repetitive motor mannerisms*" may be present. The child may have a "*persistent preoccupation with a specific part or parts of an object*" (American Psychiatric Association, 1994:67).

The diagnosis of Pervasive Developmental Disorder Not Otherwise Specified (American Psychiatric Association, 1994:65) is made when there is a "*severe and pervasive impairment*" in (a) reciprocal social interaction; (b) communication; or (c) when stereotyped behaviour, activities and interest are occur but do not completely meet with the DSM IV criteria for diagnosis of other disorders. The diagnosis of PDD (nos.) is given when the presenting features do not meet the criteria for autism because of atypical characteristics, late onset after the age of three years, or because the child may have fewer than the specified number of symptoms for a diagnosis of autism (Murry-Slutsky and Paris, 2002:2).

2.2.3. Incidence and Etiology of autism spectrum disorders

Wicks-Nelson and Israel (1997:301) state that autism is one of the more systematically investigated childhood disorders due to its '*severity*', '*unusualness*' and '*bizarreness*'. Kane (2003) reports on the increase in the incidence of autism. Wicks-Nelson and Israel (1997) suggest that the higher rate of incidence of autism should not necessarily be interpreted as an actual escalation in the incidence of autism and argue that the higher rates may in fact be due to better detection and to the broadening of the definition which has resulted in more children receiving a diagnosis of autism.

Blaxill (2004) reports on the increase in prevalence of autism spectrum disorders in the United States and in the United Kingdom. The rate of autism spectrum disorders in the Unites states increased significantly between 1970 and 1990. The rate of incidence of 3 per 10,000 children in the 1970s escalated to 30 per 10,000 children in the 1990s. The United Kingdom also experienced an increase in the rate of autism spectrum disorders from 10 per 10,000 children in the 1980s to approximately 30 per 10,000 in the 1990s. Full spectrum autistic disorder increased from 5 to 10 per 10,000 to 50 to 80 per 10,000 in both countries. According to Blaxill (2004) as a precautionary approach, the increase in incidence of autism should be considered more seriously.

Males consistently present with autism more than females. The American Psychiatric Association (1994) reports a ratio of three to five males to one female. Females often present with severe mental retardation and a higher functioning female with autism is uncommon. There is no evidence of higher socioeconomic status of the children

presenting with autism as suggested by Kanner's original impressions and studies by Gillberg indicate that there are no social class differences.

Several neurochemical, neuroanatomical, neurophysical and genetic studies have been adopted to determine the etiology of autism. Volmar et al. (1996) report that early studies by Kanner suggested that autism was a congenital disorder and directly related to deficits in the parent-child interaction. Several studies later argued against this view and suggested that the basis of autism appeared to be in some underlying disorder in the central nervous system. The many conditions observed in autism suggest that autism may be the result of insults on the central nervous system through a common pathway (Volkmar et al. 1996).

Volkmar et al. (1996) state that the term pervasive developmental disorder suggests that multiple areas of development are impaired in children with autism and therefore a comprehensive assessment of the disorder requires the knowledge and skills of various professionals. According to Volkmar et al. (1996) psychiatrists, psychologists, neurologists and speech-communication specialists are among the professionals that have a valuable role to play in the diagnosis and treatment of individuals with autism. Difficulty in processing sensory information is a key feature of autism therefore Mailloux (2001:381) argues that "*a sensory integrative approach, utilized within a comprehensive occupational therapy program, provides a critical feature of service for the child with autism*".

There is currently no cure for autism. However, several interventions and therapies such as educational approaches, behavioural approaches, dietary interventions and medication are being adopted to minimize or manage the features associated with autism.

2.3. Sensory processing traits in children with autism

The presence of dysfunctional sensory systems in children and adults with autism and other developmental disabilities is widely reported. I draw on the work of Baranek (2002), Case-Smith and Bryan (1999), DeMyer (1979), Dunn, Myles and Orr, (2002) Edelson (1995), Harrison and Hare (2004). Hatch-Rasmussen (1995), Iarocci and McDonald (2006), Jordan (1999), Mailloux (2001), Murry-Slutsky and Paris (2000), O'Neill and Jones (1997), Spitzer (2003) and Watling, Deitz and White (2001).

The DSM IV (American Psychiatric Association, 1994:68), states that children with autism exhibit unusual responses to sensory stimuli such as "*a high threshold for pain, oversensitivity to sound or being touched, exaggerated reactions to light or odors, fascination with certain stimuli*". Emer and Dunn (1998) argue that although the DSM IV's (APA,1994) diagnostic criteria for autism does not specify quality and frequency of responses to sensory stimuli, the abnormal responses experienced by children with autism is widely accepted as being clinically important.

DeMyer (1979), in her early reports of research in autism, found that impaired sensory functions were present in a large percentage of children with autism. Hyper-sensitivity to sound was observed in 42% of children with autism. This was based on parent's accounts of discomfort experienced by the child or fear reactions to high volume or pitch of certain

sounds. Poor reaction to pain was observed and these children failed to notice distant objects. She states that vestibular dysfunction could be the cause most of presenting symptoms in autism.

Iarocci and McDonald (2006) state that both past and more current theories of autism support the idea that individuals with autism process sensory information differently from others. Baranek (2002) reports empirical evidence that verify that sensory and motor difficulties exist in children with autism at some stage of their development and that unusual response to sensory stimuli have been reported in 42% to 88% of older children with autism. Harrison and Hare (2004) reports on studies that offer evidence of sensory abnormalities existing in most children with autism. In a study that consisted of a sample of 75 children with autism, Harrison and Hare (2004:728) found that 71% of the children were auditory hypersensitive 52% were tactile sensitive, 41% were sensitive to smell and 40% were sensitive to tastes. Hypo-and hypersensitivity to pain was also reported. Jordan (1999) states that even the early observations of Dr Leo Kanner supported the premise that children with autism reacted strongly to loud noises and certain objects. He also observed that these children experienced difficulties with feeding or had severe food fads. Ahn, Miller, Milberger and McIntosh (2004) report the incidence of sensory processing disorders in children without disabilities to be estimated at between 5% and 10% and in children with disabilities to be estimated between 40% and 88%. Watling, Deitz and White (2001) suggest that between 30% and 100% of children with autism have sensory perceptual abnormalities. Watling et al. (2001) report results of study that confirmed that a variety of sensory processing deficits were present in young children with autism. In a comparative of children with and without autism, they found significant differences in

behaviours related to sensory registration, sensory sensitivity, sensory seeking and oral sensitivity, distractibility and emotional reactivity in the children with autism (Watling, Deitz & White, 2001:422). Jordan (1999) suggests that hypersensitivity to sensory stimuli could be one of the key features of autism spectrum disorders. Iarocci and McDonald (2006:77) agree with Jordan and states that many of the more recent theories of autism suggest a common theme of atypical sensory processing being a "*core symptom*" of autism. Mailloux (2001) reports that children with autism display different responding behaviours to visual, auditory, tactile, and body posturing compared to individuals without disabilities. Mailloux (2001:368) further states that children with autism often have "*heightened sensitivities not only to sensory qualities inherent in various experiences and environments but also to basic variations in place and time. Children with autism can demonstrate a great deal of variability in their abilities and reactions*". These children simultaneously seek and avoid sensory stimuli. Children with autism have been reported to demonstrate tactile defensiveness, auditory and olfactory hypersensitivity, hypo-and hyper reactivity to sensory stimulation and sensory modulation dysfunction (Watling, Deitz & White, 2001:422).

The literature cited above suggests that sensory processing disorders are common features in children with autism. However, for occupational therapists, the emphasis lies with the effects of sensory processing difficulties on the occupational engagement and behaviour of children. Mailloux (2001:368) argues that the "*difficulty in registration of meaningful sensory input is often one of the most disabling and commonly observed aspects in children with autistic disorder*". These children often experience confusion, discomfort, frustration and anxiety as a result of not being able to process sensory

experiences throughout the day. The relationship between sensory processing and children's activities of daily life, including self-care, learning and playing, are reported by Fisher, Murray and Bundy (1991). In a study on sensory processing in children with Fragile X syndrome, Baranek, Chin, Greiss Hess, Yankee, Hatton and Hooper (2002) report lower levels of school participation in children who avoid sensory experiences.

Dunn, Smith Myles and Orr (2002) describe hypo and hypersensitivities to taste, tactile and auditory stimuli in children with Aspergers' syndrome and cite such examples as disliking their nails being cut, discomfort of certain fabrics, seeking intense tastes such as very sour or spicy foods. Case-Smith and Bryan (1999) report difficulties in communicating with parents or peers and limited engagement in play in children with autism.

Murry-Slutsky and Paris (2000) describe the nature of impaired sensory systems of children with autism and how they fail to react or to register sensory information from their environment or how they over react to stimuli. The under-aroused child misses much input where as the over-aroused child is overloaded by a constant stream of input. Intense or unpredictable sensory input causes stress which leads to shutdown, focusing exclusively on a single input to exclude others, behaviour that is disorganized, poor self esteem and a need to escape from the situation. Murry-Slutsky and Paris (2000) state that all of these behaviours are observed when the child is not in a calm-alert state, the child is not receptive to learning and in turn is unable to function optimally. They suggest that this information is valuable in understanding the child with autism's behaviour and difficulties.

Hatch-Rasmussen (1995) suggests that sensory processing difficulties may be the main reasons for stereotypical behaviours such as spinning, rocking and hand flapping, commonly seen in children with autism. Case-Smith and Bryan (1999) view self-stimulatory behaviours typical of autistic children, including hand-flapping, spinning and rocking, as attempts to regulate their sensory systems. Edelson (1995:1) reports research that aim to explain why people with autism engage in stereotypic behaviour. A possible explanation for these behaviours could be that they provide some form of sensory stimulation in individuals who are hyposensitive. Dysfunctional sensory processing results in a need for stimulation. The individual "*craves*" the stimulation and in turn engages in these behaviours to arouse or excite the nervous system. According to Edelson (1995:1), one specific theory asserts that these behaviours release beta-endorphins that provide the individual with a form of internal pleasure. Other theories suggest that the individual uses these behaviours to calm themselves down. In the case of hypersensitive individuals, the environment can be over-stimulating and the individual becomes sensory-overloaded. The individual engages in sensory stimulating behaviours to ignore this stimuli and "*his or her attention becomes inward focused*". Smith, Press, Koenig and Kinnealey (2005) assert that self-stimulating behaviours may interfere with the individual's independent functioning in activities of daily life and participation in meaningful occupations.

Mailloux (2001:336) cites various studies that investigate the anatomical abnormalities present in individuals with autism in order to provide insight into the neurological underpinnings of sensory deficits that individual's with autism experience. She explains that damage to the amygdala may be associated with "*withdrawal from social contact;*

compulsive, indiscriminate association of objects; decreased ability to attach meaning to situations; poor eye contact; increased temper tantrums in novel situations; and changes in responsivity to sensory stimuli". Damage to the hippocampus can result in "*hyperactivity, stereotyped behaviour, and difficulty with novel stimuli*". Both the amygdala and the hippocampus are necessary for memory involved in the processing sensory of information. According to Mailloux (2001:336) research shows that the cerebellum is involved in providing inhibitory input to the structures of brainstem and "*atypical inhibition might be involved in oversensitivity to certain sensory input, such as stimulation of gravity receptors*".

Adults with autism describe certain sensory experiences as alternately distressful or pleasurable (O'Neill & Jones, 1997). According to Anderson (1998) these feelings cannot be generalized to all individuals with autism however there are many studies that suggest that atypical sensory responses are observed in most children with autism.

Spitzer (2003) states that individual's with autism and other developmental disabilities process sensory information related to vision, sounds, touch and bodily sensations in ways that are different from other individuals. Spitzer (2003:73) cites Temple Grandin who states that these sensory processing differences should be regarded as a "*continuum of traits and experiences shared by those with and without developmental disabilities rather than dichotomous us/them categories*". According to Spitzer (2003), the challenge lies in comprehending the perspectives of individuals such as Grandin who experience sensations significantly different from neurotypical individuals therefore placing them at an extreme end of the continuum.

Mailloux (2001:369) describes the effects of sensory dysfunction on the behaviour of children with autism. "*Movement seeking frequently takes the form of rocking or rhythmic motions (usually considered to be calming or organizing to the child), or twirling and swinging motions (usually considered alerting and activating)*". These behaviours are often categorized as "*self-stimulatory*" and "*non-purposeful*". Mailloux further states that children with autism also present with difficulties in processing tactile information. Responses may vary from defensive reactions to touch and textures; a lack of registration of input or fluctuation between over- and under-responsiveness. A defensive reaction to tactile information may lead to discomfort during everyday grooming activities and eating. Visual stimuli can be overwhelming and lead to confusion. Auditory processing difficulties may manifest as the child appearing deaf or experiencing particular sounds as painful or the child is unable to tune out irrelevant background noises.

Of particular relevance to this thesis are the effects of sensory processing disorders on a child's social and emotional well-being, as it influences the relationships between the mother and child. Case-Smith and Bryan (1999) report studies that link sensory processing problems in autistic children with the ability to recognize facial expressions and emotional gestures, lack of eye contact during social interaction, failure to perceive emotional expression and impaired attention in social situations.

Mailloux's (2001:367) found that difficulties with imitation and social reciprocity in individuals with autism may be associated with poor processing of sensory information that result in poor motor planning skills. Mailloux (2001:367) suggests that difficulties

with oral praxis could be a clue into why individuals with autism have difficulties in interpreting facial expressions and gestures of others. Their poor perception of somatosensory (tactile and proprioceptive) feedback from facial and oral structures limits their ability to formulate "*the often-subtle motor plans*" that make facial expressions possible consequently impairing the foundations for social exchange from early in their development. According to Mailloux (2001) problems in the imitation of motor actions of other individuals and a lack of participation in social imitative play can result in poor development of social skills like social reciprocity and empathy.

Apart from difficulties in interpersonal relationships, disorders in sensory processing may results in strong emotional responses. Overwhelming sensory information can be painful and disorienting. The individual then withdraws and tries to avoid or escape from the situation as described by Janzen (1996):

> *…the individual with autism is in an almost constant state of overarousal, bombarded by a vast array of intense stimulation present in new, changing, and unpredictable situations. Stress from this overwhelming stimulation leads to defensive actions – the sensory system shuts down, the individual moves away to avoid the stress, or behaves in disorganized and unproductive ways that lead to failure and lowered self-esteem. The learner with autism avoids these situations because they are not only confusing and stressful but highly punishing* (Janzen, 1996:23).

Adults with autism have described their experiences of sensory processing as children. An example of such an account is that of Temple Grandin (1995). Grandin, a woman with autism, describes her sensory difficulties during childhood as follows:

> *From as far back as I can remember, I always hated to be hugged. I wanted to experience the good feeling of being hugged but it was just too overwhelming. It was like a great all-engulfing tidal wave of stimulation, and I reacted like a wild animal. Being touched triggered flight; it flipped my circuit breaker. I was*

> *overloaded and would have to escape, often by jerking away suddenly* (Grandin, 1995:62).

Grandin (1995) explained that her ears were like microphones that picked up all sounds at equal intensities. She was unable to filter out irrelevant background noises and found large noisy environments overwhelming. Some individuals with autism are aware of incoming sensory input but are unable to differentiate if it was sound, light, or other sensory stimulation. Grandin (1995:76) cites Donna Williams, an adult with autism who describes herself as a 'mono channel', meaning that she cannot process both auditory and visual input at the same time.

2.3.1. Critique of sensory integration theory

The literature reviewed strongly suggests that children with autism experience difficulties in modulating, integrating and interpreting sensory stimuli. Despite the strong anecdotal, clinical and parental reported suggestions of efficacy, there are critics of this view. Harrison and Hare (2004) report that much of the research on the sensory abnormalities that individuals with autism experience is methodologically flawed and consists mainly of firsthand accounts of adults with autism.

Sensory integration is among the most researched theories in occupational therapy (Barnard, 2004). However, efficacy of sensory integration has not yet been demonstrated empirically and has, as a result, lead to controversy over its use (Vargas & Camilli, 1999). Three studies by Ottenbacher (1982), Vargas and Camilli (1999) and Baranek (2002) report meta-analyses of existing research into the efficacy of sensory integration theory and therapy. Neither the Ottenbacher nor the Vargas and Camilli studies centred

on sensory integration efficacy for children with autism. In these studies, the study populations were children with learning disabilities or mental retardation. The study by Baranek (2002) included a review of 29 empirical studies of a variety of treatment modalities for children with autism spectrum disorders. Only three studies described classical sensory integration therapy.

Ottenbacher's (1982) meta-analysis consisted of a review of eight experimental studies on the efficacy of sensory integration produced between 1977 and 1981. From this analysis, Ottenbacher (1982) concluded that the sensory integration effect was positive for the populations intended. However, Ottenbacher's meta-analysis was criticized for methodological inadequacies in the studies that he included in the analysis and for his method of analysis (Vargas & Camilli, 1999).

Vargas and Camilli (1999) conducted a meta-analysis of several studies of which 16 studies focused on the efficacy of sensory integration treatment for children with learning disability compared to no intervention and another 16 studies compared sensory integration to alternative treatment methods. They found that older studies showed more effect, that sensory integration appeared to improve psycho-educational and motor areas of function but not other areas and the effects of sensory integration treatment was statistically equal to alternative methods of treatment. Vargas and Camilli (1999) expressed concern regarding the lack of empirical evidence in support of sensory integration.

Baranek (2002) refers to the controversy about sensory integration efficacy. She states that despite a convergence of evidence that supports the prevalence of sensory and motor

difficulties experienced by children with autism, empirical evidence of efficacy is lacking for all treatment modalities and not only for sensory integration efficacy.

Baranek (2002) reports three studies that investigated sensory integration interventions. Two of the studies used prospective AB designs with several subjects and adequate controls to study the efficacy of sensory integration treatment. The third study included a group of children with autism who were receiving sensory integration therapy and a retrospective design was used to identify predictors of positive outcomes. In the first study by Case-Smith and Bryan, five boys with autism received treatment over a thirteen week period. Only one of the boys showed significant improvements in adult interactions and no change in peer interactions. However, three of the five boys showed significant improvement in mastery of play and four of the five boys demonstrated less non-engaged play. The second study by Linderman and Steward, reported results of a single subject AB design with two, three year old children with pervasive developmental disorder. They found that one child had made gains in activity levels and social interaction but no gains were made in functional communication. The other child showed improvement in social interaction, approach to new activities and response to holding. The third study by Ayers and Tickle studied ten children with autism over a year of sensory integration therapy. They found that the subjects who were hyper-sensitive to stimuli showed more improvement than children who presented with hypo-sensitivity. All three of the studies had numerous limitations.

Schaaf and Miller (2005) state that a big challenge for occupational therapy researchers is defining treatment that is standardized and replicable as intervention is always

individualized. Another challenge lies in the interpretation of already existing research in sensory integration that have numerous limitations. Schaaf and Miller (2005:146) argue that although the public awareness of the use of sensory integration in occupational therapy has grown, there is a lack of empirical data to support the effectiveness of this approach and until such time, this approach "*will not be widely accepted by the broader scientific community*". Baranek (2002) agrees that although the theory that sensory experiences have an effect on learning is widely accepted, the mechanism through which it occurs is ambiguous and empirical data to verify is lacking. Baranek (2002) concludes that lack of empirical data does not mean that the treatment is ineffective but rather that the efficacy has not yet been confirmed.

According to Miller (2003), several studies suggest that the intervention works. There are also other studies that question whether claims of success are valid. Miller (2003) maintains that a suitable scientific assumption would be that the efficacy of sensory integration therapy is at this point neither proven nor unproven. She argues that it is hasty to condemn sensory integration therapy at this stage considering that the rigor in the methodology of past studies has been questionable. Mailloux (2004) reports on comments made by some of the parents of children that she works with:

> *The effectiveness of therapy aimed at improving sensory integration function is hard to measure with test scores. Families commonly say things like, "Life is less stressful now," "School seems to be going better," "my child and I both feel less frustrated than before," and "Now my child has friends." These kinds of qualitative changes in daily life are the ultimate goal of this therapy approach* (Mailloux, 2004:91).

Mertz (2005) argues that although the importance of sensory integration therapy is widely accepted by individuals with autism however it is not recognized by the medical

profession. She refers to the view of Temple Grandin, an advocate for sensory integration, who states that sensory integration should be a crucial part of intervention for individuals with autism. Mertz (2005) reports the findings of a survey of occupational therapists working with children with autism through which it was determined that 99% of therapist reported that they use sensory integration techniques in their therapy (Mertz, 2005).

Yack, Sutton, Aquilla (2002:38) argue that sensory integration theory does not claim to "*provide all the answers or to offer a cure*". Autism is a multi-system disorder that impacts on all areas of a child's development and sensory integration theory can help to provide possible reasons for some of the behaviours that individuals with autism display and offer intervention strategies. They explain the value of sensory integration therapy,

> *Sensory integration theory offers important insights and tools to help children with PDD perform everyday activities. Together with parents, occupational therapists can develop a variety of activity suggestions and modifications to self-care routines for a child that can improve comfort, compliance and independence* (Yack, Sutton & Aquilla, 2002:37).

2.4. The effect of autism and sensory integration dysfunction on the parent-child relationship

In this section I draw on the work of Brown and Dunn (2002) DeMyer (1979), DeGrace (2004), Dunn (2004), Cohn, Miller and Tickle-Degnen (2000), Iarocci and McDonald (2006) Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, and Plienis (1992), Mailloux (2001), Spitzer, (2003), and Wicks-Nelson and Israel (1997) in

reporting the challenges in relationships of parents and their autistic children with sensory-integration difficulties.

2.4.1 Past theories of parenting a child with autism

Psychological theories of autism have in the past emphasized the role of atypical parental personalities or atypical parent-child interaction. Wicks-Nelson and Israel (1997) provide an overview of older psychological theories by Bettelheim, Festers and Kanner that focused on dysfunctional parenting as a central factor in the development of autism. Kanner developed the concept of "*refrigerator*" parenting. He described highly intelligent professional people who were preoccupied with science, art and literature and treated their offspring's in a cold and mechanical way (Wicks-Nelson & Israel, 1997: 308).

Bettelheim hypothesised that autism manifested when a child had an unsatisfactory or threatening experience early in their development that caused them to withdraw. He argues that when the environment is not suitably responsive and parent interaction with the child is inadequately or pathological, the child may perceive this as threatening and may withdraw. The child looses the motivation to act and learn and the child "*retreats to an autistic empty fortress*" (Wicks-Nelson & Israel, 1997: 308). Fester shared Bettelheim's view that early parenting played a central role in causing autism. Fester proposed that parents of children with autism insufficiently use punishment and reinforcement to structure their child's behaviour. The child therefore lacks the foundations for a repertoire of normal behaviour. These parents were thought to have rejected the child, have a preoccupation with other activities or experience depression.

According to Wicks-Nelson and Israel (1997), empirical studies give little support to the theory of dysfucntional parenting and state that the relationship is reciprocally impacted on by the child and the parent but the child's characteristics significantly influence the parent child relationship . Wicks-Nelson and Israel (1997) assert that blaming the parents for the development of autism in their child is inaccurate.

DeMyer (1979) reported on the difficulties and pressures parents face in raising a child with autism. She stated that numerous stresses over time had significant effects on parents in their capacity of individuals and marriage partners. These stresses also impacted on the other children in the family. She stated,

> *During two decades of working with autistic and other intellectually disabled children, I have become aware of the enormous difficulties and pressures parents face in rearing them. Participating as an interviewer in interviews made me increasingly aware of these parents as people with all the usual failings and usual strengths of the human condition in a stressful situation, and decreasingly inclined to hold them responsible for infantile autism (DeMyer 1979:150).*

DeMyer (1979:150) in her study, asked a direct question about the effect the child's symptoms had on the family and on the parents. She found that mothers responded inadequately to the question or that they denied that the child with autism had any significant effect on them. However replies to other questions were descriptive of "*great upheavals in the lives of the families and of the sadness and inadequacy felt by many of the mothers*". DeMyer drew from this that many of the parents had not given much thought to the extent that their and their family lives were affected by the children with autism.

2.4.2. Current views of parenting a child with autism

In recent times, research has shifted to focus more on the effect that parenting a child with autism has on the parent. Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins and Plienis (1992: 206) describe the stress in relationships between parents and their autistic child.

Wicks-Nelson and Israel (1997:301) describe young children with autism as socially unresponsive. They do not visually track other people and they avoid parents' gaze or they have an "empty" gaze themselves. They display limited emotional expression and they resist physical contact. Wicks-Nelson and Israel (1997) suggest that such behaviours negatively impact on the early establishment of normal social and emotional bonds and parental attachment. Mailloux (2001) agrees that the physical contact between the parent and the child is important as tactile processing plays an important role when interacting with others on an emotional level and participating in various social circumstances. Rutter cited in Wicks-Nelson and Israel (1997:302) states that "*toddlers may fail to follow their parents around, to greet them when they return, or seek comfort and affection from them*". The child does not engage in joint attention interactions by pointing, showing, and making eye contact or trying to get another persons attention in order to share the experience. Wicks-Nelson and Israel (1997) maintain that children with autism show fewer of these joint attention interactions that typically develop at 9-12 months and that they also show a less positive affect toward the other person when they do engage in these interactions.

According to DeGrace (2004), there is a lack of research into the services that provide intervention and support for the families of children with autism. DeGrace further states that it is important to have insight into the daily life experiences of families of children with autism as this could provide important information on how occupational therapists can offer support to families in their occupational role performance.

The families in DeGrace's study illustrated that the challenging behaviours associated with autism have a broad impact on the family occupation. The child's behaviours challenge the ability of the family to share occupations as a whole family. Family life revolves around the needs of the child with autism and many families felt robbed due to the dependency of the child and the child's inability to share in the families positive social and emotional experiences. These families create rigid and routine family days that tend to revolve around the needs of the child with autism. They would find ways of keeping the child occupied in order to keep the child manageable and to avoid behavioural crises. Many of these families according to DeGrace (2004:547) "*appeared to mourn for a family life that they did not experience or feel that they could create*".

2.4.3. Parenting a child with sensory integration dysfunction

Iarocci and McDonald (2006) state that parents of infants with autism report sensory oddities early in the child's development. They describe the child as being easily distressed and preoccupied with tactile, visual, auditory and olfactory stimuli. The child does not respond to meaningful sensations like being called. Mailloux (2004) agrees that parents know their children best and when they instinctively feel that there is something wrong with the child, they are usually correct. Sensory integration problems are less

obvious and not commonly understood; therefore parents often take a longer time to seek intervention. Mailloux describes experiences of parents when discovering that their child has sensory integration problems.

> *Unfortunately, I commonly hear that parents, particularly mothers, have been told that the problem most likely is the result of their parenting style. Overcoming feelings of guilt often becomes part of the discovery process for parents. Feelings of relief and validation are also common. I cannot count the number of times I have heard, "This is the first time someone has put words to feelings I have had about what is going on with my child". My colleagues tell me that they hear similar comments* (Mailloux, 2004:29).

Dunn (2004) explored the impact of sensory processing on the infant-caregiver relationships. According to Dunn it is important to consider the infant-caregiver relationship from a sensory processing perspective as sensory experiences have an impact on emotional reactions of both the infant and the caregiver. An individual's response to sensory input is very personal therefore both the infant and the caregiver can have individualized responses to the same sensory events. Dunn argues that it is important to take into account all the factors that contribute or interfere with sensory processing in an individual's daily experiences. Sensory difficulties that interfere with daily life interactions can have a negative impact on the evolving relationship between the caregiver and the baby. Dunn states that sensory processing knowledge can be a powerful tool in supporting substantial infant-caregiver relationships.

A child with sensory integration dysfunction with or without autism can also have a particularly stressful effect on the parent child relationships. Spitzer (2003) states that it is the vast differences in the perception of sensations in children with autism that results in others lacking insight or sharing in social occupations with the child. She further states

that even shared activities can be experienced as physically different. A wide range of sensations is always present but different people attend to it in different ways. Therefore if two people are attending to different sensory aspects of a common object or experience, they will experience difficulties in understanding each other's perspective. It is therefore assumed that difficulties in understanding of one's perspective can lead to a conflict of interests or needs.

Cohn, Miller and Tickle-Degnen (2000) state that parents seek validation of the challenges inherent in parenting children with sensory integration problems. In one study, a mother reported:

> *I wanted confirmation that I'm not 'weird,' that Harry isn't 'bad,' that there are other children like Harry, that his problems are 'real' and not just in my head. I want to be accepted and bolstered for what I do for Harry rather than people thinking I am a bad mother* (Cohn, Miller & Tickle-Degnen, 2000:40).

Dunn (2001) reports several studies on sensory processing difficulties and its relationship to behaviour. Amongst others, she cites a study that explored the relationship between tactile defensiveness and rigid, inflexible behaviour; another that reported a child with sensory defensiveness who displayed anxiety and the need to control that negatively impacted on school and family life. Dunn (2001) suggests that rigidity and inflexibility could possibly be behaviours that reflect coping strategies for very low thresholds that quickly overwhelm the nervous systems.

Brown and Dunn (2002), in a case study that describes conflicting parent child relationships, describe how an occupational therapist could use the Adolescent/Adult

Sensory Profile (Brown & Dunn, 2002) for the parent in conjunction with the Sensory Profile (Dunn, 1999) for the child, to develop parenting interventions. Brown & Dunn (2002) demonstrate in the case why the day-to-day relationship between the mother and child has become strained. Upon analysis of the two sensory profiles, Brown and Dunn reported a vast difference in the scores. The child actively explores his environment and is constantly moving and making a noise. He is quick to respond emotionally to frustrating situations. The mother on the other hand has a definite preference for passive as opposed to active sensory processing responses. She is sensory sensitive therefore notices sensory stimuli but also has low registration so she misses information. This suggests that her modulation of responses is erratic. She is rarely involved in creating or reducing sensations and responds passively. Her child's sensory seeking behaviour can be puzzling and irritating to her. The child is also emotionally reactive and this can be challenging to someone with sensory sensitivity. Brown and Dunn (2002) suggest that although the child has a high need for sensory exposure, he would also benefit from increased structure and predictability in his environment in order to reduce frustrations and increase feelings of safety.

Dunn (2004) states that sensory processing knowledge can be at the root of relationship challenges as all human experiences are rooted in sensory-based information and the same patterns of sensory processing exist across the lifespan. Therefore, Dunn emphasizes the importance of providing insight into the meaning of behaviours from a sensory processing perspective, in order to create the best match between the person's sensory processing needs and activities and environments of interest in the individual's life.

In this chapter I described the theoretical background of sensory integration and sensory integration dysfunction. I reviewed theories on autism and described how autism and sensory integration dysfunction can influence the parent-child relationship. In the following chapter, I discuss the methodology.

CHAPTER 3

Methodology

In this chapter I review the literature on qualitative research and the phenomenological paradigm that frames the study. I describe the data sources and discuss the data collection and interpretation in keeping with the phenomenological paradigm. I provide background on the instruments uses, the Sensory Profile and the Adolescent/Adult Sensory Profile that yield quantitative data.

3.1. Methodological Considerations

Babbie and Mouton (2001) describe the stages in the evolution of social science research and state that as the social sciences developed in the last four hundred years during which time meta-scientific thinking evolved. They state that the term "metatheory" is synonymous with terminology like "philosophy of science", "metascience" and "epistemology of science". All of these terms, according to Babbie and Mouton (2001) include serious reflection on the nature of scientific inquiry.

The three most significant metatheoretical traditions are positivism, phenomenology, and critical theory and are directly linked to the three methodological paradigms in social sciences. The term methodological paradigms include both the actual methods and techniques adopted by social science researchers in addition to the underlying principles and assumptions relating to their use (Babbie & Mouton, 2001). These three paradigms are quantitative research, qualitative research and participatory action research.

As this study focused on the phenomena of sensory processing traits in mothers and children with autism, qualitative methodology based on a phenomenological perspective is used in the study. Phenomenology informs interpretive qualitative research and has its roots in philosophy and psychology. Phenomenology focuses on the subjective experience of the individual. Merriam and Associates (2002) state that from phenomenology comes the idea that people interpret everyday experiences from the perspective of the meaning it has for them only. Phenomenologists assume that experience is a valid source of knowledge and that the everyday experiences of an individual contain substantial insight into phenomena (Becker, 1992). The phenomenologist asks research questions that allow the lived understanding of the phenomena to transpire. Crepeau and Dietz (1998) assert that qualitative research is appropriate when studying the social lives of individuals or groups in order to understand their experiences from their own perspectives.

Merriam and Associates (2002) state that phenomenological research addresses everyday human experiences and experience is considered an important sociological or psychological phenomena. An interview is the primary method of data collection in phenomenological research (Merriam & Associates, 2002). Prior to the interviews the phenomenological researcher uses the technique of bracketing to explore his or her own experiences, in order to examine components of the experience and to become aware of his or her own "*prejudices, viewpoints, and assumptions*" Merriam and Associates (2002:94). They explain that these preconceptions are then bracketed, or put aside, so that they do not influence the research process.

Phenomenological reduction, horizontalization, and imaginative variation are used in addition to bracketing in phenomenological studies. Merriam and Associates (2002:94) defines phenomenological reduction as "*the process of continually returning to the essence of the experience to derive the inner structure or meaning in and of itself*", whereas horizontalization "*is the process of laying out all the data and treating the data as having equal weight*". Therefore all elements of the data are of equal importance at the initial stage of data analysis. The data is then clustered into themes and all repetitive statements are eliminated. Imaginative variation according to Moustakas (cited in Merriam & Associates, 2002) involves studying the data from different perspectives and from changing frames of reference. The final step in phenomenological research according to Merriam and Associates (2002) is to develop the structural and textual descriptions of the phenomenon, this is referred to as the 'what' and 'how' of the phenomena.

Merriam and Associates (2002:141) maintain that phenomenological methods can be valuable in understanding human experience and the meaning that the experience has for the individual. However, phenomenological methods demands rigor, openness to learning, respect for the participants and "*a sense of humility about the whole process*".

Apart from a phenomenological approach, this study also has elements of participatory action research in that it emphasized the fundamental importance of "experiential knowing" as described in Babbie and Mouton (2001). Although this study cannot be classified as being purely participatory action research it adopts some of the fundamental principles of this approach such as participatory involvement, action and change.

The study aimed to evaluate the claims and consequences of knowledge in meaningful ways. Babbie and Mouton (2001) refer to Morgan's statement that knowledge can help explain empirical facts, facilitate the understanding of meanings and allow the individual to act more appropriately. Knowledge can also empower and liberate the individual; it can highlight the relationship between everyday reality and the logic that forms that reality. This study conceptualizes mothers' knowledge of their own and their autistic child's sensory processing as well as the change in their ideas or approach after the intervention.

Hammell, Carpenter and Dyck (2000) state that qualitative methods are appropriate when the research question pertains to understanding or describing a phenomenon about which little is known. They further state that qualitative research is grounded in a concern with people's everyday realities. The researcher seeks to have insight into the experiences of individuals in order to better understand their lives and does not seek to test predetermined hypotheses or relationship between the data. Rather, the intention is to examine the data for patterns, common themes and relationships between the phenomena, and to return to the data to test these emerging theories. In doing so, the research becomes an ongoing, cyclical process until understanding is achieved.

In qualitative research, the data is extensive and in the form of descriptions or narratives. The data is collected through interviews, observations, diaries and other documents. The data becomes the source of analysis and interpretation. Lincoln and Guba (1985) state that the purpose of qualitative research is to explore the meaning and interpretation of

experience and that meaning and understanding emerge during the research process. Therefore qualitative research designs are flexible and may evolve throughout the study.

Yerxa (1991) claims that occupational therapists need to explore ways enquiry that that reflect the humanistic values that are the foundations of the profession and not the statistical methods employed by the physical sciences. Yerxa (1991) proposes that qualitative research approaches have a 'goodness of fit' for enquiring what is worth knowing for occupational therapists.

Barnard (2004:21) states that although sensory integration is among the more researched theories in occupational therapy it is unfortunate that much of the research is aimed at proving its efficacy. Sensory integration research has been criticized for the not be replicable and it is also questionable if the intervention in past studies was 'pure' sensory integration therapy. She further states that most of the past studies were conducted over ten years ago and attempted to reduce sensory integration into "*small, defined therapy inputs, which are measurable and standardized*". Barnard (2004) argues that this approach is not part of the sensory integration philosophy of individualized client centered approach and can be considered as sensory stimulation as apposed to sensory integration.

Quantitative methodology is currently less used in research into the effectiveness of sensory integration therapy (Barnard, 2004). Qualitative, evidence based research is being adopted more by occupational therapy researcher as well as other researchers in the medical field. Evidence based research continuously investigates the effectiveness of

therapeutic interventions. According to Barnard it is important to revisit all existing research in sensory integration and she states,

> "*Reviewing all prior research into a therapeutic intervention and formulating a framework of the evidence that shows the best practice methods and structures within an approach or treatment condition forms the evidence of best practice"* (Barnard, 2004:21).

Since occupational therapists need to inform their practice through deep understanding of their client's perspectives, a client-centered approach is adopted in this study. The philosophy underpinning client-centered practice is concerned with ensuring meaningfulness of intervention, valuing the client's knowledge and respecting their life experiences. Hammell, Carpenter and Dyck (2000) maintain that that adopting a client-centered philosophy places the same emphasis on understanding the client's perspective as qualitative research. As this study involves children, a family-centered approach is employed.

Family-centered care was initially defined in 1987. It served as part of a plan to provide "*family centered, community based, coordinated care"* for children with special needs and their families". The fundamental elements of this approach are widely accepted by families and professionals. Family-centered care acknowledges that the family is always the constant factor in a child's life, therefore a partnership between families and professionals is essential (Community Gateway, 2006:1). As autism is a life long condition therefore professionals cannot work with the child in isolation of the family unit as the families will be responsible for the bulk of the load of caring for the child throughout the child's life. In this study the researcher will consider the child's role

within the family unit, and the impact of disability as represented in the mother-child relationship.

The phenomenological paradigm will be the overarching methodological frame used to understand the mothers' experience of exploring sensory processing in their children and themselves. However, quantitative results yielded by the Sensory Profiles will also inform the study.

3.2. Participant selection

Hammell, Carpenter and Dyck (2000) maintain that in qualitative research the researcher selects people who are likely to strengthen the understanding of the research topic. Therefore a purposive sample was used. Purposive sampling according Walliman (2006) is when the researcher selects what he or she thinks is an appropriate or representative sample based knowledge or a selection criteria. Babbie and Mouton (2001) state that it is appropriate for the researcher to select a sample based on his or her knowledge of the population and taking the research aims into consideration. The subject population consisted of ten sets of mothers and children diagnosed with autism spectrum disorders, who attend Vera School. Participants were purposefully selected from a list of children between the ages of 5-10 years of age who display sensory modulation difficulties and parents who were willing to explore their own sensory processing, to provide a rich source of information. Information rich participants (Krueger & Casey, 2002) are those from whom one can learn a significantly. Mothers only were selected to participate in the study as the researcher had more daily contact with the mothers dropping off and fetching their children compared to the fathers.

3.3. Instruments

The Sensory Profile (Dunn, 1999) and The Adolescent/Adult Profile (Brown & Dunn, 2002) are quantitative instruments, whereas the overarching research design is in the qualitative tradition. The instruments and the qualitative methods used will be further discussed.

3.3.1. Quantitative Instruments

The instrument used to gather information on the sensory functioning of the children with autism was the Sensory Profile (Dunn, 1999) and the sensory functioning of the mothers, the Adolescent/Adult Sensory Profile (Brown & Dunn, 2002). The profiles are quantitative instruments that yield both quantitative and descriptive results.

3.3.1.1. The Sensory Profile

The Sensory Profile (Dunn, 1999) is a judgment-based, caregiver questionnaire that is best suited for the child between 5-10 years of age (See Appendix 1). It provides a standardized tool for professionals to measure a child's sensory processing in daily life activities. The caregiver completes the questionnaire by reporting on the frequency in which behaviours occur (*always* representing 100% of the time, *frequently* – 75% of the time; *occasionally* – 50% of the time; *seldom* – 25% of the time; and, *never* – 0% of the time).

The profile consists of 125 items characterizing unusual responses to various sensory experiences in children's daily lives. The profile consists of behavioural statements

reflecting sensory processing, grouped into three main sections: *Sensory Processing; Modulation; and Behavioural and Emotional Responses*. *Sensory Processing* contains six item categories, *Modulation* contains five item categories and *Behavioural and Emotional Responses* contains three item categories (Dunn, 1999:1).

The Sensory Profile was researched from 1993 to 1999. The sample included more than 1,200 boys and girls between the ages of 3 and 14, with and without disabilities. The research took place in the United States of America and included mostly white children (91.4 % of sample). A small sample of children of Native American, Asian, African American, Hispanic and other ethnic backgrounds also participated in the study. The majority of the children were from suburban communities. There were also children from rural and urban communities. The financial income of the sample population was also considered (Dunn 1999).

The purpose of the Sensory Profile (Dunn, 1999) is to serve as an instrument for relating performance strengths and difficulties in sensory processing patterns exhibited by the child. It aims to evaluate the possible role of sensory processing in the daily routines of the child. It also provides information on child's response to stimuli and the sensory systems that possibly inhibit functional performance.

Dunn (1999:2) argues that the rationale for using the Sensory Profile is that *it "uses a sensory integrative and neuroscience frame of reference and supports a family-centered care philosophy"*. The Sensory Profile involves parents and other caregivers in the process of data collection. The Sensory Profile provides the necessary theory to support theory based decision making in daily life performance (Dunn, 1999).

The validity and reliability of the Sensory Profile have been established and reported (Dunn, 1999). Sensory Profiles were completed on thirty-two children with autism between the ages of 3-13. The children with autism performed meaningfully different from children without disabilities on nearly 90% of the items on the profile.

3.3.1.2. The Adolescent/Adult Sensory Profile

The Adolescent/Adult Sensory Profile (Brown & Dunn, 2002) is a self report-questionnaire that evaluates the role of sensory processing in the individual's daily performance patterns. It also identifies and develops the individual's awareness of their sensory difficulties and offers strategies to help the individual obtain the appropriate sensory environment (Brown & Dunn, 2002).

The Adolescent/Adult Sensory Profile is designed to measure characteristics of sensory processing. Individual answers questions describing their usual response to sensation, as apposed to how they would respond at any specific time. This enables the profile to capture a more constant and enduring representation of the individuals sensory processing (Brown & Dunn, 2002).

Brown and Dunn (2002) explain that the quadrant scores obtained from the profile represent patterns of sensory processing as described in Dunn's Model of Sensory Processing. The model is based on the relationship between the neurological threshold continuum and behavioural response/self-regulation continuum. It describes the four quadrants classified as *Low Registration, Sensation Seeking, Sensory Sensitivity* and *Sensation Avoiding* (Brown & Dunn, 2002:10).

The Adolescent/Adult Sensory Profile is made up of 60 items with 15 items in each quadrant. These quadrants include sensory processing categories of taste/smell, movement, visual processing, touch, activity level, and auditory processing. These items are distributed throughout the categories (Brown & Dunn, 2002).

Evidence about the Adolescent/Adult Sensory Profile was collected through the standardization process. Theoretical foundations and psychometric evidence is extensively documented in the Adolescent/Adult Sensory Profile manual. It claims that the scores from the profile can provide reliable and valid assumptions about an individual's sensory processing patterns (Brown & Dunn, 2002).

The standardization sample for the Adolescent/Adult Sensory Profile consisted of 615 participants. A total of 38.8% of the participants were males and 61.2% were females ranging between the ages of 17 and 79 years. White participants were the majority 92% of the sample. Participants were recruited from the Psychology and Occupational Therapy Department at the University of Kansas and from a mailing list of individuals who were interested in the Sensory Profile (Brown & Dunn, 2002).

A series of studies were conducted to evaluate the reliability of the Adolescent/Adult Sensory Profile (Brown, Tollefson, Dunn, Cromwell & Filion, 2001). The studies substantiated that the four subscales of the profile were distinct and significant concepts of sensory processing preferences.

3.3.2. Qualitative methods

Qualitative data were gathered through semi-structured interviews and focus groups.

3.3.2.1. Semi-structured interviews

Semi-structured interviews are defined by Walliman (2006:92) as "*one that contains structured and unstructured sections with standardized and open-format questions"*. A semi-structured interview was conducted with each mother as part of the data gathering process. The mothers were asked to respond to two open ended questions. The questions were: 1. Describe behaviour/behaviours of your child that you find challenging and 2. How do you deal with the challenging behaviour? The rationale behind the interview was to provide the researcher with behavioural indicators for both mother and child. The child's reported challenging behaviour was framed in terms of sensory processing. Likewise the mothers response to the behaviour was interpreted in terms of the mothers' sensory processing style as deducted from the four sensory quadrants of Brown and Dunn (2002). This is in keeping with Dunn's (1997) parallel between sensory processing and temperament. Dunn (1997) proposed that sensory processing knowledge can provide valuable insight into an individual's temperament characteristics and also knowledge of the nervous system role in supporting the individual's personality and temperament (Brown & Dunn, 2002).

3.3.2.2. Focus groups

Walliman (2006:98) defines focus groups as "*a type of group interview which concentrates in-depth on a particular theme or topic with an element of interaction*". The

members of the focus group are people with an interest, experience or knowledge about the topic being researched.

Babbie and Mouton (2001) describe two ways that focus groups are used in the qualitative paradigm. The first method would consist of 8 to 12 participants sitting in a circle. This process would be managed by the researcher who would go around the circle generating a response from each of the participants, therefore getting an individual response from each of the members of the group. Babbie and Mouton (2001) warn that this method compromises the quality of the data obtained as much of the data is lost both on an individual and on a group level.

Babbie and Mouton (2001) describe the second way of using focus groups to gather information that the researcher would not otherwise be able to access and describe the method as being useful in allowing an environment in which the participants can create meaning within the group rather than individually.

Walliman (2006) refers to Bryman's statement that there are many reasons for using focus groups to collect data. These reasons are summarized. The focus group assists in developing an understanding of individuals' thinking; the participants can produce ideas and opinions not anticipated by the interviewer; the participants can be challenge each others responses; and the interactions and group dynamics form a closer representation of the real-life process of interpreting and gaining understanding of the phenomena.

3.4. Procedure

Prior to the study permission was obtained from the Western Cape Department of Education and Vera School for the researcher to conduct the research. The procedure followed to obtain consent was as follows. The researcher approached the purposefully selected mothers individually, and informed them of the aims and procedures of the intended study and of the ethical considerations around informed consent. Written consent was obtained from the ten mothers' consenting to their and their autistic child's participation in the study. The ten mothers participated in individual interviews in which the purpose of the study and a brief overview of sensory modulation was explained.

The first step was that the mothers participated in a semi-structured interview describing challenging behaviours of their child and how they deal with the challenging behaviour. Secondly, ten mothers completed the Adolescent/Adult Sensory Profile for themselves and the Sensory Profile for their child. After the information from the profiles were individually scored and analysed, the researcher provided the mother with the results of her own sensory processing traits and the sensory processing traits of her child. During this feed back interview, the researcher also offered the mothers intervention strategies when there were sensory difficulties in her own or her child's sensory profile. The researcher tried to frame and explain the challenging behaviour that the mothers described in the semi-structured interview from a sensory modulation perspective and offered possible ways of dealing with the behaviour when the mothers were not coping. Thirdly, after completion of the feedback from the profiles, the mothers participated in focus groups to discuss the impact of the information gained on understanding their

child's and their own behaviour and the effects there-of on their relationship. Two focus groups of thirty minutes each were held with two groups of mothers. The focus groups were audio-taped and transcribed.

3.5. Data collection and data sources

3.5.1. Data Sources

The data sources were:

1. The results of ten Sensory Profiles of the children with autism
2. The results of ten Adolescent/Adult Sensory Profiles of the mothers
3. The information from the semi-structured interview
4. Transcribed data from the two focus groups
5. The researcher's field notes

3.5.2. Data collection

Quantitative data was collected by administering, scoring and interpreting the sensory profiles. Qualitative data was collected during the semi-structured interviews, the focus groups and by keeping detailed field notes.

3.5.2.1. The mother and child Sensory Profiles:

As the Sensory Profile and the Adolescent/Adult Sensory Profile are standardized instruments and are scored and interpreted in a manner suggested by the authors (Dunn,

1999; Brown & Dunn, 2002). The data from the profiles informed the study by providing a sensory processing frame work of both mother and child.

3.5.2.2. The semi-structure interviews:

The purpose of the semi-structured interviews were to provide the researcher with information on behaviours of the child that the mother found challenging and how the mother dealt with the behaviours. Examining the mothers' descriptions of their childs challenging behaviour and how they handle the challenging behaviours, provided behavioural indicators of how both mother and child experienced and dealt with situations influenced by their respective sensory processing. In other words the researcher captured behaviours in which the mothers described behaviours that could be interpreted as seeking, ignoring, or avoiding sensations. These descriptions were interpreted during the feedback sessions to give the mothers a clearer understanding of how sensory processing influences behaviour her own and her child's behaviour.

3.5.2.3. The focus groups:

The focus groups were held to collect data on the mothers' experiences of the research process. Two audio-taped focus groups of approximately 30 minutes each were transcribed. Both focus groups were held at Vera School and were scheduled at times that were convenient for the mothers to attend. The first one was scheduled in the morning when the mothers were dropping off their children at school and the second one was in the evening at a time that was convenient for the working mothers to attend. Six mothers participated in the first focus and two mothers participated in the second one. Two of the

four mothers who had agreed to participate in the second focus group did not attend. As the other two mothers had arrived, the researcher decided to continue. The absence of two of the four participants probably influenced the outcome and discussion of the group. however the researcher felt that the sample of eight participants rather than ten would still be big enough to obtain adequate information. The nature of the focus group was described and the content was introduced. Permission was obtained from all the mothers participating in the focus groups allowing the researcher to audio tape the focus groups. The focus groups yielded data on the mothers' experience of completing their own sensory profiles and understanding their own sensory processing, the mothers' experience of completing their child's sensory profile and understanding their child's sensory processing, and whether the mothers found the process valuable.

3.5.2.4. The researcher field notes:

The researcher gathered additional data by keeping field notes after each individual feedback session on significant statements that the mother's made when receiving feedback on their own and their child's sensory processing. The field notes sometimes included questions that the mothers asked or experiences that they shared.

3.6. Data Analysis

The data analysis was organized into two sets of data for different purposes. The data from the Sensory Profiles and the Adolescent/Adult Sensory Profiles formed part of the first phase of the study. The purpose of the results of the profiles was to inform the mothers of their own and their child's sensory processing. The second phase of data

analysis was to determine whether the information gleaned from the results of the profiles had influenced the mothers' understanding of their child's behaviour. The data sources for phase two of the analysis were primarily the transcripts of the focus groups, informed by the findings of the semi-structured interview and the researcher's field notes. All the data was analysed by hand. Deriving at categories and themes were consistently checked by the researcher's supervisor but not by an additional independent person.

3.6.1. Phase one: Analysis of profiles

The Sensory Profiles of each set of mother and child were analysed in order to give feedback to the mother.

The sensory profiles for both the children and the mothers were scored and interpreted individually. Scores from the Sensory Profile for the children with autism were then transferred to the worksheet for calculating quadrant scores (Dunn, 1999) so that quadrant scores could be derived in the four sensory quadrants (*Low Registration, Sensation Seeking, Sensation Avoiding and Sensory Sensitive*) in order to be compared to the quadrant scores in the Adolescent/Adult sensory profile. The researcher then examined each set of parent and child profiles and looked for sensory processing patterns that would indicate a good or a poor fit for the pair.

3.6.1.1. Interpretation of profiles:

- High and low Neurological Thresholds:

According to Brown and Dunn (2002) an individual's response to stimuli can fall at any point of the neurological threshold continuum. An individual with a nervous system that has a low neurological threshold requires only low intensity stimuli to become aware of and respond to the stimuli. A low threshold is easily activated by stimuli therefore the individual would be overly responsive (Dunn, 1999). Low threshold items on the profile measures an individual's awareness of or annoyance with sensations. Low threshold responses are reflected by the Sensory Sensitive and Sensation Avoiding items on the profile.

A high threshold requires more intense stimuli for the nervous system to respond. High thresholds measure an individual's lack of response or need for more intense sensory stimuli in order to trigger a response. The individual with high thresholds is under-responsive to stimuli (Dunn, 1999). High thresholds are reflected by the Low Registration and Sensation seeking items on the profile.

- Active and passive behavioural responses:

Behaviour is described on a continuum just as the neurological responses are described on the neurological threshold continuum (Dunn, 1999). The middle of the continuum reflects goal directed behaviour and the ends of the continuum supports behaviours that are maladaptive and results in unsuccessful performance. Acting in accordance with ones threshold is on one end of the continuum and acting to counteract thresholds is on the other end. Passive behaviours are consistent with the neurological response and occur when an individual acts in accordance with the nervous system response. Low Registration and Sensory Sensitive reflect passive behavioural responses. Active

behaviours counteract the threshold and are in opposition to the neurological response and are reflected by Sensation Avoiding and Sensation seeking behaviour (Dunn, 1999).

- Quadrant scores

The frequency of behaviour can be understood in terms of standard deviations.

Table 1: The relationship between standard deviations and frequency of behaviours in the sensory quadrants.

Standard deviation	**Frequency of behaviour**
-2	Much less than most people
-1	Less than most people
0	Similar to most people
+1	More than most people
+2	Much more than most people

3.6.2. Phase two: Analysis of semi-structured interviews and focus group transcripts

3.6.2.1. Analysis of semi-structured interviews

The researcher analysed comments that the mothers made on the challenging behaviour of their child and how they respond to the behaviours and framed each of the behaviours according to the four sensory quadrants of *Low Registration, Sensation Seeking, Sensation Avoiding and Sensory Sensitive.* The researcher also based these assumptions on information from the sensory profiles.

3.6.2.2.. Analysis of focus group

Analysis of the transcribed data was done by coding and categorizing all the data. The researcher read through all the data and searched for key words or key concepts, relating to the research question. The key phrases became codes and the codes were sorted into matching categories. Finally, the categories were analysed for emerging themes. The findings were written up under themes and categories. This method of analysis was in keeping with qualitative data analysis described by Babbie and Mouton (2001) and of focus group data described by Krueger and Casey (2002).

3.6.2.3. Use of field notes

The researcher searched the field notes for significant statements that the mothers made during and after their individual feedback sessions. This provided the researcher with the mothers' impressions of the information that they received. Some of the statements included responses such as "*it was nice to know things and the reasons behind them"* and "*the profile described me accurately"*.

The data main source analysed was the transcriptions of the focus groups.

3.7. Trustworthiness

In order to guarantee trustworthiness in qualitative research the results should be an exact reflection of the participant's statements (Krueger & Casey 2002:202). Crepeau and Deitz (1998:846) state that trustworthiness of qualitative research is established if the participants agree that the researcher has remained true to their experience and the

meaning they attach to the experience, instead of interpreting them from his or her own perspective. Member checking or respondent validation (Krefting, 1991) is a method of ensuring credibility.

Hammell, Carpenter and Dyck (2000) argue that the diversity of qualitative investigation not does not allow for all qualitative research to be analyzed with the same criteria. Lincoln and Guba (1989) propose four criteria for judging adequacy. The criteria were *internal validity, external validity, reliability and objectivity*. According to Lincoln and Guba (1989) reliability is reflected in a study's ability to be consistent, predictable, dependable, stable, and or accurate. The reliability of a study is established through replication. It is assumed that every repetition of the same or comparable instruments to the same phenomena will produce results that are similar. Reliability according to Lincoln and Guba (1989) assesses the "*stability*" of the phenomena being measured. It also assesses the stability of the instrument used to assess the phenomena. However Lincoln and Guba (1989) argue that if a phenomenon can change, as change is the key to development and refinement of understanding, then reliability is ineffective as a "*goodness criterion*". Therefore Lincoln and Guba (1989) proposed that qualitative researchers use the criteria of *credibility*, *transferability*, *dependability* and *confirmability*. Over the past twenty years, these criteria have been employed and applied to establish trustworthiness of qualitative data (Babbie & Mouton, 2001).

3.7.1. Credibility

Prolonged engagement in the field is a technique of ensuring *credibility* and is described by Lincoln and Guba (1989) as considerable participation at the place of investigation to

overcome or prevent the consequences of propaganda, distortion of information or a presented “front”. Prolonged engagement is according to Lincoln and Guba (1989) is used in order to establish the relationship and to build the trust. This is essential in revealing the meaning, enabling oneself to be immersed in and understanding the culture.

As the occupational therapist at Vera School over the past four years, the researcher has substantial contact with both the mothers and their children with autism. As some of the children in the study were enrolled at the school over the last five years (some longer) the researcher in her capacity as the school’s occupational therapist was involved in screening the child when they were initially brought to the school by their parents, observing the child over a two to three week period and assessing the child for diagnosis as part of a trans-professional team and giving the parents feedback. There is ongoing evaluation of the child and the occupational therapist participates in formulating Individual Education Programmes (IEP) for every learner in the school. The IEP is an opportunity for sharing information and drawing up educational outcomes for the child. This is a three hour process and includes all the role players involved with the child. The parents are considered to be very important role players in this process as they bring with them valuable information and knowledge of the child. During this process the occupational therapist shares her professional knowledge of the child based on assessment and ongoing evaluation of the child in therapy. The occupational therapist also plays a role in social events hosted by the school and therefore has contact with the learners and their families during these events.

3.7.2. Transferability

The intention of this research was not to generalize, as the results reflected the experiences of only ten people. However, the concept of transferability (Krueger & Casey, 2002:202) suggests that others may consider whether these finding could be applicable in other contexts.

3.7.3. Dependability

Dependability according to Lincoln and Guba (1989) is concerned with the constancy of the data in due course of the study. Changes or shifts in methodology are expected in research as a product of an emergent design. Although such changes threaten dependability, they are according to Lincoln and Guba (1989) characteristics of successful inquiry and should be tracked and trackable. This will enable an outside reviewer to explore the process and consider the conclusions that were arrived at in order to develop an understanding of the key element that influenced the researcher's conclusions and understandings.

3.7.4. Confirmability

Lincoln and Guba (1989) state that *confirmability* ensures that the data, interpretations of the data and the results are separate from the researcher. This means that data can be tracked to their sources and the reasons used to construct the interpretations coherently and collaboratively is clear and understood in the narratives of the study.

Data triangulation is a method of establishing confirmability. Ideally three sources of information support confirmability. Although the researcher had mainly two sources namely the mother and the researcher herself, there were three sources from which data was obtained. This included data about the child, data from the mother, and the researchers own impressions and understanding. Data triangulation according to Hammell, Carpenter and Dyck (2000) is based on the premise that a collection of a number of views and perception will substantiate the data obtained ensuring that all aspects of the phenomena have been considered. Data triangulation was used by gathering information from multiple sources. The data included the mothers' response in the semi-structured interviews, Sensory Profiles of the children with autism, Adolescent/Adult Sensory Profiles of the mothers, transcribed data from the two audio taped focus groups and the researcher's field notes.

3.8. Ethical considerations

Walliman (2006) states that issues around ethical behaviour is of particular importance in social research and other research that study people and their relationship to each other and the world. The participants according to Walliman (2006) need to be treated with appropriate ethical consideration concerning their involvement and the information they provide. Walliman (2006:148) proposes two perspectives from which ethical issues in research can be viewed. The first being "*values of honesty, frankness and personal integrity*" and the second deals with "*ethical responsibilities to the subjects of the research, such as consent, confidentiality and courtesy*".

General ethical considerations included permission from all parties concerned. Permission was obtained from the Department of Education and Vera School for Learners with Autism prior to the study.

During the participant selection process, the nature, purpose and duration of the study was explained and voluntary participation was sought. Participants were informed that they may withdraw from the study at any time if they wished to do so. Participants were informed that interviews and the focus group would be audio-taped. Walliman (2006) proposed that transparency in the research process is needed as well as informed consent and protection of identity. The protection of human rights was ensured by obtaining informed written consent and protection of identity (Hammell, Carpenter & Dyck, 2000). Informed written consent was obtained from the adult participants, consenting to their own participation in the study. As the children with autism were not participating directly in the study, the mothers gave consent for the researcher to use information that the Sensory Profiles provided about the child and also information that they, themselves provided.

The children with autism were not directly involved in the information gathering process, as all the information regarding their sensory processing and behavioural traits was provided by their mothers.

Walliman (2006) states that research into human situations can bring up information of a sensitive nature. The researcher was aware of the personal nature of the information on the mothers sensory processing and the sensory processing of her child and was aware that the situation had to be dealt with in a sensitive manner. Therefore individual

feedback sessions where scheduled with the mothers to provide them with the information in a non threatening environment. The researcher was very aware of terminology used in the feedback session ensuring not to come across as being accusatory but merely interpreting the situation from a sensory processing perspective.

All data was safely stored and the participants were informed that the audio-tapes would be destroyed once the data has been analyzed and the study was completed. Confidentiality was ensured and maintained by non-disclosure of identity in the reporting of results.

In conclusion, in this chapter I described the theoretical background of the methodology, the research methods used and the data collection process. In the next chapter I present the results.

3.9 Limitations of the study

One of the limitations of this study is that generalisability of results cannot be inferred. This was a qualitative study with a small sample size. The purpose of the study was to obtain deeper understanding and not to provide causal relationships typical of quantitative research.

Another limitation was that two mothers did not participate in the focus groups. Their views, opinions and experiences were therefore not captured in the data. The omission of their contribution could have influenced the data and therefore the results.

CHAPTER 4

Results: Presentation and Discussion

4.1. Phase one - Results of the analysis of the sensory profiles

In this section I report the results of the sensory profiles of ten mothers and their children. The purpose of these results were to inform the mothers of their own and their child's sensory processing traits.

The sensory profiles were scored and interpreted as prescribed by Dunn (1999) and Brown and Dunn (2002). Information from the semi-structured interviews was used to support or explain information from the sensory profiles.

Results of the analysis of the Sensory Profiles for the children with autism revealed that most of the children scored high in all four of the quadrants (low registration, sensory sensitive, sensory seeking and sensory avoiding). This would mean that they would present with behaviours more than or much more than most people in all four of the sensory quadrants. The child would present with increased low registration, increased sensory sensitivity, sensation seeking and sensation avoiding behaviours more than the typical response. This is in accordance with Dunn's findings that children with autism engage more frequently in behaviours on the Sensory Profile and the items were more scattered across all factors on the profile (Dunn, 1999).

Since almost all the children present with high scores in all four quadrants of the sensory profile, it would imply that their behaviours would fluctuate as their sensory responses

fluctuate. They could at times not register sensations and at other times would be sensitive to the same sensation. They could seek a sensation and also avoid the same sensation on another occasion. As most of the children presented with a similar picture of fluctuation between the quadrants, sensory compatibility issues were examined against the variations of the mother's profiles. Each case study is presented in a table representing both mother and child performance in the different sensory quadrants in terms of standard deviations and a table reflecting behavioural descriptions, followed by a discussion of sensory compatibility for the parent and child. It is important to bear in mind that the sensory profile is a subjective questionnaire therefore the interpretation is based on the information provided by the mothers. Also this is strictly an interpretation of sensory compatibility based on the mother and child's sensory processing, and other factors may influence the dynamics of the parent-child relationship, such as personality, environment and culture. Brown and Dunn (2002) state that there are no good or bad sensory processing preferences and it should be considered if an individual's sensory processing preferences are an advantage or disadvantage to the individual and his or her life situation.

Case study 1:

Table 2: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 1 and Child 1.

	Passive		*Active*	
High Neurological Threshold	**Low Registration**		**Sensation Seeking**	
	Mother	Child	Mother	Child
	0	0	0	+2
Low Neurological Threshold	**Sensory Sensitive**		**Sensation Avoiding**	
	Mother	Child	Mother	Child
	+1	+1	0	+1

Table 3: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 1 and Child 1.

Low Registration		**Sensation Seeking**	
Mother 1	Child 1	Mother 1	Child 1
SD 0: Similar to most people	SD 0: Similar to most people	SD 0: Similar to most people	SD +2: Much more than most people Auditory processing: Enjoys noises/seeks to make noise for the noise's sake. Movement processing: Seeks all kinds of movement and this interferes with daily routines. Touch processing: Touches people an objects Doesn't seem to notice when face or hands are messy. Modulation of movement affecting activity levels: "On the go". Avoids quiet play activities.

Sensory Sensitive		**Sensation Avoiding**	
Mother 1	Child 1	Mother 1	Child 1
SD +1: more than most people Movement processing: Afraid of heights. Becomes dizzy easily. Visual processing: Bothered by unsteady or fast moving visual images in movies or TV. Touch processing: Is bothered by the feeling in her mouth when she wakes up in the morning. Finds certain fabrics uncomfortable. Auditory processing: Is distracted if there is a lot of noise around. Finds it difficult to work with background noise.	**SD +1: More than most people** Auditory processing: Distracted or has trouble functioning if there is a lot of noise around. Touch processing: Expresses distress during grooming. Expresses discomfort during tooth brushing. Becomes irritated by shoes and socks. Taste/smell processing: Will only eat certain tastes. Picky eater regarding food textures.	SD 0: Similar to most people	**SD +1: More than most people** Auditory processing: Holds hands over ears to protect them from sound. Social and emotional responses indicative of sensation avoiding: Rigid rituals in personal hygiene. Has definite fears. Seems anxious. Is stubborn and uncooperative. Has temper tantrums. Poor frustration tolerance. Overly serious. Difficulties making friends.

Analysis of sensory quadrants:

Mother 1 presents with sensory sensitivity. According to Brown and Dunn (2002) items that correspond to the Sensory Sensitive quadrant measures a passive behavioural response associated with a low neurological threshold. Sensory Sensitive items identify responses such as noticing behaviours, distractibility, and discomfort with sensations. This mother is sensory sensitive to movement and is afraid of heights and becomes dizzy easily. Her behaviour indicates sensory sensitivity to visual stimuli and she is bothered by unsteady or fast moving visual images in movies or TV. The child however seeks all kinds of movement and this interferes with daily routines and this may bother this mother.

The mother is sensitive to touch and is uncomfortable wearing certain fabrics. The child is also sensitive to touch. The mother may have better insight into the child's difficulties

with processing touch input as she has the experiences of touch sensitivity. However the child also seeks touch at times and this could bother the mother.

The mother is auditory sensitive and is distracted if there is a lot of noise around and finds it difficult to work with background noise. The child both seeks and avoids auditory input.

Being sensory sensitive, this mother is likely to have an increased level of awareness of her environment and in turn could be irritated by her child's sensation seeking behaviour but she would also have good insight into her child's sensitivities and is likely to be more in tune with his needs therefore influencing the mother child relationship positively.

Case study 2:

Table 4: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 2 and Child 2.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother 0 Child +1	**Sensation Seeking** Mother -1 Child 0
Low Neurological Threshold	**Sensory Sensitive** Mother 0 Child +2	**Sensation Avoiding** **Mother** 0 **Child** +2

Table 5: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 2 and Child 2.

Low Registration		**Sensation Seeking**	
Mother 2	Child 2	Mother 2	Child 2
SD 0: Similar to most people	**SD +1: More than most people** Has low tone and endurance.	**SD -1: Less than most people** Visual processing: Seldom likes going to places that have bright lights. Seldom likes to wear colourful clothing. Touch processing: Almost never touches others when talking. Activity level: Almost never finds activities to perform in front of others. Auditory processing: Almost never hums, whistles, sings or make other noises.	SD 0: Similar to most people

Sensory Sensitive		**Sensation Avoiding**	
Mother 2	Child 2	Mother 2	Child 2
SD 0: similar to most people	**SD +2: Much more than most people** <u>Auditory processing:</u> Is distracted or has trouble functioning if there is a lot of noise around. <u>Visual processing:</u> Is bothered by bright lights after others have adapted to the light. <u>Movement processing:</u> Dislikes activities where her head is upside down. <u>Touch processing:</u> Expresses distress during grooming. Prefers long-sleeved clothing when it's warm. Expresses discomfort during dental work or toothbrushing. Is sensitive to certain fabrics. Is irritated by shoes. Rubs or scratches out a spot that has been touched. <u>Taste/smell processing:</u> Avoids certain tastes or food smells that are typically part of children's diets. Will eat only certain tastes. Limits herself to only particular food textures and temperatures. Picky eater.	SD 0: Similar to most people	**SD +2: Much more than most people** <u>Auditory processing:</u> Responds negatively to unexpected or loud noises. Can't work with background noises. <u>Visual processing:</u> Expresses discomfort with or avoids bright lights. Covers eyes or squints to protect eyes from light. <u>Touch processing:</u> Avoids getting messy. Reacts emotionally or aggressively to touch. Withdraws from splashing water. <u>Modulation of movement affecting activity level::</u> Prefers quiet sedentary play.

Analysis of quadrant scores:

Mother 2 presents with sensory seeking behaviour less than most people. According to Brown and Dunn (2002) low scores in sensation seeking suggests that the individual does not create additional sensory stimuli and is not actively involved in intensifying the sensory environment.

Child 2 presents with low registration more than most people, sensory sensitivity much more than most people and sensory avoiding behaviour much more than most people. The mother describes the child's challenging behaviours around grooming activities. Hair washing, brushing teeth and washing her belly button and behind her ears is difficult for the child as a result of her sensory sensitivities. When asked how she deals with the challenging behaviour the mother stated:

> *I am fortunate that her teacher washes her hair at school. It has become impossible for me. I avoid washing in these two areas as she totally refuses to let me.*

The mother avoids conflict with the child by not forcing her into situations that she is not comfortable with or by avoiding the situation completely by letting someone else deal with it. This mother may not add additional sensory stimuli to her environment, therefore not giving her sensory sensitive child opportunities to experience and to habituate to sensations.

Case study 3:

Table 6: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 3 and Child 3.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother +2 Child +2	**Sensation Seeking** Mother 0 Child +2
Low Neurological Threshold	**Sensory Sensitive** Mother +1 Child +2	**Sensation Avoiding** Mother 0 Child +2

Table 7: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 3 and Child 3.

Low Registration		**Sensation Seeking**	
Mother 3	Child 3	Mother 3	Child 3
SD +2: much more than most people Movement processing: Unsure of footing when walking on stairs. Visual processing: Doesn't notice when people come into the room. Touch processing: Doesn't notice when her hands or face is dirty. Gets scrapes or bruises but doesn't remember how she got them. Activity level: It takes her more time than other people to wake up in the morning.	**SD +2: much more than most people** Auditory processing: Appears not to hear what you say. Doesn't respond when her name is called but her hearing is OK. Multisensory processing: Leaves clothes twisted on body. Sensory processing related to tone and endurance: Has low tone and endurance	SD 0: Similar to most people	**SD +2: Much more than most people** Movement Processing: Seeks all kinds of movement and this interferes with daily routines. Seeks out all kinds of movement activities. Rocks unconsciously. Rocks in desk/chair/on floor. Touch Processing: Doesn't seem to notice when face or hands are messy. Multisensory processing: Hangs on people, furniture, or objects even in familiar situations. Taste and smell processing:

			Shows a strong preference for certain tastes. Craves certain foods. <u>Modulation of movement affecting activity level:</u> Becomes overly excitable during movement activities. <u>Modulation of sensory input affecting emotional responses:</u> She is overly affectionate with others.
Sensory Sensitive		**Sensation Avoiding**	
Mother 3	Child 3	Mother 3	Child 3
SD +1: more than most people <u>Movement processing:</u> She is afraid of heights. She becomes dizzy easily. <u>Visual processing:</u> She is bothered by unsteady or fast moving visual images in movies or TV. She becomes bothered when she sees a lot of movement around her. <u>Touch processing:</u> She is bothered by the feeling in her mouth when she wakes up in the morning. She is uncomfortable wearing certain fabrics. <u>Auditory processing:</u> She startles easily at unexpected or loud noises	**SD +2: much more than most people** <u>Auditory processing:</u> Has trouble completing a task when the radio is on. Is distracted or has trouble functioning if there is a lot of noise around. <u>Visual processing:</u> Is bothered by bright lights after others have adapted to the light. <u>Movement processing:</u> Becomes anxious or distressed when feet leave the ground. Dislikes activities where head is upside down. Dislikes riding in a car. <u>Touch processing:</u> Expresses distress during grooming. Expresses discomfort at dental work or toothbrushing. Is sensitive to certain fabrics. Becomes irritated by shoes or socks. Rubs or scratches out a spot that has been touched. <u>Taste and smell processing:</u> Avoids certain tastes or food smells that are typically part of children's diets. Will only eat certain tastes. Limits self to particular food textures/temperatures.	SD 0: similar to most people	**SD +2: much more than most people** <u>Auditory processing:</u> Responds negatively to loud or unexpected noises. Holds hands over ears to protect ears from sound. Can't work with background noise. <u>Visual processing:</u> Expresses discomfort with or avoids bright lights. Covers eyes or squints to protect eyes from light. <u>Movement processing:</u> Avoids playground equipment or moving toys. <u>Touch processing:</u> Avoids getting messy. Withdraws from splashing water. <u>Taste and smell processing:</u> Gags easily with food textures or food utensils in mouth. <u>Modulation related to body position and movement:</u> Hesitates going up or down curbs or steps. <u>Modulation of movement affecting activity level:</u> Seeks/prefers quiet/sedentary play activities. <u>Emotional/social responses:</u> Has definite fears. Seems anxious. Displays excessive emotional outbursts when unsuccessful at a task. Is stubborn and uncooperative Has temper tantrums. Has poor frustration tolerance and cries easily.

Analysis of quadrant scores:

Child 3 has low registration much more than most people, sensory sensitivity much more than most people, sensation seeking behaviour much more than most people and sensation avoiding behaviour much more than most people. She fluctuates between the quadrants making her responses to situations erratic and unpredictable. This was confirmed by her mother in the semi-structured interview when she described the child's challenging behaviours.

> *…mood swing and moaning. The thing that drives me nuts – I will for example ask her if she wants a sweet. She will say yes, then I give it to her and she changes her mind and cries and says that she does not want it anymore. When I take it away, she cries and wants it over and over again.*

The mother has low registration and sensory sensitivity. She may fluctuate between high and low thresholds, sometimes missing information and at other times being very aware of her environment. According to Brown and Dunn (2002) people who have high scores for both low registration and sensory sensitivity tend to interact passively with their environment and are more likely to accept situations and circumstances instead of trying to change them. This mother is more likely to cope with her child's challenging behaviours as people with low registration find it easier to focus on tasks of interest in distracting environments and tend to be more flexible and comfortable in a wide range of sensory environments.

Case study 4:

Table 8: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 4 and Child 4.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother 0 Child +1	**Sensation Seeking** Mother 0 Child +2
Low Neurological Threshold	**Sensory Sensitive** Mother +1 Child +2	**Sensation Avoiding** Mother +1 Child +1

Table 9: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 4 and Child 4.

Low Registration		**Sensation Seeking**	
Mother 4	Child 4	Mother 4	Child 4
SD 0: similar to most people	**SD +1: more than most people** Auditory processing: Appears not to hear what you say. Doesn't respond when name is called but hearing is OK. Multisensory processing: Leaves clothes twisted on body. Sensory processing related to tone and endurance: Poor endurance/tires easily.	SD 0: similar to most people	**SD +2 much more than most people** Auditory processing: Enjoys strange noises/seeks to make noise for the noise's sake. Movement processing: Seeks all kinds of movements and this interferes with daily routines. Seeks out all kinds of movement activities. Occasionally twirls/spins self frequently throughout the day. Occasionally rocks in desk/chair/on floor. Touch processing: Avoids wearing shoes; loves to be barefoot.

			Touches people and objects. Taste and smell processing: Shows strong preferences for certain tastes. Craves certain foods. Seeks out certain tastes or smells. Modulation related to body position and movement: Takes excessive risks during play. Takes movement or climbing risks during play that compromises personal safety. Turns whole body to look at you. Appears to enjoy falling. Modulation affecting activity level: Becomes overly excitable during movement activities. "On the go". Avoids quiet play.
Sensory Sensitive		**Sensation Avoiding**	
Mother 4	Child 4	Mother 4	Child 4
SD +1: more than most people Movement sensitivity: Afraid of heights. Becomes dizzy easily. Visual sensitivity: Becomes frustrated when trying to find something in a crowded drawer or messy room. Touch sensitivity: Uncomfortable wearing certain fabrics. Auditory sensitivity: Occasionally startles easily at unexpected or loud noises. Is distracted if there is a lot of noise around. Finds it difficult to work with background noise.	**SD +2 much more than most people** Auditory processing: Is distracted or has trouble functioning if there is a lot of noise around. Touch processing: Expresses distress during grooming. Prefers long-sleeved clothing when it is warm and short sleeves when it is cold. Expresses discomfort at dental work or toothbrushing. Becomes irritated by shoes and socks. Multisensory processing: Has difficulty paying attention. Looks away from tasks to notice all actions in the room. Oral processing: Avoids certain tastes or food smells that are typically part of children's diets. Will only eat certain tastes. Limits self to particular food textures/temperatures. Is a picky eater regarding food textures.	**SD +1: more than most people** Visual avoiding: Chooses to shop in smaller stores because she is overwhelmed in large stores. Limit distractions when working. Activity level: Stays away from crowds. Avoids situations where unexpected things might happen. Auditory avoiding: Leaves the room when others are watching TV, or asks them to turn it down. Uses strategies to block out sound. Stays away from noisy settings.	**SD +1: more than most people** Auditory processing: Holds hand over ears to protect ears from sound. Emotional/social responses: Is stubborn or uncooperative. Has temper tantrums. Poor frustration tolerance. Cries easily. Has difficulty making friends.

Analysis of sensory quadrants:

Mother 4 presents with sensory sensitive behaviour more than most people and sensation avoiding behaviour more than most people. The child presents with low registration more than most people and sensory sensitivity much more than most people. He also presents with sensation seeking behaviour much more than most people and sensation avoiding behaviour more than most people. The child fluctuates between the four quadrants making his responses erratic and unpredictable. Although he is auditory sensitive, he tends to make noise and enjoys strange noises. He also seeks movement. The mother is sensory sensitive to auditory and movement stimuli and may be easily bothered by the child's seeking behaviour. In describing her child's challenging behaviour, she stated:

> *…Disagreeing, arguing about thing. He perseverates and gets quite loud…inability to modulate in crowded/busy places. He fixates on things and any attempt to make him move makes him louder. He fixates and repeats things over and over.*

Sensory sensitivity and sensation avoiding behaviour indicate a low neurological threshold response. Individual with a low threshold require a lower amount or intensity of stimuli to become aware of and respond to stimuli (Brown & Dunn 2002). Therefore the mother is easily bothered by the child's seeking behaviour. The mother also fluctuates between passive (Sensory Sensitive) and active (Sensory Avoiding) responses therefore her response to situations will depend on whether she is acting in accordance to her threshold or acting against it. Therefore there could potentially be opportunities for conflict in this mother-child relationship.

Case study 5:

Table 10: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 5 and Child 5.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother +1 Child +2	**Sensation Seeking** Mother -2 Child +2
Low Neurological Threshold	**Sensory Sensitive** Mother +2 Child +2	**Sensation Avoiding** Mother +1 Child +2

Table 11: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 5 and Child 5.

Low Registration		**Sensation Seeking**	
Mother 5	Child 5	Mother 5	Child 5
SD +1: more than most people Taste and smell processing: Occasionally doesn't smell things that other people say they smell. Movement processing: Unsure of footing when walking on stairs. Visual processing: Occasionally misses the street, building, or room signs when trying to go somewhere new. Doesn't notice when people come into the room. Touch processing: Occasionally doesn't seem to notice when face or hands are dirty.	**SD +2: much more than most people** Auditory processing: Appears not to hear what you say. Multisensory processing: Leaves clothes twisted on body. Sensory processing related to tone and endurance: Tires easily especially when standing or holding particular body positions. Can't lift heavy objects. Poor endurance/tires easily. Appears lethargic. Modulation related to body position and movement: Seems accident prone.	**SD -2: much less than most people** Movement processing: Seldom enjoys how it feels to move about. Seldom choose to engage in physical activities. Visual processing: Almost never likes to wear colourful clothing. Touch processing: Almost never likes how it feels to get her hair cut. Almost never touches others when talking. Activity level: Almost never does things on the spur of the moment. Almost never finds activities to perform in	**SD +2: much more than most people** Movement seeking: Seeks all kinds of movements and this interferes with daily routines. Seeks out all kind of movement activities. Rocks in desk/chair/on floor. Touch processing: Touches people and objects to the point of irritating others. Displays an unusual need for touching certain toys, surfaces, or textures. Always touches people and objects.

Occasionally gets scrapes or bruises but does not remember how she got them. Activity level: Occasionally seems slower than others when trying to follow an activity or task. Occasionally does not get jokes as quickly as others. Auditory processing: Occasionally has trouble following what people are saying when they talk fast or about unfamiliar topics. Occasionally does not notice when her name is called. Occasionally has to ask people to repeat things.		front of others. Auditory processing: Almost never hums, whistles, sings, or make other noises.	Doesn't seem to notice when face or hands are messy. Multisensory processing: Hangs on people, furniture, or objects even in familiar situations. Taste and smell processing: Routinely smell non food objects. Shows a strong preference for certain tastes. Craves certain foods. Seeks out certain tastes or smells. Modulation related to body position and movement: Turns whole body to look at you. Modulation of movement affecting activity levels: Becomes overly excited during movement activity. "On the go". Modulation of sensory input affecting emotional responses: Is overly affectionate with others.
Sensory Sensitive		**Sensation Avoiding**	
Mother 5	Child 5	Mother 5	Child 5
SD +2: much more than most people Taste and smell processing: Does not like strong tasting mints or candies. Movement processing: Afraid of heights. Dislikes the movement of riding in a car. Visual processing: Becomes frustrated when trying to find something in a crowded drawer or messy room. Is bothered by unsteady or fast moving visual images in movies or TV. Touch processing: Dislikes having her back rubbed. Is uncomfortable wearing certain fabrics. Auditory processing: Is distracted if there is a lot of noise around.	**SD +2: much more than most people** Auditory processing: Is distracted or has trouble functioning if there is a lot of noise around. Movement processing: Dislikes activities where head is upside down. Touch processing: Expresses distress during grooming. Prefers long-sleeved clothing when it is warm or short sleeves when it is cold. Expresses discomfort at dental work or toothbrushing. Multisensory processing: Has difficulty paying attention. Looks away from tasks to notice all actions in the room. Taste and smell processing: Avoids certain tastes or food smells that are typically part of children's diets.	**SD +1: more than most people** Touch processing: Moves away when others get too close to her. Avoids standing in lines or standing close to other people. Activity level: Avoids situations where unexpected thing might happen. Auditory processing: Occasionally asks people to turn down the TV. Occasionally stays away from noisy settings.	**SD +2: much more than most people** Auditory processing: Responds negatively to unexpected or loud noises. Holds hands over ears to protect ears from sound. Touch processing: Avoids getting messy. Withdraws from splashing water. Taste and smell processing: Gags easily with non food textures or food utensils in mouth. Modulation related to body position and movement: Hesitates going up or down curbs or steps. Modulation of sensory input affecting emotional responses: Rigid rituals in personal hygiene. Emotional/social responses: Has definite fears. Seems anxious. Displays excessive

	Will only eat certain tastes. Limits self to particular food textures/temperatures. Picky eater, especially regarding food textures. <u>Modulation related to body position and movement:</u> Fears falling or heights. Avoids climbing/jumping or avoids bumpy/uneven ground.		emotional outbursts when unsuccessful at a task. Is stubborn and uncooperative. Has temper tantrums. Poor frustration tolerance. Cries easily. Overly serious. Has difficulty making friends.

Analysis of sensory quadrants:

Mother 5 presents with low registration more than most people and sensory sensitivity much more than most people. She seeks sensations much less than most people, confirming that she is sensation avoiding.

Child 5 presents with low registration much more than most people, sensory sensitivity much more than most people, sensation seeking much more than most people and sensation avoiding much more than most people. He fluctuates between the four quadrants making his responses to situations erratic and unpredictable as described by his mother in the challenging behaviour questionnaire.

> *…impatient, shouts when he talks. He won't sleep in his own bed, won't sit in a room alone and play or watch videos'. Someone has to be with him all the time. Even when he baths, he must be able to see one of us. When K comes home from school he wants all our attention and we can do nothing but what K wants to do. Even us going to the toilet upsets him as he can't see us and the same when we bath.*

Since the mother has sensory sensitive behaviour and sensation avoiding behaviour, she presents with a low neurological threshold response which means that her thresholds are easily activated by low intensities of stimuli. She fluctuates between active (avoiding) and passive (sensitive) responses but has more of a tendency for passive responses as she also has low registration. She is more likely to become overwhelmed by her child's

challenging behaviour. She describes the conflict in their relationship when asked to describe how she deals with the child's challenging behaviour.

> *We try to prevent it, avoid it as it disrupts the household and it takes long to settle him down. It causes arguments between my husband and I and my daughter. K gets sent to his room when we can not take it anymore. K does not like the word no! Weekends are very challenging. We find it worse when we challenge him as we are tired of the fighting and arguing as it is a daily routine in our house with K. We can only take so much a day.*

Case study 6:

Table 12: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 6 and Child 6.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother 0 Child +2	**Sensation Seeking** Mother 0 Child +1
Low Neurological Threshold	**Sensory Sensitive** Mother 0 Child +2	**Sensation Avoiding** Mother 0 Child +1

Table 13: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 6 and Child 6.

Low Registration		**Sensation Seeking**	
Mother 6	Child 6	Mother 6	Child 6
SD 0: similar to most people	**SD +2: much more than most people** Auditory processing: Appears to not hear what you say. Doesn't respond when name is called but hearing is OK. Multisensory processing: Gets lost easily (even in familiar places). Seems oblivious within an active environment. Leaves clothes twisted on body. Sensory processing related to tone and endurance: Tires easily, especially when standing or holding particular body positions. Has weak grasp. Poor endurance/tires easily.	SD 0: similar to most people	**SD +1: more than most people** Movement processing: Seeks all kinds of movement and this interferes with daily routines. Seeks out all kinds of movement activities. Twirls/spins self frequently throughout the day. Rocks in desk/chair/on floor. Touch processing: Doesn't seem to notice when face or hands are messy. Multisensory processing: Hangs on people, furniture, or objects even in familiar situations. Modulation related to body position and movement: Takes excessive risks during play.

			Modulation of movement affecting activity level: "on the go" Modulation of sensory input affecting emotional responses: Is overly affectionate with others.
Sensory Sensitive		**Sensation Avoiding**	
Mother 6	Child 6	Mother 6	Child 6
SD 0: similar to most people	**SD +2: much more than most people** Auditory processing: Has trouble completing tasks when the radio is on. Is distracted or has trouble functioning if there is a lot of noise around. Touch processing: Expresses distress during grooming. Expresses discomfort at dental work or toothbrushing. Is sensitive to certain fabrics. Multisensory processing: Has difficulty paying attention. Looks away from tasks to notice all actions in the room. Taste and smell processing: Avoids certain tastes or food smells that are typically part of children's diets.	SD 0: similar to most people	**SD +1: more than most people** Auditory processing: Responds negatively to unexpected or loud noises. Holds hands over ears to protect them from sound. Visual processing: Happy to be in the dark. Touch processing: Withdraws from splashing water. Emotional/social responses: Has definite fears. Seems anxious. Displays excessive emotional outbursts when unsuccessful at a task. Is stubborn and uncooperative. Poor frustration tolerance. Cries easily. Overly serious. Has difficulty making friends. Has fears that interfere with daily routines.

Analysis of sensory quadrants:

Mother 6 presents with typical behaviour in all four quadrants of the sensory profile. The child presents with low registration to sensations much more than most people, sensory sensitive behaviour much more than most people, sensation seeking behaviour more than most people and sensation avoiding behaviour more than most people. He fluctuates between the quadrants; therefore his behaviours are erratic and unpredictable. The mother

describes challenging behaviour of her child, playing with his saliva and flicking it over objects. When asked how she deals with the challenging behaviour, she stated,

I always challenge him and command him to stop.

As this mother presents with typical scores in all four quadrants, she is more likely to be able to cope with her child's challenging behaviour. She may also have limited insight into her child's difficulties as she does not have the experience of having sensory difficulties her self, therefore she cannot reflect on how it feels.

Case study 7:

Table 14: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 7 and Child 7.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother 0 Child +1	**Sensation Seeking** Mother 0 Child +2
Low Neurological Threshold	**Sensory Sensitive** Mother 0 Child +2	**Sensation Avoiding** Mother 0 Child +2

Table 15: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 7 and Child 7.

Low Registration		**Sensation Seeking**	
Mother 7	Child 7	Mother 7	Child 7
SD 0: similar to most people	**SD +1: more than most people** Auditory processing: Appears to not hear what you say. Doesn't respond when name is called but hearing is OK. Multisensory processing: Gets lost easily (even in familiar places). Seems oblivious within an active environment. Sensory processing related to endurance and tone. Moves stiffly.	SD 0: similar to most people	**SD +2: much more than most people** Auditory processing: Enjoys strange noises/seeks to make noise for the noises sake. Movement processing: Seeks all kinds of movement and this interferes with daily routines. Seeks out all kinds of movement activities. Twirls/spins self frequently throughout the day. Rocks unconsciously. Rocks in desk/chair/on floor. Touch processing: Touches people and objects to the point of irritating others. Avoids wearing shoes; loves to be barefoot. Touches people and

			objects. Taste and smell processing: Routinely smells nonfood objects. Shows a strong preference for certain tastes. Craves certain foods. Seeks out certain tastes or smells. Modulation related to body position and movement. Takes excessive risks during play. Takes movement or climbing risks during play that compromises personal safety. Turns whole body to look at you. Modulation of movement affecting activity level: "On the go".
Sensory Sensitive		**Sensation Avoiding**	
Mother 7	Child 7	Mother 7	Child 7
SD 0: similar to most people	**SD +2: much more than most people** Auditory processing: Has trouble completing tasks when the radio is on. Is distracted or has trouble functioning if there is a lot of noise around. Movement processing: Becomes anxious or distressed when feet leave the ground. Dislikes activities where head is upside down. Touch processing: Expresses distress during grooming. Expresses discomfort at dental work or tooth brushing. Multi sensory processing: Has difficulty paying attention. Looks away from tasks to notice all actions in the room. Taste and smell processing: Avoids certain tastes or food smells that are typically part of children's diets. Will only eat certain tastes. Limits self to particular food textures/temperatures. Picky eater, especially regarding food textures.	SD 0: similar to most people	**SD +2: much more than most people** Auditory processing: Responds negatively to unexpected or loud noises. Holds hands over ears to protect them from sound. Can't work with background noise. Touch processing: Avoids getting messy. Reacts emotionally or aggressively to touch. Modulation related to body position and movement: Hesitates going up or down curbs or steps. Emotional/Social responses: Has definite fears. Seems anxious. Displays excessive emotional outbursts when unsuccessful at a task. Is stubborn or uncooperative. Has temper tantrums. Poor frustration tolerance. Cries easily. Has difficulty making friends.

Analysis of sensory quadrants:

The mother presents with typical scores in all four of the sensory quadrants. The child presents with low registration to sensations more than most people, sensory sensitive behaviour much more than most people, sensation seeking behaviour much more than most people and sensation avoiding behaviour much more than most people. He fluctuates between high and low thresholds and between passive and active behavioural responses. Therefore, his behaviour is erratic and unpredictable. He is sensory sensitive in all the sensory systems, yet, he seeks out the same sensations that he is sensitive to. His mother described behaviour that she finds challenging as follows:

> *Tantrums. He will sometimes out of the blue start screaming and biting his fingers and nothing can stop him.*

She described how she deals with the challenging behaviour,

> *After trying to give you hugs, he will push you away. I ignore him and let him scream on. He usually stops after 10 minutes.*

As a result of not experiencing sensory processing difficulties herself, this mother may be better able to cope with her child's challenging behaviours. However her insight into the extent of his difficulties may be limited.

Case study 8:

Table 16: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 8 and Child 8.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother +1 Child +2	**Sensation Seeking** Mother -1 Child +2
Low Neurological Threshold	**Sensory Sensitive** Mother +2 Child +2	**Sensation Avoiding** Mother +1 Child +2

Table 17: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 8 and Child 8.

Low Registration		**Sensation Seeking**	
Mother 8	Child 8	Mother 8	Child 8
SD +1: more than most people Touch processing: Gets scrapes or bruises but doesn't remember how she got them. Auditory processing: Has trouble following what people are saying when they talk fast or about unfamiliar topics. Has to ask people to repeat things.	**SD +2: much more than most people** Auditory processing: Appears not to hear what you say. Doesn't respond when name is called but hearing is OK. Multisensory processing: Gets lost easily. Seems oblivious within an active environment. Sensory processing related to tone and endurance: Tires easily, especially when standing or holding particular body postures. Props to support self (even during activity) Modulation related to body position and movement: Seems accident prone.	**SD -1: less than most people** Touch processing: Seldom touches others when talking. Seldom likes to go barefoot. Activity level: Seldom finds activities to perform in front of others.	**SD +2: much more than most people** Auditory processing: Has trouble completing tasks when the radio is on. Movement processing: Seeks all kinds of movements and this interferes with daily routines. Seeks out all kinds of movement activities. Rocks unconsciously. Rocks in desk/chair/on floor. Touch processing: Displays unusual need for touching certain toys, or textures. Avoids wearing shoes, loves to be barefoot. Touches people and objects. Doesn't seem to notice when face or hands are

			messy. Multisensory processing: Hangs on people, furniture, or objects even in familiar situations. Taste and smell processing: Routinely smells nonfood objects. Shows a strong preference for certain smells. Shows a strong preference for certain tastes. Craves certain foods. Seeks out certain tastes or smells. Modulation related to body position and movement: Takes excessive risks during play. Takes movement or climbing risks during play that compromises personal safety. Seeks opportunities to fall without regarding personal safety. Appears to enjoy falling. Modulation of movement affecting activity level: Becomes overly excitable during movement activity. "On the go". Modulation of sensory input affecting emotional responses: Is overly affectionate with others.
Sensory Sensitive		**Sensation Avoiding**	
Mother 8	Child 8	Mother 8	Child 8
SD +2: much more than most people Visual processing: Becomes frustrated when trying to find something in a crowded drawer or messy room. Bothered by unsteady or fast moving visual images in movies or TV. Touch processing: Bothered by the feeling in her mouth when she wakes up in the morning.	**SD +2: much more than most people** Auditory processing: Has trouble completing tasks when the radio is on. Is distracted or has trouble functioning if there is a lot of noise around. Visual processing: Is bothered by bright lights after others have adapted to the light. Movement processing: Occasionally dislikes riding in a car. Touch processing: Expresses distress during grooming. Prefers long-sleeved clothing when it is warm and short sleeves when it is cold.	**SD +1: more than most people** Taste/smell processing: Only eats familiar foods.	**SD +2: much more than most people** Auditory processing: Responds negatively to unexpected or loud noises. Holds hands over ears to protect them from sound. Can't work with background noise. Visual processing: Occasionally prefers to be in the dark. Expresses discomfort with or avoids bright lights. Covers eyes or squints to protect eyes from light. Movement processing: Avoids playground equipment or moving toys. Touch processing: Avoids getting messy. Reacts emotionally or

	Expresses discomfort at dental work or toothbrushing. Is sensitive to certain fabrics. Becomes irritated by shoes or socks. Rubs or scratches out a spot that has been touched. <u>Multisensory processing:</u> Has difficulty paying attention. Looks away from tasks to notice all actions in the room. <u>Taste/smell processing:</u> Avoids certain tastes or food smells that are typically part of children's diets. Will only eat certain tastes. Limits self to particular food textures/temperatures. Picky eater regarding food textures. <u>Modulation related to body position and movement:</u> Fears falling or heights.		aggressively to touch. <u>Taste/smell processing:</u> Gags easily with food textures or food utensils in mouth. <u>Modulation related to body position and movement:</u> Hesitates going up or down curbs or steps. <u>Modulation affecting activity level:</u> Spends most of the day in sedentary play. Prefers quiet, sedentary play. Seeks sedentary play options. Prefers sedentary activities. <u>Modulation of sensory input affecting emotional responses:</u> Rigid rituals in personal hygiene. <u>Emotional/social responses:</u> Has definite fears. Seems anxious. Displays excessive emotional outbursts when unsuccessful at a task. Is stubborn and uncooperative. Has temper tantrums. Poor frustration tolerance. Cries easily. Overly serious. Has difficulty making friends.

Analysis of sensory quadrants:

Mother 8 presents with low registration to sensations more than most people and sensory sensitive behaviour much more than most people. She seeks sensations less than most people, which confirms that she has a tendency to avoid sensations.

The child presents with behaviours much more than most people in all four of the sensory quadrants. He fluctuates between the quadrants. He seeks movement sensations which

could bother his mother as she easily becomes bothered by watching movement. He is touch, taste and smell sensitive just like his mother. She is not likely to challenge him in these areas as she also has aversions in the same areas. The child fluctuates between the four quadrants and the mother fluctuates between high (low registration) and low (sensory sensitive) neurological thresholds and also between being active (sensation avoiding) and passive (sensory sensitive) to her system. Both mother and child's responses fluctuate. This mother is more likely to be overwhelmed in different situations. Therefore there is a high potential for conflict between this mother and child.

Case study 9:

Table 18: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 9 and Child 9.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother 0 Child 0	**Sensation Seeking** Mother -1 Child +1
Low Neurological Threshold	**Sensory Sensitive** Mother 0 Child +1	**Sensation Avoiding** Mother +1 Child +2

Table 19: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 9 and Child 9.

Low Registration		**Sensation Seeking**	
Mother 9	Child 9	Mother 9	Child 9
SD 0: similar to most people	SD 0: similar to most people	**SD -1: less than most people** Visual processing: Seldom likes to go places that have bright lights and that are colourful. Touch processing: Almost never touches others when talking. Activity level: Almost never finds activities to perform in front of others. Auditory processing: Almost never hums, whistles, sings, or makes other noises.	**SD +1: more than most people** Auditory processing: Enjoys strange noises/seeks to make noise for the noise's sake. Movement processing: Seeks all kinds of movement and this interferes with daily routines. Seeks out all kinds of movement activities. Touch processing: Displays unusual need for touching certain toys, surfaces, or textures. Doesn't seem to notice when face or hands are messy. Multisensory processing: Hangs on people, furniture, or objects even in familiar situations. Taste/smell processing:

			Craves certain foods. Seeks out certain tastes or smells. <u>Modulation of movement affecting activity level:</u> Becomes overly excitable during movement activities. "On the go". <u>Modulation of sensory input affecting emotional responses:</u> Is overly affectionate with others.
Sensory Sensitive		**Sensation Avoiding**	
Mother 9	Child 9	Mother 9	Child 9
SD 0: similar to most people	**SD +1: more than most people** <u>Auditory processing:</u> Is distracted or has trouble functioning if there is a lot of noise around. <u>Touch processing:</u> Expresses discomfort at dental work or toothbrushing. <u>Multisensory processing:</u> Has difficulty paying attention. <u>Taste/smell processing:</u> Avoids certain tastes or food smells that are typically part of children's diets. Will only eat certain tastes. Limits self to particular food textures/temperatures. Picky eater, especially regarding food textures. <u>Modulation related to body position and movement:</u> Fears falling or heights.	**SD +1: more than most people** <u>Taste/smell processing:</u> Leaves or moves to another section when she smells a strong odor in a store. Only eats familiar foods. <u>Visual processing:</u> Limits distractions when she is working.	**SD +2: much more than most people** <u>Modulation related to body position and movement:</u> Hesitates going up or down curbs or steps. <u>Modulation of movement affecting activity level:</u> Spends most of the day in sedentary play. Prefers quiet, sedentary play. Seeks sedentary play options. Prefers sedentary activities. <u>Modulation of sensory input affecting emotional responses:</u> Rigid rituals in personal hygiene. <u>Emotional/social responses:</u> Has definite fears. Seems anxious. Displays excessive emotional outbursts when unsuccessful at a task. Is stubborn and uncooperative. Has temper tantrums. Poor frustration tolerance. Cries easily. Overly serious. Has difficulty making friends.

Analysis of sensory quadrants:

Mother 9 present with sensation seeking less than most people, which confirms that she avoids sensations. According to Brown and Dunn (2002:39) sensation avoiders are "*overwhelmed or bothered*" by stimuli. She has low scores for touch and auditory seeking. According to Brown and Dunn (2002), intervention is necessary for individuals who have low scores in sensation seeking if there is a lack of exploration or engagement with the sensory environment and if it interferes with the individual's performance in daily activities. This mother is bothered by her child's sensation seeking behaviour.

> *A challenging behaviour that I find with M is him being in my face all the time. He gives me butterfly kisses all the time and hugs me constantly. This might sound like loving behaviour, most of the time it's inappropriate. In shops, while I'm busy cooking, talking to someone, etc. After a while it becomes too much. Coming from a mother it does sound bad, but its not.*

Brown and Dunn (2002:39) state that "*sensation avoiders actively engage with their environments to reduce stimuli*". Individuals who avoid sensations according to Brown and Dunn create structured environments that limit sensory stimuli and enjoy being alone.

The child has sensory sensitive behaviour more than most people. He has sensory seeking behaviour more than most people and avoids sensations much more than most people. He tends to fluctuate between passive (sensory sensitive) and active (sensation avoiding) behavioural responses. He fluctuates between high (sensation seeking) and low (sensation avoiding) thresholds, and can be unpredictable in his responses. The mother is active to her system and will do whatever is necessary to make her sensory environment comfortable for her, therefore challenging her child in the process.

Case study 10:

Table 20: Results in terms of Standard Deviations of Sensory Profile quadrants for Mother 10 and Child 10.

	Passive	*Active*
High Neurological Threshold	**Low Registration** Mother 0 Child +2	**Sensation Seeking** Mother 0 Child +2
Low Neurological Threshold	**Sensory Sensitive** Mother 0 Child +2	**Sensation Avoiding** Mother 0 Child +2

Table 21: Results in terms of behavioural descriptions of Sensory Profile quadrants for Mother 10 and Child 10.

Low Registration		**Sensation Seeking**	
Mother 10	Child 10	Mother 10	Child 10
SD 0: similar to most people	**SD +2: much more than most people** <u>Auditory processing:</u> Appears not to hear what you say. Doesn't respond when name is called but hearing is OK. <u>Multisensory processing:</u> Gets lost easily. <u>Sensory processing related to tone and endurance:</u> Moves stiffly. Tires easily, especially when standing or holding particular body positions. Locks joints. Props to support self. <u>Modulation related to body position and movement:</u> Seems accident prone.	SD 0: similar to most people	**SD +2: much more than most people** <u>Movement seeking:</u> Seeks all kinds of movement and this interferes with daily routines. Seeks out all kinds of movement activities. Twirls/spins self frequently throughout the day. <u>Touch processing:</u> Touches people and others to the point of irritating others. Displays an unusual need for touching certain toys, surfaces, or textures. Avoids wearing shoes; loves going barefoot. Touches people and objects. Doesn't notice when face or hands are messy. <u>Multisensory processing:</u>

			Hangs on people, furniture, or objects even in familiar situations. Taste/smell processing: Shows a strong preference for certain tastes. Craves certain foods. Seeks out certain tastes or smells. Modulation related to body position and movement: Takes excessive risks during play. Takes movement or climbing risks during play that compromises personal safety. Turns whole body to look at you. Seeks opportunities to fall without regard to personal safety. Appears to enjoy falling: Modulation of movement affecting activity level: Becomes overly excitable during movement activities. "On the go".
Sensory Sensitive		**Sensation Avoiding**	
Mother 10	Child 10	Mother 10	Child 10
SD 0: similar to most people	**SD +2: much more than most people** Touch processing: Expresses distress during grooming. Expresses discomfort at dental work or toothbrushing. Multisensory processing: Has difficulty paying attention. Looks away from tasks to notice all actions in the room. Taste/smell processing: Avoids certain tastes or food smells that are typically part of children's diets. Will only eat certain tastes. Limits self to particular food textures/temperatures. Picky eater, especially regarding food textures. Modulation related to body position and movement: Fears falling or heights.	SD 0: 0: similar to most people	**SD +2: much more than most people** Auditory processing: Responds negatively to unexpected or loud noises. Holds hands over ears to protect them from sound. Visual processing: Occasionally prefers to be in the dark. Happy to be in the dark. Covers eyes or squints to protect them from light. Movement processing: Holds head upright, even when bending over or leaning. Modulation of movement affecting activity level: Spends most of the day in sedentary play. Prefers quiet, sedentary play. Seeks sedentary play options. Prefers sedentary activities. Emotional/social responses: Displays excessive emotional outbursts when

			unsuccessful at a task. Is stubborn and uncooperative. Has temper tantrums. Poor frustration tolerance. Overly serious. Has difficulty making friends.

Analysis of sensory quadrants:

Mother 10 presents with typical behaviour in all four of the sensory quadrants. The child presents with low registration to sensations much more than most people, sensory sensitivity much more than most people, sensation seeking behaviour much more than most people and sensation avoiding behaviour much more than most people. He fluctuates between the four quadrants. Therefore his behaviour can be unpredictable. Having no sensory processing difficulties herself, this mother will be better able to cope with her child's challenging behaviour. She described his challenging behaviour as screaming, crying, hitting and kicking type of tantrums. She described how she would cope with the behaviour.

> *I try a few things such as figuring out what the tantrum could be about and getting him what he would usually have to eat or play with. I just let the tantrum run its course because putting him in a room and closing the door doesn't help and getting angry also doesn't help. If I walk away he just follows me. Sometimes being sympathetic and calm, soothing voice helps to calm him down.*

From her description of her handling of the child this mother appeared to have a good understanding of the child. She is sensitive to his needs yet she provides him with the right challenge.

To conclude, the results of phase one, the ten case studies of mothers and their children's sensory processing traits, demonstrate the differences in the each mother and child case of their experience of sensations that affect their daily behaviour. These results formed part of the study to provide information to the mothers about their own and their child's sensory processing.

In the next section, I describe the findings that emerged from the focus groups that formed the second phase of the research.

4.2. Phase two: Findings from analysis of focus groups:

The focus groups were used to explore if and how the new knowledge that the mothers gained in completing the sensory profiles had impacted on their understanding of their child and if the process had an effect on their relationship with their child.

Several categories and three main themes emerged from the data. An over view of the themes and categories are illustrated in the table below and will be discussed in more detail.

Table 22: Themes and categories from focus groups.

Themes:	Categories:
You actually realize how similar you are to your child	• Discovering their own sensory processing • "We know them so well" • How this process has helped
I also have needs	• The mothers' expressing their needs • Having a child with special needs
They walk away and leave you with this wreck of a child	• The close emotional bond between the mother and child • The fathers role and understanding of the child

4.2.1. Theme 1: "You actually realize how similar you are to your child"

This theme reveals the mothers' experience of gaining new knowledge and insight into their own and their child's behavioural responses to sensory input by completing the sensory profiles. The data reveals the mothers' experience of gaining deeper understanding in their own sensory processing and how it helped them to better understand their child's sensory processing. The data suggests that the process has potential positive outcomes for their relationship with their autistic child. The mothers reflect on how the process has helped them.

4.2.1.1. Discovering their own sensory processing

Many of the mothers had not given their own sensory processing much thought prior to participation in this study. One mother said that when completing the profile the answers

did not come naturally to her and that she had to '*think back*' (focus group 29-11-2005). Other comments made by mothers were:

> *Personally it was something I had never thought about* (focus group 29-11-2005).
>
> *I had to recollect things...I thought I had forgotten about* (focus group 29-11-2005).
>
> *It really brought it back* (focus group 30-11-2005).

One mother said that that she knew '*certain things*' about herself but never associated them with her acting or responding to sensation in a particular way. This suggests that her knowledge about her sensory processing was not explicit. Although sub-consciously, she was aware of preferences or non-preferences she had in response to sensations. She stated:

> *You know you have those things but you never really think that, okay, this is why I'm doing, responding to a sensation* (focus group 30-11-2005).

When the mothers shared their experiences of completing their own sensory profile, one mother said that it was '*interesting*' (focus group 30-11-2005) completing the profile and another mother said that it described her exactly as she is (focus group 30-11-2005). Others said that it demanded introspection, for instance:

> *It asks you to look at your self from within* (focus group 30-11-2005).
>
> *It forces you to look at issues that you know subconsciously are there but you don't actually realize it or pay attention to it* (focus group 30-11-2005).

These statements suggest that the mothers, through a process of reflective introspection, came to a better understanding of their own behavioural responses. Another aspect of the mothers' developing insight into their own behaviour was that they gained a deeper

understanding of their challenges. Some of the mothers had known that they were not functioning at their optimum in certain areas due to sensory difficulties that they knew they had, but had not fully understood. For one mother, seeing it on paper in the Sensory Profile helped her realize that she had certain sensory issues. She said:

> *When you see yourself doing it on paper you think, okay, maybe I do pull up my nose and walk out a room when there's a funny smell, or maybe I am scared of height…You don't want to identify yourself with - I don't like that too much or I like this too much* (focus group 30-11-2005).

Another mother reflected on how the new found knowledge helped her understand her own behaviour in terms of sensory processing. She stated:

> *Putting it out there just makes it much more real. It makes you realize that we are supposed to be perfect but we are not. We've also got problems. I've got this thing about walking down stairs, even if its just two steps, I'll hold on. It's just this thing that I have* (focus group 29-11-2005).

Some mothers' interpretation of their own behaviour in response to sensory stimuli resulted in feelings of discomfort about their sensory processing challenges. It was not easy for some mothers to acknowledging their sensory preferences or to realise that their own behaviour was influenced by their processing preferences. They stated:

> *I think its stuff that you know, but maybe don't want to say* (focus group 30-11-2005).

> *You never look at it as yourself* (focus group 29-11-2005).

The difficulty in identifying ones own sensory processing traits emerged from the data, highlighting the fact that sensory processing is a tacit process. Some of the mothers found it challenging to make a choice on the different items of the sensory profile a challenge.

This suggests that these mothers experienced difficulties pin-pointing their own behaviour in response to sensations, as one of the mothers reported:

> *I had to make choices where you are on a borderline of something* (focus group 30-11-2005).

The mothers reflected on new insights into their coping strategies. Some of the mother acknowledged that their own sensory processing traits were in conflict with their need to be able to cope with their child and to meet the challenges of caring for a child with special needs. One other stated that she had to "*learn to overcome it*", "*live with it*" or "*cope*" (focus group 29-11-2005). According to the mothers, these sensory difficulties also "*build up*" (focus group 29-11-2005). The mothers refer to the cumulative effects of putting strain on their own sensory systems which could lead to more stress and in turn impede their ability to be functional and meet the challenges of caring for a child with special needs.

Many of the mothers in the study presented with sensory sensitivities. They reported such behaviours as avoiding sensations or seeking sensations less often as a result of being sensory sensitive. These characteristics were also seen in all of the children with autism. As a result of the extreme sensory sensitivities that are present in children with autism leads to the avoidance of certain sensations. The mothers, after understanding their own sensory processing, felt that they could better identify with their child's difficulties. One mother stated:

> *You actually realize how similar you are to your child* (focus group 29-11-2005).

The data thus revealed that completing their own sensory profiles was a process of self-discovery for many of the mothers. It resulted in an increased awareness of their own behaviours in response to sensations that many of the mothers had not previously considered. Despite the process being challenging, the mothers developed new insight and understanding of their own behaviour.

4.2.1.2. "We know them so well"

Even though some of the mothers experienced difficulties in making choices when completing their own sensory profiles, none of the mothers reported any difficulty in completing their child's sensory profile. The mothers were familiar with their child's sensory processing preferences and non preferences, as reflected by the child's behaviour in response to everyday situations. Their knowledge of their child stemmed from their close relationship with the child. Many of them also had basic knowledge of sensory processing from their exposure in the special school environment; therefore the language of sensory processing was not unfamiliar to them.

> *It was things I knew about, being in the school environment* (focus group 30-11-2005).

> *We knew he had those sensitivities or a lack thereof* (focus group 30-11-2005).

Other mothers attributed their knowledge of their child's sensory processing to the large amount of time that they spend with the child. They were familiar with their child's behaviour in response to various everyday situations. Even though they did not fully

understand the underlying reasons behind the behaviour from a sensory integrative perspective, the mothers knew their children well.

> *I didn't find it difficult because you see it all the time. Their ways become so well known to us* (focus group 29-11-2005).
>
> *They are with us all the time. We know them so well. We probably know everything about them* (focus group 29-11-2005).

One mother reflected on how the knowledge of her child's sensory processing had given her new insight into her child's abilities. She said that seeing that her child had sensory difficulties on the profile made her realize that there were limitations to what her child is able to do. She expressed her feelings about the new knowledge that she had gained, as follows:

> *Seeing it in black and white makes you realize…he can't do this or he can't do that…I felt I had mixed feelings with that* (focus group 30-11-2005).

Completing the sensory profiles and receiving feedback on the interpretation of the profiles appeared to enhance the mothers' knowledge and understanding of their child and his or her sensory processing traits.

4.2.1.3. How this process has helped

This category explores how the process of completing the sensory profiles and understanding sensory processing traits had helped the mothers understand more and cope better with their own sensory processing traits and with their child's sensory difficulties. One mother realized that she is sensory sensitive to noise and visual stimuli and could not understand why her child '*was the way he was*' (focus group 29-11-2005). She would often take her sensory seeking child to air shows and amusement parks to

meet his sensory seeking needs. However such activities resulted in challenges to her own sensory system. Understanding her own sensory processing and the sensory processing of her child helped her identify situations that pose challenges to her own sensory system and places strain on her relationship with her child. The process helped her reach an amicable solution.

> *It's helped me from a practical point of view. I know there's certain things that I shouldn't do because it puts strain on my system...I won't be able to operate, I'll be over stimulated. Now I won't do it. Someone else must take him* (focus group 29-11-2005).

In the case of the above example, the mother could formulate a strategy as a result of the insights gained by exploring her and her child's sensory processing. Another mother reflected on understanding her own sensory processing and the significance that this process had to her. She realized that there were alternate solutions that she could consider, instead of subjecting herself to situations that were unfavourable for her.

> *Having a child with special needs, you always try to be perfect and to be able to do everything, and with this you realize that there are issues that you have to deal with. Let someone else do it instead of forcing yourself into those situations* (focus group 29-11-2005)

The process of understanding sensory traits also brought new awareness in some mothers of alternative handling strategies for their children. New insight gained from the process of understanding her child's behaviour in response to sensations made one mother question her handling of her child. She wondered if the boundaries she had set for her child were too strict, after realizing the extent of his sensory difficulties.

> *I set very strict boundaries…so what I had to adjust to after I did the profile was are my boundaries maybe too strict?… Are we making many exceptions to the rules or are we overpowering him in certain situations where definitely you can*

> *see the sensory needs are sensitive in that area and we try to push him into it?...where in my area, I have the power to walk away* (focus group 30-11-2005).

She realized that she has sensory preferences and has the ability to make choices, whereas her non-verbal child is unable to express his feelings or needs regarding sensory issues. This process has helped her understand her child's sensory needs and limitations, therefore helping her to decide what realistic expectations would be of her child. Withdrawing on some of her boundaries and not forcing the child into situations that s are uncomfortable for him, or allowing him to engage in behaviours to meet his sensory needs, could help avoid power struggles between the mother and child and thus improve the quality of their relationship.

> *Am I over compensating because he is a child with problems or should I now cater for the sensory needs and relax on some of the boundaries…It guides you into what your limits are in certain areas* (focus group 30-11-2005).

Another mother had a similar experience and realized that her non-verbal child may have difficulties in understanding and expressing his sensory challenges.

> *When U throws tantrums I can also pull out my hair…….I realized that it must be a terrible situation for him to understand us and tell us what is wrong. It's very hard for him* (focus group 29-11-2005).

> *If you don't like something, you're not going to force it down on your child* (focus group 30-11-2005).

Understanding her own sensory processing had helped this mother realize that just as she has sensory preferences and non preferences, so does her child. She expresses how an understanding of one's own sensory experience could help one be more sensitive to the needs of the child. She uses the word 'force' in her statement, which has connotations of imposing, coercing or a power struggle. Therefore, an understanding of both the mother

and child's sensory processing needs and responding appropriately in turn could result in avoiding power struggles between the mother and child.

This process has helped many of the mothers in identifying the child's sensory needs and limitations. One mother said that although she had known certain things regarding her child's sensory processing she did not want to acknowledge them.

> *You know certain thing but you hide it behind you* (focus group 30-11-2005*).*

Another mother said that seeing her child's sensory difficulties on paper in the sensory profile and discussing the sensory issues made them more evident.

> *Putting it out there makes it much more real* (focus group 30-11-2005).

For many of the mothers, understanding their child's sensory processing helped them realize what is realistic to expect of their child.

> *It's helped me realize not to expect too much from K* (focus group 30-11-2005).

> *It's helped me realize that there are some things that are reasonable to expect of S and others that he can't do* (focus group 29-11-2005).

Another mother explained how understanding both her own and her child's sensory profiles helped her understand how friction arises in her interaction with her child. She is auditory sensitive and so is the child. Although the child is auditory sensitive, he seeks out noise and makes noises himself to block out extraneous noises. The mother is bothered by the noise that the child makes. The child becomes over stimulated from the volume of her voice when she tries to reprimand him and reacts negatively.

Understanding why he reacts the way that he does and making adjustments in her handling by exploring strategies to cope with her own sensitivities, helped avoid conflict. Therefore she made the situation less stressful for both herself and the child and in doing so, improved their relationship by reducing stress.

> *He picks up from my tone of voice and reacts and I always wondered why this child is reacting like this. I am now consciously trying to make an effort to keep to my normal voice when he does anything so he does not react in a negative way. It has definitely helped me realize that* (focus group 29-11-2005).

One mother explained how this process was valuable to her by making her aware of the influence of sensory processing in everyday behaviour. She stated:

> *It was a very good exercise to me because what it also makes me realize is when you look at children, as you say 'normal children', there's a lot of children out there with sensory problems, yet, you gave us the tools to identify, identify where the needs are. I think a lot of people actually need it* (focus group 30-11-2005).

The data revealed that the process of understanding their own sensory processing in order to better understand their autistic child's sensory processing was valuable to the mothers. Many of them had not given their own sensory processing much thought but were very aware of the sensory processing traits of their child. Understanding how their own behaviour is influenced by sensory processing made many of the mothers more aware of, and more sensitive to the sensory needs of their child. In turn, many of them reconsidered their previous handling of their child. Identifying behaviours that occur in response to sensory processing, understanding the behaviour from a sensory integrative perspective and implementing strategies to help both the mother and the child cope with various situations, helped many of the mothers deal with daily situations that they found challenging and stressful in their relationship with their child. The process gave the

mothers a tool that increased their ability to cope with their own and their child's sensory processing needs. As a result, some mothers felt that they had new strategies to prevent stressful situations in the mother-child relationship that would possibly arise from power struggles.

The data suggests that the process of exploring their own and their child's sensory processing traits appeared to provide some alleviation of the stressors and challenges experienced in their relationships with their children

4.2.2. Theme 2: "I also have needs"

This theme reveals data that suggests that some mothers came to understand the conflicting nature of their own vs their child's sensory needs. Mothers reported their experiences of having a child with special needs and some revealed the tendency to compare their child to other children who were developing typically.

4.2.2.1. The mothers expressing their needs

During the process of coming to an understanding of their own and their child's sensory processing, the mothers gained new insight into their child's behaviour. For instance, one mother reflected on a new understanding regarding her own need to hug her child and her disappointment when the child rejects being hugged.

> *I think in a lot of the situations where it is a natural thing… where you want your child to hug you. I think, its helped to set boundaries, maybe a quick hug and let go, because then I satisfy my needs but I'm also not pushing him past his boundaries as well. So that helped a lot in that perspective. You say, 'Okay, your child has a problem in that area so lets not push it', yet I also have needs* (focus group 30-11-2005).

Understanding her own and her child's sensory processing needs helped this mother in understanding both her and her child's behaviour from a sensory integrative perspective. The child's sensory profile revealed that he has sensory sensitivity to touch. Therefore the mother came to understand that the child was not rejecting her by pulling away, but instead, that he could not tolerate the sensation of being hugged. AS a result, the process helped this mother emotionally by understanding that the child was not rejecting her. It also helped her to become more sensitive to the needs of her child. However, she also expresses a desire to have her needs met and had to find the balance between meeting her needs without imposing on the sensory boundaries of her child.

Another need expressed by the mothers was the need *"to be perfect"* and the need *"to do everything"* (focus group 29-11-2005). This, according to the mothers, was a function of having a child with special needs. The mothers would try to "*do everything*" for the child, to meet the child's needs even at the expense of their own needs. One mother summarised it in a gendered way when she said:

> *Women have more of a conscience they keep giving and giving* (focus group 29-11-2005).

Where previously the mothers were aware of only the challenges of their own unmet needs, a tentative understanding developed of how certain behaviours were triggered by the child's sensory processing. Some mothers thus developed new insights into acceptance of unmet needs or to implement strategies were their own needs were met without overburdening their child's sensory system.

4.2.2.2. Having a child with special needs

The data revealed that mothers of children with autism had deep-felt responses to having a child with autism. Some mothers expressed a yearning for their autistic child to be more like other children. Other mothers described having feelings of sympathy for the child. Some stated that they would over-compensate for their child's limitations. Others would compare their autistic child to his or her siblings or to other children of that age who were developing typically. There appeared to be feelings of sadness about wanting their child to be like other children. The data suggested that the process of exploring sensory processing had elicited some of the sadness associated with having a child with special needs. One mother said:

> *We tend to compare them to other kids their age…and overcompensate for their lack of what ever* (focus group 30-11-2005).

Understanding their child's sensory difficulties helped the mothers look at their child's behaviour from a different perspective. One mother described how she would stop the child from behaviours that she though were inappropriate in the attempt to 'normalize' him. She said:

> *It's a natural thing to feel sorry for your child and we would want your child to be like other children, so maybe you're just too strict in areas where he is needing integration* (focus group 30-11-2005).

Another reported:

> *We say no! That's not socially acceptable or no! That's not what kids do…so yes we definitely look at it from a different angle* (focus group 30-11-2005).

Yet another mother said that it was difficult for her not having other children to compare her child to. Therefore, this mother did not have a clear measure of what was expected or acceptable behaviour of typically developing children the same age as her child. Another mother said she overcompensated for her child because of his special needs. This process helped one mother realize that her son's differences could be attributable to his sensory processing traits. She said:

> *It has helped me realize that U is different from other people, even his sisters* (focus group 29-11-2005).

For many of the mothers, the focus groups were an opportunity to talk about their experience of raising a child with special needs. An underlying sadness emerged when the mothers shared their desire for wanting the autistic child to be like other children. Acknowledging their child's limitations was difficult for the mothers.

> *I've realized that this is what I have and I take it one day at a time and don't push too much* (focus group 30-11-2005).

Some mothers expressed emotions of sadness or loss for the autistic child's limitations. Although there was a yearning for their child to be 'normal', there was also an acceptance of the child and an acceptance of the realities of their life with the child.

The data described under this theme revealed mothers' developing insight into the conflict between their own unmet needs on the one hand and their difficulties in coping with their child's needs on the other hand. Some of mothers revealed sadness for their children and themselves.

4.2.3. Theme 3:"They walk away and leave you with this wreck of a child"

This theme encompasses two categories, the emotional bond between the mother and child and the father's role and understanding of the child.

4.2.3.1. The close emotional bond between the mother and child:

The mothers described one of the qualities of the mother-child relationship in terms of the closeness of their relationship. All the mothers agreed that they had a closer bond with their child than the fathers, and that they acted as the child's primary caregiver. Mothers said:

> *As a mother the child is our world* (focus group 29-11-2005).

> *We have more of an emotional bond with the child than the dads do* (focus group 29-11-2005).

Some mothers speculated that the autistic children were more inclined to take out all their frustrations on the mother as a result of the close relationship between the mother and the child.

> *That's why I feel that they think we know them best, all their frustrations they take out on us* (focus group 29-11-2005).

> *I find that if C will upset him then he won't attack C, he will come running to me* (focus group 29-11-2005).

The mothers suggested that their children would more often demonstrate negative behaviours to the mothers, where the child feels emotionally 'safer' to act out towards them as compared to the fathers, who may be less tolerant to the child's challenging behaviour.

4.2.3.2. The fathers' understanding and role with the child

The mothers described incidents suggesting that the fathers had less understanding of their children, owing to the fact that they spent much less time with them than the mothers. Many of the mothers wondered if their husbands would have been able to complete their child's sensory profile as easily as they did and questioned their husbands' depth of knowledge of their child. One mother described her husband's lack of understanding of their child that became more evident to her when they completed their child's Sensory Profile together. She commented that her husband is *"still boundarying on the unreal"*. They could not agree on rating the different items on the profile and she said to him *"if you look at him with open eyes you will see that that is U"* (focus group 29-11-2005).

Another mother described her husband's inappropriate handling of the child. She described how her husband would over-stimulate their child and then leave her to deal with the child's over-aroused state on her own. She described:

> *I have this husband who will force M to give him affection, like this morning. I said leave him alone, you winding him up… you don't understand what you are doing, you wind him up and you leave me to deal with this child on my own* (focus group 29-11-2005).

This mother expressed a sense of frustration around her husband's lack of insight. Another mother, referring to the effects of her husband's handling of their child, commented:

> *They walk away and leave you with this wreck of a child* (focus group 29-11-2005).

Many of the mothers accounted their husband's lack of knowledge of their child to the limited amount of time that the fathers spend with the child. Some of the mothers commented that their husbands' long work hours resulted in them not spending enough time with the child.

> *My husband leaves before S is awake, there are these quick bursts of time he spends with him in the evening* (focus group 29-11-2005).

One mother commented that her husband '*immerses himself in his work' (focus group 29-11-2005)* and another mother reported that fathers choose work before family:

> *I think it's easier for them to do it* [work long hours] *whereas women have more of a conscience, they keep giving and giving* (focus group 29-11-2005).

The mothers agreed that their husbands or partners should have been part of the process of exploring their won and their child's sensory processing. This idea emerged from the mothers' concern that their husbands or partners had poor insight into the child's sensory processing and behaviour resulting from the sensory processing. Just as this process had given many of the mothers' new insight into their child's behaviour, the mothers believed that the new knowledge gained would have been valuable to the fathers. They thought that insights gained through the process of completing the Sensory Profiles could possibly have had a positive influence on the father-child relationship. Some mothers felt that the relationship between the fathers and their children was not satisfactory.

> *We have more of an emotional bond with the child than the dads do. That's why I think that this process will be valuable for the dads* (focus group 29-11-2005).

The mothers thought that if their partners had gained new insight and understanding of their won sensory processing by doing the Sensory Profiles, it could have contributed to alleviate the tendency to blame the mother for the child's difficulties.

> *Maybe the fathers should have their profiles done also because the child is a combination of the two of us. All good things come from the dad all the bad things come from us* (focus group 29-11-2005).

One mother who had included her partner in completing the child's sensory profile expressed how she thought the exercise was useful to them as he gained understanding.

> *He had no knowledge of autism what so ever….he had to grow into a situation…it was valuable to have him participate because it gave him a lot of understanding and you find the equilibrium in your house almost the status quo"* (focus group 30-11-2005).

After completing the child's sensory profile together, this mother believed that her partner had gained a better understanding of the child and in turn the new understanding positively influenced the relationships in their family. Seeing that the exercise had been valuable to this family unit, the other mothers agreed that the process should also have included the fathers. Just as their new knowledge of their own and their child's sensory processing positively influenced the quality of their own relationship with the child, they believed that there was such a need to influence the quality of the father-child relationship as well.

To conclude, the data suggests that the mothers experienced their husbands or partners as having less understanding of the sensory processing factors that underlie their child's behaviour. The mothers, reflecting on the process of exploring their own sensory processing, felt that the gains brought by new understanding and the positive effects

thereof on their relationships with their child, could also benefit the fathers. Consequently, they suggested that fathers should participate in such processes by exploring their own sensory processing.

In this chapter I described the results that emanated from the analysis of the Sensory Profiles of mothers and their children in phase one and the mothers' views of the effects of the knowledge gained on their relationships with their child in phase two of the data analysis. In the next chapter, I will provide a discussion of the results.

CHAPTER 5

5.1. Discussion, Conclusion and Recommendations.

This chapter contains a discussion of the findings presented in the previous chapter, the conclusion from the discussion, limitations and recommendations.

5.1.1. The impact of sensory processing on the mother-child relationship:

Raising a child with a disability such as autism is known to be difficult, stressful and challenging to parents and other family members (Case-Smith & Bryan, 1999; Cohn, Miller & Tickle-Degnen, 2000; The National Autistic Society, 2005). The behaviour of autistic children is influenced by their atypical responses to sensory stimuli. (Case-Smith & Bryan, 1999; Cohn, Miller & Tickle-Degnen, 2000; Dunn, 1997; and Watling, Deitz & White, 2001). My argument in this thesis is that by understanding their own sensory processing traits and understanding how sensory processing influences behaviour, some alleviation could be achieved of the challenges posed in the relationships of mothers and their autistic children.

The findings of this study suggests that the ten participating mothers gained deeper understanding of their own and their child's behaviour that were influenced by sensory processing, through the process of using Dunn's and Brown and Dunn's Sensory Profiles as instruments to gain this understanding. Furthermore, the new knowledge and insight provided some alleviation of tensions experienced in their relationships with their

children. The mothers suggested that their husbands or partners would benefit from developing similar understanding and that knowledge of their own and their child's sensory processing would improve their relationship with their child.

The first theme, "You actually realize how similar you are to your child", revealed how the mothers gained new knowledge of themselves and of their child. The data suggested that the process of exploring their own and their child's sensory processing traits appeared to provide understanding and some alleviation of the stressors and challenges experienced in their relationships with their children. This finding is in keeping with Dunn's (1999) statement of a therapeutic benefit experienced by parents when completing the Sensory Profiles. Case-Smith and Bryan (1999) report that helping parents to understand their child's behaviour to enable them to provide a supportive relationship is one of the key objectives of a sensory integration approach for children with autism. Ermer and Dunn (1998) state that families can understand their child's behaviours and reactions when the child's threshold for tolerance to sensory stimuli is established.

Three main patterns of sensory processing emerged from analysis and cross comparison of each set of mother-child profile. These patterns will be discussed in greater detail and each pattern will be explored further to determine how mothers with different patterns of sensory processing were coping and the impact of their own and their child's sensory processing traits had on the mother-child relationship.

Most of the children in the study presented with high scores in all the quadrants of the Sensory Profile. This is consistent with Dunn's (1999) findings that children with autism

engaged in behaviours on the Sensory Profile more frequently and that the items were more scattered across all factors on the profile demonstrating the pervasiveness of autism. Iarocci and McDonald (2006) explain that from a clinical perspective, individuals with autism demonstrate behaviours such as creating or avoiding stimuli in order to help them cope with their sensory environment when it is too overwhelming. Dunn, Saiter and Rinner (2002) state that individuals with autism are often unable to express their sensory needs making it difficult for caregivers to understand the reasons behind the challenging behaviours. Case-Smith and Bryan (1999) agree with Ermer and Dunn (1998) that insight into a child's thresholds and tolerance for sensations is important to enable families and other professionals to understand the child's reactions to everyday sensory experiences.

Behaviour in response to sensory input can have a significant impact on the mother-child relationship (Cohn, Miller & Tickle-Degnen, 2000). The child with low registration may ignore or miss information and appear uninterested and unresponsive to the caregiver in daily routines. The child with sensation seeking behaviour may move around constantly to seek out sensations that are pleasurable to themselves yet irritate others in doing so. The child with sensory sensitivity may be fussy and avoid physical contact with others and the child with sensation avoiding behaviour may create rigid routines that could govern or control family dynamics. Dunn, Saiter and Rinner (2002) state that families tend to structure daily routines around the child with sensory difficulties preferences and non preferences. Mealtimes would be designed around the child's food fads, daily grooming activities would be carried out in a particular way and family routines in general would be designed to prevent tantrums or to avoid power struggles with the child.

Often families are unaware of negotiations or compensations that they make to their daily routines and family life tends to revolve around the child with autism. Although it is the child's behaviour that may demand the structure and routine, it is the mothers who carefully engineer and maintain this structure. It is often without much comprehensive knowledge of sensory processing that the mothers quickly learn what works and what does not work for the child. It is through their daily interactions with their child that they become experts in their child as one mother in the study stated: "we know them so well".

All of the mothers in the study were familiar with their child's sensory sensitivities. Being in the special school environment, they were familiar with the language of sensory processing. They were also very familiar with their child's behaviour. Cohn, Miller and Tickle-Degnen (2000:37) state that parents have "*first-hand experience*" of their children. Mailloux (2004:29) agrees that parents have better knowledge of their children than anyone else and "*when a parent feels that something is not right, they are usually correct*". According to Dunn (1999), care-givers report a therapeutic gains from completing the Sensory Profile for their child. The items on the profile reflect everyday situations that are familiar to the caregivers. Dunn (1999) states that gaining knowledge about their children's characteristic behaviors while completing the profile provides validation that the challenges experienced by the parents and their family is real and the profile suggests that there may be ways to alleviate with these challenges.

The children in the study presented with high score in all four of the sensory quadrants of the sensory profile, meaning that the child's behaviour would fluctuate between high and a low threshold responses and fluctuate between active and a passive behavioural

responses. The child could be calm and compliant at one moment and hyperactive and disruptive at the next. Therefore behaviour in response to stimuli would be erratic and unpredictable. Not knowing what to expect may place strain on the mothers who are constantly working to meet the needs of the child. DeGrace (2004) explored the everyday occupations of families with children with autism and the demands that having a child with autism has on the family. Families in DeGrace's study stated that a major part of their day revolved around the child with autism and that much time and energy was expended in dealing with the child's demands. High levels of stress in mothers of children with autism is often coupled with helplessness and guilt around not being able to meet all the needs of the child. According to Mailloux (2004:29) "*overcoming feelings of guilt often becomes part of the discovery process for parents*".

Findings from the focus group suggested that mothers of the children with autism were working hard to meet the needs of the child with autism. Discovering that they themselves also experienced sensory processing challenges was not something completely unknown to the mothers. Some of the mothers were aware of difficulties that they experienced even though they did not fully understand the reason behind them from a sensory processing perspective. Some reported that they had tried in the past to compensate for these difficulties.

Just as their children were experiencing daily frustrations imposed by their various sensory difficulties, the parents were facing similar impasses on their own sensory systems. The need to be functional and to meet the challenges of caring for a child with special needs had forced many of the mothers to put their own sensory needs aside in

order to focus on the needs of their child. The National Autism Society (2005:5) cites Sharply, Bitsika and Efremidis (1997) reports on a study of the effects of children with autism on the family. They found that 81.9% of parents of children with autism reported that they were "*sometimes stretched beyond their limits*". The mothers in the study expressed the need to be '*perfect'* and the need to '*do everything'* for the child. An understanding of their own profiles helped them realize that they have their own sensory preferences and needs, which were often overlooked to meet the needs of their child.

5.1.2 Patterns of sensory processing traits of the mothers

The main sensory processing patterns of mothers will be discussed and the influence of the sensory processing on behaviour and in turn on the mother-child relationship will be highlighted.

Three patterns of sensory processing emerged from the analysis of the mothers' Sensory Profiles. The first pattern was that a group of mothers presented with typical sensory processing in all four quadrants of the Sensory Profile. The second pattern was that some of the mothers presented with sensory sensitivity along with one of the following: low registration more than or much more than most people; sensation seeking less than or much less than most people; or sensation avoiding more than or much more than most people. The third pattern that emerged was when the mothers presented with atypical sensory processing behaviours in all four quadrants of the profile.

- Mothers with typical sensory processing

The mothers who presented with no sensory processing difficulties appeared to be coping well with their child's challenging behaviour. However, they did not seem to have good insight into their child's difficulties and would react with challenges to the child's behaviour. For example, one mother who presented with typical sensory processing could not understand why her child would pull away when being hugged. Not having any sensory processing difficulties herself, she did not have any insight into her child's difficulty with the sensory processing of tactile stimuli. She interpreted the child's behaviour as rejecting her. Rejection could contribute to feelings of incompetence, which in turn, could influence the mother child bonding (Dunn, 2004). The child's sensory profile revealed that he was sensory sensitive and could not tolerate being hugged. This knowledge of sensory processing helped the mother realize that the child was not rejecting her but he had real sensory difficulties that influenced the way he behaved. The process helped her understand both her own needs and the needs of her child and helped to set acceptable boundaries for them both.

- Mothers with sensory sensitivities

Sensory sensitivity in one or more of the sensory systems was found in all ten of the autistic children and in five of the ten mothers who participated in the study. Brown and Dunn (2002) states that sensory sensitivity is associated with irritability and reflects the individual's high level of alertness of stimuli in the environment. As half the number of mothers presented with sensory sensitivities, the dynamics of the relationship between the sensory sensitive mothers and their child was further explored.

People with sensory sensitivity have low neurological thresholds that result in fast and intense responses to sensory stimuli (Brown & Dunn 2002). The individual may be distractible and experience discomfort due to an experience of intense stimuli. The individual may also be extremely aware of his or her environment and have sharp discrimination and attention to details.

Dunn (2001:610) reports findings of anxiety and depression in adults with sensory defensiveness. However she states that these adults did not experience pain any more than other individuals without defensiveness. Dunn suggests that rigid and inflexible behaviours could suggest coping strategies for individuals with low thresholds that quickly disorganize the nervous systems.

The mothers with sensory sensitivities appeared to have more insight into their child's difficulties that resulted from sensory processing than mothers with typical sensory processing. These mothers were more sympathetic to the difficulties that their children experienced. One mother who could remember being sensory sensitive herself as a child, did not expose her sensory sensitive child to sensory stimuli that caused discomfort. Dunn (1997) suggests that caregivers of children with sensory sensitivities need to adopt a flexible yet assertive manner in dealing with them and she stresses the importance of an empathetic approach. However, Dunn (1999) also cautions that one should be careful about withholding sensory experiences from sensory sensitive children. The caregiver should provide the child with sensory experiences in daily life functioning in a manner that supports the child to continue with a task by adapting the environment to minimize the chances of sensory discomfort. The mothers with sensory sensitivities seemed to be

coping differently with the child's challenging behaviours. Whether or not they were coping, depended on whether they were reacting actively or passively to their sensory systems. Three of the mothers that had high scores for sensory sensitivity, also had high scores for low registration. This would mean that they are more likely to interact passively with their environment and they are more likely to accept things as they are. These mothers appeared not to be coping with their children's challenging behaviours as described by them in the semi-structured interview, compared to the mothers who had sensory sensitivities but were reacting actively to their system.

Sensation avoiding would imply an active behavioural response when the individual acts to counteract the threshold. Sensation avoiding much more than most people was found in four of the mothers and in all of the autistic children. Brown and Dunn (2002:39) state that "*individuals who engage in sensation avoiding behaviours are overwhelmed or bothered by sensory stimuli*". Sensation avoiders work to actively reduce sensory stimuli in their environment and they employ habits or routines to ensure predictability in their sensory environments. Brown and Dunn (2002) further state that sensation avoiders are at an advantage in creating structure and environments that reduce offending sensory stimuli and they enjoy being alone. The mothers who were sensory sensitive as well as sensation avoiding would do whatever was necessary to make themselves comfortable in their sensory environments. Sometimes their avoiding behaviours would be in accordance with the child's sensory needs and on other occasions, it would challenge the child, depending largely on the child's fluctuating state (whether the child is seeking or avoiding sensations at the time).

Sensation seeking less than or much less than most people was found in four of the mothers. Low scores in sensation seeking suggest that the individual does not create additional sensory stimuli. This does not necessarily mean that the individual avoids stimuli, but rather, that the individual is not actively involved in intensifying the sensory environment.

Dunn (2001) describes the physiological changes that take place in individuals with high and low sensation seeking traits. Individuals with high sensation seeking behaviours experience a reduction in heart rate when a new sensory stimulus is introduced. This is interpreted as an orienting response that avails the individual to receive the stimuli. An increased heart rate is experienced by individuals with low sensation seeking behaviours. Dunn (2001) explains that this is possibly experienced as being threatening to the individual, who in turn inhibits and or avoids the new stimuli.

According to Brown and Dunn (2002) intervention for low scores in sensation seeking is necessary if it impacts on the individual's performance in activities of daily living. The individual's lack of interest in physical contact in embracing or showing affection could interfere with family relationships. One of the mothers in the study described her difficulty in dealing with her child's constant need for touch. An accumulative effect of her child's sensation seeking by touching her, would lead to an explosive reaction from the mother. Adopting strategies to deal with the situation helped prevent such outbursts, therefore influencing the mother-child relationship positively.

- Mothers with atypical sensory processing in all four sensory quadrants

Major differences between the mother and child's sensory processing was revealed when the mothers presented with low registration more than or much more than most people; sensory sensitivity more than or much more than most people; sensation seeking less than or much less than most people and sensation avoiding more than or much more than most people. These mothers, from their descriptions of their children's challenging behaviour, did not appear to be coping well and preferred to avoid situations or leave someone else to deal with the challenging behaviour. Like their child, they also had a tendency to fluctuate between high and low thresholds, being sensitive to stimuli on some occasions and not noticing the stimuli on others. Therefore they would be bothered by their child's sensation seeking behaviour if they registered it and ignore it if they did not. They also fluctuated between active and passive behavioural responses to sensations. These mothers appeared to be easily overwhelmed in challenging situations therefore not being able to cope with their child's challenging behaviours. The findings suggested that mothers who experience sensory processing difficulties themselves would have more difficulties in coping with and therefore more conflict in their relationship with their autistic children.

5.1.3. Raising a child with special needs:

The difficulties associated with parenting a child with a disability is widely reported in occupational therapy literature (Cohn, Miller & Tickle-Degnen, 2000; Parham & Mailloux, 1996). Occupational therapists are increasingly adopting a family-centered approach in providing intervention for children with disabilities (Case-Smith and Bryan, 1999; Cohn, Miller & Tickle-Degnen, 2000) in which parents, primary care-givers or

siblings are more frequently included as collaborators in the intervention for the child with the disability.

In a family-centered approach, emphasis is placed on well-being of the whole family and on the efficient functioning of the family as a unit (Cohn, Miller & Tickle-Degnen, 2000). The social and interpersonal aspects of family life are viewed as essential aspects.

Both the second and the third themes revealed some of the challenges experienced by families who were raising a child with autism. The second theme revealed the mothers' needs for self-validation and to have more control to have their own needs met. This theme revealed the process of the mothers' developing insight into the conflict between their own needs and the needs of their child. A sense of sadness for their children and themselves was expressed by some of the mothers. The third theme "They walk away and leave you with this wreck of a child" revealed the mothers' experience of their husbands or partners as not understanding or not being supportive enough in dealing with the child.

For many of the mothers, the process gave them the opportunity to share their experiences of raising a child with special needs. Some of the mothers expressed sadness around wanting their autistic child to be like other children. Similar findings were reported by Cohn, Miller and Tickle-Degnen (2000); DeGrace (2004); Case-Smith and Bryan and Mailloux (2004). Parents in Cohn, Miller and Tickle-Degnen's (2000:39) study expressed a need for their children to develop appropriate behaviours and skills to enable them to "fit in" and be socially acceptable. They expressed a need for the child to develop peer relationships, to regulate their behaviour and to have discipline, to have confidence and to be able to derive a sense of satisfaction from their own abilities and

achievements. Families in DeGrace's (2004:547) study expressed feelings of being deprived of a typical family life and "*appeared to mourn for a family life*" that they longed for.

The process gave the mothers the opportunity to talk about the difficulties that they experience. Many of the mothers felt that they were carrying more of the load of raising a child with autism than their partners. The third theme "They walk away and leave you with this wreck of a child" revealed the mothers perceptions that their husbands had less understanding of the sensory processing factors that underlie their child's behaviour and that the lack of understanding in turn influenced both the quality of and the extent of their involvement with the child.

The differences in coping with emotional stressor between mothers and fathers of children with autism have been reported (The National Autistic Society, 2005). Fathers would tend to suppress their emotions while mothers were more likely to vent theirs. The mothers would talk to friends and family members and particularly other mothers of children with autism as a way of coping with their emotions. Similar findings emerged during the focus groups. There was a shared bond amongst the mothers as they shared their experiences and frustrations. Only they could understand each others' emotions around the challenges of living with and raising a child with autism.

The National Autistic Society (2005) reports findings that mothers carry the bigger load of caring for the child with autism than the fathers did and this had a significant impact on the mothers. Majority of the fathers acknowledged the extensive challenges presented

to their families by the child with autism, however they maintained that their child's condition did not affect them personally. This was not the case for the mothers.

DeMyer (1979:150) studied the effect of early symptoms of autism on the family. She found that the mothers took on a larger share than the fathers did in the daily care and management of the child with autism therefore the effects were more direct on the mothers. DeMyer found that although the fathers were affected by the autistic child's difficulties, they relied on their work to gain a sense of achievement and self worth and also to "*gain a legitimate escape hatch*". Most of the mothers, mothering was their primary occupation and having a child with autism impacted significantly on their self-esteem.

Many of the mothers expressed their concern about their partner's lack of insight into the child's needs. One mother described how her husband would over-stimulate their child and then leave her to deal with the child on her own. Another mother with a profile similar to that of her child (both more sensitive and avoidant) was very aware of her child's needs. Being sensory sensitive herself, she would not force the child to do things that he did not want to do. She stated that there was a big difference between the way that she and her husband handled their child that sometimes lead to conflict between them. Her husband expected things of their child that she thought were unrealistic, considering the child's sensory difficulties.

Case-Smith and Bryan (1999) describe the sensory processing difficulties that underlie occupational performance in social interactions and communication in children with autism. If the fathers could understand that the children with autism experience

difficulties in attending to others and that they lack reciprocal communication as a result of poor sensory processing, it may results in improved relationships with their children with autism.

One of the mothers in the study who presented with low registration was often not as affected by her son's challenging behaviours compared to her husband. Her husband could only deal with the child's behaviour to an extent before he became frustrated. This mother could not understand why her husband often became irritated by their child's sensory seeking behaviour when it did not bother her. When describing low registration to her she said:

> *You've hit the nail on the head. I am able to cope with U and my husband gets frustrated after a while and I often wonder what is wrong with him.*

Brown and Dunn (2002) state that the advantage of low registration is that these individuals are more inclined to be comfortable and accommodating in a variety of sensory environments. They are able to attend to tasks in distracting environments more easily than some other individuals.

The National Autistic Society (2005) reports that fathers of children with autism were more significantly affected by the high levels of stress that their wives experienced as apposed to being directly affected by the child's autism. The challenges posed by the child with autism occasionally led to conflict between the parents and put strain on their marriage. The National Autistic Society (2005) reports a study by Bromley et al (2002) that suggests that one in three families of children with autism were single parents. Ermer and Dunn (1998) report that by completing the Sensory Profiles parents are able to

understand the behaviours that interfere with their child's functioning. They suggest that this process may help fathers to make modifications to their own behaviour in order to help their child.

The mothers, upon reflection of their experience of exploring their own sensory processing and the positive implications it had on their understanding of their child, thought that it would have been useful to include their partners in the process. They believed that the relationship between the father and the child would improve with more insight. Therefore they thought that such a process would help give the father a better understanding of the child's difficulties, and in turn influence the father-child relationship positively.

The findings of study support the notion of a family-centered approach. An understanding of sensory processing is beneficial to mothers and fathers as well as siblings and other family members. Cohn, Miller and Tickle-Degnen (2000) report that the parents wanting to understand their child was the central theme that emerged in their study. Parents wanted to understand their child better, to help the child learn and develop. They wanted to understand what triggered unpredictable behaviour in the child with autism. Furthermore, they wanted others to understand how difficult it was for them as parents to deal with the challenges of living with and raising a child with sensory processing difficulties.

5.2. Conclusion:

The aim of the study was to explore the nature of sensory processing in children with autism and the nature of sensory processing of their mothers. The purpose was to help mothers gain knowledge and understanding into their own sensory processing traits so that they could, on reflection, develop a better understanding of their child's sensory processing traits in order to facilitate better mother-child relationships.

The objectives were to evaluate sensory processing of ten sets of mothers and their autistic children by completing ten Sensory Profile questionnaires for children and ten Adolescent/Adult Sensory Profile questionnaires for the mothers; to analyze the sensory profiles and provide feedback to the mothers of the analyzed results; to facilitate the development of knowledge and understanding in the mothers through discussion and education, by explaining the sensory processing of their children and themselves and how it impacts on their relationship. The final objective was to explore whether the newly acquired information had informed the mothers' understanding of their own and their children's sensory processing and if it had an impact on the mother-child relationship.

The findings revealed that the mothers participating in the study had gained deeper insight and a new perspective into their own sensory processing and the sensory processing of their children. Some of the adult participants came to the realization that they were not functioning at their optimum levels in various areas, due to sensory challenges that they knew they had but did not fully understand.

Almost all the children with autism presented with sensory processing difficulties in all four of the quadrants on the Sensory Profile. Their sensory processing fluctuated resulting in behaviour fluctuations. This in turn results in challenging and unpredictable behaviour. Several studies report a high incidence of stress among mothers of children with autism (Cohn et al., 2000; Parham & Mailloux, 1996). The process of understanding both their own and their child's sensory processing had helped some of the mothers review their handling of their child. Some of the mothers thought that the boundaries they set for their child were too strict. Other mothers realized that their expectations of their children were sometimes unrealistic. This process provided the mothers with tools to identify problem areas and gave them possible solutions to everyday challenges. They understood that their experience with the child was the result of the sensory processing difficulties indicated in the child's sensory profile.

The mothers also realized that they too have areas where their sensory processing is challenged and they were often overwhelming their sensory systems when trying to meet the sensory needs of their child. Three main patterns of sensory processing traits emerged upon analysis of the mothers profiles. The first pattern was when the mothers presented with typical performance in all four quadrants of the sensory profile. These mothers appeared to be coping well with their child's challenging behaviours. The second pattern was when the mothers presented with sensory sensitivity along with low registration more than or much more than most people, sensation avoiding more than or much more than most people or sensation seeking less than or much less than most people. These mothers' coping abilities depended on whether they reacted actively or passively to their systems. Mothers who were active to their systems appeared to be coping better than the

mothers who were passive and accepted things as they were. The third pattern was when the mothers presented with sensory processing difficulties in all four of the sensory quadrants. These mothers did not seem to be coping with their child's challenging behaviours.

Some of the mothers came to the conclusion that they no longer had to subject themselves to situations that they find unpleasant and that they could let someone else handle those situations. They did not have to do 'everything' for their child with autism.

The findings from the data suggest that the mothers in the study found the process of understanding their child's and their own sensory processing valuable. For many of them it was an opportunity to speak about their experiences of raising a child with special needs and the lack of sufficient support from their husbands or partners. Mothers recommended that fathers also explore their own sensory processing to gain understanding and new insights into their relationship with their child.

Dunn (2004) stated that sensory processing knowledge can be invaluable in supporting strong infant-caregiver relationships and advised that this approach could be applied to all relationships. Understanding behaviour from a sensory processing framework could be a valuable tool for professionals to explain behaviour and to develop strategies to improve the quality of interactions that could in turn, improve the quality of life for individuals. In another study, Dunn (2001) concluded that new knowledge and insight could enable caregivers to emphasize the child's positive qualities, while simultaneously try to reduce the negative reactions that often cause discouragement or conflict.

The Sensory Profiles can provide valuable information about an individual's sensory processing and the choices that an individual makes in everyday activities as a result of sensory processing preferences and non preferences. The profiles are valuable in that they can inform the professional on how sensory processing can impact on the individual's functioning in everyday occupations. In keeping with the trend of a family centered care approach, it is important to consider the role of the family in the delivery of services to the child with autism. Cohn, Miller and Tickle-Degnen (2000:36) emphasize the "*importance of honoring parents' perspectives*" and state that successful occupational therapy outcomes must be closely linked to the daily occupations of both the child and the family unit.

5.3. Recommendations:

Parents and other family members of autistic children should explore their own sensory processing to gain knowledge and understanding of the effects of sensory processing on behaviour. The study has revealed that the mothers derived great benefits from the process of gaining knowledge and a better understanding of the child. Knowledge of sensory processing can be a valuable tool in understanding relationship dynamics. Therefore it is strongly recommended that professionals working with children with sensory modulation difficulties also consider the sensory processing of all the key role players in the child's life.

In particular, fathers or partners should explore their own and the child's sensory processing. The mothers in the study were concerned that the poor relationship between the father and the autistic child was a direct function of the fathers' lack of insight into

the child's condition. Siblings and care-givers may also benefit from knowledge and a deeper understanding of sensory processing. In keeping with the shift towards a more family-centered therapy approach, the sensory processing of all the key role players in the child's life should be considered. This could also help therapists design programmes that are congruent with the daily functioning of the family routines.

The Sensory Profiles can be used as a means of providing emotional support, alleviation of guilt and self-validation to parents, particularly mothers, who are raising a child with autism or another disability where the child presents with sensory processing difficulties. Various studies show that mothers of children with autism experience a high degree of stress, exhaustion and guilt in trying to meet the demands of the child. Completing the profiles helped the mothers realize that they themselves have real sensory difficulties that impact on their relationship with their child. The mothers came to the realization that there is something tangible about their struggle and that they are not necessarily bad mothers because they are unable to cope or meet the demands of the child helped the mothers alleviate some of the guilt. Therefore completing the profiles with mothers of children with autism could have significant implications on the mothers' psychological wellbeing.

The need for support and parent education for parents of children with autism was highlighted. It was evident from this study that mothers of the children with autism need a high level of support. Therefore more continuous parent education and support groups regarding challenges posed by sensory processing is recommended for Vera school and

other special needs schools. The value of sensory integration in the life-long support for individuals with autism could also be shared with the Autism Societies.

Sensory integration assessments can be costly and time consuming and often the child with autism is not able to participate fully in the assessment due to their challenging behaviour. Therefore the Sensory Profile is a valuable tool to gain understanding of individuals sensory processing traits. The Sensory Profiles should be included into occupational therapy undergraduate curricula as an assessment tool. The profiles can be shared with occupational therapy students in their assessment and understanding of children with sensory modulation difficulties.

As individuals with autism are often unable to report their sensory preferences and non-preferences, making it difficult for caregivers to understand their needs and consequently prevent challenging behaviours. Therefore the Sensory Profiles is a valuable tool for gaining information about an individual's behaviour in relation to sensory processing. The use of the profile use is not limited to only occupational therapists. Dunn (1999) suggests that the Sensory Profiles can be completed by other professionals such as teachers, psychologists and other therapists. However it is believed that an occupational therapist with an understanding of sensory integration has the advantage of deriving the depth of the information that the profiles have to offer.

All the learners at Vera School are profiled using the Sensory Profile or the Adolescent/Adult Sensory Profile as we realize the intense sensory processing difficulties that children with autism experience. Knowledge about the child's sensory processing

provides valuable information to caregivers on what triggers adverse responses and what could prevent or minimize such responses making it easier for the child to cope within the environment. In a school of approximately eighty five learners and only one occupational therapist, it would not be realistic to complete parent profiles as well. Therefore parents interested in understanding their own sensory processing better will be referred to a sensory consultant who has a special interest in adult sensory profiles. However it is still maintained that this has been a valuable process and it would be strongly recommended if the circumstances at Vera were to change. It would also be strongly recommended to other schools for children with Autism as a sensory integration frame of reference is crucial in the intervention for children with autism.

To be able to generalise results, a quantitative study with a large sample size needs to be done to. Further research is also indicated. It would be interesting to examine the underlying sensory processing traits that influence family relationships. Sensory compatibility between the autistic child and both parents and siblings can be explored. Siblings of autistic children often take great strain from having a brother or sister with autism. It would be useful to explore how they experience their sibling with autism and how they cope from a sensory perspective.

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Appendix 1

The Sensory Profile

SENSORY PROFILE

Winnie Dunn, Ph.D., OTR, FAOTA

Caregiver Questionnaire

Child's Name: _____ Birth Date: _____ Date: _____

Completed by: _____ Relationship to Child: _____

Service Provider's Name: _____ Discipline: _____

INSTRUCTIONS

Please check the box that **best** describes the frequency with which your child does the following behaviors. Please answer all of the statements. If you are unable to comment because you have not observed the behavior or believe that it does not apply to your child, please draw an X through the number for that item. Write any comments at the end of each section. Please do not write in the Section Raw Score Total row.

Use the following key to mark your responses:

ALWAYS	When presented with the opportunity, your child always responds in this manner, 100% of the time.
FREQUENTLY	When presented with the opportunity, your child frequently responds in this manner, about 75% of the time.
OCCASIONALLY	When presented with the opportunity, your child occasionally responds in this manner, about 50% of the time.
SELDOM	When presented with the opportunity, your child seldom responds in this manner, about 25% of the time.
NEVER	When presented with the opportunity, your child never responds in this manner, 0% of the time.

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Sensory Processing

Item			A. Auditory Processing	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
?	L	1	Responds negatively to unexpected or loud noises (for example, cries or hides at noise from vacuum cleaner, dog barking, hair dryer)					
?	L	2	Holds hands over ears to protect ears from sound					
?	L	3	Has trouble completing tasks when the radio is on					
?	L	4	Is distracted or has trouble functioning if there is a lot of noise around					
?	L	5	Can't work with background noise (for example, fan, refrigerator)					
?	H	6	Appears to not hear what you say (for example, does not "tune-in" to what you say, appears to ignore you)					
?	H	7	Doesn't respond when name is called but you know the child's hearing is OK					
?	H	8	Enjoys strange noises/seeks to make noise for noise's sake					
			Section Raw Score Total					

Comments

Item			B. Visual Processing	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
👁	L	9	Prefers to be in the dark					
👁	L	10	Expresses discomfort with or avoids bright lights (for example, hides from sunlight through window in car)					
👁	L	11	Happy to be in the dark					
👁	L	12	Becomes frustrated when trying to find objects in competing backgrounds (for example, a cluttered drawer)					
👁	L	13	Has difficulty putting puzzles together (as compared to same age children)					
👁	L	14	Is bothered by bright lights after others have adapted to the light					
👁	L	15	Covers eyes or squints to protect eyes from light					
👁	H	16	Looks carefully or intensely at objects/people (for example, stares)					
👁	H	17	Has a hard time finding objects in competing backgrounds (for example, shoes in a messy room, favorite toy in the "junk drawer")					
			Section Raw Score Total					

Comments

Item			C. Vestibular Processing	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
→	L	18	Becomes anxious or distressed when feet leave the ground					
→	L	19	Dislikes activities where head is upside down (for example, somersaults, roughhousing)					
→	L	20	Avoids playground equipment or moving toys (for example, swing set, merry-go-round)					
→	L	21	Dislikes riding in a car					
→	L	22	Holds head upright, even when bending over or leaning (for example, maintains a rigid position/posture during activity)					
→	L	23	Becomes disoriented after bending over sink or table (for example, falls or gets dizzy)					
→	H	24	Seeks all kinds of movement and this interferes with daily routines (for example, can't sit still, fidgets)					
→	H	25	Seeks out all kinds of movement activities (for example, being whirled by adult, merry-go-rounds, playground equipment, moving toys)					
→	H	26	Twirls/spins self frequently throughout the day (for example, likes dizzy feeling)					
→	H	27	Rocks unconsciously (for example, while watching TV)					
→	H	28	Rocks in desk/chair/on floor					
			Section Raw Score Total					

Comments

Item			D. Touch Processing	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
	L	29	Avoids getting "messy" (for example, in paste, sand, finger paint, glue, tape)					
	L	30	Expresses distress during grooming (for example, fights or cries during haircutting, face washing, fingernail cutting)					
	L	31	Prefers long-sleeved clothing when it is warm or short sleeves when it is cold					
	L	32	Expresses discomfort at dental work or toothbrushing (for example, cries or fights)					
	L	33	Is sensitive to certain fabrics (for example, is particular about certain clothes or bedsheets)					
	L	34	Becomes irritated by shoes or socks					
	L	35	Avoids going barefoot, especially in sand or grass					
	L	36	Reacts emotionally or aggressively to touch					
	L	37	Withdraws from splashing water					
	L	38	Has difficulty standing in line or close to other people					
	L	39	Rubs or scratches out a spot that has been touched					
	H	40	Touches people and objects to the point of irritating others					
	H	41	Displays unusual need for touching certain toys, surfaces, or textures (for example, constantly touching objects)					
	H	42	Decreased awareness of pain and temperature					
	H	43	Doesn't seem to notice when someone touches arm or back (for example, unaware)					
	H	44	Avoids wearing shoes; loves to be barefoot					
	H	45	Touches people and objects					
	H	46	Doesn't seem to notice when face or hands are messy					
			Section Raw Score Total					

Comments

Item			E. Multisensory Processing	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		47	Gets lost easily (even in familiar places)					
		48	Has difficulty paying attention					
	L	49	Looks away from tasks to notice all actions in the room					
	H	50	Seems oblivious within an active environment (for example, unaware of activity)					
	H	51	Hangs on people, furniture, or objects even in familiar situations					
	H	52	Walks on toes					
	H	53	Leaves clothing twisted on body					
			Section Raw Score Total					

Comments

Item			F. Oral Sensory Processing	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
	L	54	Gags easily with food textures or food utensils in mouth					
	L	55	Avoids certain tastes or food smells that are typically part of children's diets					
	L	56	Will only eat certain tastes (list:)					
	L	57	Limits self to particular food textures/temperatures (list:)					
	L	58	Picky eater, especially regarding food textures					
	H	59	Routinely smells nonfood objects					
	H	60	Shows strong preference for certain smells (list:)					
	H	61	Shows strong preference for certain tastes (list:)					
	H	62	Craves certain foods (list:)					
	H	63	Seeks out certain tastes or smells (list:)					
	H	64	Chews or licks on nonfood objects					
	H	65	Mouths objects (for example, pencil, hands)					
			Section Raw Score Total					

Comments

Modulation

Item			G. Sensory Processing Related to Endurance/Tone	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		66	Moves stiffly					
	H	67	Tires easily, especially when standing or holding particular body position					
	H	68	Locks joints (for example, elbows, knees) for stability					
	H	69	Seems to have weak muscles					
	H	70	Has a weak grasp					
	H	71	Can't lift heavy objects (for example, weak in comparison to same age children)					
	H	72	Props to support self (even during activity)					
→	H	73	Poor endurance/tires easily					
→	H	74	Appears lethargic (for example, has no energy, is sluggish)					
			Section Raw Score Total					

Comments

Item			H. Modulation Related to Body Position and Movement	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		75	Seems accident-prone					
		76	Hesitates going up or down curbs or steps (for example, is cautious, stops before moving)					
→	L	77	Fears falling or heights					
→	L	78	Avoids climbing/jumping or avoids bumpy/uneven ground					
→	L	79	Holds onto walls or banisters (for example, clings)					
→	H	80	Takes excessive risks during play (for example, climbs high into a tree, jumps off tall furniture)					
→	H	81	Takes movement or climbing risks during play that compromise personal safety					
→	H	82	Turns whole body to look at you					
	H	83	Seeks opportunities to fall without regard to personal safety					
	H	84	Appears to enjoy falling					
			Section Raw Score Total					

Comments

Item			I. Modulation of Movement Affecting Activity Level	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
	L	85	Spends most of the day in sedentary play (for example, does quiet things)					
	L	86	Prefers quiet, sedentary play (for example, watching TV, books, computers)					
→	L	87	Seeks sedentary play options					
→	L	88	Prefers sedentary activities					
→	H	89	Becomes overly excitable during movement activity					
	H	90	"On the go"					
	H	91	Avoids quiet play activities					
			Section Raw Score Total					

Comments

Item			J. Modulation of Sensory Input Affecting Emotional Responses	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		92	Needs more protection from life than other children (for example, defenseless physically or emotionally)					
	L	93	Rigid rituals in personal hygiene					
	H	94	Is overly affectionate with others					
	H	95	Doesn't perceive body language or facial expressions (for example, unable to interpret)					
			Section Raw Score Total					

Comments

Item			K. Modulation of Visual Input Affecting Emotional Responses and Activity Level	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
👁	L	96	Avoids eye contact					
👁	H	97	Stares intensively at objects or people					
👁	H	98	Watches everyone when they move around the room					
👁	H	99	Doesn't notice when people come into the room					
			Section Raw Score Total					

Comments

Behavior and Emotional Responses

Item			L. Emotional/Social Responses	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
♡		100	Seems to have difficulty liking self (for example, low self-esteem)					
♡		101	Has trouble "growing up" (for example, reacts immaturely to situations)					
♡		102	Is sensitive to criticisms					
♡		103	Has definite fears (for example, fears are predictable)					
♡		104	Seems anxious					
♡		105	Displays excessive emotional outbursts when unsuccessful at a task					
♡		106	Expresses feeling like a failure					
♡		107	Is stubborn or uncooperative					
♡		108	Has temper tantrums					
♡		109	Poor frustration tolerance					
♡		110	Cries easily					
♡		111	Overly serious					
♡		112	Has difficulty making friends (for example, does not interact or participate in group play)					
♡		113	Has nightmares					
♡		114	Has fears that interfere with daily routine					
♡		115	Doesn't have a sense of humor					
♡		116	Doesn't express emotions					
			Section Raw Score Total					

Comments

Item			M. Behavioral Outcomes of Sensory Processing	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		117	Talks self through tasks					
		118	Writing is illegible					
		119	Has trouble staying between the lines when coloring or when writing					
		120	Uses inefficient ways of doing things (for example, wastes time, moves slowly, does things a harder way than is needed)					
	L	121	Has difficulty tolerating changes in plans and expectations					
	L	122	Has difficulty tolerating changes in routines					
			Section Raw Score Total					

Comments

Item			N. Items Indicating Thresholds for Response	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		123	Jumps from one activity to another so that it interferes with play					
	H	124	Deliberately smells objects					
	H	125	Does not seem to smell strong odors					
			Section Raw Score Total					

Comments

FOR OFFICE USE ONLY

ICON KEY	
	Auditory
	Visual
	Activity Level
	Taste/Smell
	Body Position
	Movement
	Touch
	Emotional/Social

THRESHOLD KEY	
	Neither low nor high
L	Low
H	High

SCORE KEY	
1	Always
2	Frequently
3	Occasionally
4	Seldom
5	Never

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SENSORY PROFILE

Winnie Dunn, Ph.D., OTR, FAOTA

Summary Score Sheet

Child's Name: _____ Gender: ☐ Male ☐ Female

Questionnaire Completed by: _____

Relationship to Child: _____

Service Provider's Name: _____

Discipline: _____

	YEAR	MONTH	DAY
Date Tested			
Date of Birth			
Chronological Age			

The child receives the following service(s)

- ☐ Early Intervention/Preschool Services
- ☐ Regular Education
- ☐ Special Education
- ☐ Occupational Therapy
- ☐ Physical Therapy
- ☐ Speech Therapy
- ☐ Other (please specify) _____

Child's condition(s)

- ☐ Mental Retardation
- ☐ Specific Learning Disability
- ☐ Speech or Language Impairment
- ☐ Autism/Pervasive Developmental Disorder (PDD)
- ☐ Asperger's Syndrome
- ☐ Emotional Disturbance or Serious Behavioral Difficulties
- ☐ Attention Disorder (ADD, ADHD)
- ☐ Visual Impairment/Blindness
- ☐ Hearing Impairment/Deafness
- ☐ Cerebral Palsy
- ☐ Fragile X
- ☐ Tic Disorder (e.g., Tourette's)
- ☐ Multiple Disabilities
- ☐ Traumatic Brain Injury
- ☐ Other Neurological Disorder
- ☐ Other Health Conditions (e.g., cardiac disorder, asthma)
- ☐ Other (please specify) _____

Other comments

_____

_____

_____

_____

_____

_____

_____

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Factor Grid

Instructions: Transfer from the *Caregiver Questionnaire* the item raw score that corresponds with each item listed. Add the Raw Score column to get the Factor Raw Score Total for each factor.

FACTOR 1 — Sensory Seeking

Item	Raw Score
8	
24	
25	
26	
44	
45	
46	
51	
80	
81	
82	
83	
84	
89	
90	
94	
123	
Factor Raw Score Total	

FACTOR 2 — Emotionally Reactive

Item	Raw Score
92	
100	
101	
102	
103	
104	
105	
106	
107	
108	
109	
110	
111	
112	
121	
122	
Factor Raw Score Total	

FACTOR 3 — Low Endurance/Tone

Item	Raw Score
66	
67	
68	
69	
70	
71	
72	
73	
74	
Factor Raw Score Total	

FACTOR 4 — Oral Sensory Sensitivity

Item	Raw Score
55	
56	
57	
58	
59	
60	
61	
62	
63	
Factor Raw Score Total	

FACTOR 5 — Inattention/Distractibility

Item	Raw Score
3	
4	
5	
6	
7	
48	
49	
Factor Raw Score Total	

ICON KEY

	Auditory
	Visual
	Activity Level
	Taste/Smell
	Body Position
	Movement
	Touch
	Emotional/Social

FACTOR 6		
Poor Registration		
Item		Raw Score
	35	
	42	
	43	
	95	
	99	
	115	
	116	
	125	
Factor Raw Score Total		

FACTOR 7		
Sensory Sensitivity		
Item		Raw Score
→	18	
→	19	
→	77	
→	78	
Factor Raw Score Total		

FACTOR 8		
Sedentary		
Item		Raw Score
	85	
	86	
→	87	
→	88	
Factor Raw Score Total		

FACTOR 9		
Fine Motor/Perceptual		
Item		Raw Score
	13	
	118	
	119	
Factor Raw Score Total		

Factor Summary

Instructions: Transfer the child's score for each factor to the column labeled Factor Raw Score Total. Then plot these totals by marking an X in the appropriate classification column (Typical Performance, Probable Difference, Definite Difference).*

Factor	Factor Raw Score Total	Typical Performance	Probable Difference	Definite Difference
1. Sensory Seeking	/85	85 ---------- 63	62 ---------- 55	54 ---------- 17
2. Emotionally Reactive	/80	80 ---------- 57	56 ---------- 48	47 ---------- 16
3. Low Endurance/Tone	/45	45 ---------- 39	38 ---------- 36	35 ---------- 9
4. Oral Sensory Sensitivity	/45	45 ---------- 33	32 ---------- 27	26 ---------- 9
5. Inattention/Distractibility	/35	35 ---------- 25	24 ---------- 22	21 ---------- 7
6. Poor Registration	/40	40 ---------- 33	32 ---------- 30	29 ---------- 8
7. Sensory Sensitivity	/20	20 ---------- 16	15 ---------- 14	13 ---------- 4
8. Sedentary	/20	20 ---------- 12	11 ---------- 10	9 ---------- 4
9. Fine Motor/Perceptual	/15	15 ---------- 10	9 ---------- 8	7 ---------- 3

*Classifications are based on the performance of children without disabilities ($n = 1,037$).

Section Summary

Instructions: Transfer the child's score for each section to the Section Raw Score Total column. Then plot these totals by marking an X in the appropriate classification column (Typical Performance, Probable Difference, Definite Difference).*

Sensory Processing	Section Raw Score Total	Typical Performance	Probable Difference	Definite Difference
A. Auditory Processing	/40	40 ---------- 30	29 ---------- 26	25 ---------- 8
B. Visual Processing	/45	45 ---------- 32	31 ---------- 27	26 ---------- 9
C. Vestibular Processing	/55	55 ---------- 48	47---------- 45	44 ---------- 11
D. Touch Processing	/90	90 ---------- 73	72---------- 65	64 ---------- 18
E. Multisensory Processing	/35	35 ---------- 27	26 ---------- 24	23 ---------- 7
F. Oral Sensory Processing	/60	60 ---------- 46	45 ---------- 40	39 ---------- 12
Modulation				
G. Sensory Processing Related to Endurance/Tone	/45	45 ---------- 39	38 ---------- 36	35 ---------- 9
H. Modulation Related to Body Position and Movement	/50	50 ---------- 41	40 ---------- 36	35 ---------- 10
I. Modulation of Movement Affecting Activity Level	/35	35 ---------- 23	22 ---------- 19	18 ---------- 7
J. Modulation of Sensory Input Affecting Emotional Responses	/20	20 ---------- 16	15 ---------- 14	13 ---------- 4
K. Modulation of Visual Input Affecting Emotional Responses and Activity Level	/20	20 ---------- 15	14 ---------- 12	11 ---------- 4
Behavior and Emotional Responses				
L. Emotional/Social Responses	/85	85 ---------- 63	62 ---------- 55	54 ---------- 17
M. Behavioral Outcomes of Sensory Processing	/30	30 ---------- 22	21 ---------- 19	18 ---------- 6
N. Items Indicating Thresholds for Response	/15	15 ---------- 12	11 ---------- 10	9 ---------- 3

*Classifications are based on the performance of children without disabilities (n = 1,037).

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Appendix 2

Worksheet for calculating quadrant scores

WORKSHEET FOR CALCULATING QUADRANT SCORES
ON THE SENSORY PROFILE (Dunn, 1999)
For Children Ages 3-10 years

Quadrant 1 Low Registration		Quadrant 2 Sensation Seeking		Quadrant 3 Sensory Sensitivity		Quadrant 4 Sensation Avoiding	
Item	Raw Score	Item	Raw Score	Item	Raw Score	Item	Raw Score
6		8		3		1	
7		24		4		2	
47		25		14		5	
50		26		18		9	
53		27		19		10	
66		28		21		11	
67		40		30		15	
68		41		31		20	
69		44		32		22	
70		45		33		29	
71		46		34		36	
72		51		39		37	
73		59		48		54	
74		60		49		76	
75		61		55		85	
		62		56		86	
		63		57		87	
		80		58		88	
		81		77		93	
		82		78		103	
		83				104	
		84				105	
		89				107	
		90				108	
		94				109	
		123				110	
						111	
						112	
						114	
Quadrant Raw Score Total		Quadrant Raw Score Total		Quadrant Raw Score Total		Quadrant Raw Score Total	

Quadrant Summary

Instructions: Transfer the Quadrant Raw Score Totals form the Quadrant Grid to the corresponding Quadrant Raw Score Total box. Plot these totals by marking an X in the appropriate classification column (Typical Performance, Probable Difference, Definite Difference)***

		←Less Than Others*			More Than Others→*	
Quadrant	Quadrant Raw Score Total	Definite Difference	Probable Difference	Typical Performance	Probable Difference	Definite Difference
Low Registration	/75	**	75------73	72---------64	63-------59	58-------15
Sensation Seeking	/130	**	130--124	123----_103	102----92	91------26
Sensory Sensitivity	/100	**	100----95	94----------81	80------73	72-------20
Sensation Avoiding	/145	145---141	140---134	133-----113	112---103	102-----29

*Note: see 'expanded cut score theory' explanation at www.sensoryprofile.com
** There can be no Definite Difference for this quadrant.
***Classifications are based on the performance of children without disabilities (*n*= 1,037).

Alpha coefficients of Quadrant Groupings

Quadrant	Number of items	Alpha with ALL children in national sample	Alpha with only typical children in national sample
1. Low Registration	15	.8748	.7950
2. Sensation Seeking	26	.9280	.9012
3. Sensory Sensitivity	20	,8894	.8409
4. Sensation Avoiding	29	.9048	.8717

Appendix 3

The Adolescent/Adult Sensory Profile

ADOLESCENT/ADULT SENSORY PROFILE™

Catana Brown, Ph.D., OTR, FAOTA
Winnie Dunn, Ph.D., OTR, FAOTA

Self Questionnaire

Name: _____ Age: _____ Date: _____

Birthdate: _____ Gender: ☐ Male ☐ Female

Are there aspects of daily life that are not satisfying to you? If yes, please explain. _____

_____

_____

_____

INSTRUCTIONS

Please check the box that **best** describes the frequency with which you perform the following behaviors. If you are unable to comment because you have not experienced a particular situation, please draw an X through that item's number. Write any comments at the end of each section.

Please answer all of the statements. Use the following key to mark your responses:

ALMOST NEVER	When presented with the opportunity, you **almost never** respond in this manner (about 5% or less of the time).
SELDOM	When presented with the opportunity, you **seldom** respond in this manner (about 25% of the time).
OCCASIONALLY	When presented with the opportunity, you **occasionally** respond in this manner (about 50% of the time).
FREQUENTLY	When presented with the opportunity, you **frequently** respond in this manner (about 75% of the time).
ALMOST ALWAYS	When presented with the opportunity, you **almost always** respond in this manner (about 95% or more of the time).

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Item		A. Taste/Smell Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	1	I leave or move to another section when I smell a strong odor in a store (for example, bath products, candles, perfumes).					
	2	I add spice to my food.					
	3	I don't smell things that other people say they smell.					
	4	I enjoy being close to people who wear perfume or cologne.					
	5	I only eat familiar foods.					
	6	Many foods taste bland to me (in other words, food tastes plain or does not have a lot of flavor).					
	7	I don't like strong tasting mints or candies (for example, hot/cinnamon or sour candy).					
	8	I go over to smell fresh flowers when I see them.					

›mments

Item		B. Movement Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	9	I'm afraid of heights.					
	10	I enjoy how it feels to move about (for example, dancing, running).					
	11	I avoid elevators and/or escalators because I dislike the movement.					
	12	I trip or bump into things.					
	13	I dislike the movement of riding in a car.					
	14	I choose to engage in physical activities.					
	15	I am unsure of footing when walking on stairs (for example, I trip, lose balance, and/or need to hold the rail).					
	16	I become dizzy easily (for example, after bending over, getting up too fast).					

mments

Item		C. Visual Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	17	I like to go to places that have bright lights and that are colorful.					
	18	I keep the shades down during the day when I am at home.					
	19	I like to wear colorful clothing.					
	20	I become frustrated when trying to find something in a crowded drawer or messy room.					
	21	I miss the street, building, or room signs when trying to go somewhere new.					
	22	I am bothered by unsteady or fast moving visual images in movies or TV.					
	23	I don't notice when people come into the room.					
	24	I choose to shop in smaller stores because I'm overwhelmed in large stores.					
	25	I become bothered when I see lots of movement around me (for example, at a busy mall, parade, carnival).					
	26	I limit distractions when I am working (for example, I close the door, or turn off the TV).					

Comments

Item		D. Touch Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	27	I dislike having my back rubbed.					
	28	I like how it feels to get my hair cut.					
	29	I avoid or wear gloves during activities that will make my hands messy.					
	30	I touch others when I'm talking (for example, I put my hand on their shoulder or shake their hands).					
	31	I am bothered by the feeling in my mouth when I wake up in the morning.					
	32	I like to go barefoot.					
	33	I'm uncomfortable wearing certain fabrics (for example, wool, silk, corduroy, tags in clothing).					
	34	I don't like particular food textures (for example, peaches with skin, applesauce, cottage cheese, chunky peanut butter).					
	35	I move away when others get too close to me.					
	36	I don't seem to notice when my face or hands are dirty.					
	37	I get scrapes or bruises but don't remember how I got them.					
	38	I avoid standing in lines or standing close to other people because I don't like to get too close to others.					
	39	I don't seem to notice when someone touches my arm or back.					

omments

Item		E. Activity Level	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	40	I work on two or more tasks at the same time.					
	41	It takes me more time than other people to wake up in the morning.					
	42	I do things on the spur of the moment (in other words, I do things without making a plan ahead of time).					
	43	I find time to get away from my busy life and spend time by myself.					
	44	I seem slower than others when trying to follow an activity or task.					
	45	I don't get jokes as quickly as others.					
	46	I stay away from crowds.					
	47	I find activities to perform in front of others (for example, music, sports, acting, public speaking, and answering questions in class).					
	48	I find it hard to concentrate for the whole time when sitting in a long class or a meeting.					
	49	I avoid situations where unexpected things might happen (for example, going to unfamiliar places or being around people I don't know).					

Comments

Item		F. Auditory Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	50	I hum, whistle, sing, or make other noises.					
	51	I startle easily at unexpected or loud noises (for example, vacuum cleaner, dog barking, telephone ringing).					
	52	I have trouble following what people are saying when they talk fast or about unfamiliar topics.					
	53	I leave the room when others are watching TV, or I ask them to turn it down.					
	54	I am distracted if there is a lot of noise around.					
	55	I don't notice when my name is called.					
	56	I use strategies to drown out sound (for example, close the door, cover my ears, wear ear plugs).					
	57	I stay away from noisy settings.					
	58	I like to attend events with a lot of music.					
	59	I have to ask people to repeat things.					
	60	I find it difficult to work with background noise (for example, fan, radio).					

Comments

Summary Score Sheet

Quadrant Grid

Instructions: Transfer from the *Self Questionnaire* the item raw score that corresponds with each item listed (refer to the *User's Manual* for directions on how to obtain item raw scores). Add the Raw Score column to get the Quadrant Raw Score Total for each quadrant.

QUADRANT 1 — Low Registration	
Item	Raw Score
3	
6	
12	
15	
21	
23	
36	
37	
39	
41	
44	
45	
52	
55	
59	
Quadrant Raw Score Total	

QUADRANT 2 — Sensation Seeking	
Item	Raw Score
2	
4	
8	
10	
14	
17	
19	
28	
30	
32	
40	
42	
47	
50	
58	
Quadrant Raw Score Total	

QUADRANT 3 — Sensory Sensitivity	
Item	Raw Score
7	
9	
13	
16	
20	
22	
25	
27	
31	
33	
34	
48	
51	
54	
60	
Quadrant Raw Score Total	

QUADRANT 4 — Sensation Avoiding	
Item	Raw Score
1	
5	
11	
18	
24	
26	
29	
35	
38	
43	
46	
49	
53	
56	
57	
Quadrant Raw Score Total	

SCORE KEY	
1	Almost Never
2	Seldom
3	Occasionally
4	Frequently
5	Almost Always

ICON KEY	
—	Low Registration
ς	Sensation Seeking
◎	Sensory Sensitivity
|	Sensation Avoiding

Quadrant Summary

Instructions: Choose the appropriate Quadrant Summary Chart and then transfer the Quadrant Raw Score Total from the previous page to the corresponding Quadrant Raw Score Total box. Plot these totals by marking an X in the appropriate classification column (Much Less than Most People, Less than Most People, etc.).*

Quadrant Summary Chart for Ages 11–17

Quadrant	Quadrant Raw Score Total	Much Less Than Most People	Less Than Most People	Similar To Most People	More Than Most People	Much More Than Most People
		– –	–	=	+	+ +
1. Low Registration	/75	15 ——— 18	19 ——— 26	27 ——— 40	41 ——— 51	52 ——— 75
2. Sensation Seeking	/75	15 ——— 27	28 ——— 41	42 ——— 58	59 ——— 65	66 ——— 75
3. Sensory Sensitivity	/75	15 ——— 19	20 ——— 25	26 ——— 40	41 ——— 48	49 ——— 75
4. Sensation Avoiding	/75	15 ——— 18	19 ——— 26	26 ——— 40	41 ——— 48	49 ——— 75

*Classifications are based on the performance of individuals without disabilities ($n = 193$).

Quadrant Summary Chart for Ages 18–64

Quadrant	Quadrant Raw Score Total	Much Less Than Most People	Less Than Most People	Similar To Most People	More Than Most People	Much More Than Most People
		– –	–	=	+	+ +
1. Low Registration	/75	15 ——— 18	19 ——— 23	24 ——— 35	36 ——— 44	45 ——— 75
2. Sensation Seeking	/75	15 ——— 35	36 ——— 42	43 ——— 56	57 ——— 62	63 ——— 75
3. Sensory Sensitivity	/75	15 ——— 18	19 ——— 25	26 ——— 41	42 ——— 48	49 ——— 75
4. Sensation Avoiding	/75	15 ——— 19	20 ——— 26	27 ——— 41	42 ——— 49	50 ——— 75

*Classifications are based on the performance of individuals without disabilities ($n = 496$).

Quadrant Summary Chart for Ages 65 and older

Quadrant	Quadrant Raw Score Total	Much Less Than Most People	Less Than Most People	Similar To Most People	More Than Most People	Much More Than Most People
		– –	–	=	+	+ +
1. Low Registration	/75	15 ——— 19	20 ——— 26	27 ——— 40	41 ——— 51	52 ——— 75
2. Sensation Seeking	/75	15 ——— 28	29 ——— 39	40 ——— 52	53 ——— 63	64 ——— 75
3. Sensory Sensitivity	/75	15 ——— 18	19 ——— 25	26 ——— 41	42 ——— 48	49 ——— 75
4. Sensation Avoiding	/75	15 ——— 18	19 ——— 25	26 ——— 42	43 ——— 49	50 ——— 75

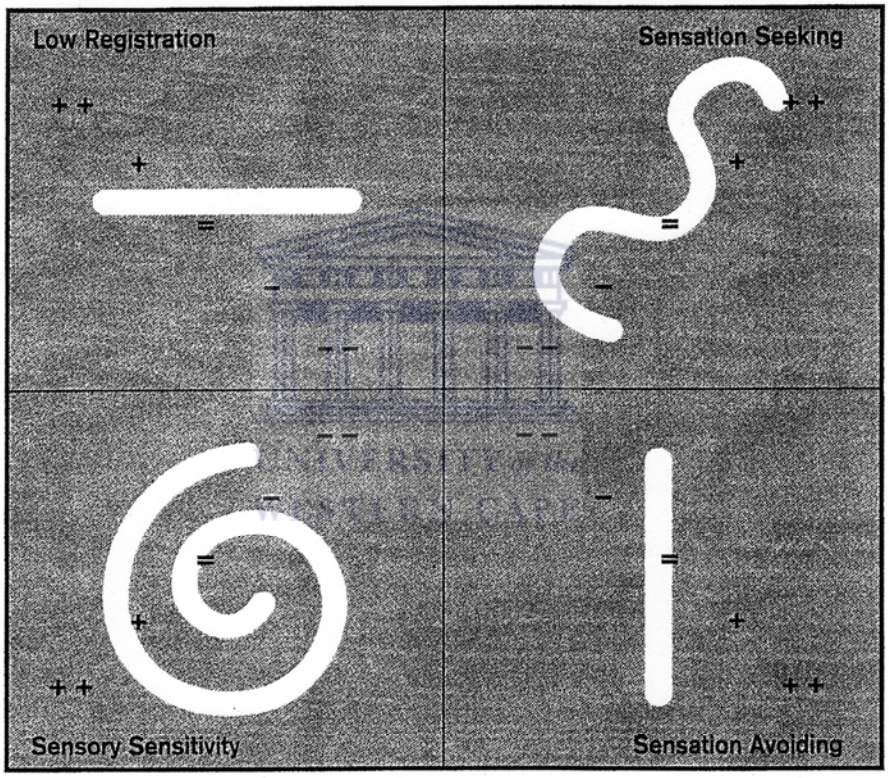
*Classifications are based on the performance of individuals without disabilities ($n = 261$).

Quadrant Profile

Instructions: Transfer the information from the classification columns of the Quadrant Summary Chart (the areas marked with an X) to the Quadrant Profile. Circle the classification symbol in each quadrant below that corresponds with the classification information for that quadrant. Finally, check the appropriate age box.

The following symbols are used to represent the classifications on the Quadrant Profile:

– –	Much Less Than Most People
–	Less Than Most People
=	Similar to Most People
+	More Than Most People
+ +	Much More Than Most People



See chapter 5 for more information regarding interpretations and intervention.

Check the correct age:

- ☐ 11–17 years
- ☐ 18–64 years
- ☐ 65 years and older