

**EXPLORING OCCUPATIONAL THERAPY INTERVENTION FOR YOUNG  
CHILDREN WITH AUTISM SPECTRUM DISORDER IN SOUTH AFRICA**

A dissertation submitted to the  
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in fulfilment of the requirements for the degree of  
Master of Occupational Therapy

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## DEDICATION

To my parents, long suffering family, friends and colleagues who supported me and continue to inspire me.

‘Wisdom is the lost property of the believer, let her claim it wherever she finds it’

Prophet Muhammad (peace and blessings be upon him)

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## OPERATIONAL DEFINITIONS

Occupational Therapy: facilitates participation in meaningful activities of daily life (such as self-care skills, education, work, or social interaction) despite impairments or limitations in physical or mental functioning.

ASD: is a developmental disorder characterized by impairment in the ability to form normal social relationships and communicate with others and by stereotyped behavior patterns, which often manifest as a preoccupation with restricted and repetitive activities, lacking in imagination as well as by the presence of atypical sensory experiences.

Sensory Integration: is the neurological process that organizes multiple sensory modality inputs from one's own body and the environment, in order to use the body or act effectively within the environment.

Sensory Modulation: is the ability to manage one's response to multiple sensory stimuli in a graded manner, so as not to over nor under respond.

Sensory Modulation Dysfunction: is an inability to modulate sensations resulting in three main categories of behavioural responses;

- Sensory Over responsive profile: exhibits an exaggerated response to sensations, accompanied by high arousal levels
- Sensory Under responsive profile: a diminished response to sensations, with low arousal levels
- Sensory Craving profile: seeks out sensation, with high arousal levels

Sensory Diet: A planned and scheduled activity programme designed to meet a child's specific sensory needs

Dyspraxia: a disorder of sensory integration characterized by an impaired ability to plan and execute skilled, non-habitual coordinated movements (also referred to as motor planning difficulties)

Dosage: the prescribed frequency of therapy as a means of intervention

## **ABBREVIATIONS**

ASD: Autism Spectrum Disorder

APA: American Psychiatric Association

ABA: Applied Behavioural Analysis

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, fifth edition

OT: Occupational Therapy or Occupational Therapist

SLT: Speech Language Therapist

SPD: Sensory Processing Disorder/ Dysfunction

IADL: Instrumental Activities of Daily Living often referred to by participants by old terminology of ADL (activities of daily living)

OT-SI: Sensory Integration Occupational Therapy

SI: Sensory Integration (Ayres theoretical and clinical practice framework)

SIT: Sensory Integration Therapy

SMD: Sensory Modulation Disorder

AAC: Augmentative and Alternative Communication

TEACCH: Treatment and Education of Autistic and related Communication Handicapped Children

PP: Private practice

SNS: Special needs school

H: Hospital

## **ABSTRACT**

Occupational Therapy is amongst the top three interventions sought for young children with ASD in South Africa. Due to scarce local research on OT for ASD, this study explored the nature as well as perceptions of OTs on intervention for ASD. Using a qualitative exploratory study design, semi-structured interviews were conducted with twenty OTs in public and private health, as well as special needs education. Thematic analysis was used to analyse transcribed data. OTs descriptions and perceptions of assessment, direct and indirect intervention as well as challenges facing families and undergraduate and qualified OTs in South Africa were explored. Assessment for ASD utilised play based skilled observations with limited use of standardised tests. Developmental approaches were preferred to behavioural ones, with the majority of OTs referencing the Sensory Integration (SI) framework for assessment and therapy, even if they were not SI certified practitioners. The value of SI in reframing a child's behaviour for parents was significant. The South African Model of Creative Ability was a unique local application to practice for ASD. Intervention in education was most ASD specific, including AAC and visual approaches due to a comprehensive programme and greater levels of team collaboration. A family focussed practice was most evident in private and public health. Direct individual therapy was predominant, with all sectors struggling to provide the intensity of therapy recommended for ASD, due to unique contextual challenges. Undergraduate training is insufficient preparation for working with ASD and a need for local OT specialists was identified. Implications for research and practice are discussed.

**Keywords:** occupational therapy, autism spectrum disorder, South African practice patterns, public and private health, special needs education

## CHAPTER ONE

### INTRODUCTION

#### 1.1 ASD “Epidemic”

There has been an explosion of research and interest in autism in the last fifteen years due to the increased incidence of ASD worldwide. ASD affects one in every eighty eight children and one in every fifty four boys in the USA, according to latest Centers for Disease control and Prevention (CDC) report (Baio, 2012). This is an alarming twenty three percent increase in rate of ASD prevalence between 2006 and 2008 (Centers for Disease Control and Prevention, 2012). The sharp rise in incidence has led scientists to question whether this is a true increase in cases of ASD or due to improved diagnostic rates(Chakrabarti & Fombonne, 2005).

At present the cause of ASD is unknown. Three commonly cited factors are genetic make up, environmental causes and a combination of both these factors (Bogdashina, 2006). One of the critical historical advances in aetiology has been the acceptance of ASD as having a neurobiological basis, not a psychological one (Howlin, 1997). There are still many unanswered questions about ASD. These relate to all aspects of the condition such as aetiology, theoretical explanations of aetiology, classification and diagnosis, neuro-bio-chemical mechanisms contributing to impairments, effective interventions for ASD as well as the question of a “cure” for ASD (Rutter, 2005).

#### 1.2 SA Prevalence

With scarce epidemiological studies in South Africa, it is speculated that a large proportion of children with ASD are probably undiagnosed and untreated. The estimated statistic of people living with ASD in SA is three hundred thousand (B. Papadakis, personal communication, Autism South Africa, May 20, 2011). Autism prevalence in SA is estimated to be ten per thousand children (Jacklin & Stacey, 2010).

### **1.3 Definition and Core Deficits**

Autism Spectrum Disorder (ASD) is a lifelong developmental spectrum disorder that emerges within the first three years of life. It is characterised by pervasive impairments in the areas of language and communication, social and interpersonal relationships, behaviour that is restrictive and repetitive as well as hyper or hypo reactivity to sensory input. Core deficits in social interaction and communication give rise to significant disability with different challenges arising at various phases during a person's lifespan (Watling, Tomchek, & LaVesser, 2005).

### **1.4 The Role of OT in ASD**

Autism research regarding a cure or prevention is far from realisation. Early identification, and appropriate, effective and efficient interventions seem the most practical routes to reduce the burden of the disability upon the child, the family and society. Occupational therapy is one such recognised intervention for ASD (Ayres & Tickle, 1980; Miller-Kuhaneck & Glennon, 2004; Stancliff, 1996).

Occupational Therapy is a client centred profession that facilitates a client's meaningful engagement in daily life occupations. Occupations fall into areas of work, education, play, leisure, instrumental activities of daily living (IADL) and social interaction (Watling, Tomchek, & LaVesser, 2005). OTs utilise meaningful activities, specialised techniques and environmental adaptations in the context of a therapeutic relationship to facilitate occupation in clients.

In the context of paediatric practice, OTs work in early intervention within the home, hospitals, in schools as well as in community settings. OT covers a wide range of disabilities, both physical as well as socio-emotional. OT for children with ASD aims to facilitate skills and development in all performance areas to enable participation in age appropriate life occupations (Watling et. al, 2005).

Instrumental activities of daily living (IADL), relate to self-care skills of hygiene, grooming, dressing and feeding. At school, accessing the curriculum may require improvement in handwriting skills while accessing the playground may involve improvement of gross motor and social skills. Play, as an occupation of childhood may also be the focus and not just the medium of intervention. Intervention is based

on an individualised assessment that may include standardised tests. OTs routinely provide intervention for sensory processing, gross and fine motor skills, self care, play, attention, socialisation and problem behaviours (Case-Smith & Miller, 1999; Watling, Deitz, Kanny, & McLaughlin, 1999). OT is thus an important component of a comprehensive and multidisciplinary programme for children with ASD (Case-Smith, 2010).

### **1.5 Previous Research in the Field**

Occupational therapy's history of involvement in Autism Spectrum Disorder (ASD) in general and in South Africa in particular, is relatively short and not well documented. Internationally, between 1967 and 1999, only six studies in the field of ASD and occupational therapy were found (Watling, et al., 1999). Two surveys in 1999 documented practice of American occupational therapists with young ASD populations, with sample sizes of two hundred and ninety two (Case-Smith & Miller, 1999) and seventy two OTs (Watling, et al., 1999).

Watling et al studied the practice patterns of American OTs for children with ASD, between the ages of two and twelve years (Watling, et al., 1999). They posted questionnaires to experienced OTs providing intervention for children with ASD. Their sample of seventy two was analysed for data such as format, duration and location of typical OT therapy sessions, collaboration with other professionals, termination of services, evaluation and intervention practices including standardised tests used, approaches or theoretical frameworks used as well as techniques utilised. A section on education and training in terms of its value for working in the field as well as preferred methods of training were solicited. Results revealed that common practice patterns for American OTs were: individual 1:1 intervention, utilising SI theory, developmental theory and then behavioural theory in order of most frequently referenced frameworks. Non-standardised assessment was common, with high levels of inter-professional collaboration during assessment and intervention (Watling, et al., 1999). Recommendations for future research was to explore patterns in greater depth, whilst differentiating between education and health sectors. Further exploration of the nature of team collaboration was also suggested.

The survey by Case-Smith and Miller, randomly targeted members of the American Occupational Therapy Association's Sensory Integration Special Interest Section or their School Special Interest section (Case-Smith & Miller, 1999). Two hundred and ninety two of the five hundred surveys mailed were usable. Apart from demographic data, Likert scale ratings were used for frequency of problems observed and addressed in intervention, extent of improvement in specific areas, frequency of use of in intervention approaches and specific models of service delivery as well as perceived confidence in these approaches.

Sensory processing, motor planning and fine motor function were common intervention goals. The area of most improvement was sensory processing, with least improvement reported in cognition and play skills. Sensory integration and environmental modification were the most frequently used approaches in which OTs reported the greatest expertise.

Since 1999, a number of articles regarding occupational therapy intervention for ASD have emerged in the developed world (Jasmin, et al., 2009; May-Benson, 2010; May-Benson & Koomar, 2010; Schaaf & Miller, 2005; Watling, Deitz, & White, 2001; Watling & Dietz, 2007; Werner DeGrace, 2004). A database search for published ASD research at SA universities between 2000 and 2011, listed 21 theses. In Occupational therapy, three published studies were listed. These dealt with aspects of service provision (Hooper, 2009), parent child sensory compatibility (Pillay, 2011) and efficacy of sensory integration intervention (Wallace, 2009). Thus research in the field of ASD and OT in South Africa is clearly in its infancy.

Intervention embraces assessment, therapy and support services to the child and family. This study will confine itself to describing intervention of a developmental skill based nature for two to twelve year olds. Components of OT programmes such as vocational rehabilitation or social skills training, will not form part of the intervention practices under study, as these are areas of individual study in themselves. OTs are likely to provide services to young children with ASD within three settings: public health service, private practice and special needs educational facilities both public and private, therefore these settings will be explored.

## **1.6 South African Challenges**

The South African scenario presents unique challenges to health and education service delivery. The burden of an apartheid era structure and unequal distribution of resources continues to present a challenge. A national health insurance is proposed for the near future. The Education White Paper 6 (Department of Education, 2001) and the National Health Act [61 of 2003] (Government Gazette Republic of South Africa, 2004) were attempts to address the inequalities post apartheid. Despite the good intentions of legislation, factors such as a burdened health care system and limited resources, are likely to have hampered health service provision and educational inclusion (Hooper, 2009). Rising incidence rates of ASD across income groups, will ultimately lead to a greater demand for services in public and private health care as well as in public schools. Despite lacking the range and depth of resources of developing countries, there is an ethical and constitutional obligation to provide services to this population in SA.

It has been argued that intervention for ASD, requires specialists, preferably trained or experienced therapists who understand the complexities and core challenges of the disability (Mcgee & Morrier, 2005). However, this has implications for South Africa as a developing country with limited resources. Specialisation would require financial and human resources and the development of training programmes. OTs in community service positions and in public hospitals are likely to bear the brunt of service provision due to increased prevalence rates of ASD in the SA population. New graduates currently require some skills in ASD intervention to begin addressing these needs. The need for ASD specific OT intervention to match the future demand in the South African population is a looming challenge.

## **1.7 Problem Statement**

How are OTs in South Africa providing intervention for young children with ASD and what are their perceptions of intervention?/ what is SA OT practice for ASD ?

## **1.8 Rationale**

As a clinician working in an early intervention setting, the researcher became aware of a lack of information regarding SA OT practice with ASD, specifically regarding assessment and treatment. There is a clear challenge to provide ASD specific OT services in SA (Hooper, 2009). A preliminary understanding of current practice that emerges from this study, will contribute to describing occupational therapy services for children with ASD in healthcare and educational settings in South Africa. This will provide useful practice guidelines for OTs new to the field of ASD. The study will highlight the role of occupational therapy in the field. It will serve as a springboard for future research in the field of OT and ASD. The study may contribute towards developing a South African framework of guidelines for occupational therapy practice in the field of ASD. Information arising from the study can inform South African policy on service provision for ASD populations. A unique South African focus may emerge. With regard to education and training, it will unveil recommendations for undergraduate, postgraduate and continuing professional development training. In addition, there is a pressing need to document and explore current practice of OTs in the South African context, as few such studies exist. This study will follow up on recommendations of the Watling (1999) study, to examine practice patterns in greater depth and to differentiate between education and health sectors. This will enhance the understanding of contextual factors within sectors and its impact on intervention.

## **1.9 Research Question**

What is the nature of practice and the perceptions of OTs, regarding OT intervention for children with ASD in the sectors of public health, education and private health care in SA?

## **1.10 Brief Outline of Chapters Two to Five**

### ***Chapter two: Literature Review***

In this chapter, the literature is reviewed. It will describe and define key concepts in ASD and OT intervention for children with ASD. An overview of ASD's defining

characteristics and commonly prescribed interventions precedes the discussion on OT assessment and intervention for ASD. OT assessment, therapy, indirect intervention, teamwork, undergraduate and postgraduate training and challenges facing SA families is reviewed. Current international and local research in the field is critically evaluated, with the focus on OT intervention.

### ***Chapter three: Methodology***

This chapter outlines the research methodology. It includes the study aims and objectives, the research design, sampling, ethical considerations, data collection instrument and procedure as well as data analysis. This chapter describes the researcher as the data-gathering instrument. It also discusses the establishment of trustworthiness of the research and ethical considerations.

### ***Chapter four: Results and Discussion***

This chapter presents the results and interpretation thereof. The results are presented using tables, figures and direct quotes from participants. Findings are discussed in the context of available literature, possible reasons for the findings as well as its significance for the SA context.

### ***Chapter five: Conclusion and Recommendations***

Conclusions drawn from the study are presented together with clinical and research implications and limitations of the study.

## CHAPTER TWO

### 2.1. AUTISM SPECTRUM DISORDER

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder characterised by pervasive impairments in social communication and interaction. ASD was previously described as a “triad” of impairments in social interaction, communication and restricted and repetitive behaviours in The Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision (DSM IV-TR) (American Psychiatric Association, 2000).

The May 2013 edition of the DSM-5 has collapsed diagnostic criteria of communication and social interaction into one (American Psychiatric Association, 2013). Other significant revisions include replacing the umbrella term Pervasive Developmental Disorders (PDD), with Autism Spectrum Disorder, recognising the spectrum of disabilities without identifying four distinct subtypes of Asperger syndrome, childhood disintegrative disorder, pervasive developmental disorder not otherwise specified and autistic disorder. Further, DSM-5 now distinguishes three levels of severity of ASD according to the level of support required (American Psychiatric Association, 2013). The most significant revision for OT as a profession, has been the inclusion of sensory features for the first time under the category of stereotype motor and verbal behaviours.

Co-morbidity of other medical conditions with ASD is high, with rates of between eight and thirty seven per cent reported (Dover & Le Couteur, 2007). Common co-occurring conditions are intellectual impairment, epilepsy, metabolic disorders, mood disorders and learning disabilities. Anxiety is common and often leads to behavioural problems. Poor self regulation may contribute to anxiety but there may also be a biological basis for anxiety in ASD (Loveland & Tunali-Kotosky, 2005). There is also a possible relationship between obsessive compulsive disorder (OCD) and ASD seen in the repetitive and ritualistic behaviours (Loveland & Tunali-Kotosky, 2005). The lack of intellectual impairment is considered a good prognostic indicator, though even “high functioning” individuals continue to struggle with social

relationships, aspects of communication and independent living throughout their lives (Howlin, 2005b).

### **2.1.1. Diagnostic and Characteristic Features of ASD**

#### **2.1.1.1. Impaired communication and social interaction**

Delayed language development is an alarming signal for parents in terms of developmental milestones and is often the sign that alerts parents to seek help (Chawarska & Volkmar, 2005). Communication includes verbal or spoken language as well as non-verbal abilities such as gestures. Some children with ASD never develop expressive language and even in those individuals with good language skills, such as Asperger syndrome, understanding of irony and humour is impaired (Bogdashina, 2006; Chawarska & Volkmar, 2005).

A lack of social and emotional reciprocity is an early marker for the identification of ASD in the young child. Non-verbal behaviours such as eye contact, joint attention, shared enjoyment, use of gestures and facial expressions are often absent (Chawarska & Volkmar, 2005). The child with ASD may not express pleasure in interaction, such as a smile of joy directed at the mother when she walks into a room. Typically the child may isolate himself, preferring to play on his own, "rejecting" parental advances thus creating the perception of an "unreachable child". People with ASD face significant challenges in developing normal peer relationships (Carter, Davis, Klin, & Volkmar, 2005).

#### **2.1.1.2 Restrictive, repetitive and stereotyped behaviours, interests and activities**

Repetitive movements may include rocking, flapping hands, spinning objects, self-injurious behaviours or lining up of toys. The need for "sameness" or rigid adherence to rituals and routines is a marked feature of ASD (Rapin, 2005). A departure from these routines or blocking of ritual behaviour may cause significant distress and lead to emotional outbursts or "meltdowns". Interests of children with ASD are often restricted to a few activities. They may show attachment to objects or fascination with a topic to the exclusion of other interests. Make believe or symbolic play is often absent (Rogers, Cook, Meryl, 2005). Researchers have interpreted the

cause of repetitive stereotype behaviours as a number of possible explanations. These include co-morbid anxiety disorder, obsessive compulsive disorder, attempts at self regulation or difficulties with ideation and motor planning (Audet, 2010).

### **2.1.1.3 Sensory Features**

A fourth dimension of impairments strongly associated with ASD is that of sensory processing disturbances. Sensory processing disturbances while not unique to ASD, are a significant feature of ASD, reported widely in the literature (Baranek, David, Poe, Stone, & Watson, 2006; Greenspan & Wieder, 1997; Tomchek & Dunn, 2007) and in anecdotal evidence of adults living with ASD who are able to relate their experiences (Grandin, 1996; Mukhopadhyay, 2008). These sensory disturbances, may underlie behavioural idiosyncrasies common in persons with ASD such as flapping, rocking or even self-injurious behaviours (Baranek, Foster, & Berkson, 1997; Boyd, McBee, Holtzclaw, Baranek, & Bodfish, 2009; Gabriels, et al., 2008).

A number of studies have documented over and under responsiveness in seventy to one hundred percent of children with ASD (Adamson, O'Hare, & Graham, 2006; Baranek, Boyd, Poe, David, & Watson, 2007; Tomchek & Dunn, 2007). In one study, over ninety percent of thirty three children with ASD presented with sensory abnormalities across the various sensory systems of hearing, vision, touch, taste, smell and movement (Leekam, Nieto, Libby, Wing, & Gould, 2007). In a sample of two hundred and fifty eight participants, including children with ASD, sixty nine percent of those with autism had sensory symptoms (Baranek, David, Poe, Stone, & Watson, 2006).

### **2.1.2 Sensory Responsivity in ASD**

There is evidence to the effect that children with ASD have a heightened sense of sensory perception, experiencing sensations that are more intense (Reynolds & Lane, 2007). However, not all children with ASD experience intense sensory perception. For some children with ASD, their experience of sensations may be lowered (under responsiveness) or it may fluctuate between over and under responsiveness (Baranek, et al., 2006; Ben-Sasson, et al., 2003).

Those who are hypersensitive (over-responsive) to sensations may experience sounds as excruciatingly loud, light touch as painful, movement may be scary, and light may be hurtful to the eyes. Hypersensitivity to strong smells or tastes, result in restricted diets.

In those who are hypo-responsive (under-responsive), experience of sensations is dulled. They may not experience pain from a wound nor tune into sounds. They may crave movement and bright and stimulating visual images. Under (hypo) responsivity for taste and smell may lead one to seek out smells and a variety of tastes, often not restricted to food items.

### **2.1.3 Sensory Processing Disorder**

In OT literature, sensory integrative dysfunction is classified as *Sensory Processing Disorder (SPD)*. Sensory Processing refers to a number of processes such as registration, integration, modulation and organization of sensory information, including a behavioural response (Tomchek, 2010). Registration is the actual physical experience of the sensory stimuli, such as a touch on the hand. Integration is the process in the brain that makes sense of that touch experience together with other information from the other senses and the environment in order to respond appropriately.

SPD is classified into three types of disorders that are distinct but may co-occur in a child. Refer to table 2.1 below. A discussion of sensory modulation disorder and sensory based motor disorders especially dyspraxia will follow. These disorders of SPD commonly occur in persons with ASD. (Adamson, O'Hare, & Graham, 2006; DeMyer, et al., 1972).

Table 2.1: Classification of Sensory Processing Disorders (SPD)

Adapted from “Concept Evolution in Sensory Integration: A Proposed Nosology for Diagnosis” by Miller, L; Anzalone, M; Lane, S. Cermak,S; Osten,T, 2007, *American Journal of Occupational Therapy*,61(2), p 137

Sensory Processing Disorders (SPD)		
<p>Sensory Modulation Disorder</p> <p>Sensory Over Responsive</p> <p>Sensory Under Responsive</p> <p>Sensory Craving</p>	<p>Sensory Discrimination Disorder</p> <p>Visual</p> <p>Auditory</p> <p>Tactile</p> <p>Vestibular</p> <p>Proprioception</p> <p>Taste/Smell</p>	<p>Sensory based Motor Disorder</p> <p>Postural Disorder</p> <p>Dyspraxia</p>

#### 2.1.4 Sensory Modulation Disorder (SMD)

*Sensory modulation* is the regulation of sensory processing so as to not over, nor under respond to sensory stimuli. A well modulated response is socially and emotionally appropriate in nature and graded for intensity (Lane, Miller & Hanft, 2000). Poor regulation of sensory input results in *Sensory Modulation Disorder (SMD)* (Miller, Anzalone, Lane, Cermak, & Osten, 2007), which has been documented in persons with ASD (Adamson, O'Hare, & Graham, 2006).

Poor modulation means that children with ASD struggle to respond in an appropriate manner to sensory information within their environment, by ignoring insignificant stimuli and attending to important sensory information. Sensory experiences due to hypersensitivities (SOR) become overwhelming, resulting in emotional and behavioural responses such as withdrawal and avoidance or flight

and fight reactions (Dunn, 2007). In children who are hyposensitive (SUR), poor attention to the external environment results in a withdrawn and non-alert child. Poor sensory modulation, whether SOR or SUR, also affects attention and has negative implications for a calm regulated state in which learning and interaction can occur.

#### **2.1.4.1 Types of SMD**

Sensory modulation dysfunction has 3 subtypes: *Sensory over-responsivity (SOR)*, *Sensory under-responsivity (SUR)* and *Sensory craving (SC)* (Miller, et al., 2007).

##### **2.1.4.1.1 Sensory Over Responsiveness (SOR)**

Sensory over responsive experiences impact on physiological arousal levels and emotional states of anxiety (S. Green & Ben-Sasson, 2010). A child who is SOR has an aversive reaction to sensory stimuli or an exaggerated response out of proportion to the stimuli. It may last longer than a typical response. This exaggerated response is due to sensation being perceived as threatening, often resulting in a fright, fight, flight reaction. Their arousal levels are high with the autonomic system signalling “danger” mode (Tomchek, 2010). These are the children who are typically *sensory defensive* (in one or more sensory systems).

##### **2.1.4.1.2 Sensory under responsiveness (SUR)**

A child who is under-responsive (SUR) has a dampened response to stimuli, needing higher intensity and duration of stimuli to register the sensation and react. They are often passive, self absorbed and lethargic, displaying low arousal levels (Tomchek, 2010).

##### **2.1.4.1.3 Sensory Craving (SC)**

The sensory craving (SC) child is actively seeking sensory experiences. They crave unusually high levels of stimuli. They touch everything, are on the move and often engage in risky behaviour such as climbing very high. Their behaviour is often socially unacceptable such as bumping persons or not respecting physical

boundaries (Miller, et al., 2007) Their arousal levels are often high, resulting in poor focus (Anzalone & Williamson, 2000).

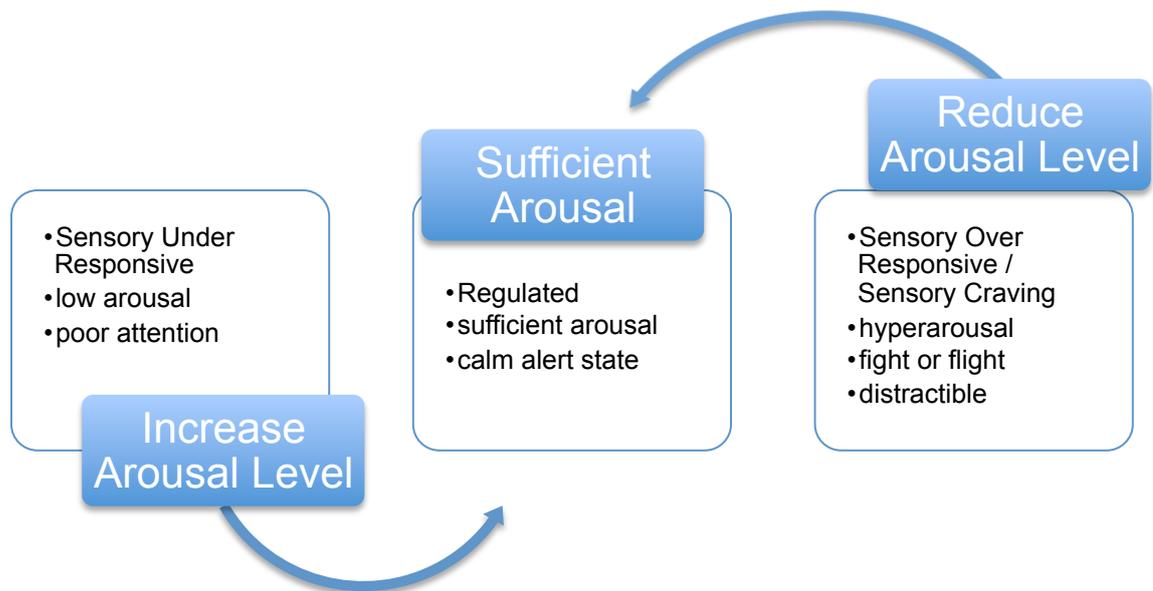


Figure 2.1: Sensory Modulation and States of Arousal

Profiling a child's sensory processing style, enables the OT to make recommendations on the teaching style, teaching materials and modifications to class and home environments. Providing the correct sensory stimuli and environment facilitates an increase or decrease in arousal levels which assists the child to maintain optimal arousal for learning (Anzalone & Williamson, 2000).

### 2.1.5 Motor Skills and Dyspraxia in ASD

Motor deficits (apart from motor stereotypies) whilst not universal in persons with ASD, are highly prevalent (Dawson & Watling, 2000). A recent meta analysis of motor deficits concluded that it is a potential core feature of ASD (Fournier, Hass, Naik, Lodha, & Cauraugh, 2010). Motor planning or dyspraxia as a significant feature of ASD first appeared in the literature in 1972 (DeMyer, et al., 1972) and recent studies seem to confirm dyspraxia as a core feature (Rogers, et al., 2003).

Dyspraxia as understood within the medical and psychological literature, relates to difficulties with a variety of imitation tasks: imitation of body postures, imitation of facial movements and actions on objects (Rogers, et al., 2003). Studies have shown that even children with high functioning autism, have problems with complex and novel tasks when compared to typically developing peers (Baranek, et al., 2005).

Studies suggest that in highly functioning children with ASD, there may be intact execution of a movement but atypical movement preparation. During the movement preparation phase, there is a lack of anticipation, which may explain difficulties with motivation and attention for action (Baranek, 2002). Another possible cause for poor sequencing of actions may be due to difficulties with visual feedback mechanisms that guide movement in children with ASD (Baranek, 2002).

Motor imitation underlies many motor difficulties in ASD, and may be the underlying cause for the non development of gestures to communicate, with oral motor dyspraxia strongly linked to language difficulties (Rogers, et al., 2003). Studies have shown imitation of body movements is more impaired than object imitation skills in young children and that oral praxis problems may be common in ASD (Baranek, et al., 2005). The effect of poor imitation in infancy is likely to impact on the emotional connection and interpersonal relationships that rely on synchronisation of body postures, voices, facial expression and emotional states (Baranek, et al., 2005).

Ayres conceptualised the developmental nature of this difficulty in performing novel acts as dependant on adequate sensory integration (Lane, et al., 2000). Praxis within the SI framework, encompasses ideation (conceptualisation), motor planning (organising a plan of action in time and space) and execution of the action sequence, which is more than just motor imitation (Parham & Mailloux, 2010). There is a cognitive element as well. Ideation appears to be problematic in ASD but few studies have focussed on this aspect of praxis. Researchers have pointed to the lack of ideas generated by children with ASD for object and symbolic play which they refer to as a “generativity” deficit (Lewis & Boucher, 1995).

Clinicians will confirm that motor planning or praxis continues to be challenging beyond early school years and is a component of dysfunction that begs further investigation. Dyspraxia is one of the most disabling factors in ASD as it impacts

gross and fine motor skills, play skills, speech production, ability to use tools and the ability to write or type on a communication device (Stackhouse, 2010). Dyspraxia thus has significant implications for independent living skills.

### **2.1.6 Visual perceptual skills in ASD**

A large proportion of children with ASD have limitations in sensori-motor and cognitive development, as ASD is a condition of early onset (Prior & Ozonoff, 2007). Many researchers feel that “integrative” deficits are responsible for perceptual difficulties (Prior & Ozonoff, 2007). This line of theorising is similar to that of SI theory, further validating Ayres on the importance of processing and integrating sensory experiences for function. Yet, individuals with ASD have some specific skills that are enhanced or superior to non-autistic individuals.

Perception in children with ASD has many idiosyncrasies, and varies across the cognitive spectrum. Visuo-spatial abilities, rote memory and attention to detail tend to be areas of strength on intellectual testing, with higher performance than verbal IQ s (Prior & Ozonoff, 2007). Yet, some children with ASD struggle with visual perceptual skills. Cognition in ASD, has some unique features in terms of learning style. While IQ may range from intellectual impairment to genius, learning style is often gestalt oriented, with difficulty generalising knowledge to new contexts (Audet, 2010).

*Attention* in children with ASD are reported to have “over focused” attention, with deficits in shifting attention between sensory modalities. It has been suggested that difficulties with attention are due to experiences of overwhelming environmental stimuli, resulting in over focus on an aspect of the environment in an attempt to gain a measure of control (Prior & Ozonoff, 2007). The processes by which attention is directed in children with ASD, echoes the SI theory of sensory modulation dysfunction. SI theory refers to the difficulty of the brain in processing sensory information from multiple sources simultaneously, resulting in the child feeling overwhelmed. In SOR children, this may result in withdrawal and over focus on an element in the environment. Difficulty with concentration is common.

### **2.1.7 Play Skills in ASD**

Play in children with ASD has shown to have two key impairments: a paucity of spontaneous symbolic play and in those that do demonstrate symbolic play, it is stereotypic and repetitive compared to typically developing children (Rogers et al., 2005). Functional play (play with real objects to recreate real life situations for example a tea set to represent tea time) is qualitatively and quantitatively different in children with ASD (May-Benson, 2010).

A lack of symbolic play, once considered unique to ASD (Wing, Gould, Yeates, & Brierly, 1977) is linked to a number of possible theories, with poor “generativity” due to executive dysfunction the most viable explanation proposed (Rogers et al., 2005). This correlates with SI theory of ideational dyspraxia. According to SI theory, ideation is the first of five processes in praxis, which is the ability to conceptualize a motor goal and ideas on how this may be achieved (May-Benson, 2010). It is called “generativity” in ASD literature and is not to be confused with creativity. OT-SI literature views difficulty with ideation as a possible cause of restricted and repetitive play common in children with ASD (May-Benson, 2010).

### **2.1.8 Diagnosis of ASD**

The current average age of diagnosis in the USA is four to four and a half years (Centers for Disease Control and Prevention, 2012). The goal is to diagnose ASD earlier, by age two, so as to implement early intensive intervention for best results. Recent attempts to diagnose ASD at a younger age of two years have been promising (Filipek, et al., 1999). South Africa’s average age at diagnosis in an urban area is four years, which is two years after initial concerns were raised (Hooper, 2009). As a developing country with limited resources, reducing the age at which ASD diagnosis is made, remains an important and significant challenge.

There are a number of standardised tools for screening and diagnosis of ASD, some examples of which are the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore & Risi, 1999) The Checklist for Autism in Toddlers (CHAT; Baron-Cohen et al.1992) and The Childhood Autism Rating Scale (CARS; Schopler, Reichler and Renner, 1980) (Lord & Corsello, 2005).

### **2.1.8.1 OT Role in Diagnosis**

The occupational therapist as a member of the multidisciplinary team may play a contributory role in the diagnostic process. Occupational therapy evaluations of sensory motor skills in infants may be an useful contribution to early diagnosis (Baranek, 1999a). Occupational therapy's contribution to the early diagnosis of ASD will have practical benefits for screening, early identification and intervention (Baranek, Parham, & Bodfish, 2005). OT can play a diagnostic role in the following three areas:

#### **2.1.8.1.1 SPD as a Diagnostic Indicator**

The acknowledgement of sensory processing dysfunction as a feature of the diagnostic criteria of ASD in the DSM-5, reinforces the role of the OT as a significant member of the team. It also highlights the role of OTs in screening and diagnosis, paving the way for OTs to become significant contributing members of the team in the screening of infants at risk and early diagnosis in childhood. The area of diagnosis has not been explored sufficiently within OT literature and is an avenue for further research.

Research studies have produced conflicting results regarding the presentation of sensory symptoms in early childhood and the different chronological ages or stages at which they become apparent for reliable diagnosis of ASD (Baranek et al., 2005). *The Infant /Toddler Sensory Profile* (ITSP; Dunn, 2002) is useful in identifying toddlers with ASD from their typically developing peers (Ben-Sasson, et al., 2003). The study concludes that sensory abnormalities should be considered distinguishing symptoms and as such, should be a consideration in the diagnostic algorithms for young children.

#### **2.1.8.1.2 Motor Skills as Diagnostic Indicators**

Research in the area of motor skills in the birth to two year age range may also be an early indicator for a diagnosis. Imitation assessment may be a useful diagnostic indicator in young populations, though research in this area is in the early stages (Vanvuchelen, Roeyers, & De Weerd, 2011). An important role for OT may also be differential diagnosis such as that of Developmental Co-ordination Disorder (DCD).

There have been a number of retrospective studies of toddlers in an attempt to identify early sensory or motor features of ASD (Baranek, 1999b). Research in this field of sensory and motor features of ASD is in its infancy.

#### **2.1.8.1.3 Play Skills in Diagnosis**

Play is another occupation that may yield early diagnostic indicators at around twenty two months of age when it begins to differ qualitatively from typically developing peers (Chawarska & Volkmar, 2005).

#### **2.1.9. Family Life and ASD**

The cascading effects of increased ASD incidence and necessary interventions for persons diagnosed with ASD has significant economic effects on the health care system, the educational system, the labour markets as well as on families. The estimated financial burden to the state is significant (Lord & Bishop, 2010). Families bear the brunt of not just economic burdens but emotional ones as well.

Early intervention is important in reducing lifetime care costs by two thirds (Autism Society, 2011), thus the need to diagnose early. Tremendous economic costs borne by the state, has provided impetus to funding for ASD research in developed countries (Miller-Kuhaneck & Glennon, 2004). In developing countries such as South Africa, limited resources add to the burden of care of families. OTs play a role in reducing the burden of stress on the family through interventions that support family life and routines with children with sensory processing disorders, such as ASD (Copeland, 2006; Dunn, 2007).

#### **2.1.10 Theories of Autism**

*Theory of mind, executive function, central coherence and complex information processing* are theories of autism that have implications for understanding the context in which perception, cognition and social function occurs. To date no definitive theory exists. Minshew's theory of a deficit of complex information processing, while simpler than other theories, seems more comprehensive. It explains the relative strengths and weaknesses in cognition and behaviour due to differing abilities to process information from multiple sources, namely verbal,

motor, sensory and perceptual. Neuropsychological tasks that require less information processing are spared, whereas more complex higher order information processing may be impaired (Prior & Ozonoff, 2007). This theory resonates with OT-SI theory of processing numerous and varied sensory stimuli successfully for “integration” and function. Poor processing was likened by Ayres to a “traffic jam” in the brain, limiting adaptive responses to environmental demands (Ayres, 1979). Minschew’s theory validates the role of SI in enabling a child to cope with multiple sensory and environmental demands.

## **2.2. INTERVENTIONS FOR ASD**

Early identification and appropriate, effective, efficient interventions, is the practical route to reduce the burden of disability upon the child, family and society (Rogers & Vismara, 2008; Rutter, 2005). A range of interventions may be recommended to address developmental delays and symptoms associated with ASD. A child may receive intervention from a multidisciplinary team within a variety of contexts.

The context for intervention may include the home, mainstream or special needs schools, residential facilities, clinics or private practices. Members of the team may include a medical doctor (general practitioner, paediatrician, child psychiatrist, paediatric neurologist), educator, occupational therapist, speech language therapist, physiotherapist, clinical and educational psychologists and school nurse amongst others.

The two most popular approaches used in established programmes are the developmental and behavioural approaches (Ospina, et al., 2008). Interventions for ASD may be categorised according to table 2.2 with programmes or therapies commonly used, listed within each category. Interventions fall into various categories, with the psycho-educational and therapeutic approaches usually located either within the behavioural or developmental approach. As the behavioural and developmental approaches have a significant history and practice base within ASD, the approach is reviewed below. OT together with other popular complementary approaches will be discussed in greater detail thereafter, being the focus of this study. Despite studies on efficacy of various types of intervention, there is no

conclusive evidence as to which works best (Case-Smith & Arbesman, 2008; Ospina, et al., 2008; Rutter, 2005).

International guidelines on effective programmes for children with ASD recommend the following (National Research Council, 2001):

- Early intervention, at young ages
- Goals need to be individualised and regularly monitored
- Twenty five hours per week of active engagement with a low child to adult ratio of no more than 2:1 for part of the day
- Family participation is a critical component of the programme

Table 2.2: Common interventions for children with ASD

<b>Therapy based Interventions</b>
<i>Occupational therapy</i>
Traditional sensory motor perceptual programmes
Ayres Sensory Integration Therapy (ASI)
Auditory Integration therapy (AIT)
<i>Speech and language therapy</i>
Traditional speech-language therapy
Augmentative and Alternate Communication (AAC) such as the Picture Exchange Communication System (PECS) (Bondy and Frost, 1996), dedicated communication devices and use of technology such as iPads
<i>Physiotherapy</i>
<b>Multidisciplinary Approaches</b>
Social Communication Emotional Regulation Transactional Support Programme (SCERTS) (Prizant, Wetherby, Rubin, Laurent, Rydell, 2003)
DIRFloortime based on the Developmental Individual Difference Relationship model (DIR) of Dr. Greenspan (1992)

Table 2.2 continued

<b>Educational Programmes</b>
Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) (Schopler, 72)
Denver model (Rogers et al., 1987)
<b>Behavioural Approaches</b>
Applied Behavioural Analysis (ABA), Discrete Trial Training (DTT), Pivotal Response Training (PRT) and Positive Behavioural Support (PBS)
<b>Medical:</b> Pharmaceutical drugs for behavioural symptoms such as inattention, hyperactivity, insomnia and mood regulatory disorders
<b>Dietary:</b> Gluten free casein free diet
<b>Complementary therapies:</b> Animal assisted therapy, music therapy

### 2.2.1 THE BEHAVIOURAL APPROACH

This approach is based on the principles of operant conditioning, where behaviour is viewed in terms of antecedents (preceding events) and consequences (events that follow it). By changing the events, behaviourists aim to change the behaviour. In children with ASD, the aim is to teach skills and reduce undesirable behaviour. Behavioural interventions first popularised by the work of Lovaas, (1987) has a long history with ASD (Lovaas, 1987; Shea, 2004).

While behavioural therapy improves functioning, claims that children with ASD who undergo intensive behavioural therapy “recover” and no longer display autistic “symptoms” are exaggerated (Magiati & Howlin, 2001). The effectiveness of using a behavioural approach has been reported in the literature (Zachor, Ben-Itzhak, Rabinovich, & Lahat, 2007), though methodologically flawed studies have inflated results (Magiati & Howlin, 2001; Shea, 2004). A recent Cochrane review found the state of research evidence to be limited and reported some evidence for the effectiveness of early intensive behavioural intervention for some children with ASD (Reichow, Barton, Boyd, & Hume, 2012).

Traditional behavioural approaches use highly structured environments for intensive one on one instruction, which is therapist directed. More contemporary approaches use incidental learning and incorporate natural settings such as snack time for learning (Corsello, 2005). There is more of an effort towards child directed communication, with choice making opportunities and a less structured training routine (Prizant, Wetherby, & Rydell, 2000).

Positive Behavioural Support (PBS) is an approach that seeks to understand the purpose of challenging behaviour and promote the development of skills that will diminish the need to engage in that behaviour. Positive behavioural support (PBS), incidental teaching in natural settings and pivotal response training (PRT) are more compatible with OTs developmental frame of reference (Prizant & Rubin, 1999).

A criticism of the behavioural approach, is the tendency to disregard the neurobiological or sensory basis for some behaviours. A child who engages in repetitive stereotyped behaviours is often reacting to sensory information and stress. Ignoring such behaviour in an attempt to extinguish it, can lead to distress and frustration on the part of the child. This is not conducive to learning or relationship building.

According to the OT SI framework, planned ignoring or “extinction” will be ineffective due to the root cause of the behaviour being sensory in nature. Understanding the child’s sensory needs and the role that their stereotypies or rituals play in controlling anxiety is a humane response to these behaviours. Accepting these behaviours rather than aiming to extinguish them and meeting the sensory needs in the teaching environment can allow for optimal learning. Anecdotal reports of some adults living with ASD regarding their experiences of ABA are less than positive. Donna Williams infers the message of the approach as wanting to “cure” her of her autistic traits, saying “I am not meant to exist as myself” (Bogdashina, 2006, p. 141).

Other criticisms of the approach are whether gains are maintained over time and the lack of generalization of skills and behaviours across contexts (Bregman, Zager, & Gerdtz, 2005). Even contemporary ABA approaches still measure the child’s communication in discrete responses versus within a social interaction context (Prizant, et al., 2000). ABA is also not as sound in terms of understanding typical

developmental sequences and does not acknowledge the interdependency of aspects such as socio-emotional development and communication for example (Greenspan & Wieder, 2006). The expense of doing intensive behavioural intervention is high, and as such is not affordable for the majority of South Africans.

The role of behavioural intervention in understanding, managing and educating children with ASD is undisputed. This approach targets the core deficits of ASD and attempts to reduce behavioural symptoms, which if untreated, negatively impact on social and educational capacity.

### **2.2.2 THE DEVELOPMENTAL APPROACH**

This approach encompasses a number of intervention models such as DIRFloortime, SCERTS, SIT and traditional OT and SLT. It is widely considered a valid approach in assessing and treating ASD (Prizant & Rubin, 1999). Its framework is based on an extensive body of research on child development and this, together with an awareness of developmental processes and individual abilities guide goal setting. These approaches are child directed with an emphasis on a facilitated interactive learning style (Prizant & Wetherby, 2005). Skill development begins at the level at which the child is performing successfully, and is facilitated to the next level.

Developmental approaches traditionally viewed development as a sequential pattern. More recent perspectives acknowledge the role of the environment in promoting neuro-plasticity, and the impact of the child on the environment is also important (Kramer & Hinojosa, 2010a). In typical development, each level supports growth for the next stage of development, thus skills are stage specific. Foundational skills need to be strong to form the basis for development of higher-level skills.

### **2.2.3 BEHAVIOURAL VERSUS DEVELOPMENTAL APPROACH**

A comparison of the effectiveness of the developmental and behavioural approaches to intervention is contradictory and inconclusive (Ospina, et al., 2008; Zachor, et al., 2007). Currently, both behavioural and developmental interventions are widely used in ASD programmes and are often blended (Wetherby & Woods,

2008). Commonalities between the behavioural approach and others used in ASD intervention are aspects such as programme intensity (20 or more hours per week), early intervention (preschool years) and parental involvement (Howlin, 2005). Currently therapy services are likely to be offered within comprehensive ASD specific programmes, which integrate behavioural and educational approaches (Watling, Deitz, Kanny, & McLaughlin, 1999).

#### **2.2.4 AUGMENTATIVE AND ALTERNATE COMMUNICATION (AAC)**

For the individuals with ASD who do not develop speech, alternate forms of communication need to be established. AAC may involve unaided systems, which involve the use of the person's own body through manual signing and gestures. Aided systems involve the use of symbol systems, the use of high technology devices such as iPads or computers. The Picture Exchange Communication System (PECS; Bondy & Frost, 1998) involves exchanging pictures for objects and builds up to making sentences using picture exchange.

AAC is usually the role of the SLT, though others within the team may be involved to an equal degree. Team members support its implementation across contexts of therapy, home and school. The OT may facilitate the child's ability to use technology, which is dependant on fine motor skills and praxis abilities (Paul & Sutheland, 2005). Incorporating visual schedules in therapy sessions is useful for enabling the child to follow the sequence of activities planned. Pictorial, written or within task schedules (sequential pictorial representation of an activity eg. hand washing) can aid independent IADL performance at school or home.

#### **2.2.5 SOCIAL STORIES**

This approach uses pictorial representation, often line drawings, to tell a short story about a particular social event. It is an attempt to teach appropriate social behaviour in a situation that has lead to or may lead to problem behaviour. A social story is written from the perspective of the child and is read repeatedly before the specific situation, such as going for a haircut. Social stories are used to complement the OT programme (Case-Smith & Arbesman, 2008). Social stories are used by any of the team members, including parents, teachers and therapists, who may write a social

story for home, school or therapy situations. It has shown positive outcomes in reducing problem behaviour, though research on social stories is not yet substantial (Wright & McCathren, 2012).

### **2.2.6 TEACCH (Treatment and Education of Autistic and related Communication-Handicapped Children)**

This approach uses highly structured learning environments with a strong emphasis on visual information. The educational programme uses visual schedules of activities for the day, thus supporting transitions and guiding routines (Case-Smith, 2010). There is an emphasis on skill development and communication. There are few studies on the effectiveness of this approach, with some positive results for its use in home environments (Harris, Handleman, & Jennet, 2005).

### **2.2.7 AUDITORY INTEGRATION TRAINING (AIT)**

This approach involves listening to electronically modified music via headphones to dampen auditory hypersensitivities and thus improve concentration, learning and behaviour (Kuhaneck & Gross, 2010). “Therapeutic Listening” and “So Listen” are programmes often used by OTs in conjunction with SIT. SI OTs believe in the calming effect of input via the auditory system (Hall & Case-Smith, 2007). A Cochrane review found no evidence to recommend its use, especially in view of the cost (Sinha, Silove, Hayen, & Williams, 2011).

## **2.3 OCCUPATIONAL THERAPY AND ASD**

Occupational therapy intervention for children with ASD aims to facilitate social participation and engagement in occupations using therapeutic processes directed at the client, the activity, and the environment (Watling, Tomchek, & LaVesser, 2005). The environment is especially important in intervention for ASD, considering their specific difficulty with generalization of skills across contexts (Watling, Tomchek, & LaVesser, 2005).

Internationally, a Canadian pilot study of four speciality centres indicated that seventy eight per cent of children with ASD had received OT services (McLennan, Huculak, & Sheehan, 2008). Further, an internet survey study, found that SI

occupational therapy was the third most common intervention sought by parents for their children with ASD (V. A. Green, et al., 2006). In Johannesburg, South Africa, a parents survey revealed that OT was among the top three interventions sought (Hooper, 2009). Clearly there is a demand for OT specific ASD services in South Africa, highlighting the need to research occupational therapy services for ASD.

The discussion on OT for ASD will flow according to three areas: assessment, direct intervention and indirect intervention. Under assessment, the four procedures that may be followed for an assessment are discussed, thereafter areas of assessment are described together with the standardised or non-standardised assessments that may be used. As an introduction to the areas of assessment, table 2.3 lists and briefly describes the standardised tests used by OTs.

### **2.3.1 OT ASSESSMENT**

#### **2.3.1.1 Assessment format**

Assessment of a child with ASD is not straight forward, due to core difficulties in language, sensory processing and behaviour. An experienced therapist is critical to the evaluation process. An OT with limited experience of ASD, may be inclined to perceive the child as “un-testable” (Tomchek & Case-Smith, 2009). Non-standardised assessments are common, using structured observation of the child in multiple natural settings or observation using play. Even informal evaluations may require repeat visits and observation in more than one context. Play often forms a framework for evaluation of children with ASD (Tomchek & Case-Smith, 2009). Skilled observation is reliant on the experience of the OT.

OTs have a specific and defined role within the team evaluation, which is the sensory motor evaluation (Tomchek & Case-Smith, 2009). However the OT role is not restricted to these aspects and an experienced OT will assess aspects of communication, play, behaviour as well as functional daily living skills known as instrumental activities of daily living (IADL). The format of an assessment, comprising of two, three or four procedures is reflected in figure 2.2 below.

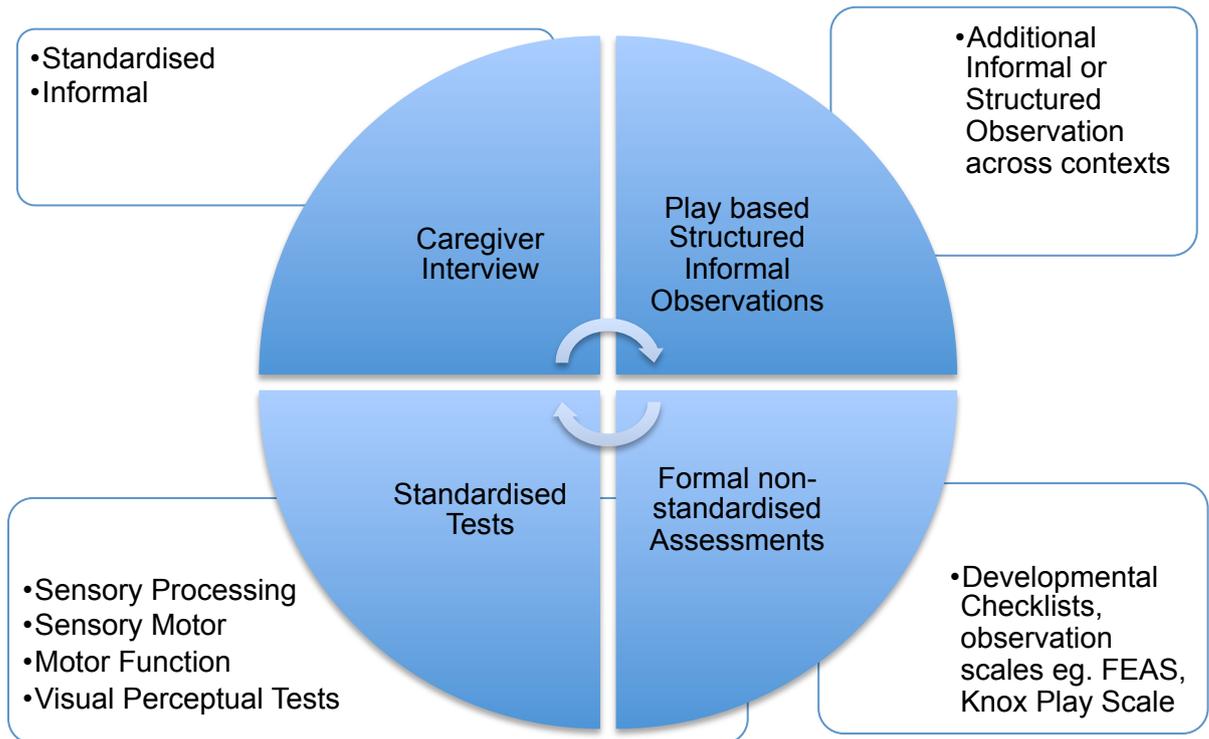


Figure 2.2: OT Assessment Tools

### 2.3.1.1.1 Caregiver Interview And Observation

Most evaluations should begin with a parent interview and include the child with ASD's perspective (dependant on age) as far as possible. This is then augmented with observation of the child in daily life tasks at school or home and finally a formal assessment session. Dependant on the context, all three steps may not be possible or the interview or observation may occur with another team member or within an interdisciplinary or transdisciplinary team assessment.

Observation may be in a structured play based format or informal observation in different contexts such as during lunch break on the playground or during snack time. During play based structured observations, the OT will note that type of toys and materials the child engages with. The OT will attempt to engage in social reciprocal play based on the child's interests. Skilled observation focuses on aspects such as how the child engages with objects, persons and the physical environment and not just on what the child does (Watling, 2010). Interaction during

play between OT and child allows for an indication of the level of abilities in various aspects of function such as social and language skills, imaginative play, motor skills, sensory processes and functional skills. This initial structured observation is often an indication of whether the child will cope with formal assessment procedures.

### **2.3.1.1.2 Standardised Assessment**

Standardised tests are unlikely to be a valid measure of the child's abilities due to a number of difficulties associated with ASD such as, processing verbal instructions, poor motivation or co-operation, deficits in motor imitation and a short attention span. Additional unfavourable elements for standardised assessments is the unfamiliar environment, finite time frame to complete tasks and a lack of evaluation instruments specific to ASD (Domingue, Cutler, & McTarnaghan, 2000). While there is a place for standardised testing for a child with ASD, it does require adaptations (Fillipek *et al* 2000). Among the recommended modifications is multiple sessions to complete a test, augmenting instructions and interpreting scores with caution (Watling, 2010).

Most standardised tests used in OT are based on norms for populations in the developed world.

#### ***Standardised Tests***

A number of standardised occupational therapy tests may be used with children with ASD, often with adaptation. Commonly used standardised tests are tabulated according to broad performance areas.

Table 2.3: Standardised Tests used in OT for children with ASD

STANDARDISED TESTS	DESCRIPTION
<i>SENSORY PROCESSING INTERVIEWS</i>	
The Sensory Profile (Dunn, 1999), Short Sensory Profile SSP (Dunn, 1999) Sensory Profile School-Companion (Dunn, 2006), Infant Toddler Sensory Profile (Dunn, 2002)	Ages 3-10 years  Thirty minutes to administer (125 items)  SSP completed in ten minutes (38 items) and useful to measure modulation  SP has Diagnostic value in differentiating typically developing children from those with ASD
Infant/Toddler Symptom Checklist (ITSC; DeGangi, Poisson, Sickel & Wiener, 1995)	Ages 7 – 30 months  10 minutes to administer  Screening for toddlers at risk of developing SI and related difficulties
Sensory Processing Measure (SPM; Glennon, Miller-Kuhaneck, Henry, Parham, & Ecker, 2007)	Ages 5- 12 years  Ecological assessment, with three forms for school, home and community environments. Home and classroom forms take 20 minutes, school environment form 5 minutes  Norm referenced standard scores for five sensory systems, praxis and social participation
<i>SENSORY INTEGRATION / SENSORY MOTOR TESTS</i>	
Sensory Integration and Praxis Test (SIPT; Ayres, 1989)	Ages 4-8 years  Up to 3 hours to administer: 2 hours testing and 1 hour scoring  Tests praxis in various forms: on verbal command, oral, postural, sequencing and constructional
Test of Sensory Integration (TSI; DeGangi & Berk, 1983)	Ages 3-5 years  Administered in thirty minutes, Praxis may be inferred
Miller Assessment for Preschoolers (MAP; Miller, 1982)	Ages 2.9 - 5.8 years  Administered in 40 minutes  General developmental screening instrument. Tests cognitive, language, sensory motor and praxis abilities. Sensory integration abilities can be inferred

Table 2.3 continued

Miller Function and Participation Scales (M-FUN-PS; Miller, 2006)	<p>2.6 – 7.11 years old.</p> <p>Administered in 60 minutes</p> <p>Tests fine, gross and visual motor functioning, including praxis</p> <p>Includes a home, class and test observation checklists Sensory integration abilities can be inferred</p>
Bruininks-Oseretsky Test of Motor Performance, 2 <sup>nd</sup> edition (BOT-2) (Bruininks, 2005)	<p>Ages 4 - 21 years</p> <p>Administered in 60 minutes (complete form), a short form of the test can be administered in 20 minutes</p> <p>Fine, gross and bilateral motor co-ordination</p> <p>Sensory integration abilities can be inferred</p>
<b>TESTS OF VISUAL PERCEPTION</b>	
Beery-Buktenica Developmental Test of Visual Motor Integration, Beery-Buktenica Developmental Test of Visual Perception and Beery-Buktenica Developmental Test of Motor Co-ordination, fourth edition, Beery & Buktenica, 1997	<p>Ages 2-18 years</p> <p>All three tests can be administered within 15 minutes</p> <p>Visual perception and Motor co-ordination have time limits of 3 and 5 minutes respectively</p>
Developmental Test of Visual Perception second edition, (DTVP-2; Hammill, Voress, Pearson, 1993)	<p>Ages 4-10 years</p> <p>Administered in 30 minutes</p> <p>Tests spatial, figure ground, form constancy and closure perception visual motor integration, motor coordination and motor speed</p>
Test of Visual-Perceptual Skills (non-motor) Revised, (TVPS; Gardner, 1996).	<p>Ages 4-12 years</p> <p>Administered in 30 minutes</p> <p>Tests visual discrimination, memory, sequential memory, figure ground, form constancy and closure perception</p> <p>No motor component</p>

### 2.3.1.1.3 FORMAL NON-STANDARDISED ASSESSMENTS

There has also been a move away from formal standardised evaluations towards functional, play based observational strategies (Domingue, et al., 2000). Non-standardised assessments are especially relevant for the SA due to our multilingual,

multicultural context. These are usually developmental scales, play scales or the parent child interaction Functional Emotional Assessment Scale (FEAS; Greenspan, DeGangi, Wieder, 2001).

Numerous norm and criterion based *developmental scales* have been developed for use internationally as well as locally. One SA developed checklist is *The WITS Developmental Profile (Stewart-Lord, 1980; 1998)*, a non-standardised screening for developmental areas of gross and fine motor co-ordination as well as adaptive responses of speech, social interaction, play, understanding and IADL of feeding, dressing, bathing and toileting. A developmental age for the child can be obtained based on observations and history taking for children aged between one and seventy two months. Others include the *START (1990)* a home teaching programme and another developed by an OT, *Carla Grobler's Developmental Checklist (2011)*.

A non-standardised play assessment that has shown promise is the *Revised Knox Preschool Play scale (PPS; Knox, 1997)*. It uses observation of spontaneous play in familiar indoor and outdoor environments for children aged six months to six years. It assesses praxis, space and materials management as well symbolic play and social participation. A study using this scale, was able to differentiate children with ASD from matched neuro-typical controls indicating clinical utility (Restall & Magill-Evans, 1994). *The Test of Playfulness (ToP) (Bundy, 1997)* may be useful in evaluating ideation in children with ASD (Baranek et al., 2005).

*Functional Emotional Assessment Scale (FEAS; Greenspan, DeGangi, Wieder, 2001)* is an assessment of parent child interaction. It evaluates the ability of the child to engage in reciprocal interactions, organise play behaviours, communicate and pay attention, for ages seven months to four years.

### **2.3.2 AREAS OF ASSESSMENT**

Performance components typically affected in ASD of specific relevance to OT are, muscle tone and gross motor skills (Page & Boucher, 1998 ), imitation skills or dyspraxia (Rogers, Cook, & Meryl, 2005), dexterity or fine motor skills (David, et al., 2009; Milne, et al., 2006), sensory processing (Schaaf & Miller, 2005), social

interpersonal communication skills (Greene, 2004) and cognitive perceptual skills (Prior & Ozonoff, 2007). According to the AOTA guidelines, the following areas of assessment are suggested: play, school occupations, adaptive behaviour and instrumental activities of daily living (IADL), gross motor skills, fine motor and visual motor skills, visual perception and sensory processing. As ASD is primarily a disability of social communication and behaviour, these aspects will also be specifically noted during an OT assessment (Tomchek & Case-Smith, 2009).

Assessment of the following areas is discussed below: sensory integration, motor skills, cognition, play and IADL.

### **2.3.2.1 Assessment of Sensory Integration (SI)**

The presence of atypical sensory processing in children with ASD has been discussed in detail earlier. Expanding on the work of Ayres, various taxonomies of SI dysfunction have been proposed. The most relevant for this discussion are Sensory Modulation Disorder (SMD) and Dyspraxia (Parham & Mailloux, 2010). Dyspraxia assessment is dealt with under Motor skills.

The initial parent or teacher interview yields important information about developmental history, IADL, classroom and playground skills as well as environments. A questionnaire, within a structured interview with the caregiver is added for comprehensiveness. A number of caregiver instruments are detailed in table 2.3 above. Two studies have shown *The Sensory Profile* (Dunn, 1999) to discriminate children with ASD from typically developing children (Kientz & Dunn, 1997; Watling, Deitz, & White, 2001) and in another study, it discriminated between ASD and non-specific developmental delays (Rogers, et al., 2003).

Direct observation may be informal skilled observation within an ecological setting during functional life tasks for example observing a child during snack or outdoor play or in the classroom. Observation of a child's food preferences, ability to stay seated and focus in class, movement skills and playground equipment choices are all indicators of sensory processing abilities and a child's sensory profile. Informal observations can also take place in the OT room using the SI suspended equipment

and toys with sensory properties to determine vestibular and tactile processing respectively.

Standardised assessment of sensory integration can be conducted by using tests outlined in table 2.2 above. The gold standard in terms of assessing sensory integration is the *SIPT*, however it is designed for mild learning disabilities and there are numerous disadvantages of using this test for ASD. Firstly it does not quantify sensory modulation, which is a significant aspect in ASD (Baranek, et al., 2005), the length of administration of the test (two hours with additional time needed for scoring) makes it inappropriate for children with ASD and for OTs in SNS and hospital settings. Anecdotal evidence indicates that some SA OTs in the field of ASD, are frustrated at having to train on the SIPT to be SI certified. While the treatment has great value, the SIPT assessment is irrelevant for children with ASD. All of the standardised tests in table 2.3 above are American, standardised on their populations and possibly irrelevant for our multilingual multicultural population. Further, the cost of purchasing these tests is high.

### **2.3.2.2 Assessment of Motor Skills**

OTs assess the following aspects of motor function which may be areas of concern in ASD: posture, gait and balance, co-ordination and praxis, gross motor skills (mobility and ball skills), fine motor manipulation and lateralisation skills, oral and ocular motor skills. While motor deficits may appear in a subtype of children with ASD, even in those with relatively good gross motor skills, praxis difficulties are often still evident (Baranek, Parham & Bodfish, 2005). Studies have shown that children with ASD had significantly more difficulty on gross and fine motor tasks on the *Test of Motor Impairment* (Stott, Moyes, & Henderson, 1972) and comparatively poorer co-ordination on the *Bruininks-Oseretsky Test of Motor Performance* (Bruininks, 1978) as well as poor performance on all the praxis tests on the *Sensory Integration and Praxis Test* (Ayres, 1989) (Baranek, Parham & Bodfish, 2005).

Two studies indicate the importance of praxis, as it featured strongly in OT assessment (Case-Smith & Miller, 1999; Watling, et al., 1999). In one study, eighty nine percent of two hundred and ninety two OTs surveyed, provided intervention for motor planning difficulties (Case-Smith & Miller, 1999). The standardised tests of

motor skills designed by OTs, often have praxis components, but even on other tests, motor imitation abilities can be inferred. Oral motor praxis may be overlooked by OTs, but should form part of a comprehensive evaluation, as it is common to most children with ASD and implicated in feeding difficulties (Baranek, Parham & Bodfish, 2005). Both the SIPT and MAP have subtests for oral motor praxis.

### **2.3.2.3 Assessment of Visual Perception**

American OTs surveyed agreed that visual perception was less of a problem compared to other components assessed in children with ASD (Case-Smith & Miller, 1999). Standardised tests typically used with other conditions such as ADHD, test components of visual perception that are foundation skills for academic tasks of reading, writing and mathematics. Tests may include visuo-motor skills by testing drawing abilities (Beery-Buktenica Developmental Test of Visual Motor Integration, Beery-Buktenica Developmental Test of Motor Co-ordination, fourth edition, Beery & Buktenica, 1997, Developmental Test of Visual Perception second edition, (DTVP-2; Hammill, Voress, Pearson, 1993) or they may test visuo-spatial abilities without motor elements (Beery-Buktenica Developmental Test of Visual Perception, Beery & Buktenica, 1997 and Test of Visual-Perceptual Skills (non-motor) Revised, (TVPS; Gardner, 1996).

### **2.3.2.4 Assessment of Play**

Play was found to be a significant area of difficulty in a USA survey of OTs (Watling, et al., 1999). Play in children with ASD is primarily impacted by difficulties in visual perception, sensory processing, imitation, ideation, praxis and language. The assessment of play skills is often informal, identifying skills, developmental levels and aspects such as praxis, ideation and imagination. Informal play scales have been discussed under formal non-standardised assessments.

### **2.3.2.5 Assessment of Instrumental Activities of Daily Living (IADL)**

Research has shown a clear link between atypical sensory processing and motor difficulties on preschool children's independence in IADL, relating to self care issues (Jasmin, et al., 2009). This study found strong correlations between sensory motor

skills and functional skills concluding that delayed independence in IADL skills of children with ASD places a burden of care on parents.

IADL skills include dressing, feeding, toileting and hygiene, grooming and sleep. IADL skills may be affected by a range of underlying difficulties associated with ASD, such as motor coordination and dyspraxia, sensory sensitivity, behaviour issues related to routines as well as communication deficits (LaVesser & Hilton, 2010). Parents have reported difficulties around nail trimming, hair and face washing and hair brushing (Tomchek & Dunn, 2007) due to sensory oversensitivity for touch, which may lead to avoidance of these tasks. Auditory oversensitivity often interferes with toileting, as the sound of flushing may be uncomfortably loud to the child.

Feeding issues in ASD are particularly influenced by sensory issues, which lead to restricted diets (Schreck, Williams, & Smith, 2004). Eating is particularly impacted by sensory over sensitivities to taste, smell, loud sounds of crunching as well as textures (Schwarz, 2003). Other issues are utensil use or independent feeding related to fine motor co-ordination, as well as chewing difficulties due to oral motor control (LaVesser & Hilton, 2010). Motor planning difficulties also account for difficulty with the fine motor aspects of many IADL tasks such as doing buttons and zips, opening lunch containers or using a fork (LaVesser & Hilton, 2010).

Assessment of IADL occurs through naturalistic observation in the actual setting where the task occurs or structured observation in another environment. Activity analysis of the task, assessment of the child's abilities and an environmental assessment are aspects to consider during evaluation (LaVesser & Hilton, 2010). While there are international OT measures such as the School Function Assessment (SFA; Coster, Deeney, Haltiwanger & Haley 1998), it is culturally inappropriate for the SA context. Locally, unstructured parent interviews are the most likely avenue to pursue IADL independence enquiry.

### **2.3.3 OT INTERVENTION**

#### **2.3.3.1 Theoretical Approaches used in OT**

An overview of common approaches to intervention of specific relevance to OT and ASD will be discussed under the main categories of developmental skill acquisition, sensory integration, play based, relationship based and behavioural interventions (Case-Smith & Arbesman, 2008). Other models of relevance typically used in conjunction with the primary model are also discussed.

##### **2.3.3.1.1 Developmental Skill Acquisition Approach**

A developmental approach focuses on the attainment of skills in the sequence observed in typically developing children and is used across professional disciplines in paediatric practice. It acknowledges the role of environmental influences (nurture) as well as the biological maturation process (nature) upon development. While this model traditionally uses a hierarchical approach to skill attainment, current emphasis tends to be more holistic with a focus on the person and development in relation to life roles and the environment (Law, Missiuna, Pollock, & Stewart, 2001).

While traditional OT assessment tools are still age or stage specific, developmental theory is still useful for promoting development from one skill level to the next. As OTs, Kramer and Hinojosa argue, that our perspective is broader than just skill development but focuses on how skill translates into functional performance (Kramer & Hinojosa, 2010a). OTs using a functional developmental frame of reference draw on a number of legitimate perspectives for promoting skills according to the neuro-typical sequence of development (Kramer & Hinojosa, 2010a). Children whether diagnosed with ASD or not, are very likely to be referred to OT during childhood for delays in attaining motor and cognitive developmental milestones. Assessment establishes a baseline of skills from which further development is facilitated in all areas, in order to reach the next developmental stage. An understanding of neuro-typical child development guides goal setting for each stage of growth.

Proceeding in a sequential manner, therapy aims to close the gap between chronological age and requisite skills. The OT uses reinforcement, practice and

modelling of skills to scaffold the child's performance in a natural learning environment (Case-Smith, 2010). An understanding of the delayed as well as atypical nature of development in ASD is essential in designing assessment and intervention for ASD within this framework. A thorough knowledge of ASD is useful in differentiating between developmental and cognitive delays in children.

Numerous norm and criterion based developmental scales have been developed for use internationally as well as locally. The WITS Developmental Profile (Stewart-Lord, 1980; 1998), is a locally developed non-standardised screening. A developmental age for the child can be obtained based on observations and history taking for children aged between one and seventy two months. Others include the START (1990) a home teaching programme and another developed by an OT, Carla Grobler's Developmental Checklist (2011).

#### **2.3.3.1.2 Neuro-Developmental Therapy (NDT)**

NDT theory is based on motor control rooted in the neurological sciences. It's a "hands on" approach relying on physical handling of the client to prepare the muscles, facilitate movement and inhibit abnormal movements and reflexes. It is primarily concerned with muscle tone, postural control and motor function. It relies on therapeutic handling by the therapist during active functional tasks. NDT facilitates typical movement to replace atypical patterns (Barthel, 2010).

It aligns with SI theory in recognising the role and influence of sensory information on motor responses. NDT is also similar to SI in that it relies on the active participation of the child in a functional activity, which is often play-based for motivation. It also relies on the skills of the therapist in responding to the child's needs and creating the right environment for participation (Barthel, 2010). NDT courses train therapists under the supervision of an experienced tutor. NDT and SI are often practiced together in paediatrics.

#### **2.3.3.1.3 Sensory Integration Intervention (SI)**

Ayres identified problems with registration and orientation to sensory information in children with ASD (Ayres & Tickle, 1980). Referral to OT commonly occurs for sensory processing difficulties, as some OTs are trained specialists in sensory

integration therapy (SIT). SIT is the most common model of intervention used by OTs for children with ASD in the USA (Case-Smith & Miller, 1999; V. A. Green, et al., 2006; Watling, et al., 1999). Ninety five percent of two hundred and ninety two OTs surveyed provided SI therapy often to always (Case-Smith & Miller, 1999). Occupational therapy with its sensory integrative framework of practice is uniquely equipped to provide intervention for the sensory processing and dyspraxia difficulties experienced by many children with ASD.

Sensory integration therapy described, is “to provide and control sensory input especially the input from the vestibular system, muscles, joints and skin in such a way that the child spontaneously forms the adaptive responses that integrate those sensations” (Ayres, 1979, p. 140). This neural process of successful integration allows one to act on the environment in a planned purposeful way (Fischer, Murray, & Bundy, 1991).

SIT thus challenges the child via a series of successively more complex adaptive responses during active play, to enhance brain organisation. An organised brain is an efficient sensory processor, allowing for improved function. This ability to change brain function is based on the principle of neural plasticity, a well-established concept in neuroscience literature. Child directed activity is crucial to tapping into intrinsic motivation, affect, cognition and praxis (Anzalone & Williamson, 2000).

SIT as was originally practiced by Ayres, is direct intervention through individual sessions between OT and child. SIT is conducted within gym type rooms with specialised equipment such as suspended swings, climbing blocks, ramps and scooter boards. The rich sensory environment is an invitation to play, providing opportunities for tactile, vestibular and proprioceptive input in particular. Intervention is intensive, occurring between one and two times a week for forty five minutes to an hour for between six months and two years (Parham & Mailloux, 2010).

#### **2.3.3.1.3.1 Principles of Ayres SIT**

- It is *child driven* (follow the child’s inner drive or lead in play)
- Encourages *active engagement* (child initiates activities, not a passive recipient)

- Provides a *just right challenge* (the activity must provide sufficient challenge to elicit an adaptive response, while still providing a measure of success)
- Facilitates an *Adaptive response* (the challenge of the play activity results in a response that increases the repertoire of skills and strategies to cope with challenges)

In an attempt to develop a fidelity instrument for SIT, researchers have expanded on the above principles, by listed ten core elements of the sensory integration intervention process (Parham et. al, 2007). These include and expand on the above principles in addition to other elements, such as ensuring physical safety, supporting optimum arousal, guiding self-organization, fostering a therapeutic alliance, maximizing a child's success, arranging the room to engage the child and creating a play context. The child driven and active engagement principles are worded as "collaborate on activity choice". An important inclusion is the element of providing a rich varied sensory environment, which includes tactile, vestibular and proprioceptive experiences.

### **2.3.3.1.3.2 SIT for ASD**

SIT for children with ASD poses specific challenges for each of the above four principles (Mailloux & Roley, 2010). Inner drive is often a challenge as their choice of activity or equipment may be counter therapeutic or result in negative behaviour such as repetitive stimulatory actions. Following the child's lead can result in disorganised behaviour due to an open environment with multiple equipment choices. Difficulty with sensory modulation may result in rapid changes in arousal levels, requiring skilled monitoring of subtle signs in the child to adjust input for success. Dysfunction in sensory motor and cognitive areas make independent adaptive responses difficult. Due to the daily variability in a child's regulation and mood, the just right challenge is difficult to anticipate.

For children with ASD, a typical SIT sequence is joint attention, sensory registration, arousal and modulation, perception and discrimination, motor skills and praxis (Mailloux & Roley, 2010). Proprioceptive input and deep pressure are important in sensory diets, especially as preparation for tactile experiences they find unpleasant (Mailloux, 2001). Due to particular difficulty with praxis, the use of visual or written

clues such as a picture sequence or written instructions may guide task initiation and completion.

Dyspraxia is a significant component of therapy in children with ASD (Case-Smith & Miller, 1999; Watling, et al., 1999). The concept of praxis within SI theory and practice is unique in that it delineates the various processes from ideation to motor planning to sequencing and execution of actions. It further postulates that praxis has a sensory basis for the disorder. Ayres linking of motor performance and sensory function has been validated by researchers in other fields (Dewey, 2002). Praxis in SIT is encouraged through facilitating abilities in sensory processing, initiation and sequencing, timing, bilateral co-ordination and imitation (Mailloux, 2001).

SIT relies on the skill of the OT in careful monitoring of the session moment by moment, and creating a balance between structure and freedom in play so as to achieve goals. Due to this nature of SIT, fidelity has proved difficult to achieve (Parham et al., 2007). To address this weakness, The Sensory Integration Fidelity Measure has been developed together with a manualised treatment protocol specifically for research purposes (Parham et al., 2011). Best practice SIT has expanded Ayres work, in areas of high intensity dosage recommendations, a focus on family generated functional goals with the emphasis on improving family life together with parent education and coaching (Miller, 2012a). This entails indirect SI intervention in the form of “sensory diets” and environmental modifications. Group SIT is another area of relatively new practice in SI.

### **2.3.3.1.3.3 Group SIT**

Group SI intervention has been explored primarily due to funding and staffing challenges. Group treatment is unable to achieve the same results as individual therapy. An innovative use of group based SI intervention, has been the development of the Alert programme (Williams & Schellenberger, 1994) which helps children monitor their arousal levels and use sensorimotor activities to change their levels of alertness for function (Williams & Schellenberger, 1994). Another group application of SI of relevance to ASD is geared towards improving social skills (Piantinada & Baltazar, 2006).

#### **2.3.3.1.3.4 SI in Consultation**

In a consultation model, (indirect intervention) SI is most useful in modification of activities, routines and environments as well as teaching compensatory strategies (Parham & Mailloux, 2010). An essential part of an SI therapy programme involves education or demystification of SI concepts and processes for the team, especially parent and teacher. Understanding a child's unique profile (SOR, SUR, SC) for each sensory system, allows for designing intervention that utilises their strengths and compensates for weaknesses. SI principles will guide strategies across contexts of home, school and the community.

#### ***SI Home / School Strategies***

The "*sensory diet*", (a term coined by Wilbarger, 1984) is prescribed scheduled daily sensory activities to assist with modulation and participation in daily routines.

Sensory diets are an important part of school and home carry over within an SI programme. It alerts teachers and caregivers to changes in arousal levels and provides guidelines to regulate levels in order to function.

Sensory input may be calming or alerting, depending on the needs of the child. Sensory strategies most used are proprioceptive or heavy muscle work activities, firm pressure touch and movement strategies such as jumping or swinging (Mailloux, 2001). Weighted vests which provide calming proprioceptive input, together with a sensory diet, have been widely used in OT (Olson & Moulton, 2004). A study reviewing seven studies using weighted vests found no evidence of its effectiveness, though further research is indicated (Stephenson & Carter, 2009).

Sensory Defensiveness is common in children with ASD due to their hypersensitive systems and may manifest as anxiety, tantrums, avoidance or distractibility. A technique known as the Wilbarger Therapressure Protocol, (Deep Pressure Proprioceptive Technique (DPPT), Wilbarger & Wilbarger, 1991) is widely used by OTs to treat sensory defensiveness. There is controversy about the protocol due to its passive application of stimuli versus active initiation from the child, which is considered a foundational tenet of Ayres SI approach (Kimball, et al., 2007). The SPD foundation lists the Wilbarger protocol under alternate and complimentary

therapies (Miller, 2012b). A review recommended its use with caution due to its poor research evidence base (Weeks, Boshoff, & Stewart, 2012).

Managing the *sensory aspects of the environment* as well as tasks within the home and school are also crucial to maintaining a well modulated state (Anzalone & Williamson, 2000; Dunn, 2007). Environmental adaptations are designed to reduce sensitivities or increase arousal levels and may include changes to lighting, textures of floor or seat coverings, reducing noise levels and managing smells. Sitting on a ball or air cushion in class and regular movement breaks in between activities, are examples of appropriate strategies to meet a vestibular need for movement.

#### **2.3.3.1.3.5 Value of SIT**

SIT has gained widespread acceptance worldwide, as a valuable intervention approach (Schaaf & Miller, 2005a). It is widely advocated within the profession as well as by professional team members such as parents and teachers, who have used principles of this approach successfully in their classrooms and homes (Emmons & McKendry Anderson, 2005). Temple Grandin in her autobiographical account of living with ASD, has spoken extensively about her sensory issues further providing validation for the SI framework. She writes about the value of deep pressure and proprioceptive input as a calming, organising strategy via the use of her “hug machine” (Grandin, 1996). Despite criticism from within and outside of the profession regarding evidence of efficacy, SI is widely practiced internationally.

#### **2.3.3.1.3.6 Scientific Credibility**

Despite the benefits of SIT, it is still categorised as “unestablished” therapy by some within the scientific community, due to the lack of sufficient scientific evidence regarding its theoretical basis and efficacy (The National Autism Center, 2009; American Academy of Pediatrics, 2010). A recent policy statement by the American Paediatric Association cautions clinicians to advise families about the lack of scientific evidence supporting SI as a form of treatment, without going as far as to discredit it as an approach (Zimmer & Desch, 2012). The National Autism Standards Project considered SI as “unestablished” due to methodological weakness of studies, but not “ineffective” (Whitney & Miller-Kuhaneck, 2012).

OTs have argued that the profession is relatively new, without a long tradition of research, yet there are more than eighty studies researching the effectiveness of SI intervention (Schaaf & L. Miller, 2005b). There has also been criticism from within the profession, against favouring of SI interventions to the exclusion of other evidence based approaches (Rodger, Ashburner, Cartmill, & Bourke-Taylor, 2010). There are positive developments in SI research, towards proving efficacy with scientific rigour (May-Benson & Koomar, 2010). A SA study showed benefits of OT-SI for children with ASD in a number of areas such as readiness for toilet training due to improved interoceptive tactile awareness, improvement in sleep wake cycles and in emotional regulation (Wallace, 2009).

The SI framework due to its unique focus on sensory processing is undeniably a valuable component of OT intervention for the child with ASD (Adamson, et al., 2006). Occupational therapy is uniquely positioned to provide intervention addressing this potentially overwhelming and functionally limiting aspect of ASD. The value of SI needs to be balanced against the tendency for some OTs to view SI OT as “the” intervention, to the exclusion of other valuable evidence based approaches (Rodger, et al., 2010).

#### **2.3.3.1.4 Ecological Model**

The person-environment-occupation model (PEO) is an ecological model of OT based on the systems theory (Law, et al., 1996). This ecological approach has significant relevance in ASD intervention, as learning in natural contexts is an important intervention principle. This model observes the interaction between the variables of the child, the environment and the expectations of the environment on the functional performance of the child (Clark, Miller-Kuhaneck, & Watling, 2004).

For children with ASD, the value of environmental modifications, especially learning environments, have a crucial role to play in successful outcomes. The TEACCH model uses environmental modification in their system of providing visual supports such as a visual schedule in classrooms (Case-Smith, 2010). Other models such as SI, behaviour modification and biomechanical approaches may also guide environmental modification.

### **2.3.3.1.5 Play as Occupation**

Another uniquely occupational therapy focus, is to intervene in the primary occupation of childhood, which is play. Play is significantly affected in children with ASD, as play lacks imagination and tends to be stereotypical, solitary, repetitive and restricted in pattern and interests. Sensori-motor and functional play may be present, but symbolic play is often restricted, if present (Case-Smith, 2004). Three OT frames of reference use play as a modality of intervention. These are the developmental, functional and sensory integration frameworks (Knox, 2005). Yet, within the OT profession's occupation frame of reference, play should also be seen as an outcome or goal in itself. Play skills are the basis for social interaction, further emphasising their importance in ASD. Thus OT play intervention may focus on improving performance components, play skills and socialisation as well as play per se, thus facilitating playfulness (Morrison & Metzger, 2001).

### **2.3.3.1.6 Relationship Based Approach: DIRFloortime**

Another play-based approach is that of Greenspan's DIRFloorTime model (1992), The Developmental Individual Difference Relationship based model (DIR), targeting social and emotional growth. Affect, intent and relationships are emphasized within a developmental approach whilst accounting for individual differences in motor, sensory, language and cognitive function. A DIR programme includes intensive OT and speech language therapy in addition to two to five hours of daily interactive "DIRFloortime" play with caregivers and therapists (Prizant, et al., 2000).

This model resonates with OTs due to Greenspan's acknowledgment of the role sensory processing plays in the developmental trajectory of children with ASD, as well as the child directed play based format. He advocates for understanding the child's sensory processing profile and working to their strengths in designing social interaction based intervention (Greenspan & Wieder, 2006).

OTs have trained in this approach, incorporating Floor Time within their practice, to facilitate emotional and cognitive growth as well as meet OT specific aims. Eighty seven percent of OTs surveyed in America fourteen years ago used the DIRFloortime approach (Case-Smith & Miller, 1999) with a probable likelihood of

this figure having increased over the years. In SA the popularity of this approach is growing, with OTs currently in training with two programmes on offer. One is an online training programme with the Profectum Foundation ([profectum.org](http://profectum.org)) and the other is through courses run in SA, by an American based certified instructor ([atotalapproach.com](http://atotalapproach.com)).

#### **2.3.3.1.7 Visual Perceptual Approach**

OTs address visual perceptual skills that impact on function, typically academic skills for young children. Visual perceptual skills are integral to academic tasks of reading, writing and math. OTs use perceptual training programmes based on learning theories to remediate deficits (Schneck, 2010). School based OTs tend to have a sensory-motor-perceptual focus .

#### **2.3.3.1.8 Model of Creative Ability (MoCA)**

This model was conceptualised in the 60's by a South African OT, Vona du Toit, to facilitate growth in the creation of self. It is a developmental model that examines the relationship between motivation and action, whilst providing strategies to elicit motivation (du Toit, 2004).

MoCA provides a means of assessing a client's creative ability level and providing the stimuli and environment to facilitate growth to the next level. She identified criteria for determining a client's performance level together with comprehensive guidelines for intervention at each of the nine levels of the model. Each motivation level corresponds to types of action or performance expected. For example the lowest level of tone corresponds with pre-destructive action, whilst the next level of self-differentiation is destructive and incidentally constructive action. The highest level is that of competitive contribution that is society centred.

Paediatric OTs apply the model to categorise a child's level and plan appropriate play based activities for that level. It provides guiding principles on activity selection, presentation of the activity as well as handling and grading of tasks. Therapists often struggle with motivation in children with ASD (Mailloux & Roley, 2010), and MoCA's guidelines for eliciting participation in activity may prove useful in sparking interest and motivation. Earlier stages of MoCA are therapist directed, with

transition to client directed stages as the quality of motivation changes through progression to higher levels. In this regard, it straddles behavioural and SI intervention in respect of both child and therapist directed phases. Categorisation of social awareness of norms, others and the environment according to MoCA's levels may be especially applicable to social interaction and engagement difficulties common in ASD.

It is widely taught in undergraduate programmes in SA, has gained international exposure and is being used in the UK and Japan (Sherwood, 2013). MoCA started as an approach rooted in psychiatry and work readiness programmes, but has evolved in application to diverse populations including paediatrics.

### **2.3.3.1.9. Behavioural Approach**

Principles of the behavioural approach are utilised by OTs in establishing a positive, supportive environment for therapy, as well as managing behaviour (Bregman, et al., 2005). OTs seek to decrease problem behaviours such as aggression, self-harm, disruptive behaviour and tantrums through functional analysis of a child's behaviour. Strategies commonly implemented include those directed at antecedents such as removing a stimulus or trigger for problem behaviour, extinction based strategies such as ignoring bad behaviour to avoid reinforcement and changing the features of the environment (Case-Smith, 2010).

Positive Behavioural Support (PBS) may include contingency methods of rewards, positive reinforcement, alternating preferred and non preferred activities and meeting sensory needs through manipulation of the environment (Watling, Miller-Kuhaneck, & Audet, 2010). OTs utilise behavioural principles when creating an environment where difficult behaviours are less likely to occur. These may include establishing predictability and consistency, creating a calm atmosphere, reinforcing appropriate behaviours, and using "do" rather than "don't" statements to direct the child to the desired behaviour (Watling, et al., 2010).

The SI approach of modifying the environment ties in with the philosophy of modifying antecedents. However, within the developmental and SI approaches, understanding the underlying causes of behaviour from a neurobiological

perspective has greater validity. A tantrum may be seen in the light of sensory issues and not just antecedents and reinforcers. In the SI approach, a child may be allowed a jump on the trampoline before a work task as a preparation for work as opposed to a behaviourist lens viewing it as a reward prior to a task.

#### **2.3.3.1.10 Other Approaches Used In OT**

The *biomechanical* framework is useful for facilitating functional movement and providing adaptive equipment and devices.

The *motor learning* framework is useful in addressing motor planning difficulties or dyspraxia in children with ASD. The motor learning approach stresses the importance of skill acquisition through doing the task to improve performance. This approach is congruent with SI in active participation driving learning which occurs within the context of cognition and perception (Buitendag & Aronstam, 2010). In motor learning, contextual factors are prioritised over those of neuro-maturation.

#### **2.3.3.2 Application of frames of reference to practice**

The reality outside of theory is that OTs hardly ever use a single frame of reference to treat a child. Frames of reference are limited by their theoretical bases and as such do not comprehensively address all of a child's difficulties (Kramer & Hinojosa, 2010b). Frames of reference are often addressed in sequence according to which is most relevant for a particular stage. They may provide different perspectives on the same problem when used in parallel. The integrated use of frames of reference mean that they are used in combination. Some frames of reference have similar characteristics such as SI and NDT, which are easily combined in approach and technique (Kramer & Hinojosa, 2010b).

Across professional services, there is support for a range of approaches as no single approach is suitable nor equally effective for every child (Prizant & Rubin, 1999). Whilst no one approach may be indicated, components of various approaches may be appropriate for an individual.

It is expected that OTs may use a combination of approaches to address the needs of the child with ASD, which is the recommended route as experts have cautioned

against exclusive use of any single approach (Howlin, 2005a; Rodger, et al., 2010). The use of an eclectic intervention approach for ASD, has however been criticised, from the perspective of research into efficacy of an intervention (Dillenburger, 2011).

### **2.3.3.3 Eclectic Approach: Intervention for IADL**

Intervention for IADL incorporates a range of approaches: developmental, environmental (sensory and physical adaptations), acquisitional based on teaching and learning theories, behavioural as well as SI. Treatment for IADL is a good example of an integrated eclectic approach.

The acquisitional approach shares aspects with the behavioural approach in using practice, feedback, repetition and reinforcement of component steps (LaVesser & Hilton, 2010). It is most useful in teaching dressing and other self-care routines in a step by step mastery approach. Other strategies that work well, are providing visual supports such as a picture sequence for dressing, using physical and verbal prompts during the task, chaining (mastering each step at a time beginning with the first (forward chaining) or the last (backward chaining) and adapting the task or the environment (LaVesser & Hilton, 2010). Video modelling of tasks has shown some success in teaching skills such as toileting when combined with operant conditioning (Keen, Branigan, & Cuskelly, 2007).

Social stories are commonly used especially for toileting and mealtimes (Bledsoe, Myles, & Simpson, 2003). Sensory strategies may include a sensory diet of calming deep pressure and proprioceptive activities prior to a difficult routine such as brushing teeth (Dunn, 2007). Sleep and toileting difficulties are best addressed through the behavioural approach, together with SI environmental adaptations and strategies (LaVesser & Hilton, 2010).

The OT survey studies found that self care was less emphasized in intervention, with no specific mention of addressing the sensory aspects of ADL (Case-Smith & Miller, 1999). 2.3.2.4 Conclusion on OT Frameworks for ASD Occupational therapy intervention for children with ASD draws on a range of approaches from within the profession, and from allied professions such as psychology and medicine. The OTs

choice of approach to assessment and therapy may be determined by a number of factors such as professional training, personal preference, government policy, work setting, resources and or the needs of the child and family. Traditional OT, MoCA, DIRFloortime as well as SIT is rooted in a play based developmental approach, relying on the initiative of the child and framed within an understanding of typical development. These are usually primary frames of reference, which are blended with elements and techniques of behavioural and NDT approaches. The importance of an eclectic approach is emphasised.

## **2.4 INDIRECT INTERVENTION: MODES OF COLLABORATION**

### **2.4.1 FAMILY COLLABORATION**

OTs collaborate with families in settings of hospitals, schools and private practices. The advantage of hospitals and private practice settings is regular direct parent contact. In schools, due to large learner numbers and logistics of routines, parent contact may be less regular and often indirect.

#### **2.4.1.1 A Family Centred Approach**

“Family-centred service recognizes that each family is unique; that the family is the constant in the child’s life; and that they are the experts on the child’s abilities and needs” (Law, et al., 2003). The shift from a medical model to client and family centred practice, has gained currency worldwide (Brown, Rodger, Brown, & Roevers, 2007; Wallen & Doyle, 1996). Whilst SA policy articulates this shift (Department of Education, 2001), the practice of professionals in health and education may not reflect a family centred approach (Struthers, 2005). SA Universities have moved from medical models to social developmental models (Joubert, 2010). This shift to family centred services even elsewhere in the developed world, is notoriously difficult to achieve (Espe-Sherwindt, 2008). In this model, parents are considered to be the primary team members, with whom final decisions reside.

Professionals need to be prepared to deal with issues beyond the child with ASD, as stressors result in difficulties such as marital stress, sibling issues and financial stress amongst others (Domingue, et al., 2000). Framing parenting within an occupational perspective, allows OTs to understand the family routines, challenges, cultural differences and parenting styles of families (Hanna & Rodger, 2002).

#### **2.4.1.2 Parent OT relationships**

Parent therapist collaboration is a critical element of family centred practice. It is especially important considering the intense stressors faced by families of children

with ASD (Werner DeGrace, 2004). Viewing parents as equal partners and as experts on their children builds a foundation of trust and respect for collaboration. Sensitivity to family values and traditions is also important for good relationships (Domingue, et al., 2000), especially in a country such as SA with many cultural traditions.

Parent–professional relations are not devoid of conflict, with professionals citing frustrations such as non-attendance of meetings by parents and failure to follow through on programmes (Bailey, 1987). Parents also have negative experiences of the professional team.

Therapist training in SA and worldwide may not prepare them with the skills needed for a family centred approach (Domingue, et al., 2000; Struthers, 2005). Skills needed are open communication, building relationships, collaborating on goals, interviewing skills and negotiating priorities amongst others (Domingue, et al., 2000). A SA study confirmed the need for therapists in the education sector, to develop such specific competencies in order to provide indirect support to parents, teachers, schools and the community (Struthers, 2005).

#### **2.4.1.3 IEP development**

A critical collaboration exercise is developing an IEP (individual education plan) that guides education and therapeutic intervention during the school years. As partners, parents should be involved in setting goals for their child together with education and therapy staff. Whilst this is legislated in the USA, it is not uniformly enforced across SA. Schools in Kwa-Zulu Natal (KZN) are specifically encouraged to consult and include parents in IEP development (Office of the Premier KZN, 2011).

#### **2.4.1.4 Parent training**

The belief in the caregiver as an agent of change has led to parent education and empowerment, as well as parents taking on roles of teacher and therapist. Active involvement in the child’s programme applies especially to parents of children with ASD, as many programmes recommend intense engagement and training of parents to continue intervention in the home (Harris, et al., 2005). Parent training equips parents to work with their children with positive results for the child and

family (Koegel, Bimbela, & Schreibman, 1996). Parent training needs to be practically oriented and specific to ASD to be effective (Marcus, Kuncze, & Schopler, 2005). SA research indicates that caregivers appreciated skills transference training and requested more of this form of support (Hooper, 2009). However, taking on therapist and teacher roles can be an additional stress to families. Parents are likely to experience chronic stress, which can be compounded by intervention demands made on them (Mcgee & Morrier, 2005). OTs need to respect parents decisions regarding their degree of involvement and be sensitive to the unique dynamics of different families (Domingue, et al., 2000).

#### **2.4.1.5 Support groups and advocacy**

Support groups for parents and siblings provide information and emotional support through opportunities to share experiences. OTs may be involved in supportive roles to existing ASD support groups and advocacy organisations. As part of indirect intervention and support to families, OTs refer families to local support groups. Advocacy for the child within the school or the community also falls within the scope of indirect intervention OT services (Case-Smith, Rogers & Johnson, 2001). Struther's study identified a need for SA therapists to become involved in advocacy by partnering with communities for the benefit of their clients (Struthers, 2005). Autism South Africa (ASA) a national NPO with provincial branches and Action in Autism, a Kwa-Zulu Natal based NPO, provide support and counselling for families and are involved in advocacy and awareness campaigns.

#### **2.4.2 WORKING IN PROFESSIONAL TEAMS**

Indirect intervention involves consultation and collaboration in carrying out intervention outside of direct contact between therapist and child. Indirect intervention programmes such as education and training, emotional support, support groups and home programmes were discussed under working with families above. The focus in this section is on inter-professional collaboration, though parents are considered part of the team.

As indirect intervention occurs with and via other team members it relies on trusting and co-operative relationships between members. Three models of teamwork are

briefly outlined. Teams may interact in a multidisciplinary, interdisciplinary or trans-disciplinary way. Consultation and advocacy are discussed.

## **2.4.2.1 TEAM COLLABORATION STYLES**

### **2.4.2.1.1. Multidisciplinary team**

Team members function independently, providing separate assessments and intervention plans according to their professional roles. This information is shared amongst the team, but intervention is profession specific (Choi & Pak, 2006). The team is structured hierarchically with the head of the team making the decisions. The head is often the medical doctor in health settings.

### **2.4.2.1.2 Interdisciplinary team**

In the interdisciplinary team model, members have substantial knowledge of each profession's discipline, with role flexibility and role blurring (Choi & Pak, 2006). This involves a deeper level of collaboration, with team members assessing and or developing intervention plans jointly. There is a sharing of collective expertise towards common goals (McCallin, 2001).

### **2.4.2.1.3 Transdisciplinary team**

In transdisciplinary teamwork, skills and not just goals are shared (Choi & Pak, 2006). The transdisciplinary approach is unique in that, a single member representing the team, provides the service on behalf of all the disciplines. Also called a primary service provider model, it is predominantly used in early intervention settings in the community in the USA.

The transdisciplinary approach is ideal for family based services in home settings for children from birth to three years, where parents prefer to deal with one therapist (Dunn, 2000). Intervention is planned jointly by the team, and implemented in an integrated session by the primary therapist. This requires role release, free exchange of information and a team that understands the strengths and weaknesses of team members. This system can work in government health and education, but is less suited to private health and education due to payment complexities. In school settings, this primary service provider is often the teacher (Dunn, 2000).

#### **2.4.2.1.4 Consultation**

*Consultation* refers to the problem solving partnership between the OT and the rest of the team. Practical problem solving with therapists also provides emotional support for parents and teachers. The focus is on education and training so that the service may be enhanced or a programme implemented. Supervised therapy involves training a team member such as the parent or teacher, in implementing a specifically designed programme (Dunn, 2000). The implementation of the programme is monitored on an on-going basis to ensure success.

Some have argued for consultation as a mode of indirect intervention to replace direct intervention for most pupils (Bundy, 1995). The consultation approach can lead to a perception of unequal power relations between the “expert” and the team member needing advice. The power relationships between therapists and teachers can be problematic in this model where the OT can be seen as the “expert” dictating to the teacher (Struthers, 2005). Yet, studies have shown positive results in student performance when weekly OT teacher consultation occurred and it also led to a favourable view of OT by teachers (Spencer, Terkett, Vaughan, & Koenig, 2006). Further, teachers preferred OT services that were directly linked to academic goals and more compensatory than remedial in nature (Spencer, et al., 2006). Consultation has worked successfully in areas such as NSW Australia, where it is the primary mode of intervention (Struthers, 2005). Consultation in one study, had low correlations for perceived improvement in SI and self care (Case-Smith & Miller, 1999). The other aspect of indirect intervention considered to be best practice in school settings, is environmental adaptation of the classroom (Spencer, et al., 2006).

#### **2.4.2.2 Team Skills for Indirect Intervention**

Indirect intervention relies on skills around communication and collaboration amongst team members. A survey of one hundred and five therapists in special needs schools in the Western Cape, indicated that they lacked confidence in implementing indirect intervention and that collaborative teamwork was poorly developed (Struthers, 2005). In SA, the inclusion policy recommends the formation of multidisciplinary district support teams, whose primary purpose is to support the

school system to accommodate the learner. The mode of service delivery would be indirect and consultative (Department of Education Directorate: Inclusive Education, June 2005). The successful implementation of this policy will require team members to be trained in skills needed for successful collaboration (Struthers, 2005).

The challenge is to see services as more than direct contact time with the child, and to strengthen indirect services through programme planning and integration of OT goals into the comprehensive intervention plan (Case-Smith, 2010). A SA study concurs with the need to increase indirect intervention in education (Struthers, 2005). Further, teacher support in the form of adapting content, and the curriculum was identified as a need. OTs have also been challenged to use their voice in advocacy (Struthers, 2005).

## **2.4.3 DIRECT INTERVENTION AND SERVICE PROVISION MODELS**

### **2.4.3.1 Individual “Pull out therapy”**

This is individualised therapy by the OT with one child and is the traditional form of intervention. Direct intervention services were used by eighty two per cent of OTs providing intervention to children with ASD (Watling, et al., 1999). It involves removing a child from their environment to attend therapy in a separate location. This has been termed “pull out” therapy in schools, and is a model which isolates therapy from daily life routines (Case-Smith et al. 2001; Dunn, 2000). It interrupts learning time and further may be a source of social embarrassment (Struthers, 2005). Studies have proved the value of working with learners in the natural performance context, yet “pull out” intervention that is remedial in nature is still popular in schools (Spencer, et al., 2006).

### **2.4.3.2 Integrated Therapy**

The move towards “integrated therapy”, aims to provide services within a child’s natural context or daily life routines. This concept is especially important for children with ASD, as they struggle to generalise skills across different contexts. Integrated intervention may take place within the classroom, with the OT still focussed on directly assisting the one specific child within their classroom routines (Case-Smith et al., 2001). Another integrated approach is *collaborative teaming*, which involves sharing of skills and information across disciplines, with a strong child centred focus. Practically this may take the form of block scheduling, where a number of team members together, provide intervention within a classroom (Case-Smith, 2005).

### **2.4.3.3 Group Therapy**

Direct intervention may also take the form of group therapy. The advantages of group therapy are cost savings and efficiency, as well as peer modelling, which is especially relevant in ASD .

#### **2.4.4 OT Dosage**

Research has shown that intensive models of intervention is needed for ASD, ranging from twenty five to forty hours of engagement per week over a few years (Case-Smith, 2010). OTs would ideally form part of an interdisciplinary team providing direct services within this period of intensive engagement. Traditional direct intervention models in OT provide therapy one to two times per week over a longer period of a few years. More recent recommendations for OT-SI are for high dosage “intensives” of three to five times per week over a short term (Miller, 2012a), with up to two years of intervention considered typical. Direct services correlated highly with SI intervention for children with ASD and the OTs surveyed perceived the most significant improvement to be in sensory processing (Case-Smith & Miller, 1999).

DIRFloortime recommends nine hours per week with many of the educational programmes like TEACCH and Early Start Denver model utilising full day programmes. OT dosage needs for ASD require intensive models, which should see individual therapy coupled with indirect intervention in the form of influencing the programme implemented by the team. The viability of intensive intervention will be influenced by factors such as cost, access and availability of resources.

#### **2.4.5 Evidence Based OT Practice for ASD**

OT as a profession subscribes to the need for research evidence to guide practice (Scheer, Arbesman, & Lieberman, 2008). OT for ASD occurs within the developmental, behavioural, educational, sensory integration and relationship based approaches. Case-Smith identified common themes that span studies of interventions for ASD within these frameworks, that have a bearing on best practice (Case-Smith, 2010).

- an assessment and intervention plan that is individualised and specific to that child
- intervention must target core deficits of ASD namely functional communication and social participation

- intervention should actively engage the child in meaningful activity through choice, use of motivating activities and natural reinforcers
- intervention needs to be intensive (many hours per week over a period of time) as well as comprehensive utilising multiple approaches (direct as well as indirect intervention within a interdisciplinary team)
- promotion of skill generalisation across contexts
- family centred intervention including education and support for families

#### **2.4.6 SA Context of OT Assessment and Intervention Services**

The setting for occupational therapy services often determines aspects of service provision within the broader framework of education and health policy in SA.

##### **2.4.6.1 Education**

In educational environments, the assessment process may be tailored to determine eligibility for special needs schooling or for OT services. American Occupational Therapy Association guidelines recommend that school OT services should tailor assessment and intervention with a school occupation focus. The OT service must aim to improve the child's ability to perform in academic and non-academic tasks within the contexts of school, which include classroom, playground and extracurricular activities (Tomchek, 2010).

##### ***Inclusion Policy in SA***

This education focus is echoed in the SA context of inclusive education, with recommendations for support services to move away from the medical model towards an educational social model (Department of Education Directorate: Inclusive Education, June 2005; Struthers, 2005). SA has not developed role specific guidelines for OTs in education, which has been identified as problematic (Dube, 2012; Struthers, 2005). The Gauteng Department of Education (GDE) has begun to address this in a draft guideline on the role and scope of OTs at schools (Dube, 2012). It also identified the inadequate exposure of OT students to paediatrics and school based therapy.

Aspects of the inclusion policies of White paper 6 have been discussed under direct and indirect intervention. The long term process to implementing this policy, will see current special needs schools fulfilling an outreach role to mainstream schools and becoming resource centres, while continuing to educate learners with high support needs. Mainstream schools will upscale to full service schools able to support learners with special needs, whilst receiving support from district teams as needed (Department of Education, 2001). Progress in implementation of these policies has been slow, with the regional KZN Education Department recently committing to an action plan for services (Office of the Premier KZN, 2011).

### ***Inclusion Implementation Plan***

A recent national meeting with the Minister of Social Development Ms B.Dlamini, also resulted in resolutions amongst which was that all seventy two special needs schools in KZN must accept learners with ASD by 2014 (Department of Social Development, 2013, May 9). The statistics of young children with disabilities accessing early learning facilities is currently very low at four to five percent, based on 2010 household survey statistics (Right to Education for Children with Disabilities). It is predicted that there will be increased demand for OT services at schools as of 2014.

#### **2.4.6.2 Health**

Post apartheid reorientation of the public health system also resulted in policy changes in line with a focus on primary health care (Department of Health, 1997, 16 April.). Public hospital restructuring took the form of four levels of care. Community clinics are the first contact with the system from which patients may be referred onto Level 1 district hospitals, to level 2 regional hospitals with general specialised care, to level 3 provincial tertiary hospitals with sub-specialist care and finally onto level 4 central hospitals providing the highest level of multi-specialist care (Stack & Hlela, 2002). Staff posts were cut in the intended redeployment process of staff to lower tier hospitals, resulting in a migration of professionals from the public sector. In an interview with one KZN provincial official, he was quoted as listing staff personnel shortages to include that of occupational therapists (Stack & Hlela, 2002).

A positive impact has been free health care for children under six years of age, though children in SA may be accessing services much later due to late diagnosis (Hooper, 2009). A government disability grant is available to children and adults with ASD. The private health sector in SA services 16,2 % of the population (Hooper, 2009). Health care in the private sector is of a high standard but unlikely to be interdisciplinary in nature.

## **2.5 EDUCATION AND TRAINING FOR PROFESSIONALS IN ASD**

### **2.5.1 Postgraduate Training**

In Canada, a lack of post graduate specialist OTs was identified as a barrier to the provision of OT services (Law, 2006). Currently there is no ASD specific postgraduate university training programme in SA. SA professionals have identified the need for a structured post-graduate programme (Geertsema, du Plessis, & Swanepoel, 2011). There is a demand in SA, for professionals who understand autism to serve people with ASD and their families (Hooper, 2009).

ASD training should be interdisciplinary, drawing on expertise within one's discipline as well as on one's familiarity with ASD (Mcgee & Morrier, 2005). Autism specialists need skills and knowledge specific to ASD (Simpson, 2004). These specialists or "front line trainees" may be any of the professionals who diagnose, assess, plan and provide intervention for ASD, such as medical doctors (paediatricians, paediatric neurologists, child psychiatrists), audiologists, speech language therapists and OTs (Mcgee & Morrier, 2005).

Another avenue for training is to provide hands on mentoring. Professionally run, mentoring can be more costly being a one on one programme. It reaches fewer individuals compared to university group training and is also dependant on personnel (Mcgee & Morrier, 2005).

### **2.5.2 Undergraduate Training**

In terms of undergraduate training in SA, the need for including neuro-developmental conditions has been raised (Mubaiwa, 2008), as well as greater exposure to paediatric OT and school based therapy (Dube, 2012). Interdisciplinary

training is another recommendation in international literature as it prepares professionals to work collaboratively (Howell, Whitman, & Bundy, 2012). There has also been a call to train student therapists in skills needed for collaborative indirect intervention to meet inclusion needs in South African education (Struthers, 2005). SI is part of entry level training for OTs in the USA (Case-Smith & Miller, 1999). SI is taught on an elementary, introductory level at most universities in SA. Universities differ with regard to the content of SI that is taught to undergraduate students.

### ***Summary Of Chapter***

ASD prevalence rates are rising worldwide. The review of the literature revealed that research in ASD is an emerging field, with little published research locally. OT is one of a number of accredited interventions that a child may receive in public or private health and education in SA. OTs collaborate with professional team members and families to provide intervention. OT in SA is amongst the most highly sought after interventions across public and private health sectors in SA (Hooper, 2009).

Intervention for ASD is long term, covering multiple developmental areas, utilising a multidisciplinary team. Assessment relies on skilled play based observation as standardised tests may not be a valid form of evaluation. Standardised tests may be used in an adapted way. Assessment is comprehensive, covering multiple areas with OT specific areas being sensory motor and IADL assessment.

OTs reference a number of frameworks and approaches, the most popular being SI, developmental, DIRFloortime, AAC and behavioural. Intensive OT dosage is recommended for ASD. The SI and developmental frameworks are most referenced by OTs in guiding intervention. The value of the SI approach in treating sensory processing disorders is recognised but needs greater scientific credibility through research. Individual therapy aims to improve sensory modulation dysfunction common in ASD, to allow for a state in which learning can occur. Indirect SI intervention is directed at providing teachers and caregivers with strategies to regulate arousal levels through sensory diets and environmental adaptations. Therapeutic interventions that are comprehensive and eclectic in approach are considered best practice, together with a family centred services approach.

ASD being a complex condition requires specialists, which is a need that has been identified in SA. Undergraduate programmes have limited exposure to school based OT, and paediatric content taught across SA universities varies. Training for skills in collaborative teamwork has been recommended. SA's burdened public health system and proposed inclusion plans for special needs education are important contextual factors influencing assessment, intervention, dosage and service provision models. The need for OT services for ASD is likely to rise in all sectors, especially public health and special needs education.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 INTRODUCTION**

“Qualitative research findings have been shown to be necessary to the advancement of health research” (Sandelowski, 2004,p. 1374). Sandelowski argues for the utility of qualitative research in transforming knowledge for clinical practice and the positive impact this has on evidence based practice. This study aims to “hear the voices” of experienced OTs in the field and in so doing, provide useful clinical guidelines for practice as well as recommendations for education, training and policy. The study aims to explore OTs perceptions around intervention for ASD and not just descriptive information around the nature of OT practice.

#### **3.2 AIM OF STUDY**

To explore the perceptions of OTs regarding intervention for 2 to12 year old children with ASD in educational, public health and private practice settings in South Africa

#### **3.3 OBJECTIVES OF THE STUDY**

- To explore current assessment practices of OTs working with children with ASD in SA
- To explore current direct and indirect intervention practices of OTs working with children with ASD in SA
- To explore the need for further education and training for OTs in the field of ASD
- To explore similarities and differences between practice settings of public health, education and private practice settings

### **3.4 RESEARCH APPROACH AND DESIGN**

A qualitative method of in depth enquiry, using an interpretive paradigm was deemed most appropriate for this study. A qualitative approach allowed for the exploration of the OT's perspective of practice patterns, without limiting the information to description of OT assessment and treatment practices. Their personal views and experiences, particularly within the SA context of health care and education could be explored in depth. Exploration of the "how" and "why" of typical practice trends deepen one's understanding of OT practice with young children with ASD within the three specific contexts of SA practice. Noting similarities and differences between sectors allows for a contextual understanding of challenges faced within each sector. An interpretivist approach allowed for an understanding of the experiences of participants and how they interpreted their experiences, providing insider knowledge, so to speak, about their practice (Scotland, 2012). The interpretivist approach values the contribution of context to experiences and was useful for my study, which compared information across practice contexts (Scotland, 2012).

This study is based on two similar quantitative survey studies carried out in the USA in 1999 (Case-Smith & Miller, 1999; Watling, et al., 1999). These were among the first studies documenting OT practice in the USA. While it provides a wide range of information on the "what" of OT practice, in depth information on the "why" of OT practice is limited by the survey design of the study.

Qualitative research aims for complexity as well as a holistic understanding of the subject (Creswell, 2009). Hence a replication of these studies would yield limited depth, contextual information and limit opportunity to explore perspectives on practice. Trends in practice patterns, motivation for using specific therapeutic approaches and personal experiences cannot be explained or interpreted outside of a qualitative paradigm. As an initial study of this kind in SA, the researcher felt that a qualitative approach would provide the descriptive detail and personal perspectives necessary to deepen our understanding of SA OT practice.

Another advantage of using a qualitative approach was successful participant selection. Being a relatively new field of practice in SA, it was presumed that few

OTs practice in this field. The nature of ASD intervention often calls for expertise or specialists in ASD. A qualitative interpretive approach with purposive sampling allowed for the rich descriptions from skilled OTs in the field.

### **3.5 SAMPLING TECHNIQUE**

Criterion purposive sampling was used. This allowed for the selection of a small number of participants, who were likely to yield the most useful information on OT and ASD due to their experience in the field (Leedy & Ormrod, 2010).

### **3.6 PARTICIPANT SELECTION CRITERIA**

OTs who have extensive experience with ASD or have further training in the field were best candidates for providing in depth information on practice. Skill due to further training and years of experience in the field were not both necessary criterion for inclusion. Therefore, OTs who met the following criteria were selected to participate in the study. The OT had to be:

- registered with the HPCSA in the year of the study
- working with children with ASD aged 2-12 years in SA
- working in any of the following sectors: education, public health or private practice
- have a minimum of 2 years experience in the management of children with ASD
- further qualifications such as SI certification or training in ASD specific approaches are an advantage but not essential

Purposive sampling, resulted in some OT participants having ASD specific training such as Ayres Sensory Integration and DIRFloortime. Excluding OTs without SI certification or similar further qualifications or training in ASD specific courses, would have restricted sample size, especially in public health and education sectors. Further, it would have reduced heterogeneity of the sample, which is important for exploring perceptions around dominant theoretical frameworks and the need for further training of OTs to practice in the field. Further training is an

indication of higher skill levels, which coupled with experience in years of practice were advantageous but not essential for inclusion in the study.

### 3.7 DESCRIPTION OF PARTICIPANTS

Participants were selected from three provinces, Kwa-Zulu Natal (KZN), Gauteng province (GP) and Western Cape (WC). Twenty participants in total were interviewed in eighteen practice settings, with four participants interviewed in dyads, both in SNSs. The all female group of participants ranged from twenty eight years to fifty seven years of age, with occupational therapy experience of between four and thirty five years. Their experience with ASD ranged from two to twenty seven years.

Five of the participants previously worked in more than one setting with children with ASD. This included private practice (PP), an early intervention community centre, special needs schools (SNSs) as well as government hospitals (H). Practice settings ranged from eighteen (current) to twenty three (including previous settings) in total. All OTs qualified in SA. Nineteen of twenty participants had some further training of value in ASD, with twelve OTs certified as SI practitioners. Participants are described in the table 3.1 below:

#### 3.7.1 Additional qualifications

The researcher was interested in post graduation training that had relevance to ASD, even though it may not be exclusively for ASD. In summary, all OTs except one, had some additional training relevant to ASD intervention. Twelve OTs have trained in courses that are of particular value in ASD such as SI, NDT, Makaton signing, PECS, DIRFloortime and Therapeutic Listening. See table 3.1 below.

Table 3.1: Additional Qualifications of OTs

ADDITIONAL QUALIFICATIONS	NUMBER of OTs with ADDITIONAL QUALIFICATIONS and PRACTICE SETTING
SENSORY INTEGRATION (SI)	Twelve of the twenty participants are certified sensory integration practitioners. Three participants were in the process of training. Two participants were trainers or lecturers on the SI programme in SA. Three of the SI trained OTs worked in two government SNS, one OT worked in hospital, while the

	remaining eight were in private practice.
MASTERS IN OT	Three OTs have a Masters qualification. One has a master's degree in perception and two OTs have a master's in early intervention. One therapist was enrolled in an OT masters programme at the time of the study.
HONOURS	One has a psychology honours with a diploma in trauma counselling.
DIRFLOORTIME	Six were in training with the DIRFloortime approach of Greenspan, with another about to begin the process.
NDT	Five are certified NDT practitioners.
AAC	Two have training in an international signing system Makaton, and one in Picture Exchange Communication System (PECS). Two of the OTs with hand sign training are in SNSs, one in a government hospital.
AUDITORY INTEGRATION TRAINING (AIT)	Three were trained in the Therapeutic Listening Programme, one OT in the Tomatis So Listen Programme. All four OTs were in private practice.
ADOS	Two OTs who were working in a government ASD special needs school, have some ADOS training.

### 3.7.2 Spectrum and age range treated

The majority of participants indicated that they worked with the full range of the spectrum, with most of their caseload being individuals with moderate to severe impairment levels. The range of moderate to high functioning children, were seen more in private practice (PP). The bulk of intervention seemed to be in the early intervention phase, with older children entering government hospital systems for the first time at older ages.

### 3.7.3 Current practice settings

Eight OTs are in *private practice*, three of who are practicing in private special needs schools. Two of the three OTs who practice in private SNS also have practices outside of the SNS. Six OTs practice in *government special needs schools*. Six OTs work in *government hospitals*. The hospitals are across a range of psychiatric, referral and regional hospitals including one specialist hospital. For the purpose of the discussion, SNS and hospital refer to government institutions and SNS (P) refers to a private SNS.

### 3.7.4 Previous work settings with ASD

As five of the OTs previously worked in a variety of settings with ASD, their experience in each of the settings was also drawn upon. Current practice settings refer to their current sector of employment working with ASD, be it public or private health or education. One OT worked at a community NGO run early intervention centre, which will be categorised as an NGO in the health sector.

### 3.7.5 Racial and practice setting demographics

One African, six Indian and thirteen White OTs were interviewed. Seven of the thirteen white participants were in private practice, five in SNS and one in hospital service. Four of the six Indian OT, worked in hospitals, one in PP and one in an SNS. One African OT worked in a hospital.

### 3.7.6 Provincial demographics

The OT participants were spread across three provinces: Eight in Western Cape (WC), seven in Gauteng (G) and four in Kwa-Zulu Natal (KZN).

Table 3.2: Abbreviations for table 3.3

PP	Private Practice
H	Government Hospital
SI	Sensory Integration certified
SNS	Special Needs School
NDT	Neurodevelopmental Therapy
AIT	Auditory Integration Training (Therapeutic Listening or So Listen programmes)
PECS	Picture Exchange Communication system
ADOS	Autism Diagnostic Observation Schedule

Table 3.3: Participant Profiles

Participant	Age	Race	Years in OT practice	Years of ASD experience	Current Practice Setting	Province	Further Education and Training	Range of ASD clientele
A	31	W	8	6	PP	WC	SI	Full spectrum
B	35	I	7	2	H	WC	Course on ASD	Full spectrum more severe
C	28	I	5	4	H	G	Masters in perception	Full spectrum
D	53	W	32	20	PP	WC	SI (Instructor), NDT, DIRFloortime (incomplete), Therapeutic Listening	Full spectrum
E	46	I	24	4	PP SNS (private)	G	SI, NDT, Honours in Psychology, trauma counsellor	Full spectrum
F	50	W	29	3	SNS	KZN	SI, Makaton	Full spectrum more severe
G	24	I	4	4	H	G	SI	Full spectrum
H	35	I	12	11	H	KZN	-	Full spectrum
I	57	W	35	12	PP	KZN	SI, AIT (Therapeutic Listening)	Full spectrum
J	46	W	24	4	PP	KZN	SI, NDT	Full range, more moderate
K	36	W	18	4	PP SNS (private)	G	SI, exposed to DIRFloortime, Masters in Early Intervention	Full spectrum
L	30	W	3	2	SNS	G	In DIRFloortime and SI training, trained in ADOS, CARS, courses on TEACCH, ABA	Moderate - severe
S	26	W	4	3	SNS	G	In DIRFloortime and SI training, Makaton, CARS, courses on TEACCH, ABA	Moderate - severe
M	34	W	11	9	PP	G	SI, AIT (Therapeutic Listening), DIRFloortime (In Training)	Full spectrum
N	38	I	15	5	SNS	WC	SI, PECS, DIRFloortime (introductory course)	Full spectrum
T	28	W	7	SNS	WC		SI, PECS, DIRFloortime (introductory course)	Full spectrum
O	41	W	19	10	H	WC	Enrolled in masters in OT	Moderate-

							programme	severe
P	50	W	27	27	PP	WC	SI, SI course instructor, AIT (Tomatis), DIRFloortime (1st module), NDT	Full spectrum
Q	40	A	10	4	H	WC	NDT	Full spectrum
R	28	W	4	3	SNS	KZN	Masters in early childhood intervention	Wide range, not very severe

### 3.8 DATA COLLECTION METHOD

In depth semi-structured interviews were conducted with OTs who met the above criteria. Participants were selected from public health settings, special needs schools with ASD units and private practices in the KwaZulu-Natal, Gauteng and Western Cape provinces.

The researcher conducted semi-structured in depth interviews with OTs for up to 120 minutes. Whilst some interviews lasted 90 minutes as originally expected, some took up to 120 minutes due to further exploration of aspects of practice or perceptions of practice. Participants were probed for further comment when interesting or controversial information emerged. Participants also explored their areas of passion or concern in greater depth. As a result, there was more information gleaned in some areas with less information gathered in other areas. Due to time constraints, some aspects of the schedule were not given sufficient time for full or in depth exploration. Participants discussed aspects of personal interest in greater detail compared to other aspects. These varied according to their skill, experience or passion. Participants asked for clarification when unsure of what was being asked of them. Participants asked for examples of common theoretical frameworks or techniques used.

The interviews took place in a quiet and private location convenient to the participant, either at the workplace or their home, except for one interview, which was conducted in a hotel coffee shop. This was due to the participant travelling out of her province. This allowed for most of the interviews to occur within a natural setting, in which they were comfortable (Creswell, 2009). The interviews were

personally conducted by the researcher and recorded via digital audio recorder. An experienced typist transcribed the audio interviews.

The taking of field notes during and after interviews was used to back up audio recordings. They provided essential back up for technology failure. The researcher used the interview guide to structure the interview, using open-ended questioning and probes to elicit greater detail.

### 3.9 DATA COLLECTION INSTRUMENT

An Interview schedule (refer to appendix F) was used to guide the discussion during in-depth semi-structured interviews. This allowed the researcher to gather relevant information across all interviews conducted. The design of the interview schedule was loosely based on surveys describing practice patterns of OTs in the USA (Case-Smith & Miller, 1999; Watling, et al., 1999). The aim was to gather information on OT practice covering seven sections. These sections covered assessment, direct and indirect therapy, therapeutic intervention approaches, service delivery models, teamwork and education and training.

The motivation for inclusion of above sections or components of an OT intervention is discussed in the table below.

Table 3.4: Interview Schedule

SECTION	THEME	MOTIVATION
A	Biographical Information	It provides background information about the OT, which provides important contextual information as well as educational and skill levels in relation to other participants.
B	Assessment	Assessment constitutes the first step upon referral for a child with ASD. Due to the core deficits in ASD, assessment is challenging and often different to typical evaluations in format, context and content (Tomchek & Case-Smith, 2009). The use of informal non-standardised tests as well as standardised tests was explored.
C	Direct intervention	Therapy between a child and their OT may take different formats and be influenced by different paradigms according to an OTs training or perception of success. Therapy for a

		child with ASD follows principles that may be different from therapy for other paediatric conditions due to the very nature of ASD and its core deficits in communication, social interaction, language and behaviour. The researcher wanted to explore a typical session and whether OT with children with ASD has any unique features
D	Indirect intervention	Indirect intervention may take a number of forms and is an essential component of intervention in any OT programme. Core deficits in communication may emphasise advocacy roles, while behavioural challenges may require greater parental support. Indirect intervention may differ across sectors.
E	Teamwork	A crucial component to any successful intervention, teamwork is especially important for children with ASD owing to their difficulty generalising skills across contexts. Therefore, models of interaction, levels of collaboration and importance of teamwork for education and health contexts was explored.
F	Further education and training	It is speculated that few OTs work in this field in SA, despite rising ASD prevalence rates. Training institutions will need to rise to the challenge. The opinion of skilled OTs in the field is a valid indication of any need for further education and training on a postgraduate level. They will also be able to comment on undergraduate training in preparing OTs for working with persons with ASD.

The interview guide used open ended type of questioning (Patton, 2002), as described below. Probes or follow up questions allowed a participant to expand on ideas expressed, in an effort to obtain the necessary depth of information and rich detail.

Table 3.5: Type of Interview Questions

Type of Question	Example
<i>Open ended questions:</i> are “leading” questions, which allow the participant to express feelings, thoughts and perceptions in rich detail.	<i>“Tell me about indirect intervention”</i>
<i>Experience and behaviour questions:</i> relate to a typical OT session or day in the life of an OT working with children with ASD.	<i>“Describe a typical therapy session with a child with ASD”</i>
<i>Opinion and values questions:</i> relate to the cognitive aspect of how OTs may judge or interpret occupational therapy processes.	<i>“Elaborate on the most important frames of reference you use to guide intervention”</i>
<i>Feeling or emotive questions:</i> deal with affective responses to working in this field.	<i>“How do you feel about working with families”</i>
<i>Knowledge questions:</i> factual information about OT and ASD	<i>“Tell me about the service provision model you use”</i>

### 3.10 PILOT STUDY

A pilot interview was an important preparatory and recommended step in the implementation of the research (Creswell, 2009). This afforded the opportunity to test the interview process and interview schedule with someone who shared the characteristics of the participants, in an effort to make any improvements needed for a successful interview. The pilot interview was also an opportunity to practice interview skills. The pilot interview assessed the suitability of the schedule in terms of the following:

- Ability to answer the research question
- Clarity of questions
- Phrasing of questions
- Order of questions to form a logical sequence
- Length of the interview

The schedule was revised as described in the table below.

Table 3.6: Description of Pilot Study

AIM	PROCEDURE	RESULTS and REVISIONS
To determine clarity of audio-recording	Placement of recorder on a table close to the participant, with a short distance between interviewer and participant	Low battery resulted in partial recording of the pilot interview. A backup recording device was used in the event of a repeat of equipment failure. Clarity of audio material was good
To obtain feedback regarding the clarity, phrasing, sequencing and appropriateness of questions to answer the research question	The interview was conducted according to the interview schedule. Thereafter, the participant's opinion was sought regarding the interview content	The sequence of the question on successful intervention was moved to improve flow of the discussion from indirect intervention to the end of the section on working with families as it rounded up the discussion
To strengthen interviewer skills and create familiarity with the interview schedule	Participant's feedback was sought regarding interview style and skills	No changes were required
To determine if the length of the interview was within the allocated 90 minutes or sufficient to complete the interview	The interview was timed and took 90 minutes to complete.	Due to the lengthy interview time, the question regarding discharging a child was removed as not much useful information was gained
To practise and evaluate the data analysis procedure	Coding of data was practiced. The quality of information was evaluated to be sufficient to meet research objectives	

### 3.11 DATA COLLECTION PROCEDURE

The following events occurred in the sequence below:

- A research proposal was submitted to the UKZN Research Ethics Higher Degrees Committee (REHDC) for review and ethical clearance. An ethical clearance certificate was issued (Appendix A), granting the researcher permission to proceed with the study (ethical clearance number HSS/0060/012M).
- Written permission was sought from the Superintendent Generals of the respective Provincial Departments of Education (DoE) and Health (DoH),

for approaching OTs based at schools and hospitals or clinics to participate in the study.

- Upon receiving permission from DoE and DoH of Gauteng, Western Cape and KZN, an e-mail invitation to participate in the study was sent to all OTs registered with the Occupational Therapy Association of South Africa (OTASA)
- Three OTs responded via email indicating their willingness to participate in the study
- Provincial schools and hospitals as well as private practitioners were approached directly to further recruit participants and ensure sufficient spread across all three sectors.
- Written information was e-mailed to participants regarding the nature of the study, benefits of the study, their role and details regarding data collection and distribution (Appendix C)
- The participants were asked to complete the document of informed consent (Appendix B). This was distributed and collected via email
- Date, time and venue for interviews were scheduled via email with telephonic follow up, according to the participants' convenience and the data collection period time frames. Queries were responded to.
- E-mail reminders were sent a week and a day before the interview and reminder telephone calls were made one day prior to the interview

Interviews were conducted and audio recorded

### **3.12 DATA ANALYSIS**

Thematic analysis was used to analyse the data from the initial stages of data gathering, on an on-going basis. While qualitative research favours an inductive approach, deductive strategies were also utilised in the analytic process. This is unavoidable due to the framework of occupational therapy philosophy and family centred practice that is the lens for viewing the data. It is also argued that the researcher lacks absolute neutrality (Hennink, Hutter, & Bailey, 2011). Deductive

codes were drawn from topics in the interview guides such as assessment, intervention, theoretical frameworks, teamwork and education and training. However, inductive strategies were exclusively utilised to develop themes as analysis relied on data driven codes. Inductive strategies were used in code development, comparison and reasoning during data analysis (Richards & Morse, 2007). The credibility of inductive codes was determined by repetition across transcripts, strong emphasis, topic changes or specific phrases. These offered unique perspectives not necessarily anticipated by the researcher, such as clinical dilemmas in SI practice.

The data was transcribed verbatim, followed by immersion in the data. This involved repeated readings of all transcripts to get an overall impression of the content. Thereafter, line-by-line manual coding began (Richards & Morse, 2007). Colour marking of units of meaning within the script allowed for a label or code to be assigned to it. These codes were descriptive for participants and topic related for other data (Richards & Morse, 2007).

Related codes were grouped or organized into categories according to the interview schedule such as assessment for example. Once all data sets were coded and categorized, analytic processes of questioning and comparing the data generated new categories. This exploratory and analytical process included description, examining the categories from various angles, comparing categories (OT in schools, public hospitals and private practices), identifying patterns and asking questions of the data. Common threads in the data generated main themes and subthemes. Repeated data searches according to code, topic, theme and subthemes, was conducted across transcripts. Comparison across transcripts was done for codes and categories, for subgroups of participants (according to SI training or work sectors).

### 3.13 DATA ANALYSIS PROCESS

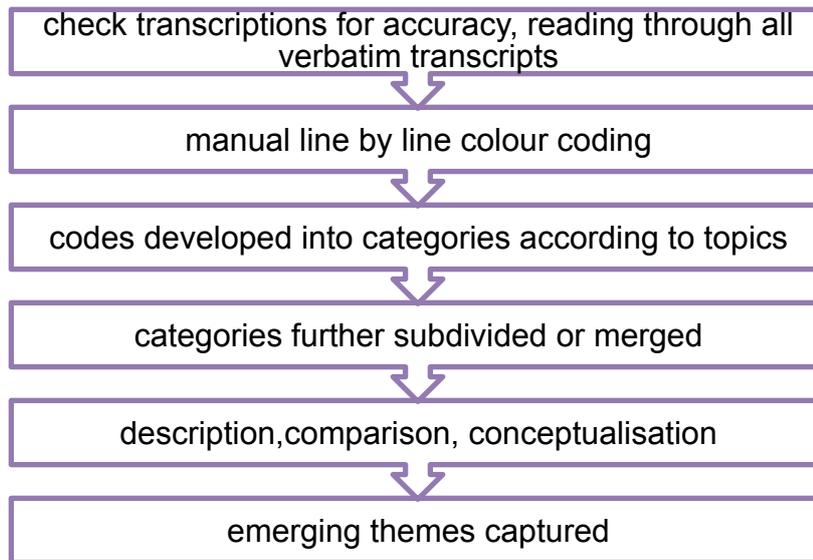


Figure 3.1: Data Analysis Flow Chart

### 3.14 ISSUES OF TRUSTWORTHINESS

Trustworthiness covers aspects of credibility, dependability, confirmability and transferability (Mouton, Babbie, Boschhoff, & Vorster, 2008). Each aspect was covered through mechanisms built into the study as outlined below.

#### 3.14.1 Credibility

This refers to how true the researcher's findings are to the data, in other words "can I believe the results?"

This was ensured through the following steps:

- **Pilot interview:** the interview schedule and the researcher's ability to conduct interviews was tested via a pilot interview to determine any deficiencies in the research instrument and researcher interviewing style. The pilot interview also gauged the average length of the interview.
- **Member checks:** was used in interviews through clarification to ensure

information was captured correctly. During data analysis, transcripts were checked against audio recordings for accuracy.

- The use of *interview venue* of choice for the participant, which included their home, practice setting or other appropriate confidential venues.

*Peer debriefing*: took the form of regular meetings with research supervisors to ensure that data analysis is a credible process representative of the actual data collected.

#### **3.1.4.2 Dependability**

It refers to how well the study may be replicated to obtain similar results.

Use of an audit trail, to track decisions made at each stage of the data gathering and analysis process allowed the supervisor to confirm the results of the study.

#### **3.1.4.3 Transferability**

It refers to whether the findings may be applied with other respondents in another context.

- The use of thick description provided sufficient rich detail for comparison across contexts.
- The use of purposive sampling to obtain a broad range of information that is contextually rich was an attempt to ensure some heterogeneity in the sample. Differing skill sets, geographical and work settings were present in the sample. Ethnic diversity was present to a degree with three South African race groups represented (African, Indian, White)

#### **3.1.4.4 Confirmability**

It refers to the neutrality and objectivity of the data.

This was ensured through both supervisors review of selected transcripts to confirm coding schemes and accurate analysis of the data. By obtaining agreement between three persons, confirmability and dependability of the data was

established.

### **3.1.5 ETHICAL CONSIDERATIONS**

#### **3.1.5.1 Informed Consent, No coercion**

Informed consent for voluntary participation in the interview was obtained from all participants via a covering letter and information document. The information document outlines the purpose of the study and anticipated consequences of the study. Participants were given a signed copy of the informed consent form indicating that the participant may withdraw from the study at any stage without bearing any negative consequences.

#### **3.1.5.2 Protection from Harm or Beneficence**

There were no risks to participation in the study, as research was conducted with OTs who were not a vulnerable population. There were anticipated beneficial consequences for the participants in terms of gaining insight into their practice as well as for the profession in terms of recommendations from the study.

#### **3.1.5.3 Anonymity and Confidentiality**

Research participants were informed that confidentiality of documentation and anonymity of identity is assured. Participants names were not be used or revealed during the course of the research as well as in the research report. This was addressed by assigning participants codes to identify them in the study. Audio data and written data transcribed to the computer are stored in password-protected files. A back up copy of audio data will be stored on a CD in a locked cupboard. Audio and transcribed data will be destroyed 5 years upon completion of the study.

## **CHAPTER FOUR**

### **FINDINGS AND DISCUSSION**

#### **INTRODUCTION**

The discussion is presented according to the broad themes of assessment, therapy or direct intervention and service provision models, modes of collaboration in terms of teamwork, education and training on undergraduate and postgraduate levels and challenges to families in SA.

Results of the study are presented as thematic schemes. Figure 4.1 is a representation of emergent themes.

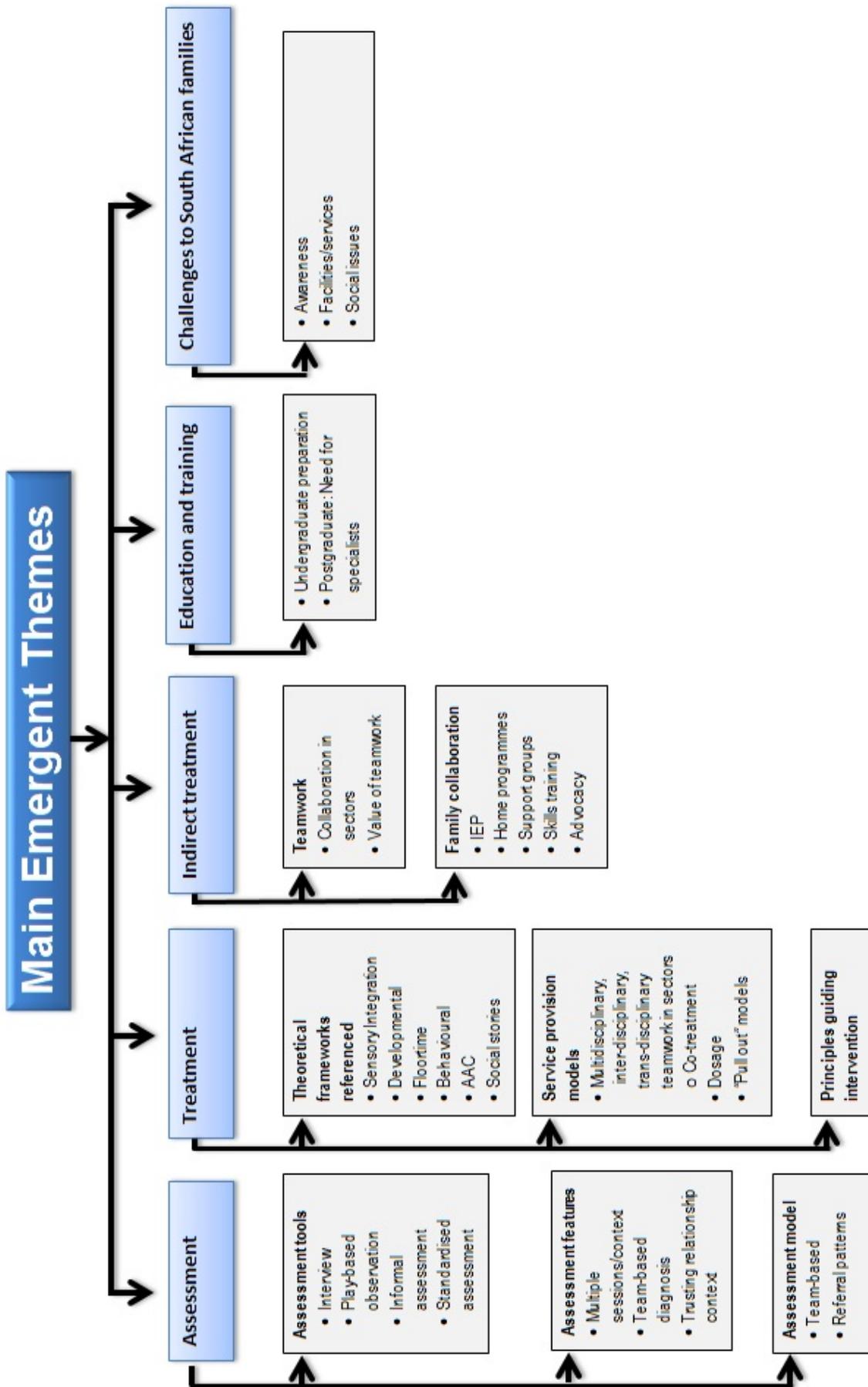


Figure 4.1: Overview of Main Emergent Themes

# ASSESSMENT

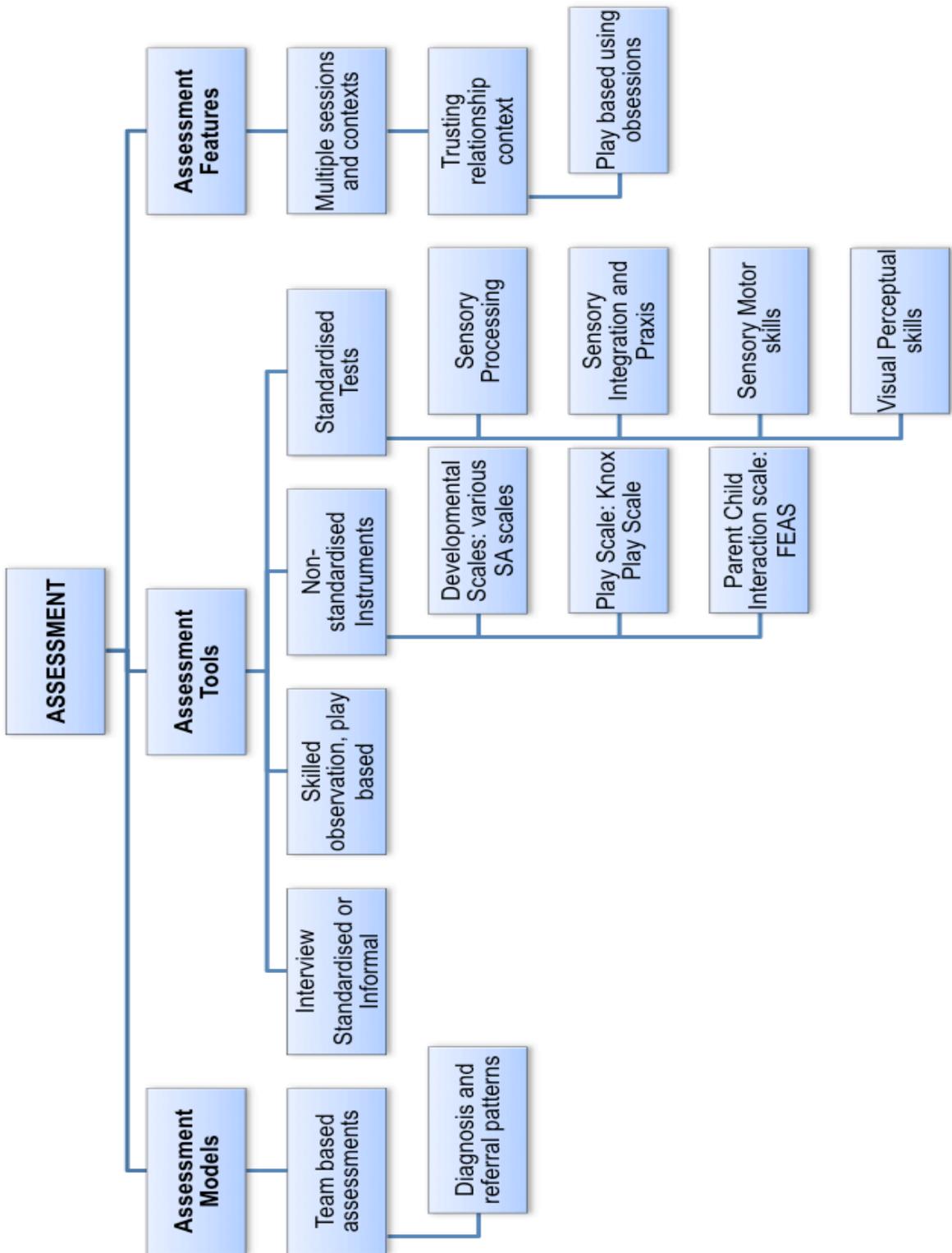


Figure 4.2: Assessment Themes and Subthemes

## **ASSESSMENT**

### **4.1 ASSESSMENT TOOLS**

It was found that the assessment format consisted of a caregiver interview, structured play based observation and in some cases additional non-standardised or standardised testing. The discussion will be presented according to these four assessment tools. Areas or components assessed are addressed under treatment themes in the relevant sections, as components assessed automatically form part of the treatment programme.

#### **4.1.1 CAREGIVER INTERVIEW**

In the study, the caregiver interview combined background information with a detailed sensory processing history, which was commonly the standardised Sensory Profile (SP)(Dunn, 1999). The general interview included enquiry into aspects such as sensory preferences especially around IADL, the child's behaviour in different environments, occupational roles of the child including play, as well as roles of the family, family routines and family support systems.

*C: "...in the interview...I asked them about the environments, like how they adapt to the new environment. Then I also asked them a lot about...what behaviours predominate through the day ..."*

*Q: "...we start with the ADL... if they're toileting...their bathing and their dressing and eating...to hear from the parents' perspective how the child plays and then if she has noticed anything different."*

The general interview revealed an understanding of ASD and sensory behaviours, as well as a family centred approach. The scope of enquiry included parent and sibling roles as well as an effort to gain the parent's perspective. A detail informal interview could provide substantial information, should a standardised option on specific aspects such as sensory processing not be possible.

#### 4.1.2 INFORMAL ASSESSMENT

All the participants used informal play based sessions all or most of the time for assessment purposes. The use of informal assessment using play and skilled observations is supported by the literature (Tomchek & Case-Smith, 2009) and part of the trend towards using measures that provide a more holistic profile of a child's strengths and challenges (Domingue, et al., 2000). The value of informal play based assessments over standardised testing for ASD amongst the participants was clear. These findings concur with those of American OTs who preferred methods of structured observations for assessment (Watling, et al., 1999).

*C: "I've done a standardised assessment on... two of our autistic children in my years (4) at X (hospital)".*

*J: "definitely if there's any indication of autistic, I don't put pressure of an assessment at all ..."*

Skilled observation reflected an awareness of the various performance components to note in children with ASD, as well as the signs of ASD. OTs are perhaps particularly adept at the use of informal assessments and conclusions drawn from observations, as they are trained in the use of activity as assessment and treatment. The OTs understanding of developmental norms was also important as OT B elaborates below.

*G: "we just watch them for a few minutes... and then there might be specific things that we want to look at, so if we pick up a music toy that... makes a noise...we're observing the cause/effect or we have...a little feely box...you see either he's not wanting to touch things or like jelly and water...we...use selected tasks, almost like pre-selected tasks"*

*B: "the psych...or doctors, they won't detect things like the way the child draws, the grip used for their age... the planning involved... so that's where the OT can pick up on those skills."*

#### **4.1.2.1 Formal Non-standardised instruments used by OTs**

Non-standardised instruments used by participants fell into three categories: developmental checklists, a play scale and a parent child interaction scale.

#### **4.1.2.2 Developmental checklists**

The developmental screening checklists named by some of the participants were South African developed instruments. Locally developed scales included:

- The START (1990)
- WITS Developmental Profile (Stewart-Lord, 1980; 1998)
- Rita Edwards Developmental Checklists (Accelerate Pre-school Enrichment Programmes, 1987) (out of print)
- Carla Grobler's Developmental Checklist (Grobler, 2011)

Hospitals used developmental profiles the most. Three hospitals specifically mentioned the WITS Profile and the START, other participants did not name their developmental checklists. Grobler's checklist was used in the community early intervention centre. One SNS and one hospital used the Rita Edwards profile from the Accelerate Pre-school Enrichment series, which is no longer in print.

*R: "...so I could go the route of standardised testing... with the extra concept and fine motor games, the odd activity, or you have to scratch that completely and you work purely on (a) developmental checklist, with all the areas that I discussed earlier, the gross motor, the fine motor, the sensory motor, the sensory skills, everything."*

#### **4.1.2.3 Knox play scale**

Play as an occupation is within the OTs scope of practice and also a medium of intervention. Play was specifically targeted in private practice and hospitals, probably due to the younger ages of children seen in these sectors. Academic concerns probably take priority in SNSs. In OT E's SNS, play was assessed and

formed the basis of a home programme. OT P (in PP), was the sole OT to use an OT play scale for its value in child parent interaction and as an appropriate play level guide for the parent.

*E: "Play as a medium of teaching...(and) for developmental reasons, moving them from one level to another... The parent always gets a list of activities in terms of play..."*

*J: "I look at play development very much... normal development and the stages of play..."*

*P: "I tend to then use Sue Knox play scale ...because it's a very nice method for Mom to know where to play next."*

#### **4.1.2.4 Functional Emotional Assessment scale (FEAS) (Greenspan, DeGangi, Wieder, 2001)**

Another play based assessment, the FEAS is scored on the parent child interaction during play with three types of toys: symbolic, sensory and movement toys. Two OTs in PP used this scale.

*D: "... we do the video session, a play session with the child and the parents... that's a 15 minute session and, in some instances there is some coaching..."*

The utility of this scale is limited by the need for video technology, though mobile phones could possibly be used instead. One would also need training in the use of FEAS. There may be value in the use of the FEAS in SA, as it is a short, inexpensive and easy to use scale. It targets parent child interaction and thus empowers parents to deliver regular intervention through play with the child at home.

Developmental checklists are useful inexpensive instruments that can be used by newly qualified OTs in any context. They are also useful in developing appropriate goals and speak a common language across the multidisciplinary team. The Knox

Play Scale is a potentially useful and possibly under-utilised scale in SA. The advantage of the FEAS over the Knox play scale is that it is ASD specific, and targets core deficits in an integrated multidisciplinary format.

#### **4.1.2.5 Sensory questionnaires**

Two hospital based OTs used informal or non-standardised sensory evaluation questionnaires, which provided some indication of the hyper or hyposensitivity of each sensory system. These were free, so no costs were incurred. The informal questionnaires are neither as comprehensive nor quantifiable compared to their standardised counterparts, possibly limiting its value for parent insight into sensory processing and behaviour. A non-standardised version is less valuable in assessing progress and of low value for research purposes.

#### **4.1.3 STANDARDISED ASSESSMENT**

Standardised tests were used to measure (in order of priority) sensory processing, sensory integration and praxis, sensory motor function and visual perceptual skills. A small number of participants (less than five) used standardised tests for children older than 4 years as an initial evaluation, provided that the ASD level of severity allowed for formal assessment. Standardised tests when used by most participants, was usually after significant levels of intervention and in some cases, as a school readiness and placement evaluation.

Standardised tests had to be adapted for use with ASD, such as allowing for a longer time to complete it, or splitting the test between two shorter sessions. The use of standardised tests was least prevalent in hospitals and most frequent in private practice. Standardised tests used by the participants for each of the four areas are presented in the table below, followed by discussion.

Table 4.1: Standardised Tests used by OTs in the Study

STANDARDISED TESTS			
SENSORY PROCESSING PROFILES	SENSORY INTEGRATION	SENSORY MOTOR	VISUAL PERCEPTUAL / COGNITIVE
<i>Sensory Profile</i> (SP)(Dunn,1999)	<i>Sensory Integration &amp; Praxis Test</i> (SIPT) (Ayres, 1989)	<i>Miller Assessment for Preschoolers</i> (MAP)(Miller,1982)	<i>Beery-Buktenica Developmental Test of Visual Motor Integration (VMI), Visual Perception and Motor Co-ordination</i> , 4th edition, (Beery & Buktenica, 1997).
<i>Sensory Processing Measure</i> (SPM)(Parham et al, 2007)	<i>Test of Sensory Function in Infants</i> (TSI) (DeGangi, Greenspan, 1989)	<i>Miller Function and Participation Scales</i> (M-FUN-PS) (Miller, 2006)	<i>Developmental Test of Visual Perception 2nd edition</i> , (DTVP-2) (Hammill, Voress, Pearson, 1993)
<i>Infant Toddler Symptom Checklist</i> (ITSC)(DeGangi, 1995)	<i>DeGangi-Berk Test of Sensory Integration</i> (DeGangi & Berk, 1983)		<i>Test of Visual-Perceptual Skills (non-motor) Revised</i> , (TVPS) (Gardner, 1996)
			<i>Psycho-educational Profile</i> (PEP)(Schopler, Lansing, Reichler & Marcus, 2004)

#### 4.1.3.1 Standardised Sensory Profile Instruments

##### 4.1.3.1.1. Sensory Profile (SP)(Dunn, 1999)

Sensory profile (SP)(Dunn, 1999) is used across all sectors, with all but two hospitals and one SNS not using this particular profile. It is clearly an important component of the OT assessment, profiling sensory systems for the OT and the family. Fourteen of twenty OTs in the study, indicated that they used the SP. The SP is also popular internationally, with eighty one percent of sixty eight OTs surveyed, indicating that it was frequently or always used (Watling, et al., 1999). SP for the caregiver is most commonly used in PP and Hospital services, as the parents brought their children in for therapy and were the primary team members.

Two SNSs use The Sensory Profile-School Companion (Dunn, 2006), which is completed by the teacher.

There were contradictory views on whether the full version (SP)(Dunn, 1999) or the short version (The Short Sensory Profile)(Dunn, 1999) was most useful in the ASD population. OT G preferred the shorter version as it honed in on sensory modulation, which she felt was the key issue with ASD. An OT in another hospital preferred the full version. OT P had strong views on the value of the full version for parents in understanding their child's difficulties.

*G: "the short sensory profile works better than the long one. It's (full version) not really appropriate to autistic kids. It's (short version) just zoning in on the modulation."*

*C: "...use the full version because I think that gives you a bigger picture, if I'm going to do it – if they're (caregiver) going to understand the shorter version I feel they'll understand the longer version."*

*P: "I will not touch the short version...that you can put on record. It's unfair to do that to a parent. You need to do a decent job for the parent. I know for research people... its okay, but ...not for understanding a child properly and knowing what's going on"*

### **Use of SP with non-English Language speakers**

It was reported that the SP with illiterate parents takes much longer and is therefore not always used with non-English speakers in one hospital. In another hospital, it was frequently used, even though it often took an hour to administer to illiterate parents. The SP use with non-English language speakers may be influenced by whether the OT is fluent in an indigenous language or by the availability of a translator. Time constraints may also influence its use with non-English speakers or those who are illiterate.

*C: " I use the sensory profile with the children, very occasionally, because I find that the care-givers in our...setting – are struggling often to understand...the profile itself ...so if I have to do it I have to sit with them one-on-one right through the profile...so I use it very rarely."*

Q: "...those who are illiterate... who don't understand English... I actually have to go through it and... it takes almost an hour."

#### **4.1.3.1.2 Other Standardised Sensory Profiles**

The *Sensory Processing Measure (SPM)* (Parham et al, 2007) has become popular due to its contextual value (Miller-Kuhaneck & Henry, 2009). One SNS had just received their SPM at the time of the interview but had not yet begun using it. OT A was using the SPM as well as the SP, at the time of data collection.

Two OTs in PP preferred the *Infant/Toddler Symptom Checklist (ITSC)* (De Gangi, 1995) to the *Infant Toddler SP* (Dunn, 2002) for its functional value in the younger age band.

The sensory component of ASD is diagnostically and functionally significant. A standardised assessment of sensory processing and its impact on areas of function is an important quantifiable evaluation for the team. The SP and SPM are American tests that are in use in SA. The SPM has greater school and contextual relevance, while some sections are less relevant to SA. The SP is currently in use with parents from indigenous language groups. A move towards standardised assessment of sensory processing for ASD in SA settings will have positive outcomes for clinical use, parent education and research purposes.

#### **4.1.3.2 Tests Of Sensory Integration**

##### **4.1.3.2.1 Sensory Integration and Praxis Test (SIPT)(Ayres, 1989)**

The SIPT was used by only three of twelve SI certified OTs, all three within private practice. Five OTs in private practice did not use the SIPT at all to assess children with ASD. Three OTs in PP used the SIPT on select children who had the ability to cope with the level and length of the test. The SIPT was not used in hospital or school settings. There are a number of reasons for limited SIPT use. The SIPT assessment is more expensive for parents than using a battery of other standardised tests. This restricts its use to families who are able to afford it in the private health care sector.

*A : "...usually...do...a MAP or a SIPT...some kids - the higher functioning autistics, they can cope with it"*

*P: "...on assessment, 90 percent you know, I get into the SIPT. If I can SIPT, I'll SIPT. If I can use the Miller assessment of the pre-schooler I will, if I can use the DeGangi-Berk I will, if I can't I use them adapted..."*

*G: "I do do the SIPT... I'm very selective about it... more and more, and in Cape Town I'm finding that parents are finding it terribly, terribly expensive..."*

The length of time taken to administer the SIPT, and the level of skill and concentration required for it, restricts its utility to those children who are eligible in terms of ASD severity level. It is a complicated test to administer and score, reducing the likelihood of its use by OTs in practice. In one study, thirty one percent of seventy two OTs never used the SIPT, while only fourteen percent used it frequently (Watling et. al, 1999). Many OTs confide that they use SI as a treatment but don't use the assessment tool, relying instead on clinical judgement to diagnose SI difficulties.

*K: "... I'd never be able to carry out the SIPT..."*

*D:"...to put her through the SIPT I don't think would be really useful because I think I've got a good grip on what her areas of difficulty are in terms of practical, in terms of sensory modulation..."*

#### *4.1.3.2.2 Test Of Sensory Function In Infants (TSI)(DeGangi & Greenspan, 89) and Test Of Sensory Integration (TSI)(Degangi & Berk, 1983)*

Two OTs in private practice were using these tests.

#### 4.1.3.3 Tests Of Sensory Motor Function

*Miller Function & Participation Scales (M-FUN- PS)(Miller, 2006) and Millers*

*Assessment For Pre-Schoolers (MAP)(Miller,1982)*

Four OTs in PP used the (MAP), and one OT in PP the (M-FUN-PS)

*A: "... because it (MAP) does do a broad spectrum of skills, and it can also be quite play – you can do it in quite a fun way with them."*

#### 4.1.3.4 Visual Perceptual Standardised Tests

These test listed below, were developed for children with learning disabilities and developmental delays and were also used by the participants for ASD assessment. These tests were also used occasionally or frequently for children with ASD in American practice (Watling, et al., 1999). Standardised test administration was often split into more than one session by participants in the study, to allow the child to cope, which is in line with guidelines on ASD assessment (Tomchek & Case-Smith, 2009). Where standardised assessment was possible, eight PP OTs, three SNS OTs and two hospital OTs used the following tests:

- Beery-Buktenica Developmental Test of Visual Motor Integration (VMI), Visual perception and Motor co-ordination, fourth edition, (Beery & Buktenica, 1997)
- Developmental Test of Visual Perception second edition, (DTVP-2) (Hammill,Voress, Pearson,1993)
- Test of Visual-Perceptual Skills (non-motor) Revised, (TVPS)(Gardner, 1996).

*P: "I'll do a BEERY – if that's what all I can get in. Ja, if I can get (in) the DTVP-2 I would, so even if I have to break it up into three sessions, that's what I do."*

Visual perceptual tests were the only segment of standardised tests that are used across all three sectors. These tests were most popular in private practice and

private SNS sectors. One hospital based OT did not even use any of these tests as no formalised assessment was possible in that setting.

*Q : "...they are referred at age of 3 and then usually they struggle with most things...after they had maybe two years of therapy...I will actually do this (DTVP-2, Beery Developmental tests), maybe a year before they actually have to be placed."*

*O: "...the standardised assessments just doesn't work with these children"*

#### **4.1.3.5 ASD specific interdisciplinary tests**

*Psycho-Educational Profile (PEP) (Schopler, Lansing, Reichler & Marcus, 2004)*

The PEP was used in one SNS team assessment setting.

#### ***Discussion Summary on Standardised Tests***

Standardised OT assessment has a role in ASD. It is most applicable to children with higher levels of functioning, and even then may be used in an adapted form. The greatest value of standardised tests for OTs seems to lie in the assessment of sensory processing, sensory integration and motor skills in the early phase of intervention, yet none of these tests are designed specifically for ASD. Sensory questionnaires are suitable for ASD though designed for a broader population.

It is unclear whether OTs in PP use standardised tests the most because of the lower level of ASD severity of their client base, or whether there may be a perceived level of greater accountability for rendering quantifiable services in private healthcare.

Tests of visual perception were used after substantial levels of intervention and as part of a school placement plan. Their popularity in SNSs is understandable due to an academic focus. Their use in hospitals is probably due to them having access to the tests. Tests of visual perception may have less value for therapy in non-school going or younger children as clinical evaluation would suffice.

In private practice tests of sensory integration and sensory motor skills were used more frequently than visual perceptual tests, and may even be preferred. Most clinicians preferred clinical evaluation of sensory integration and praxis through observation or by using tests of sensory motor function from which sensory and praxis abilities could be inferred. Ayres SIPT has limited clinical utility for assessing children with ASD (Watling et.al, 1999; Parham et.al, 2000) and is especially inappropriate for SA school and hospital settings due to time and cost factors.

Standardised tests seem to hold most value for private practitioners and OTs in the SNS sector. The utility of standardised tests depends on a number of factors including the level of severity of ASD, home language spoken by the family, as well as on the length, cost, administration and scoring of the test itself. The clinical value of American tests for the SA population is questionable due to the multilingual context. Perhaps the use of a standardised sensory profile has the most value in reframing parent perspectives and may even play a role in dispelling cultural myths linked to behavioural idiosyncrasies.

## **4.2 ASSESSMENT FEATURES**

The study revealed the following common and unique aspects of assessment for children with ASD:

- Assessment occurred across multiple sessions and contexts where possible.
- Assessment occurred in the context of a trusting relationship

### **4.2.1 Assessment occurred across multiple sessions and contexts where possible.**

Assessment of a complex condition such as ASD required multiple assessment sessions in order to formulate valid baseline conclusions according to the literature (Tomchek & Case-Smith, 2009). The participants in hospitals and private practices, indicated that assessment occurred over more than one session. Multiple assessment sessions allowed for the child to adjust to unfamiliar persons and environments, which is a common difficulty for many children with ASD due to their rigidity. International recommendations for multiple observation opportunities was not always possible outside of SNS s in SA (Tomchek & Case-Smith, 2009).

Assessment typically occurred within the OT room in the hospital, school or private practice. Due to the nature of schools, the additional assessment session often involved observation in other contexts or during school activities. SNS was the only setting that allowed observation of the child in other contexts such as the playground or classroom. The observation was often incidental as opposed to a structured one. In PP, another context for observation was not common, but possible in the family's home or as a school visit. OT D in private practice used an alternate context for assessment if it was indicated.

*J: "...for my younger kids I always have two play sessions – the first one is definitely getting to know that they can feel comfortable with me..."*

*S: "...also observation...We also spend time... randomly on the playgrounds ...we go with them to toy library."*

*D: "if I don't feel that I've got enough information I do another play session with another ... one of the parents or... I might do it at home or at school...I would do it more than once, in different settings with different people...a clinic setting, you know, can be really challenging for some of these children"*

#### **4.2.2 Assessment in the context of a trusting relationship**

The therapeutic relationship forms the framework within which skill facilitation occurs. Participants indicated that familiarity with the OT, allowed for the development of a trusting relationship between OT and the child for future success. For most participants, the initial interaction in the assessment was largely non-invasive, on the child's terms, and a gradual introduction to a new physical and social environment. Limiting sensory stimuli in order to make the environment less stimulating or threatening for the child, was sometimes necessary to prevent sensory overload.

*J: "I treated a little boy on his father's feet for about three sessions... the relationship is paramount, and those first three, four sessions is where you make or break it...if the child trusts you, you can really make them go where you want to..."*

*G: "sometimes if a child is being quite destructive, then we have a little room that's just simply empty, there's nothing inside..."*

### ***Equipment and Materials for Assessment***

The study found that, informal assessment required minimal equipment, excellent observation skills and an ability to engage in playful interactions with the child, as well as knowledge of ASD. Participants indicated that a variety of toys and equipment was used as assessment materials, for areas of sensory processing, conceptual and cognitive as well as gross and fine motor skills.

Toys or activities such as jelly, water, and squishy toys were selected for their sensory properties and puzzles or cause and effect toys for their cognitive properties. The "feely box" and similar tactile materials mentioned by OT G above provides insight on tactile processing and sensory responsiveness. Equipment such as suspended swings were used to assess sensory processing of vestibular sensation, while balls were used to assess gross motor skills such as catching, throwing and kicking. Fine motor skills were also assessed using toys and drawing materials. Symbolic play was assessed with toys such as a baby doll or cars.

All but one facility (hospital) had access to gross motor rooms with some suspended equipment like a platform swing or hammock. Equipment such as a mini trampoline and large gym balls were also available. During motor skills observation, the motor planning component was important, as mentioned by OT C below. This will be discussed further under the SI theoretical framework.

*C "...assessment material, so it's a variety of different types of toys, so ...things that feel squashy or your pretend play toys...cause and effect type of toys and – a whole variety of toys where I can interact with the child...and take them to a table top where I try and look at their fine motor ... I look at their motor development throughout this, how they're planning...bring out a form board...ball skills..."*

### 4.3 ASSESSMENT MODELS

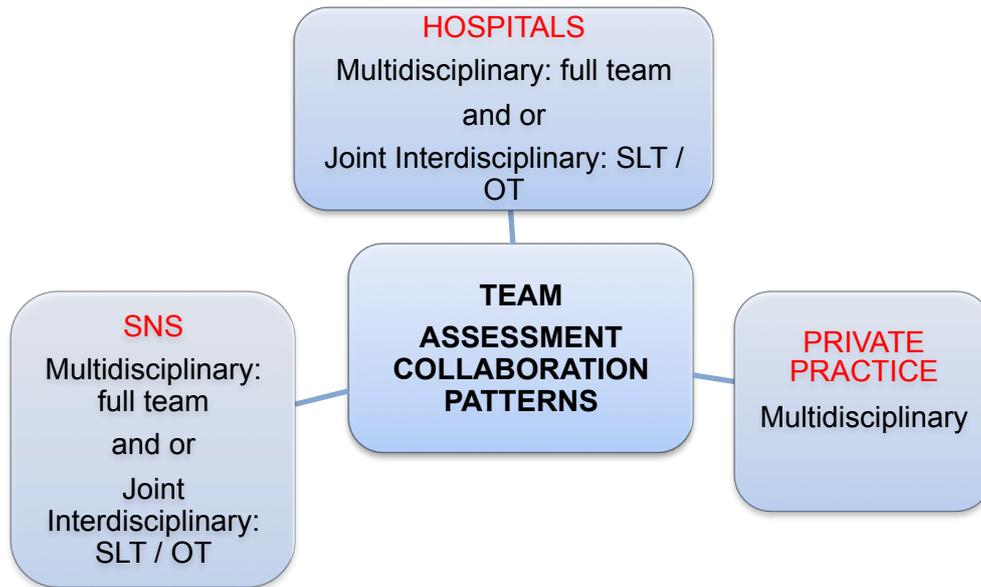


Figure 4.3: Team assessment collaboration patterns across sectors

Ten OTs worked in teams to conduct initial assessments. These teams were small or large depending on practice setting, and functioned in interdisciplinary or multidisciplinary ways. Some team assessments were multidisciplinary, with individual members meeting to discuss each professional's findings for a holistic picture of the child. Six OTs indicated that they were part of less formal collaborative interdisciplinary joint assessments between OT and any of the following professionals, SLT, PT and educator. Assessment collaboration between these three team members was also found to be frequent in an American study (Watling, et al., 1999).

Four of the team assessments took place in hospitals, five within SNS and one within a community based NGO centre offering early intervention. Three OTs worked as part of large multidisciplinary teams of more than four professionals in two hospitals and one SNS setting. Five out of six hospital based OTs participated in multidisciplinary and or joint interdisciplinary assessments. OTs in nine of ten SNSs engaged in multidisciplinary and or joint interdisciplinary assessment, except for one OT working in a private SNS.

The difference between multidisciplinary practice in hospitals and SNSs compared with that of PP, was that findings are shared at team meetings in hospitals and SNSs. The level of interaction between team members in PP is not formalised and seldom involved team meetings to share assessment findings, unless it was a group practice. Team based assessment in hospitals was restricted by staff shortages. Hospital OTs were unable to attend multidisciplinary clinics and assessments regularly due to their patient load. An analysis according to the three sectors follows.

#### **4.3.1 SNS**

*S: “when we initially assess the child it is with a speechy and an OT and then we compile the report together, and then we do classroom observation and then we’ll pull the child out for a more formal assessment where we look at skills.”*

*T: “especially with the PEP (Psycho-Educational Profile) we usually try and do it with two of us at a time, so either one of us with a psychologist or a speech therapist.”*

#### **4.3.2 Community based NGO Early Intervention Centre**

*K: “...our assessments...being a full team (OT,SLT, PT) it made a huge difference...everybody you know, addressing different aspects... the team would observe and come together to draw up findings.”*

#### **4.3.3 Hospitals**

*C: “...we book them in assessments where there’s an occupational therapist and a speech therapist in the session.”*

*G: “Unfortunately, at our hospital we (OTs) don’t go to the autism clinic...because we don’t have enough staff...there may be about between 8 to 10 speech therapists working only in paediatric – the OTs are only three.”*

### **4.3.2 OTs Contribute To Diagnosis Within Teams**

OTs who contributed routinely to ASD diagnosis worked in government hospitals. OTs in PP referred parents to doctors for diagnosis, but this process was variable, depending on the vulnerability of parents and the perceived need for a diagnostic label.

#### ***Referral Pathways within hospitals***

Referral of children flowed both ways between developmental clinics and OT. Clinics referred children with ASD or suspected ASD to OT. OTs who suspected an ASD diagnosis in children attending therapy, referred to developmental clinics with a diagnostic query. OTs and SLTs were often the first team members to assess a child, alerting doctors to a suspected diagnosis of ASD. Doctors who suspected a diagnosis of ASD relied on feedback from OTs once therapy was initiated.

*O: "...psychiatry unit here has got, um, a multidisciplinary clinic on a weekly basis...they would sometimes also ask the occupational therapist to come and observe a patient with them if there is a diagnostic query around the child"*

*C:" our paediatric team works very closely, so we work in collaboration a lot, like, they won't make a diagnosis without my input in it ever. We've always tried to make that together."*

#### ***Team Assessment Using Standardised Diagnostic Tests***

Two OTs were able to participate in *Autism Diagnostic Observation Schedule* (ADOS) assessments in one Gauteng hospital, which drew OTs into the role of diagnosis in an interdisciplinary setting. They observed the ADOS being implemented from behind a one-way mirror by trained professionals. These OTs have also participated in outreach community diagnostic team clinics with Autism SA, using the *Childhood Autism Rating Scale* (CARS) assessment.

The CARS was used in four team assessment settings (one government SNS, one private SNS, a community NGO and a hospital), with team members such as SLT, PT, the teacher or psychologist to assess children. The team using the CARS in the community NGO setting used its diagnostic value as a basis for referral to the

doctor. Internationally, the CARS was used frequently or always by only twenty two per cent of sixty six OTs but it is unclear in which context or practice setting (Watling, et al., 1999).

*L: “the therapist will generally play with the child and...try and get them to interact in the area that the CARS assesses, and the doctor will ask about background information, collateral ...”*

*S: “...they actually will sit with the kid and carry out the assessment (ADOS) and then the rest of us will sit on the other side of the mirror and obviously have... the form with us, make observations...and then the whole team will then sit together and score and discuss...”*

Children under six years or those on a disability grant receive free treatment in public health. This makes early identification especially important for the majority of South Africans, who utilise public health facilities. The value of a diagnostic label in public health allows access to specialised services such as therapy. An ASD diagnosis also makes the family eligible for a monthly disability grant. Early identification and diagnosis in public health is a challenge, and an important step to accessing specialised and support services for families.

The value of a diagnosis in private health care is beginning to change. Parents who may be struggling with acceptance prefer not to “label” their child, whilst accessing therapy services. The diagnostic label has up till recently had no significant financial benefits aside from eligibility for a disability grant. However, some parents have successfully requested extended benefits from their medical aid providers on the basis of a diagnosis. This advocacy and subsequent financial benefit of services over a longer term, significantly changes the value of a diagnosis for private health care consumers.

*D: “...I've got a client who's got two children...one has a diagnosis of Asperger's disorder and the other...of ADHD. ...(medical aid X) has granted them...extra funding, so ...both of those children's OT speech, play therapy intervention is now covered... so now...diagnosis is important.”*

The need for early identification and referral for specialised services for children at risk, is crucial not just in terms of successful outcomes, but also in accessing financial support for families across health care settings and income levels. OT is one of a number of professionals including nurses, psychologists, physiotherapists, SLT and doctors who are front line workers able to detect early developmental difficulties in babies. Community service OTs are likely to be front line workers who will encounter ASD in hospitals and communities. The availability of OT services in public and community health settings may be an important factor in early identification of babies at risk.

Wide scale screening will require larger numbers of OTs to be employed in health services. Training on ASD identification at undergraduate level or as in service training, would be an important component of a comprehensive programme of early identification of children at risk for developing ASD. More OTs working in the field of developmental disabilities is another factor that may impact improved rates of early diagnosis.

#### 4.2 TREATMENT

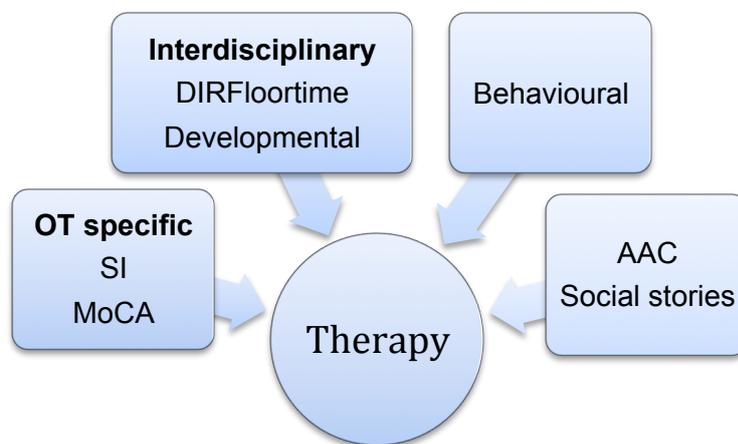


Figure 4.4: Theoretical Frameworks and Approaches Guiding OT Intervention

## **4.2.1 THEORETICAL FRAMES OF REFERENCE AND APPROACHES GUIDING PRACTICE**

### **4.2.1.1 SENSORY INTEGRATION (SI)**

Nineteen of the twenty participants mentioned SI, as an essential frame of reference, even those who were not certified SI therapists. As a primary frame of reference, SI guided assessment and intervention and clearly had theoretical and clinical value for OTs, team members as well as children and their families. Despite the value of SI for ASD, there were some clinical practice dilemmas that raised the need for greater clarity on a number of clinical practice issues. It also opened debate on contentious issues such as the scientific credibility and efficacy of SI.

Clinical issues were related to fidelity of SIT for ASD and philosophical issues of identity. Are OTs identifying themselves as SI therapists instead of OTs who are SI trained? Is there a danger of an SI tinted lens distorting our prioritisation of goals and how SI is conceptualised as a model within a dynamic context. The clinical utility of SI for SA is also explored in the light of this discussion.

The themes under this section, SI as a frame of reference for OT intervention, is represented in the figure below.

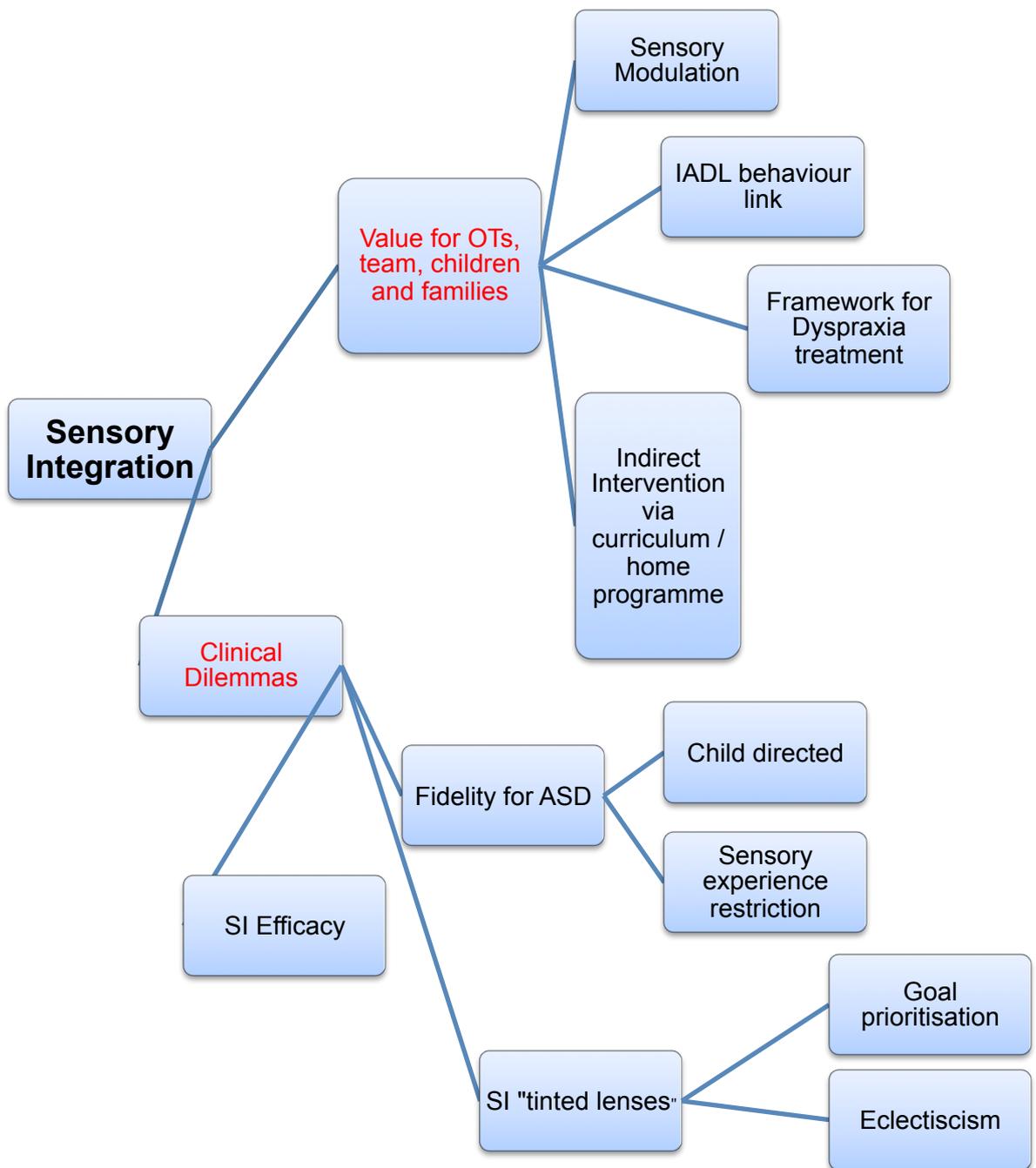


Figure 4.5: Themes and Subthemes in SI as a Frame of reference for ASD

#### 4.2.1.1.1 Subtheme 1: Value of SI For OTs, Team Members, Children and Families

##### 4.2.1.1.1.1 The value of SI as the primary frame of reference for SMD

Nineteen of the twenty participants mentioned SI, as an essential frame of reference, even those who were not certified SI therapists. Whilst non SI trained

OTs are not providing SI treatment in their sessions, they use it as a theoretical model to understand sensory processing difficulties, manage arousal levels, adapt or structure the environment and advise families regarding “sensory diets” and routines.

### ***Sensory processing assessment***

Nineteen participants routinely assessed the sensory processing component in children with ASD. The SP (Dunn, 1999) or informal sensory questionnaire, a sensory history as well as skilled observation was the format for assessing this component.

*A: “...with the informal assessment ...I put sensory first... because a lot of the kids I find have sensory modulation problems...”*

*C: “During those assessments I look at all the sensory aspects as well, so I look at how they register information, I look at what kind of sensory stimuli they can handle, um, I ask Mum ...different questions regarding their sensory system.”*

This is in conformity with American studies, in which sensory processing features strongly in OT assessment (Case-Smith & Miller, 1999; Watling, et al., 1999). OT B who was not SI trained, did not feel that SI was her primary frame of reference. She referenced the behavioural framework primarily, as well as MoCA. However, she did use the SI framework for a basic screening of sensory processing difficulties if the team felt this was an area of concern. Many OTs, felt regulation or modulation is such a large component of the ASD diagnosis, that it becomes a primary focus of intervention.

*G: “... I don't know how you get to just using visual perceptual stuff if the kid is not modulated. I don't know how you'd be using a behavioural approach if the kid is not modulated, so that's why for me, SI ... really none of my autistic kids are modulated.”*

*O: “I do see effects with the more sensory approach with the autistic children... If I look at some of the children that gets referred... because there's a developmental delay, um, the sensory integration role isn't that*

*significant to me...but because of autistic children has such a lot of sensory issues, I definitely see better results with regards to the sensory things..."*

### ***Sensory modulation is the start (intervention)***

Participants indicated that therapy for sensory processing difficulties in ASD, focussed primarily on modulation difficulties. Sensory regulation or modulation was often the starting point of intervention in an individual treatment session. Fifteen of the OTs in thirteen practice settings started therapy sessions focussed on sensory modulation. The emphasis on sensory processing in intervention was also common in American practice (Case-Smith & Miller, 1999; Watling, et al., 1999). Determining arousal levels and modulating levels to attain a calm alert state were deemed key to the success of a session.

*P: "The first thing, I want to regulate the child. "*

*N/T: "...because the sensory difficulties are so prominent in some of the children, that is the focus before we can get to any of the gross motor, fine motor difficulties."*

Not all OTs started sessions with sensory modulation activities. Four (three non SI trained) OTs said that they may or may not start with sensory modulation and gross motor activity, depending on the child's state of regulation at the start of the session. If the child was well modulated, they may start with a desk-top visual perceptual or fine motor task. There remained an awareness of sensory modulation needs, though the session may not have addressed it at the start. In children who were well modulated, one OT commented that the treatment approach is similar to that of children with ADHD, but with greater emphasis on social behaviour and role modelling.

*R: "you'll have a very modulated young boy who comes in, you could be like you're treating a learning disabled child...you're going to do the typical like learning game, uh, educational game with the child..."*

*E: "sometimes in a session I will not do any SI at all...because some of the kids are not so florid..."*

OT B, working with an inpatient population of children with severe impairment levels and co-morbid intellectual impairment, focused on sensory stimulation, skills training and behaviour management. While some aspects of the programme at OT B's institution such as the use of proprioceptive and vestibular stimulation during gross motor activity, resembled SI activities, these were primarily sensory motor in nature and not for sensory integration or modulation purposes. Other non-SI trained OTs may also use sensory motor activities but for a sensory modulation purpose, thus still referencing the SI framework.

Sensory Modulation for the participants, was key to managing a child with ASD. It was typically the starting point of most sessions, and was monitored throughout. It was addressed when necessary, at any point in a session. A modulated state was considered the essential starting point and a gateway to learning and interaction.

Foremost for OTs in the study, was modulation as the catalyst for engaging with the environment and people. It was important to one OT that the children enjoy Sensory Integration Therapy (SIT). This enjoyment sparked motivation, which many OTs struggled to elicit in children with ASD. Enjoyment lends itself to learning and engagement in relationships. The value of SIT in enabling a modulated calm alert state, was important for learning and managing behaviours.

*O: "sensory integration approach has definitely made a huge impact on how he responds to his environment... the Mom could find a difference in terms of how she bonds with him, how she plays with him...she says she can now actually play games with him, take him to the park and she can see he enjoys it. In the past she would take him and come back and there wasn't really...now she can actually say that they have fun together."*

*G: "SI, for me, what I like is that its not imposing anything on the child... and the kids enjoy it...."*

*G: "SI... unlocking that learning... One of the reasons why we've landed up working with them (SLT) so closely, is because of the autistic kids, because they got to a point where they were like, we don't know what to*

*do. They just won't sit down, they're biting me and they're hitting me and then we're like why don't you come down to OT..."*

#### **4.2.1.1.2 The value of Sensory processing in managing IADL**

IADL assessment received only six specific mentions in assessment, despite it being a vital component of occupational assessment in any diagnostic group. IADL was one of the aspects that some of the participants felt was a unique OT contribution, together with OT solutions arrived at through clinical reasoning, activity analysis and team problem solving. In two research studies, fewer difficulties were noted around self-care, with most problems related to oral-motor feeding and hygiene (Case-Smith & Miller, 1999; Watling, et al., 1999).

Surprisingly, the role of sensory sensitivities and processing problems did not feature overtly in the discussion around IADL by participants, but it was implicit. OT P related how the environment was adapted to reduce the tactile discomfort after a hair cut. OT P also used social stories around IADL issues such as mealtimes. Motor planning issues related to IADL received one mention. The role of motor planning difficulties in IADL independence was not raised by other participants directly, but implicit in the discussion around using techniques such as backward chaining for learning dressing tasks.

*P: "we often cut (hair) outside at the pool because then you can dip them in the water afterwards, get rid of the hair..."*

*D: "...definitely ADL. I mean plenty of those parents come with sleeping problems, so you know, there's a lot of discussion around, uh, self-regulation... Feeding, eating... toilet training... lots of understanding of the physiology, and really the registration and motor planning that's involved in toilet training."*

Participants acknowledged, that IADL activities may be restricted in the range of skills practised in therapy sessions. Skills related to dressing and undressing were commonly practised as it was part of the routine of a session such as removing shoes before gross motor play and putting shoes on again after the session. Backward chaining techniques were often used in such dressing/undressing tasks.

One SNS based OT mentioned that she had to make a concerted effort to keep an IADL focus within the overall academic focus of a school OT programme. The particular disadvantage of school settings is that the family focus is not as strong as in settings such as private practice and hospitals. School function becomes the focus in academic settings, rightly so, though IADL of self-care, feeding and dressing may easily be overlooked.

Areas of self-care and hygiene, aspects such as hair washing and nail clipping as well as self care routines, were addressed indirectly through consultation with parents. SIT addresses the de-sensitisation aspect related to difficulties with IADL directly, whilst using a functional and environmental adaptation approach to performance of IADL in the home. The strong link between sensory processing difficulties and IADL is a significant component of parent education and advice for children with ASD. Sensory sensitivities made some IADL tasks unpleasant for children, who demonstrated avoidance or resistant behaviour towards such tasks. This created practical difficulties for families.

*H: "they just cannot understand why they cannot comb their child's hair, or why bath time is such a big fight ..."*

*P: "I often work as a consultant for them. I say give me a functional thing...tell me what you're struggling with, and then I'll spend more time with Mom just analysing, clinical reasoning, how to overcome that functional problem, so if its your daily routine, your morning routine, toileting or whatever, its just to go functional."*

Private practices and hospitals are frequently the first intervention settings, which naturally places emphasis on family coping strategies and difficulties experienced in earlier developmental stages such as feeding, sleeping, toileting and hygiene. The impact of OT intervention and practical sensory strategies on family life routines and activities would feature strongly at this early stage of intervention. IADL has always been seen as the OT role within the team. Sensory strategies, social stories, motor learning techniques, behavioural and SI adaptation of the environment were all strategies used by participants in dealing with IADL. The added benefit of SI theory and practice in deepening parental understanding of such difficulties in children with

ASD is a significant contribution by OT. The depth of understanding of sensory processing difficulties and the link between these and behaviour around IADL is a unique dimension that OT unveils for parents. The role of dyspraxia in delayed independence in IADL is also a significant factor in parental understanding of the impact of ASD on function.

The linking of sensory processing difficulties and challenging behaviours in IADL is pivotal in reframing a parent's understanding of their child. OTs act primarily as consultants on improving independence in IADL. Raising parental awareness on the role of sensory processing difficulties on IADL behaviours is a significant contribution from the profession, drawing on SI theory. OT also provides solutions to improving independence in IADL drawn from many approaches such as environmental, behavioural, AAC, motor learning and SI.

#### **4.2.1.1.3 SI as a valuable framework for dyspraxia intervention**

Praxis (motor planning) was specifically mentioned as a component assessed by six participants, indicating that it should thus form an equally significant part of their intervention, concurring with the significance of praxis in OT intervention for ASD in the literature (Parham & Mailloux, 2010). Five OTs reported praxis to be amongst the unique aspects OTs targeted, thus confirming that praxis would feature in their treatment. Praxis received one specific mention under treatment, but clearly forms an integral part of SI treatment sessions, which challenges a child to produce adaptive responses. Motor planning together with fine motor skills were the most common motor goals in one study (Case-Smith & Miller, 1999), confirming the significance of praxis in ASD intervention.

*G: "...motor planning is quite a big problem in the kids with autism ...kids that ... won't know how to climb on to the trampoline...they don't know how to get on to the platform swing..."*

*M:" just through observation, we often see mostly planning difficulties coming through"*

It is surprising that praxis did not receive a wider mention amongst participants under assessment and treatment sections. Praxis can be a significant source of

disability in learning motor skills and initiating and executing actions (Rogers, et al., 2003). Personally, demystifying praxis together with sensory issues is one of my most significant clinical roles during IEP development and counselling of parents. OT P also raised the role of praxis issues in her parent consultation sessions.

*P: “parents hang on to the word “praxis” because it’s a better diagnosis.”*

*A: “... then I would try and go more into the motor side, challenging their praxis...”*

*P: “I’ve got one child who can’t imitate, so he can’t –(maintain) postural control, I mean he is on that equipment, but he cannot imitate and learn something.”*

Praxis is obviously assessed and treated in sessions but only a handful of OTs singled out praxis as a significant component of their intervention. It is however possible that praxis is less clear or prevalent in children on the spectrum, who are functioning at a more skilled level. This raises the issue of assessment of dyspraxia within sensory modulation disorder in ASD.

### ***Sensory Modulation Dysfunction or Dyspraxia?***

The manifestation of praxis in ASD, was raised by two experienced SI trained OTs. They questioned whether their observations were related to sensory modulation difficulties or “true” praxis. There arises the question of whether dyspraxia can be confused for sensory modulation difficulties or whether SMD effectively masks dyspraxia.

It seems, that younger children or children in initial intervention stages, often present with sensory modulation disorder (SMD) which may mask dyspraxia. SMD affects the child’s ability to interact with the environment, due to sensory overload. SMD may overshadow the real presence of an underlying lack of skilled ability to act on the environment (dyspraxia). Perhaps the presentation of dyspraxia in children who are more skilled is subtle, making it difficult to differentiate between SMD and dyspraxia.

*J: "... that's one of my therapeutic weaknesses. I always see modulation and not praxis... very often autistic children look dyspraxic but it's just that interaction, I think, so its not the true dyspraxia that you see in a sensory integration child."*

*P: "It's (praxis) a hard one to test, because what you find is (in) the younger child – often people call it modulation, and its actually ideational praxis".*

Whilst dyspraxia may present as modulation difficulties in young children in early intervention phases, dyspraxia is most likely still present in most children with ASD (Baranek et al., 2005). SMD may be the commonest manifestation of SI disorders in ASD, but an overlap of SI disorder types is not uncommon. Dyspraxia according to the research on motor skills in ASD can be considered a co-morbid condition (Baranek et al., 2005) . Even children who have good gross motor skills or are higher functioning on the spectrum, may still struggle with motor planning on a fine motor and oral-motor level or in the sequencing of actions (Baranek, 2002).

There may be a lack of awareness as to the nature and presentation of motor skill deficits in ASD amongst clinicians. SI practitioners who treat children with classical SI disorders may lack insight into the extent and presentation of dyspraxia in ASD. As an area that is under researched in ASD, (Baranek et al., 2005) the manifestation, extent and improvement rate of motor skills and dyspraxia across the full range of the spectrum is an avenue for further enquiry. The need to study dyspraxia in ASD, according to the DSM-5 categorised three levels of support, will contribute towards interdisciplinary knowledge on motor skills in ASD as well as guide clinical practice. OT SI provides a framework for dyspraxia research within the profession, which can contribute to the motor skills and imitation studies research from other disciplines.

#### **4.2.1.1.4 Indirect intervention: The value of SI beyond one-on-one therapy**

According to participants, SI was powerful when embedded within school programmes and home routines. It allowed for the adaptation of the environment in

homes and classrooms through managing the sensory properties of lighting, sound and textures. The value of “therapising” the curriculum contributed activities and techniques for teachers in the form of classroom activities and routines. For parents, a sensory diet influenced activities and routines in the home (discussed further under home programmes). The education and awareness around the sensory profiles of the child was useful in managing arousal levels and influencing participation. The power of SI to modulate arousal levels and influence participation, moved beyond the therapy room into homes, classrooms and community spaces when parents and teachers were empowered.

*A: “information, like this is where you can buy a weighted blanket, this is where you can get dark ...colour... like blocking curtains”*

*E: “SI is not just suspended equipment. There’s so many other areas to it, and that you can implement in – you can put into any curriculum ...”*

*F: “I am involved with each teacher, my half-an-hour a week with that child is not good enough, but where I can rather put things...into position, like in the classrooms... let them have the right equipment ...so they get their sensory input...make teachers aware of what is a holistic programme, because I mean they come with their teaching skills but with autism you have to incorporate the sensory...I’ve equipped them to have enough activities for fine motor...gross motor... for following actions. Its my role to adapt ...(curriculum) for the teachers”*

The use of SI in this form of indirect intervention may be its most useful and viable application in the SA context due to limited resources and in keeping with the inclusionary approach of White Paper 6. Indirect SI intervention in the school phase, may be the solution to OT service provision and SI dosage challenges within SNSs.

#### **4.2.1.1.2 Subtheme 2: Clinical Practice Dilemmas**

Whilst Ayres work is being researched and updated, there were practice areas that lacked clarity for clinicians in terms of SI fidelity for ASD, as well as concerns

around SI and efficacy. Another potential area of conflict is a philosophical one related to OT identity.

#### **4.2.1.1.2.1 SI “purists” and fidelity**

The majority of SI trained OTs mentioned that they were not “pure SI” therapists. By this they meant either or both of two things. The first is that their SI sessions were not completely child directed and the second was the use of an eclectic approach in therapy.

Fidelity of SI practice for ASD refers to how true SI practice remains to the principles of the approach. Two aspects of the fidelity measure as designed by Parham (Parham, et al., 2007) were raised in terms of practice for ASD specifically. These were: collaborating in activity choice or Ayres principle of letting the child lead and provision of a sensory rich environment, including elements of tactile, proprioceptive and vestibular stimulation.

*S“...there should be courses on SI in ASD, because those, according to me they are two very different things.”*

#### ***Letting the child lead***

In terms of child directedness, the need for greater structure for a condition such as ASD, led to uncertainty as to whether a session was sensory motor or sensory integration in nature. The key difference was the opportunity for the child to lead play versus being directed as to what activity or equipment he should engage with. Three OTs raised the issue of a conflict between child directedness and the use of visual schedules in a session.

*L/S:” We don’t do pure SI ... because we’re using autism specific (intervention), it kind of contradicts some of the ...(SI principles)... the visual schedule helps...but...(then) they’re (children are) not leading ...”*

*T: “(we use) structure – big one – we use special schedules to sort of show what’s going to happen in a session, we’ve got rule cards, sort (of) for the behaviour that we want...”*

Recommendations in academic texts acknowledge the need for greater structure or directedness for children with ASD (Parham & Mailloux, 2010). It further recommends the use of visual schedules for aiding ideation, concretising a sequence of actions, encouraging initiation, sequencing and completion of tasks. This broad recommendation needs to be expounded in greater detail, as the use of structure in the form of visual schedules can influence child directedness if not managed appropriately. Schedules should allow a child to lead within their capacity by offering visual symbols or photographic choices for choosing equipment and planning the activity sequence. There should be opportunity for some self initiated play or flexibility within components of a schedule and the OT has to consciously attempt to elicit this as opposed to following a rigid structure. Clarity on the use of schedules in SI whilst maintaining fidelity to the principle of collaboration on activity choice is needed.

### ***Sensory experience restriction***

Five OTs specifically mentioned pre-selecting activities or equipment and restricting the type of stimulation available to the child in a session. They found that this restriction, allowed a child to cope and function in a more organised way, especially due to the inability of children with ASD to regulate their input, thus easily tipping into overload. OT I preferred proprioceptive to vestibular input, to start a session, as she perceived it as leading to greater success. Limiting equipment choices however, meant limiting the type and variety of sensory experiences available. A sensory seeking child may love vestibular input, which is less “organising” than proprioceptive input. Yet, removing vestibular equipment may lead to an inability to gauge the child’s true “sensory need”. Further, sensory experience restriction does not meet the fidelity measure, in provision of a sensory rich environment of tactile, proprioceptive and vestibular stimuli.

Perhaps there needs to be greater clarity on what constitutes a sensory rich environment for children with ASD in the literature and whether restriction of sensory experiences falls within the principle of the need for higher levels of structure for ASD.

*C: "I generally follow the child's lead in the session, but often it will be with equipment that I have chosen or materials that we have chosen together as a team..."*

*O: "... am I doing or am I not doing sensory integration because I think I am often giving more structure...than what you would do in a true sensory integration therapy session... because its not that you want to direct the child, its just that you're...trying to give him the containment that he needs to function and as soon as he's able to cope with a bit less structure you will let go and you will allow that child to direct more"*

*A: "Definitely, I don't think I do pure SI, there definitely is structure...and also obviously limiting some of the sensory input because sometimes, like with the vestibular they can get very overloaded..."*

There was uncertainty amongst OTs that use SI in a more structured, less child directed way as to whether it flouts the fidelity measure. The reality that there is limited potential for child directed play in children who are low functioning on the spectrum might not be clearly acknowledged in the literature. This acknowledgement would mean that the use of SI in its classical form for this group of children might have limited clinical value. The heterogeneity of ASD has made the development of specific intervention protocols difficult. Research on sensory subtypes in ASD point to the possibility of tailoring SI intervention to suit each subtype (A. Lane, Dennis, & Geraghty, 2011). The question of the type of child with ASD that would most benefit from a specific type of SI intervention has been raised in the literature and is dependant on further research that can reliably identify sensory processing subtypes or sensory based autism phenotypes (National Research Council, 2001). SI has the flexibility to integrate with other ASD specific approaches, which extends SI's applicability to settings such as SNSs, where eclecticism is commonly practiced.

#### **4.2.1.1.2.2 Efficacy of SI**

The opinions of OTs both SI and non-SI trained were strongly and unequally divided between SI as credible science and the sceptical camp. OT E was sceptical though

she used SI amongst other approaches. The majority of participants concurred with the literature within OT and outside of the profession, critical of SI's small research base. Despite an apparent lack of scientific credibility, most participants believed strongly in SI as an approach (Parham & Mailloux, 2010). OT D believed in and practiced SI, but was critical of its research base and also of its evolution as a theory and model for clinical application.

The lack of research, led OT D to pursue a masters degree in the field of SI. She placed the blame on the SI community or OT profession for its lack of research, the non-exposure of SI to the wider community and keeping it discipline specific, thus limiting the growth of SI as an interdisciplinary model. OT E criticised the absence of concrete measures to assess efficacy. She identified the lack of structure or "concreteness" in SIT as making it less measurable and thus difficult to validate.

*D: "that's why I did my research in SI... I did feel that it was a problem....I also think it's ...the SI community's problem. They didn't...do the research....they also kind of kept it under covers...almost like there was a threat to share it...that's why I feel like I've moved into a much broader context where actually I'd rather work very, very multidisciplinary, trans-disciplinary for the child. Yes, I do think ...that we haven't got enough of a research basis, but actually what I think is that SI is limited."*

*E: "... I've done SI and I've done psych, so I've done a lot of behaviourism – you know you can't dispute that the one is complete and the one is not. So who's to say that it does work... I will use it as a medium like I will use any other medium... with behaviourism its much more concrete. You say this is what I'm going to do... that is the behaviour, its measurable... SI, how measurable is it?"*

The scientific nature of SIT has always come under criticism and continues to provoke debate both within and outside the profession (Parham & Mailloux, 2010). The research base has grown substantially in the recent past, and the introduction of a fidelity measure, manualised protocol and goal attainment scaling instrument is a significant step towards credible future research (Pfeiffer, Koenig, Kinnealey, Sheppard, & Henderson, 2011). One study found preliminary support for SI

interventions in children with ASD, but cited the need for further research (Pfeiffer, et al., 2011). Despite criticism, SI is popular and widely practiced even in South Africa.

#### **4.2.1.1.2.3 “SI Tinted Lenses”**

The viewing of OT through “SI tinted lenses” was a theme that emerged from the data around the prioritisation of goals and the views around eclecticism in OT practice. These two aspects have implications for the identity of OTs and to what extent SI colours their identity and perspective on therapy.

##### ***Prioritisation of goals***

All OTs addressed a number of OT components within a session, though the emphasis or range of components addressed simultaneously varied. Whilst some OTs worked on all areas simultaneously, others have a staged or hierarchical approach to skill development. SI being a neuro-maturation developmental approach, that was viewed hierarchically, has led some SI trained OTs to delay treatment for “end stage” developmental skills until a foundation for these has been established. The most common example that emerged was that of fine motor co-ordination, which was often addressed at a much later stage in therapy by two SI OTs.

*M: “an older client – who age appropriately, should be doing a lot of that (fine motor skills) but he's nowhere near on a sensory level ready to do that ...(in) initial stages in therapy, I really wouldn't even go there... until I felt that the sensory or the postural was at a point that they could manage that.”*

*M: “...the sensory stuff at that point is so key that it makes no sense to be looking at fine motor or gross motor, its really not relevant to the child at that point.”*

*I: “...on the fine motor...I come in more strongly at a later stage of course...its such slow progress on those lines that I tend to then work where there's a little bit quicker results, possibly.”*

For these OTs, there is a greater focus in therapy, on SI components than on functional skills though SI as conceptualised within OT does prioritise function (Parham & Mailloux, 2010). Another SI therapist OT P, is adamant that as OTs we always address the core of our profession, which is function. The functional perspective taken by OT P and E ensures that a child is able to participate in life stage appropriate tasks through adaptation. This shows eclecticism in the application of theoretical frameworks.

Furthermore, the uneven pattern of development in ASD, means that skill development may not occur in predictable stages. The developmental framework may be more functional in terms of working at a child's level in all areas to achieve age appropriate expectations (Kramer & Hinojosa, 2010a). In the opinion of OT E, there is a real danger of holding back the child's development in following an approach that is sequential in nature. The argument is that the window of opportunity in early intervention must be seized to full effect by working on all areas simultaneously.

*E: "On the other hand, what worries me – I'm talking from a realistic point of view now ...So if you're going to go the ideal route of yes I'm going to do six months of SI then I will handle fine motor and gross motor, by which time that child who was already developmentally two years behind, is now three years behind. You've lost valuable time."*

*P: "we're so busy treating...the underlying cause but you forget about the kid's... functional side. And sometimes you've actually got to give them functional skill training to cope, and the methods to overcome it, and then you can work on the processes later on– so first you've got to teach the child to do something and then you'll develop the process later on. Just for that family to cope. "*

Goal prioritisation according to a theoretical bias, clashes with a family focussed intervention approach that values family priorities. OTs need to be aware of the danger of viewing intervention through SI lenses as opposed to a more holistic OT and family focussed intervention lens. A holistic approach would balance the various frameworks and ideally adopt a family and function focussed approach.

### ***Eclecticism and SI***

Two participants alluded to the use of an eclectic approach as “not pure SI”. An eclectic approach is considered best practice (Case-Smith & Miller, 1999). The majority of OTs acknowledged the use of multiple theoretical frameworks in practice and agreed on the value of eclecticism. Yet there may still be a tendency to view themselves as “SI therapists” as opposed to “OTs with SI training”. OT is more than SI, and retaining the occupation focus is critical to one’s professional identity as occupational therapists. OT P’s statement is an indication of how strong the identity of “SI therapist” can become, potentially overpowering that of an occupational therapist. It exposes a possible vulnerability of SI OTs to adopt an exclusivist or predominantly SI approach, identifying themselves as “sensory integration therapists”, not occupational therapists, trivialising the holistic identity of OT.

*P: “ I would say my ethos is SI approach, but no, no, its OT – I’m an OT, its an OT approach...”*

*Q: “a competent therapist... it will be a wise thing that you mix them (frameworks), because if ...you’re just going to follow SI, then there’s a lot that you’re going to miss.”*

A tendency to view OT through “SI tinted lenses” can lead to an over focus on some aspects of intervention, ignoring client needs appropriate to the phase of intervention. It may result in a less functional approach or lead to the clouding of important goals due to perceived SI priorities. SI should be practiced with other approaches that are evidence based, as SI is yet to prove its efficacy. There is a need to integrate SI with ASD specific approaches, within a comprehensive approach.

*L: “And then there’s the problem with the school setting versus the private setting...in the private setting they’re not using a lot of TEACCH, MAKATON because they don’t know about it really...and children who are going to private OT and getting the SI...(its) not necessarily autism specific ... its just then the SI”*

### ***Conclusion on SI as a theoretical framework***

Robust engagement with the SI theoretical model is important for growth. SI theory is dynamic and being revised as new research findings emerge. As a young model, research is advancing though practice, which seems to have outstripped the pace of research. OTs in practice may not be aware of the latest academic research and theoretical debates. Keeping up to date on the latest research and developments in the field of SI is less likely amongst OTs outside academia. Some of the criticisms above may be unfounded or a tad harsh. Nevertheless they represent opinions of OTs in the field and need to be addressed on a professional practice level.

OT professional bodies need to present both sides of the SI efficacy debate as well as opportunities to pursue continuous professional development in this area. The need to bridge academia and clinical practice seems particularly relevant for SI for ASD.

#### **4.2.1.2 THE DEVELOPMENTAL FRAMEWORK**

Ten OTs (half the participants) specifically mentioned a developmental approach, though all therapists probably referenced it. Even OTs with a strong SI focus, would utilise the developmental framework for assessing and treating gross and fine motor skills in particular. It was also the second most referenced framework after SI, by American OTs (Watling, et al., 1999). SI is housed within the broad scope of a developmental framework, though here, developmental refers to normative milestones as guidelines for assessment and intervention. Thus, the developmental approach is easily blended with the SI approach. One may have expected a stronger mention of this framework, seeing as ASD is classified as a developmental disorder.

A developmental approach to treatment is systematic, clear cut and accessible for therapists and parents alike. Measurable goals, makes this approach scientifically credible and easy to research. OT E in response to the question of what successful intervention is, responded:

*E: “ Developmental approach...Look, it is measurable. I think I always lean towards what is measurable, what is concrete...”*

*I: "its more your developmental frameworks that I go with, and I... can't emphasise it enough that that's what... I like..."*

*R: "developmental ...because... you've just got to meet them where they are, so your assessment is not about judging them according to norms and standardised tests, its judging them where they're at, and where do I take them next."*

A criticism of the developmental approach raised by Participant C, is that it is not always a perfect fit. Atypical development is common in ASD. Uneven developmental profiles can be confusing for parents and lead to unrealistic expectations. Nevertheless, it is a valuable framework for training parents and caregivers. The advantage of this approach for professionals is its common sense step-by-step nature. This makes it accessible to newly qualified OTs and it is also used across the professional spectrum forming a common, mutually understood framework for the team.

#### **4.2.1.3 THE BEHAVIOURAL FRAMEWORK**

Four OTs mentioned using a behavioural approach, in applying principles of behaviour modification and positive behavioural support (PBS). Key principles of SI conflict with the behavioural approach, which explains why so few SI OTs considered the approach as a guide to intervention. Some OTs mentioned using principles of the approach, which is probably a realistic representation of the practice of all participants.

*J: "very often because the kids have been in ABA, then we've used some of that"*

Applied Behavioural Analysis (ABA) seemed to be the form of behavioural therapy that most OTs were aware of, or had exposure to. Four OTs admitted not having enough knowledge of ABA to comment in a balanced way, admitting possible bias. Others acknowledged ignorance of the approach, but offered opinions that were openly critical or negative.

Negative comments were centred on aspects of the behavioural philosophy that they disagreed with. These opinions were that the approach is opposed to those of SI and DIRFloortime, in that it is therapist driven and not child centred. ABA restricted thinking and did not allow for the display of intent on the part of the child. ABA was extreme conditioning, which developed splinter skills that had little value in the real world. Skills drilled in ABA sessions were not generalised across contexts. One OT felt that goals set by ABA were unrealistic and would not be achieved within the allocated time frames. The majority felt that ABA ignored sensory regulation, which is a crucial aspect OTs address in the learning context within an SI framework. The high cost of individual, one on one ABA therapy and its affordability for most South Africans was also raised.

*P: "there's a difference between teach and experience...and that is where your Floortime and SI comes in, its about experiencing. I call it a process ...you will learn more if you work it out yourself than if someone shows you how to do it."*

*E: "I don't know enough about it... so I might be a bit biased, but from my understanding, its very mechanical, its very situation specific and it's a lot of drilling. For me its extreme conditioning...my general feeling with something like that is... how much can a child generalise to other situations."*

*J: "ABA goes against everything in me as an SI therapist. I mean it just kills me if I watch a child doing ABA, especially if they haven't looked at the regulatory state of the child, and that's how I got into autism ..."*

*E: "how does one justify the number of hours in manpower for one child... It does not make sense to me"*

A few OTs had experiences of team meetings where clashing approaches were advocated. Two OTs experienced difficulty in working with a child who was undergoing SI and ABA therapy simultaneously. SI philosophy is fiercely child directed, relying upon initiation from the child versus ABA 's stimulus response

based approach. One OT had more positive experiences working with a facilitator who used a more naturalistic behavioural approach.

*I: "I've got one little girl... she's been so hammered with ABA that ...she's just a little robot... so I know some therapists won't work if the two theories are so in – so clashing – but yes, I do work with her ...and her Mom has suddenly stopped ABA a bit and gone with the developmental framework."*

*J: "...naturalistic therapist– I feel I can work in that environment, and we work together. We've actually had joint sessions together"*

The importance of understanding or acknowledging the sensory basis for challenging behaviour embodies the OT SI philosophy. This philosophy can co-exist with behavioural principles, provided that there is always the awareness and acknowledgement of sensory processing difficulties and their subsequent impact on behaviour (Katz & Brodrick, 2013). Most OT s acknowledged using general behaviour principles in sessions, such as setting boundaries, use of reward systems, positive reinforcement, consistency, modelling social behaviour and understanding the role of contextual or setting events.

*P: "I believe in discipline, I believe in consequences and I believe in being firm and setting boundaries, but I believe in understanding the behaviour."*

*B: "behaviour modification is another aspect we really focus on because a lot of these kids have behavioural difficulties and parents are unable to deal with their behaviour. ...OT has a major... role in that..."*

A few OTs were more accommodating, whilst admitting that they were not that knowledgeable. They acknowledged that ABA had a place in ASD intervention, like other approaches. It may even be complementary to an OT-SI approach, as the ABA approach has high levels of structure, while SI has low levels of structure. This allowed the child to benefit from both levels of structure and gain flexibility. Two SI OTs acknowledged the value of ABA in getting compliance behaviour, which is an important first skill for learning.

*G: “nearly all of our kids who are attending therapy here are part of the ABA (online) programme’. I personally like it (ABA parent home programme), just because it’s ... empowering the parent... giving the parent their own strategies and their own way of handling the child. I was also a little bit sceptical at first, but that’s because I didn’t know much about ABA, but... I see gaps in the SI treatment ...I see gaps that ...only ...someone with a behavioural approach, that kind of knowledge, can fill ...SI I sometimes feel that its too unstructured ...I think they can work well to complement each other.”*

*P: “However, it does sometimes get control of the child... but you haven’t sorted out the process.”*

*J: “that rigid way, for the autistic child that has got no organisation, it may be a good starting point, and I’ve seen it...he just performs”*

The behavioural approach is a significant and relevant presence in the field of ASD. Information and awareness of the approach will contribute to a better understanding of its value and application by OTs within a comprehensive integrated programme for the child. A blended or eclectic approach allows OTs to borrow useful strategies from the behavioural approach whilst remaining true to OT philosophy.

#### **4.2.1.4 NEURO-DEVELOPMENTAL THERAPY (NDT)**

Four mentioned using an NDT approach for physical components like postural control as well as stretching tight tendons that resulted from toe walking. NDT correlates highly with SI as an approach. The application of SI based proprioceptive techniques correlate with those of NDT. Its value is limited to the physical components of ASD.

#### **4.2.1.5 VONA du TOIT MODEL OF CREATIVE ABILITY (MoCA)**

An unexpected theoretical framework referenced by three OTs was the Model of Creative Ability (MoCA), developed by South African OT Vona du Toit. OTs in all three sectors used the model as an assessment and treatment planning guide.

Two OTs found value in treatment planning for children on the spectrum. OT B was working in a psychiatric setting, where this model is well represented in South Africa. She used the model's guide for activity selection and presentation according to the child's level of creative ability. The other OT has a paediatric private practice, where application of the model is unlikely to be the norm. The third OT was keen to revisit its use in her SNS setting.

*B: "it (MoCA) tells you the child on what level they are at ... (which allows you to) pitch activities (at the right level), because it... gives you a guideline in terms of...how you can present activities to them..."*

*I: "creative participation (MoCA) will be a framework ... that I'm using more of... I think that's a definite very useful, (approach)"*

*F: "I think levels of creative ability definitely... because (of) their (its) functionality"*

MoCA 's application in an SNS and PP, is in line with its current vision of application to diverse conditions. As a SA model, it presents exciting opportunities for application to paediatrics. The similarity of SI and MoCA as frames of reference and their combined use in paediatric therapy has been explored in a recent SA publication (van Rensberg, 2013). MoCA's applicability to ASD is an avenue for further research, regarding its clinical value for assessment of creative ability levels and its graded treatment guide, especially as it targets motivation and social participation, which are deficits in ASD.

#### **4.2.1.6 DIRFloortime (Greenspan, DeGangi, Wieder, 2001)**

Three OTs indicated the use of DIRFloortime as an important framework for assessment and intervention. Five OTs were at various stages in training, with OT D at the most advanced level of training. OT D felt that DIRFloortime was her main frame of reference together with SI. OTs M and P also used techniques of the approach, blending them with SI. OT P even used the term "SI-DIRFloortime" to describe her therapy.

*P: "SI is there and floor time is there."*

OT D described how SI and DIRFloortime are so closely linked and how the approaches were integrated within sessions. This concurs with the literature that OTs viewed SI and DIRFloortime to be compatible approaches (Case-Smith & Miller, 1999). OT P found that for the purposes of parent coaching, she needed to separate the techniques of SI and DIRFloortime. She found value in DIRFloortime's facilitation of parent child interaction, and preferred DIRFloortime play to any other home programme format, even SI.

*D: "if the child is really still functioning at three levels of emotional development, so if they're at a stage of self-regulation, facilitating engagement and really working on non-verbal communication, um, I think that the whole child-directed approach is critical and one uses a lot of sensory motor, a lot of rough and tumble, lots of, um, physicality in the sessions and so the SI is really, really useful to get to self-regulation..."*

*P: "I'm actually having a separate session once a month on Floortime with the Mom, because they get confused. Because we go between our techniques... its empowered the parent... it helps the parent develop their relationship"*

OT D felt that DIRFloortime *"is very applicable to public health"*. DIRFloortime is a transdisciplinary approach, which has value for SA in terms of providing comprehensive intervention through a single therapist. An OT using DIRFloortime can fulfil the roles of a number of professionals by targeting many areas of development in a holistic and integrated manner. In the private sector, it also has economic benefits of reducing the need for multiple therapists. There is a danger however, of not referring to other professionals when using this approach.

*D: "I've moved into a much broader context where actually I'd rather work very, very multidisciplinary, trans-disciplinary for the child...we 'v got a couple of children from lower socio-economic families... and there we very much work in a trans-disciplinary way, so one therapist..."*

It is an intensive one on one approach with potential to train parents to provide intervention. DIRFloortime training may be a means of providing access to therapy for more families in SA.

#### **4.2.1.7 ALTERNATIVE AND AUGMENTATIVE COMMUNICATION (AAC)**

The use of iPads as a therapy tool or communication device was not utilised much by OTs. If children are using iPads as communication devices, these were not always brought along to OT sessions in one SNS. OT A in private practice, made use of a child's iPad communication app "verbal victor" to promote communication and participation in therapy sessions. iPads and similar AAC technology devices are expensive and not affordable to most clients using public health and many in government SNS services.

*A: "...the iPad – to make decisions and be active with the session...I want that motivation from him, so that's why its been more on a communication level...(you can adapt the programme to say) I want the horse-swing..."*

*C: "We've got a few children...we know will fly with iPads, but ...resources don't allow us to do that...its sustainable in therapy but its not sustainable for our care givers at all. Because to use...any sort of technology in therapy is ... of no benefit, if they don't have it at home."*

An innovative solution is the use of mobile phones, which most South Africans own. Line drawings is another useful "no technology tool". Signing systems such as Makaton and Tiny Hands are formal systems of signing, which three OTs in SNS have trained on. A few OTs, three in hospitals and one in PP used gesturing to augment communication. Makaton signing was used in three SNSs. PECS was used on a limited or needs basis across sectors in nine settings (two PP, three SNS, four H).

*C: "...suggested to parents with children... that are having much difficulty adjusting to us in our environment, is ...to take a photo of us and then before they come just to show them that, so we try and use the cell phone."*

*G: "we've used... photographs (for) making choices"*

*K: "I'll draw little pictures on a board and then once we've completed the activity we can take it off"*

*C: "We use the PECS system quite often in a therapy session... the speech therapist...will go and make the pictures necessary for the activity... so that we can work jointly together."*

Visual schedules were used in four SNSs, four H and four PP settings. Two hospitals used them most with the in-patient programmes. In all SNSs it was used in the classrooms, but not necessarily in OT. Less than ten OTs used it in therapy to choose activities and to aid communication of expectations as well as to aid transitions. Apart from picture communication symbols, line drawings and cell phones were also used to develop timetables or sequenced steps of a task. The use of photographs for visual schedules was common.

*G: " we started using a visual schedule in therapy..."*

*A: "I've done shoelaces (using)... photos, and backward chaining."*

*M: " visual timetables work very well...we sometimes use it in therapy to plan a session, so we've taken photographs of all the different equipment... first we're going to do this and then that, or which of these would you like to do and then form a step-by-step activity for them where they know what's coming next or they know when its finishing so that definitely works very well"*

#### **4.2.1.8 SOCIAL STORIES**

OTs were aware of social stories as a strategy, often initiated and used by other team members such as teachers or parents. These members usually wrote the social story and implemented it as a strategy. Six OTs (one in hospital, two in SNS and three in PP) were directly involved with social stories as a strategy, teaming with other members for writing and implementation of the story. Some OTs perceived social stories to be for high functioning children only.

*F: “then together (teacher and OT) we’ll write a social story and work on it...”*

*P:”... I will give the parent the outline, but they do (write) it.”*

### **Conclusion on frameworks guiding intervention**

In summary, a number of frameworks guided intervention, usually simultaneously. The clinicians’ perspectives on the value of a framework including its drawbacks, was discussed. OTs appreciated the value of most approaches but did not raise the notion of some approaches assuming more significance, especially with regard to the developmental stage of a child’s life. Eclectic intervention was evident in the practice of all the OTs, though not all OTs utilised ASD specific intervention.

### **4.2.2 PRINCIPLES GUIDING INTERVENTION**

OTs in the study, were asked what they considered to be successful intervention for a child with ASD. OT perspectives on successful intervention were analysed within the framework of international best practice guidelines and evidence-based practice (EBP) (Case-Smith, 2010) as discussed on pages 58/59. Collectively, many elements of best practice were evident in the reflections of what successful intervention meant for OTs themselves, the children and their families. The following points arose, under each of which discussion will follow, preceded by the appropriate guideline recommendation (Case-Smith, 2010).

- Early and Intensive intervention
- An Individualised programme that is developmentally appropriate, targeting core deficits together with the use of visual supports
- Measurable treatment and meeting goals within realistic time frames
- An Eclectic and Holistic approach to treatment, utilising the multidisciplinary team
- Intervention is long term with treatment appropriate to a child’s life stages
- Intervention should facilitate family life

#### **4.2.2.1 Early detection and early intensive intervention**

*Guideline: intervention needs to be intensive (many hours per week over a period of time) as well as comprehensive utilising multiple approaches (direct as well as indirect intervention within a multidisciplinary team).* The importance of early diagnosis was raised together with the importance of early and intensive therapy. Participants considered early and intensive intervention to be ideal. Early detection was raised by OT M as key to early intervention. The issue of dosage intensity is discussed under service provision. Involving the full team necessary can also aid intensity of intervention. A group private practice (OT D) recommended twice weekly OT and SLT sessions with their children in addition to sessions with the psychologist and other intervention such as ASD specific schooling. The involvement of the full team is addressed under further under another point below.

*D: “start as early as possible...”*

*M: “we’re restricted because of the financial side...if parents...could tap into a fund, that would allow them to have unlimited therapy... because we just see such amazing progress when the children can come for more than one session a week.”*

#### **4.2.2.2 An Individualised programme that is developmentally appropriate, ASD specific, targeting core deficits together with the use of visual supports**

*Guideline: an assessment and intervention plan that is individualised and specific to that child.* Individualised programmes are based on an assessment of the child’s level of ability in all developmental areas. Comments were that an individualised programme is unique to that child and specific in its use of approaches developed for ASD. The programme for each child should be individually tailored and reviewed frequently to ensure relevance. Awareness of a child’s sensory profile was an important part of the individualised component for OT F. ASD specific intervention, utilised visual supports that have proven successful in approaches such as TEACCH and AAC. OTs recommended that the team intervention approach should integrate a number of approaches and be ASD specific. Success was seen as the improvement of core deficit areas of social interaction, communication and

behaviour as well as daily life skills. The need to update the programme regularly to keep pace with improvements was also important (OT D).

*F: “an individualised programme for each child, um, coming in exactly at the level of the child, for each individual area of learning... bringing in fun and enjoyment in it so that the social side and the communication side can be developed at the same time... knowing whether your child is sensory dormant, sensory sensitive and making sure that you have a specific, – not (only) SI specific but...its not just an overall programme that you take, its got to be (ASD) specific.”*

*R: “developmental aims, not zoning into one, looking at the child as a whole and not ignoring certain aspects ...every child is different... its not a recipe. There’s no recipe.”*

*D: “...tailoring the programme to the child’s needs and constantly changing it”*

*L/J: “ you’re...using a lot of approaches... But then its always autism specific... using...TEACCH...or the visual schedules...MAKATON ... them being in the school (ASD specific)... I think really produces the most success.”*

*K: “...more two-way communication, seeing an improvement in play... is he improving in aspects that are going... to be more functional...”*

#### **4.2.2.3 Measurable treatment, meeting goals within realistic time frames**

The developmental approach is synonymous with successful intervention for OT E, as it is a measurable approach. The importance of realistic goals and realistic time frames to achieve set goals was evident in responses. Goals may take longer to achieve than in neuro-typical children and the importance of persistence was raised.

*D: “Developmental approach. Look, it is measurable...I always lean towards what is measurable...”*

Q: *"I do not look for a big change, because I know that it will never come quick...to see a big change it can take a year, so I always look for the small thing(s) and... highlight it to the Mum"*

N: *"persistence, like persevering... because sometimes even though it seems like nothing is being taken in, one day you get...a surprise"*

#### **4.2.2.4 An eclectic and holistic approach to treatment, utilising the multidisciplinary team**

*Guideline: ...intervention needs to be comprehensive utilising multiple approaches (direct as well as indirect intervention within a multidisciplinary team. (Case-Smith,2010) OTs across all three sectors advocated for the importance of eclecticism in OT and in the general ASD intervention programme.*

P: *"There's no one answer in the approach...and there's no one technique...there's a whole list."*

G: *"...the nature of the work means that you have to be recruiting different areas of knowledge and speciality – just for your one treatment"*

N/T: *"A multidisciplinary approach...the way we use a combination of interventions and strategies"*

Involvement of all necessary team members, both medical and non-medical ensured that intervention was comprehensive and holistic. Holistic intervention for OT A, meant seeing the human being within the diagnosis of ASD.

M: *"hooking them up with other professionals...if they haven't had speech identified, or maybe they need play therapy, family therapy... or even... nutritional things... a support system"*

D: *"...involve the whole team"*

A: *"Yes, it is clouding a lot of the other things about their child, but it is a part of their child. There is other things that he's really good at...because often they focus on autism and that's it."*

#### **4.2.2.5 Intervention is long term with treatment appropriate to a child's life stages**

OT E spoke of therapy that should be tailored to age specific roles and tasks across the child's lifespan. The issue of school occupation goals taking precedence over therapy type clinical goals was raised by OT S. OT I was able to provide solutions to the challenge that new life stages posed for the child and family.

*E: "its lifelong therapy...at different stages in their lives, they have different challenges, so therapy is always indicated."*

*S: "our frame of mind going in is not education-based enough... with those goals..."*

*I: "now that he's older the demands are possibly, different...as OTs we always come up with new ideas because the Mum said to me" two years ago you said you haven't got new ideas and you're still coming up with new ideas", so I think ...our training and our makeup makes us, inventive, or you know resourceful."*

#### **4.2.2.6 Intervention should facilitate family life**

*Guideline: family centred intervention including education and support for families (Case-Smith,2010) .Facilitation of family life appeared under the following sub-themes:*

*Intervention should facilitate family life through greater independence in IADL and participation in occupations*

Improved levels of independence in routine activities, engagement in life stage appropriate occupations, such as schooling or play relieved families of a greater burden of care. Participants considered the following important for families.

*A: "to get them functional, whatever that means for that child...to try and get them into some form of schooling."*

*J: "...the Mom said that was the first time ever she could sit and have a cup of tea and watch her child play."*

*G: "we can look at the fine motor skill, we can look at the gross motor skills, but the most important thing is to get these kids to be as independent as they can possibly be..."*

*L/S: "when you hear about the small things and you see that they – the family coping better...I can take my child shopping...I don't have to feed them any more, you know."*

#### **4.2.2.7 Success is seen as parents who are their child's best advocate**

Participants viewed the process of empowerment as, imparting knowledge and empowering parents with strategies and skills to become therapeutic agents for the child within and outside the home.

*C: "when you get the parent to fight back... the parent buys into your intervention and then carries over your therapy into their home environment"*

*G: "I think successful intervention would be happy parents...empowered parents "*

#### **4.2.2.8 Long term and everyday coping strategies for families facilitates daily routines.**

OTs found that enabling parental understanding of the sensory modulation and behaviour link, was the key to de-mystifying and humanising ASD for parents. It facilitated the parent child relationship, which made family life easier. The role of sensory processing strategies in managing these routines was mentioned.

*M: "to make sense of the child's problems to the parents...a lot of the parents 'oh if I'd only known that's what he needed and he wasn't jumping or banging his head because ... he was naughty, if I'd just understood' ...for me, that's the most important thing, is to make sense of that child for that parent and to be able to empower them to meet their*

*child's sensory needs in an appropriate way...they get a lot of flak from family...not really understanding especially before they're diagnosed..."*

*A: "... contact with Mom is so important (reassure her that) she is doing the best, and also de-mystifying autism"*

*J: "I see myself as being successful if the parent starts enjoying their child...these poor parents have got so little that they can do with their child or enjoy with their child....the one child... they couldn't go to the beach together... and to be the person that helps that child feel better... and then give the parents some strategies so that they can have a family outing together."*

#### **4.2.2.9 A family occupation focus**

OTs in the study, were aware of their family focussed holistic role in enabling occupation of family members and not just the child. Parents needed support to cope with their daily routines and facilitation of joint parent child routines was also important.

*J: "ultimately my success (lies) in what I try and do for the parents...(and) that they can do things with their child..."*

*P: " Functional occupation performance in everyday life, and not only occupational performance of the child but the parents. Because you often look at the parents' routine...you've got to support them in their routine... just to be able to cope with the child."*

#### **4.2.2.10 A family-centred service philosophy**

The importance of a holistic approach was close to the heart of the OTs, who considered OT to be one such approach. For some OTs, the parents were considered to be the team leaders who made the decisions for their child. OTs viewed family goals as important, reflecting a family centred approach to intervention. An important aspect of a family centred approach for OT P, was understanding the uniqueness of that family unit.

*P: "the family is the most important in relationships... I go with the parents where they are. If they want to go into a technique, even if I don't agree, I'll support them... on their path..."*

*G: "it just depends on what the child specific (level is) – what their parents think is most important... we try and... set a goal with Mum."*

*P: "We sometimes don't look at people's beliefs enough and their ethos - their family set-up. The family – what's their culture..."*

The OTs covered four of the six guideline recommendation of Case-Smith in her chapter on evidence based practice (Case-Smith, 2010). Points that were not specifically covered under successful intervention were promotion of skill generalisation across contexts and that intervention should actively engage the child in meaningful activity through choice, motivating activities and natural reinforcers.

#### **4.2.3 SERVICE PROVISION MODELS**

These will be discussed according to patterns in the three sectors. Apart from the most common individual one on one and small group therapy sessions, intensive block therapy and co-treatment were used. OT dosage will be discussed together with service provision models.

Table 4.2: Service Provision Models across Sectors

	Private Practice	Hospitals	NGO (Community based)	SNS Private (School based Private practice )	SNS (Government)
One on one individual	X	X	X	X	X
One on one and Small group sessions or paired	X		X	X	X
Group sessions only					X
Intensive block therapy	X	X	X		
Co-Treatment (OT/SLT)		X	X		X

#### 4.2.3.1 Private Practice

*Individual therapy* is the primary form of intervention for all private practice OTs. As OT K infers below, it is the expected format for services in PP.

*K: “in certain settings... people are more open to try different approaches, but ...in your private practice setting...it’s one-on-one.”*

A few OTs utilised opportunities for social skills interaction, by pairing two children. This is usually done via an overlap of two consecutive children’s sessions. For one private practice based at an SNS (private), group sessions for gross motor activities occurred regularly. Only one OT in private practice ran small groups using the Alert Programme to raise self-awareness and teach management strategies for sensory

modulation. The opportunity for intensive block scheduling of OT does present itself in the private practice setting, but was dependant on parent's financial resources. One OT reported having used intensive block therapy.

*P: "Intensive – I've only done them twice...it was every day for an hour.*

#### **4.2.3.2 Hospitals**

*Individual therapy* was most common, with some *co-treatment* or paired OT and SLT sessions. Four of the six hospital OTs, partnered with SLTs to co-treat some children. One hospital ran stimulation groups, which some children with ASD were able to join. A SA study raised the issue of infrequent dosage in public health and called for investigation into the viability of "short term intensive outreach services" (Hooper, 2009). Two hospitals experimented with *intensive block therapy*, which is regular intervention for six weeks followed by less regular therapy. Intensive block therapy worked well for families who could afford the time and the cost of a weekly commute. However the cost of frequent commutes to the hospital was not affordable to most families. This hampered the viability of intensive block therapy in public hospitals. Sufficient human resources, was also a factor impacting on effective service provision.

*C: The consistency... it's a better reinforcement, I think...parents are not overwhelmed. You don't give them as much in one session to take home. There's lots of positive reinforcement going and it works much better, you see much more improvement..."*

*Q: "we told the parent we're going to see them intensively for six weeks, they might come the first, second or the third week, after that they might just not pitch because... they... work... so it's a day off."*

*C: "we offer parents the opportunity to come for six weeks in a row for block therapy, so we see them once a week for six weeks...(then they go back to monthly therapy sessions), so parents that are not working or can afford to come – unfortunately its very few – come for the six week period.... But we do not have enough staffing and resources to do that for every child"*

Commuter costs raises the issue of where services are located. Locating services within communities reduces the need for regular travel. The costly commute to hospital is then reserved for less frequent medical visits, not therapy and support services. However, this does not solve the problem of human resources needed to staff community health centres.

*Q: “the parents financially they actually can’t afford (it)...remember we’re not a hospital that is actually close to the community...so to come here a number of them have to use two taxis, if not three”*

#### **4.2.3.3 SNS Government**

School OTs commonly used *group therapy* to reach all pupils within the school who needed intervention, as *individual therapy* was not possible for all children. All school OTs commented that they would like to do more one on one intervention, but were constrained by time and human resources. SNSs typically ran a combination of groups and individual sessions, with pupils receiving either or both forms of OT. Pupils were screened according to need or priority of need, so not all pupils received OT.

*S: “you’re going to prioritise a child with severe sensory and behavioural issues over a child who is functioning well but they are not writing...the ones who are disruptive in the class ...we unfortunately, do prioritise them”*

OT F empowered teachers to run sensory stimulation and fine motor groups with their classes, which is a form of *indirect group therapy*. Using strategies of skills transference and role release, she enabled “therapisation” of the curriculum.

“Therapisation” of the curriculum embeds components of an OT sensory and developmental programme into the regular class routine. Developing such class programmes has been hailed as the solution to service provision dilemmas apart from its value in successful outcomes for the children (Struthers, 2005). Developing programmes for teachers to implement should not be seen as adding to the burden of teachers, but embedding therapeutic elements within activities and routines. “Therapisation” may occur due to long term exposure to therapy and informal

collaboration, as opposed to a conscious policy shift towards greater indirect intervention in lieu of direct services. Class based interventions that moved therapy from OT to the classroom in line with inclusionary principles was in the early stages of being practised in some SNSs.

*S: "We want to support the learning environment, because that's what the school's about. We're setting up a lot of programmes. it's the plan... that we will do as little as possible individual um, therapy, but more class-based um interventions"*

*E: "You know what for me would be the most crucial indirect training, that is almost akin to therapy, is that the OTs can get into those schools and rewrite the curriculum. So if you put all of that into a curriculum...and then you top that up with your individual therapy."*

*R: "they (teachers) just integrate principles and ideas- you walk into the classrooms and then it might look just like a therapy (session)... teachers that have been so therapised...they also expect ...even more new things. As OT that's a huge role, is thinking new ways, innovative, creation – because...therapy s been here for so long."*

#### **4.2.3.4 NGO Community Centre**

A combination of *individual and group therapy* was offered in this setting. Groups were conducted by one or two therapists. The OT for example ran a sensory group. The groups served an additional purpose of relieving the child and therapists from individual therapy for a short while. The child would move between individual and group therapy similar to the concept of intensive block therapy.

*K: "...at the baby therapy centre ... we used to run small groups with the Mums ...it was run by on OT and a speech therapist."*

#### **4.2.3.5 SNS Private**

In one school, *individual sessions* were provided due to parents paying fees for contact time. The private health care cost structure and school ethos are likely to

influence the service provision models at private institutions. The school was not keen on OT K doing group work.

*K: “because of the kind of setting that I’m in – I’m still very much the outsider that comes in and does my little thing and goes home, and not necessarily integrated into the whole programme.”*

In two other private SNSs, *group therapy* occurred for visual perceptual, fine and gross motor groups in addition to *individual sessions*. Groups occurred within a social milieu, which was especially important for children with ASD to develop their social skills. Groups occurred in the classroom or in OT. The value of working in the classrooms is described in the quotes that follow:

*E: “Look, in private, one-on-one in any situation is so much more preferable than group, but with the autism kids...the group is there for a therapeutic reason – you want the interaction in a situation of two...”*

*E: “ideally, a session in which you’re in the classroom with them, because then you can look at the impact of sensory issues and all other issues in terms of general functioning where modulation really has to be attacked.”*

#### **4.2.3.2 CO-TREATMENT BETWEEN OT AND SLT**

A number of OTs partner with SLT in *co-treatment* of a child during a session. This occurred in four of six hospitals and one SNS. These OT/SLT partnerships extended from assessment through to treatment. This did not imply that all sessions were co-treatment sessions. Co-treatment occurred for a number of reasons:

- sensory regulation for successful SLT sessions
- difficult to manage children where two therapists were better than one
- mentoring, where one therapist who was experienced in the field, guided the less experienced therapist.

Co-treatment often occurred at the start of therapy, when sensory issues needed addressing. As sensory processing improved over time, services reverted to individual OT and SLT sessions.

*O: "if we really have a difficult patient then we'll treat together".*

*G: "... we do get to a point where we feel that once the modulation improves we separate the two (OT and SLT)."*

The success of co-treatment depended heavily on an excellent working relationship between OT and SLT. While co-treatment is more likely in SNS and hospital settings, it was also possible within group practices in the private sector (OT D). Co-treatment was seen as valuable for the children and for the OTs themselves.

*G: "...so we always work together... There was a speech therapist that I worked really well with for the first half of the year, but then she left...so now its adjusting to new therapists and the way they work."*

*D:"I have worked with an OT and a speech, but...we haven't quite got it right yet, to be honest. I think our speech therapist at the moment is maybe too, still a bit too behaviour orientated... somehow we're not quite on the same page."*

The possible advantage or disadvantage of combined OT- SLT sessions may be the time and human resource factor. The question of whether co-treatment saves time or not may depend on ones therapeutic philosophy and the ability to work together as a team. A combined therapy session that is well planned, should allow for the achievement of both SLT and OT goals within the session. If SLT and OT did not occur on the same hospital visit, combined sessions saves time and money for the family. The human resource disadvantage is that two therapists are treating one child in the time each could be seeing two children, in hospitals with long waiting lists.

*E: "I never co-treat because of time constraints. You can co-treat, it's a wonderful idea, but if you have unlimited amounts of money and time, its beautiful, its an ideal setting but, realistically, I don't think its an option."*

It is beyond the scope of this work to explore co-treatment further. Co-treatment was raised as a valuable and common practice in hospitals in SA. Its implications for service provision in government hospitals needs exploration in the context of financial resources to access therapy. Combined sessions may reduce the number of visits, travel costs and time taken off work for families. This ties in with Hooper's recommendation of a multidisciplinary team consultation for holistic case management and to reduce the number of appointments (Hooper, 2009).

#### **4.2.3.3 PULL OUT SERVICES MODEL WITHIN SCHOOLS**

OT in both private and government SNSs, use a “*pull out*” service where the child or group of children are removed from class for therapy in the OT room. This has been criticised as a less integrated approach, where OT has less than the desired impact on the child's classroom performance (Dunn, 2000).

*S: “Because it doesn't help to take the kid out for half-an-hour and then pop them back in and then what? I know for me personally it's been quite a mind shift, because you feel you're not doing enough.”*

Even if groups are run in the classroom, unless the teacher is involved in the planning and running of the group, integration between therapy and classroom function is still limited. The full value of collaborative class based therapy approaches did not seem to be used in SNSs. The differentiation between class based intervention and OTs running groups in the classroom was not clearly distinguished by participants. Class based intervention has the potential to utilise human resources creatively, empower team members, as well as impact on translation of therapy skills into the classroom.

#### **4.2.3.4 DOSAGE AND SERVICE PROVISION MODELS**

In this study, OTs in *PP* were seeing children weekly or twice per week for thirty to forty five minutes. Dosage may be reduced to once fortnightly when significant progress was made.

In *hospitals*, children were seen once in two, three or four weeks, for between twenty and sixty minutes. One hospital's outreach distance home programme was monitored every three months.

In *SNSs* therapy is provided according to need as well as human resource availability. Some children received both individual and group sessions, while others received group therapy only. Some children did not receive OT at all. Sessions were usually thirty minutes weekly for both individual and group sessions.

Table 4.3: OT Dosage across sectors

<b>DOSAGE</b>	<b>PP</b>	<b>HOSPITALS</b>	<b>SNS</b>
SESSIONS per WEEK	1-2	0	1 individual and or 1 group
SESSIONS per MONTH		1-2	
SESSION LENGTH (in minutes)	30-45	20-60 min	30 min

OT Dosage varies significantly between private health care and public health services in SA. Staffing challenges impact dosage in both public health and SNSs. High intensity dosage in private healthcare is financially challenging for parents. Even if they are able to access extended cover for long-term therapies, the financial costs of providing for a child with ASD is significant. OT dosage for ASD in the light of recommendations for intensity of intervention, is a challenge for all three sectors in SA.

OT in SNSs is more likely to be group based though regular, as individual therapy is often reserved for the “most deserving” cases. Deciding who deserves therapy, raises ethical issues. Ethical dilemmas may be avoided through alternate indirect therapy provision models or collaborative class based intervention, thus allowing access to therapy for all who need services.

International guidelines on contact hours in early intervention recommend between twenty five to forty hours per week of active engagement. Therapy dosage may vary

between one and as recent guidelines indicate, up to five times per week, with two years of therapy considered typical in SI (Parham & Mailloux, 2010). Dosage for ASD requires intensity and dosage has to be reviewed in the light of this recommendation.

Dosage impacts effectiveness of intervention. Infrequent intervention is likely to have less effective outcomes. In one study, the frequency of direct therapy correlated highly with OTs perceived improvement in sensory integration (Case-Smith & Miller, 1999).

*M: “we just see such amazing progress when the children can come for more than one session a week... two to three sessions a week would be ideal, and even possibly looking at... block therapy...”*

#### **4.2.3.4.1 SI Dosage**

Dosage for SI therapy has been a source of controversy in the USA. Recent developments have criticised the impracticality of such frequent intervention in the real world (Alterio, 2012). The challenge of human resources and those related to social conditions of poverty are unlikely to change in SA in the near future. Thus, creative solutions to service provision may allow for better utilisation of human resources for more frequent access to therapy. Creative service provision options may be possible in schools, though unlikely to succeed in hospitals due to factors such as transport costs.

The viability of SI as a treatment modality in public health is questionable, due to infrequent sessions resulting in limited effectiveness of SI. Dosage is at best once in two weeks, at worst once in four weeks. The viability of SI in public health raises the feasibility of training SI OTs for public health. Yet the demand is perhaps greatest in this sector. Dosage effectiveness for public health is a significant drawback.

*O: “I’m hesitant to call it sensory integration, um, because...I don’t know if its done frequent(ly) enough, I don’t know if we’re getting that carry over that’s supposed to happen...I’m hesitant to say that its pure sensory integration in its true form, if I cannot offer that regular intervention.”*

*G: "...SI, the treatment course, I was the only therapist there from a government hospital and I explained to them...We are seeing more SI kids than you... research is showing SI problems are more prevalent in a lower socio-economic status in any case. We are seeing more kids than you are seeing in private..."*

### **4.3 INDIRECT INTERVENTION**

Indirect intervention covered the following aspects: home programmes and individualised education plans (IEPs), teamwork, support services for families, advocacy and reflections on working with families of children with ASD.

#### **4.3.1 TEAMWORK**

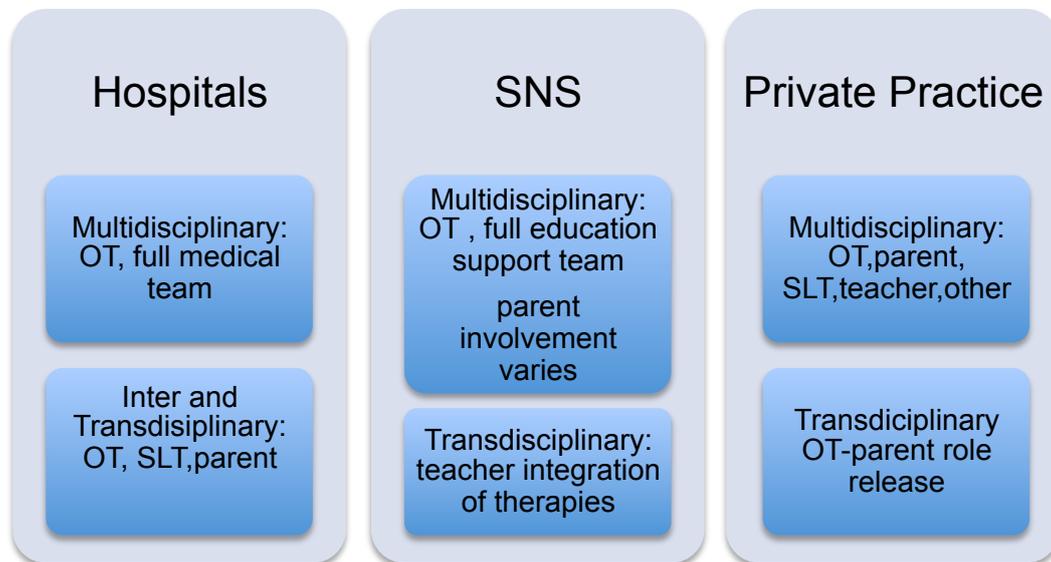
Teamwork will be discussed in terms of the following: team members, team liaison, teamwork style and the importance of teamwork.

##### **4.3.1.1 Team members**

The teams included professionals across the health and education sectors from child psychiatrist, neuro-developmental paediatrician, paediatrician, medical officer, psychologist, speech language therapist, physiotherapist, nurse, social worker, educator, remedial teacher, facilitator, OT and parents.

### 4.3.1.2 Teamwork style and liaison according to sectors

Table 4.4: Teamwork styles across sectors



#### 4.3.1.2.1 Hospitals

Hospitals OTs consulted at, had large multidisciplinary teams with varying levels of collaboration amongst the different members. The strongest collaboration in hospitals was between OTs and parents and SLTs and thereafter between OTs and medical specialist colleagues. There were opportunities for regular team meetings and case discussions with open communication channels available to staff. Unfortunately, some team meetings have been discontinued due to human resource challenges and heavy workloads. Multidisciplinary teams in hospitals offered the opportunity for inter and transdisciplinary learning. One example is the opportunity to observe ADOS assessments.

*C: "Previously, we had a meeting once a month in which the child psychiatrist, the neuro-developmental paediatrician, the speech therapist and myself would meet and if we had any cases to discuss... That meeting has fallen away due to time constraints and manpower... but we can easily call up somebody"*

*O: “they often invite us... if it’s a patient that we’ve been seeing, to sit with the ADOS and see if we don’t maybe see something that we haven’t been seeing in therapy...”*

There seems untapped potential for research collaboration in these settings. The advantage of a large team is the one stop comprehensive service to clients. While each discipline had its unique contribution, collaboration was good, with interdisciplinary and some aspects of transdisciplinary teamwork styles evident between OT and SLT. Co-treatment occurred regularly or on an ad-hoc basis in four of the six hospitals.

#### **4.3.1.2.2 SNS**

SNSs also supported large teams, with the strongest collaborations between OT and teachers as well as OTs and other therapists. Direct parent contact with OT, was limited to formal IEP meetings or progress meetings through the year. Parents had the most contact with the class teacher and communication with OT was usually through an OT or school homework book. In all SNSs, while the predominant form of teamwork was multidisciplinary in nature, there were elements of interdisciplinary as well as transdisciplinary practice.

Professional roles tended to be clearly defined and in one SNS, professional identities were jealously guarded. Some teachers and therapists worked well together, using skills transference for the benefit of all parties involved. In three of the four SNSs, skills transference was actively encouraged. Teachers seemed to be the most transdisciplinary in approach as they integrated various therapies within the classroom. Co-treatment occurred at one SNS.

The relationship between OT and teacher impacted on the success of service provision styles like class-based intervention. The professional team had many opportunities for informal discussions on a daily or weekly basis. Scheduled, regular formal team meetings of case discussions also occurred during the year.

*R: “each profession is very competitive by nature, so you’ve got huge barriers to break... I mentioned assessment findings of gross motor quite*

*in detail and the physio was very offended...there's actually a very specific role here..."*

*F: "it really just depends on the teacher...but its more towards them really wanting you to come in and give your input than not wanting you there...maybe its more on their own terms, like if they want help they'll come..."*

*T: "we do have to be careful that when other people are using our techniques that they're using them correctly...but I think generally, the feeling here is, if you can use my techniques its great, you helping the child, so it's a very open approach"*

#### **4.3.1.3.3. PP**

Private practice OTs formed strong collaborative partnerships with parents. The rhetorical question below, captures the family centred philosophy of private practice, in which the parent is the most important team member. OT P also raised the importance of fathers in the team as they brought objectivity and financial concerns to the fore.

*P:" when you're private you don't get enough team work, when you're in school, the parents aren't involved in the team...and who's the more important player, the team or the parents?"*

*I: "I always see the parents as the main person in the team..."*

*P:" The father is the objective one who is paying the money and often the objectivity is actually what we need. We don't give the father enough in the role."*

All private practices worked primarily in a multidisciplinary way, with elements of interdisciplinary practice. it seems that OTs who had previous work experience in multidisciplinary teams, were more likely to use interdisciplinary and even trans-disciplinary techniques and practices.

*A: “ things like ...what sounds to start with...the AAC as well – we work very closely with the speechie ... things like the prompt approach with the manipulation of the mouth...”*

*P: “I’m interdisciplinary but you don’t do what you can’t do and you don’t do it at the cost of the child and you don’t do it at the cost of them not going to other therapists.”*

Private practitioners except for the group practice, had less regular contact with their professional team members. The effort to sustain regular communication with peers was time consuming and thus not as frequent as they would have liked. All the private practitioners interviewed made an effort to arrange team discussion meetings or telephonic communication with other team members during the course of intervention. In the early intervention community centre, the approach was primarily inter and trans-disciplinary. OT D was part of a multidisciplinary group practice in a clinic type setting, where co-treatment had been used previously.

*I:” team consultation is probably the thing that I fall down on the most... not getting enough time to contact other people on the team... six monthly or so... it’s a school visit.”*

*K: “I definitely contributed to the skills and the knowledge of OT but I just found that my other colleagues had such a good knowledge of what we were doing that... if I wasn’t present, that they wouldn’t be able to assess or address my aspects.*

#### **4.3.1.3 The Value of Teamwork**

All OTs agreed on the importance of teamwork, especially for ASD.

*K: “autism affects absolutely every area of functioning... there’s got to be teamwork and collaboration if there’s going to be any kind of carry over from one aspect to the other...”*

The themes that emerged under the value of teamwork were:

- Teamwork allows for focused intervention that is OT specific and avoids duplication.
- The contribution of each discipline's expertise allows for the development of common and realistic goals for the team.
- It ensures accountability, as the team has to deliver on goals set. Teamwork promotes the holistic development of the child and leads to improved progress for the child.
- There is consistency and carryover across environments.
- Teamwork provides support for the family and the team and saves time
- Teamwork "therapises" the curriculum and family life

*T: "its quite important that everybody is using the same sort of techniques, that there's consistency in the approach...to have that sort of structure and routine so that they know what's expected of them - if behaviour is consistent, the response to behaviour is consistent"*

*R: "...second opinions, providing support. Just support, because working with autistic children is hard. You want to be reassured- I'd find it very hard working in isolation..."*

*E: "... its so crucial. If you don't ...have a common curriculum and if the therapy aims are not in the curriculum, we're wasting our time...one session of half-an-hour therapy in one week is not going to do anything...All of the OT aims need to be in the curriculum, ideally..."*

#### **4.3.2 FAMILY COLLABORATION**

OTs were aware of the life long disability issues that families faced, the stressors of relationships, finances, the lack of facilities and services as well as the need for emotional support. The lack of support services such as respite care in SA, was raised by OT I.

Positive comments about working with families were the appreciative nature of families, the satisfaction of fostering parent child and family relationships, relieving the burden of families through greater independence of the child and providing coping strategies for families. The OT parent relationship emerged as an important support for families.

*J: "I said I don't know what I can do for your child any more. She says... I'll still come. You know, for them its also that support and I think an OT... we become an ally."*

*I: " (ASD is) just an all-consuming diagnosis ...it just affects every second of the day wherever the families are...I think it's the most stressful existence"*

On a personal level, four OTs noted their own emotional strain when working with ASD, and the importance of debriefing or ideally taking a break after two years of working with the same child. This raised the issue of professional burnout. One OT mentioned that there were probably too few OTs in the field in SA, so burnout would impact severely on human resources and service provision.

*I: " absolutely draining...I learnt that in America you're only allowed to work with the same autistic child for two years, then you have to change therapists, for the therapist's sake and for the family's sake"*

*J: " it must be definitely the most taxing, the most demanding of all the types of children that I see. I always say that one child with autism takes the energy and preparation of at least two, if not three, other children..."*

Less positive, were experiences of frustration with parents due to denial of diagnosis issues, non-acceptance of recommendations and lack of teamwork or collaboration on therapy goals. All OTs found ASD a challenging but rewarding condition to work with.

*A: "...you need to give your recommendation, but...ethically they have the choice to either accept...or not, and that's been very difficult."*

*J: "...frustration when they just don't come to the party...they're happy to dump the child..."*

*F: "even in my church I don't feel as alive as I am here, because I know that this is the purpose that God has for me right now... I really am enjoying what I'm doing"*

#### **4.3.2.1 Individualised Education Plan (IEP)**

An individualised education plan (IEP), is the document drawn up by the team outlining a child's educational and developmental goals for the school year. In the study, the frequency with which IEPs were reviewed, varied between every six months, to annually, or every two years. OTs as part of the team of educator, therapists, parents and other professionals contributed goals related to OT specific areas. The main themes to emerge under IEP development were the parent's role in IEP development, team collaboration on goals and the overall focus of IEP goals.

Parent's contribution to IEP development is considered best practice (Hanna & Rodger, 2002). All SNSs except for one, routinely consulted or included parents in IEP development. One SNS excluded parents from the IEP process as part of its operational policy. The loyalty of OTs can be tested, by having to take sides between a parents right to be involved and school policy. OT roles in reinforcing school hegemony needs to be raised as an ethical concern. Despite school policy excluding parents from IEP development planning, OT R made a concerted effort to communicate via the homework book to parents to include their goals for her programme. She noted that parent attendance of parent teacher feedback meetings was very poor. One possible reason is that parents who are not valued and consulted as equal partners in their child's education are unlikely to "buy in" to intervention.

*N/T: "I don't think we've ever had at least one member of the family not come to an IDP, so in that sense they are involved...they appreciate our input, but they also are able to give us their input..."*

*R: "each department sets their own goals and then shares them with the rest of the team. There's been the odd parents that feel that they should*

*be (part of the IEP meeting) and as soon as we feel that we would like them to be there, then we might call them and have another meeting- But that's only very rarely if we feel that they would benefit from it"*

It is possible that some schools consult parents in a less inclusive way. Parents are asked to contribute to IEP via written communication and not during a team meeting. This may be a time saving measure but further reduces parent contact in a setting where parent's involvement and contact with the team is already limited. A parent's absence from a meeting limits the level and value of discussion around goal prioritisation. One may query whether an IEP meeting is viewed as a consultation with the "experts" or true collaboration between equal partners. The Medical model view of the parent emasculates their power and influence, whereas the recommended family focussed services model views parents as experts with whom the ultimate power to make decisions resides.

*E: "we call the parents in, ask them if they're in agreement, and then we add on a parent's section, and say to them 'what would you like us to add on that's specific to you'...we revise the whole thing to include theirs, and then we give them a copy which they sign."*

*A: "It was more like 'this is what we recommend, what do you guys think?...it (parent input on IEP) wasn't at the initial phase and they weren't there to fight it out, although some parents did fight it with us...But some just arrived and said yes, yes, yes, yes..."*

Poor professional teamwork sometimes resulted in protracted disagreement amongst team members about prioritisation of goals.

*E: "the teacher, OT, speech would spend half-an-hour deciding okay, this is the most important language goal, which is a bit ridiculous..."*

*A: "they weren't involved in the initial meeting when we were all kind of fighting about which goals were more important than whose."*

Two OTs experienced a conflict between a health and an education focus, in the school context. OTs predominantly train within the health sector and may struggle to

reframe goals within an educational context. Goals can become skewed in favour of clinical versus academic or functional goals in a school context. The lack of policy governing OT in education in SA, further fuels uncertainty around goal setting.

*L/S: “our IDPs may be a bit too therapy based and we need to in future try and move it more to an education kind of based ...(but) health discharges the children at six, so who is going to work on independent skills unless they can afford private therapy? So in the end, it kind of is our role as well ...”*

While there is room for healthy debate around goal setting, parent involvement from the outset is crucial to prioritisation in a family focussed intervention model. The lack of a school policy governing therapy also contributes to the debate around the prioritisation of goals. An education focus in SNSs would guide overall team goal setting and resolve conflict between clinical and educational priorities. The role of therapists in education needs to be addressed at policy level to clarify roles and goals in school contexts (Dube, 2012; Struthers, 2005). In most instances, across sectors, parent goals were an important part of the therapy plan. OTs may need to advocate for the parents right to be involved on a more collaborative level, such as in IEP development.

#### **4.3.2.2 Home programmes**

Home programmes form an important portion of the recommended twenty five to forty hours per week intensive intervention for ASD (National Research Council, 2001). In all but one SNS setting, OTs used home programmes as part of their intervention across all sectors. Most OTs gave parents ideas of informal home programme type activities. At the early intervention community centre, home programmes were in written form. In other settings, home programme ideas were often based on the therapy session, and involved extending a good session. Three of the home programmes tended to be developmental in nature and included sensory stimulation. Four OTs included sensory diets in their home programme advice to parents.

*M: “home programmes its again, first sensory based so we would suggest... that they would get a trampoline or a hammock or a weighted jacket or weighted blanket, or brushing or the therapeutic listening, and then more specific like a proprioceptive home programme that deals with sucking, chewing, blowing, all of that kind of calming, organising and put in a system incorporating different messy play and baking and, um, desensitisation programmes where there’s oral with the brushing, those kind of things...”*

*T: “... because we’ve got a very long waiting list, we’ll give some strategies that they can use at home... we do sensory diets...resources for home like little schedules...”*

Considering the strong SI allegiance by OTs in the study, it was surprising that sensory diets were not widely used as home programmes amongst participants. SI therapist and instructor OT P, felt that SI home programmes were too complex for parents and preferred a developmental and play based home programme. OT J gave a list of ideas to parents but commented that sensory diet home programmes required more careful on going monitoring. The fact that advice can easily be misconstrued, ties in with the perspective of P, who felt that SI was too complex for home programmes. Considering that SI difficulties impact significantly on children with ASD, it was expected that sensory diets would feature more prominently in home programmes, to aid modulation and IADLs.

*J: “an article ...on proprioceptive activities I used that ... to give to parents and say, look what your child’s doing already and then come back to me, but... parents totally miss the plot sometimes...those sort of things I find very scary, because your, parents hear what they want to hear...that is the other thing that I’ve learnt is not to have a once-off... they’ve got to tell me what’s worked and what hasn’t worked”*

*P: “my home programme with the parents are normally what they can cope with ...you can’t give them SI because that’s too difficult to understand, but so they do the developmental things”*

One hospital had access to a toy library, which then formed part of the home play programme. It allowed disadvantaged communities access to play resources. Most SNSs and hospitals provided access to some resources like visual symbols for schedules. One hospital provided home programmes in place of therapy for families in outlying areas. It was developmental in nature and included sensory stimulation activities. One SNS also provided home programmes for those children on the waiting list for school admission. The Therapressure programme (Wilbarger) is used selectively with clients by at least six of the OTs across sectors. AIT was used as a home programme by four OTs in private practice. AIT required considerable financial resources as well as parent commitment to a strict schedule and was thus only viable for a select population.

*G: "I don't use it (Wilbarger therapressure programme) that often. Like you'll see kids squirm and they just want to go away from you... if they're showing that reaction I won't use it, I can treat tactile defensiveness in another way"*

*D: "we don't use it (therapeutic listening) a lot ...the families really struggle with the routine of therapeutic listening, you know it takes a very long time and it ...takes a lot of commitment, SO LISTEN is sometimes more helpful but its not as well graded..."*

OT P cautioned OTs regarding the judicious use of home programmes due to its impact on the family. She warned against using home programmes at the expense of the family's relationships. Home programmes could also become a burden or hindrance to family life. The DIRFloortime approach can put additional pressure on parents to become the therapists. The risk of parent burnout was raised, which is acknowledged in the literature (Hanna & Rodger, 2002). The importance of making therapy a part of routine activities versus a prescribed series of exercises was important for success.

*J: "...the mother was doing something in the bath, doing here, doing there – the poor mother didn't have time to do anything else... definitely the way I work, it is taking the things they're learning and making it part of every day."*

*P: "...but any home programme is never at the cost of the relationship between the mother and the child, or, I would say you are mother first...some Moms.. I'm saying...you are doing too much, you're burning yourself out."*

Home programmes were widely used across sectors. It comprised of sensory diets and developmental and sensory stimulation play activities. Home programmes were an extension of therapy, a means of access to therapy for isolated communities, as well as a means to provide interim intervention prior to accessing facilities for those on waiting lists. It could be empowering for parents but may also lead to an additional burden and burnout.

#### **4.3.3.3 Support services**

All OTs across sectors referred families to support services. Support services ranged from referral to support groups, providing on site support groups, training of teachers, facilitators and parents, school visits and school or workshop placement. Indirect training of caregivers is addressed in the teamwork section above. Formal support programmes, education and training sessions will be identified here.

#### **4.3.3.4 Support groups**

All hospital OT departments in the study ran support groups as it was identified as a need. Some hospital support groups collaborated with larger community organisations such as Autism South Africa (ASA) to deliver support services in Gauteng and Western Cape province hospitals. The KZN hospital referred parents to NGO Action in Autism in Kwa-Zulu Natal. OTs in public health were most involved in the running of support groups, whilst those in other sectors recommend attendance to parents. OTs made parents aware of upcoming events, such as educational talks and support group meetings in the school and in the community.

One OT indicated that community driven initiatives would be preferable, to address issues of stigma. One SNS ran a support group for siblings of children with ASD. The need and value of support services was strongly identified by participants across sectors.

O: “ we’ve got a good relationship with Autism South Africa. They’ve got somebody that comes in on a weekly basis, um, to give parents a bit more practical guidelines ...an autism support group for parents between occupational therapy, the speech therapist, and our social worker, which was aimed more at how can we give advice, how can we give information um, to the parents or caregivers...we talk about topics that they identify as needs.”

C: “ a better support service for the parents not run by us but run by somebody else within the community... That, for me...is very important because there’s such a stigma for these mums.”

A: “the value of other autistic parents talking to other autistic parents...they just have a connection that no OT can reach...”

S:” especially with autism because of the behaviour ...and the rigidity... the other sibling often gets lost in the process, so we’re really trying to give them a sense of you’re also important...”

#### **4.3.3.5 Formal skills training**

Formal training opportunities for caregivers and other professionals were not common. While information sessions happened regularly through support groups and OT sessions, only three OTs were involved in workshops for skills transference and practical strategies training for parents, educators and therapists. One SNS provided this type of skills training as a regular outreach service. A SA study confirmed that caregivers requested continued education and support services and practical training (Hooper, 2009). Other research also confirms the value of practical training (Marcus, et al., 2005). The inclusion policy implementation plan for 2014, (Department of Basic Education, 2011) will require school staff to be adequately trained for working with autistic learners. Currently there is some training run by SNS staff in the Western Cape and in Kwa-Zulu Natal.

The OT at a Gauteng hospital who is experienced in ASD intervention, provided support for other OTs who needed mentoring through the organisation of formal workshops as well as informal observation opportunities.

*T: “ once a term we have a workshop... for teachers and therapists in mainstream schools”*

*G: “...the doctors phoning... saying ... why don't you see the patient...but we shouldn't actually be doing that, we rather empower those therapists to see the kids themselves, and also with the people calling in for help, we said, lets rather do this workshop...we also get therapists from a specialised... hospital who just comes to observe some of our sessions with ASD kids here.”*

#### **4.3.3.6 Advocacy**

Advocacy roles arose in three areas: school access and placement, improving policy and services and access to assistive devices or technology within schools.

Hospital and private practice OTs were active in lobbying for school placement for their clients. OTs provided guidance to parents regarding placement in suitable schools or facilities. Schools that accepted children with ASD were few and they often needed lobbying to gain admission for the child. OTs may not be the best professionals to facilitate school placement. Two OTs found better results if recommendations came from the team doctor (hospital) or the psychologist (PP). One specialist hospital had a designated team member and process in place to facilitate placement. OT B felt that accessing schooling for the children was not the role of OT in hospital services.

*Q: “ we've got a team called NATED...if you' ve got a problematic case ...that is a platform to present...so advice will come from different angles and... there will be a doctor that represents special schools.”*

*A:” I do try and advocate for kids to get into schools but, I don't know, its better if it comes from a psychologist.”*

*O:” for us it was easier if we recommend to our doctors and they initiate placement, um, but I will phone the school...we struggled tremendously to get children into places but once the doctors use their authority um, its just easier to get them in”*

The overlap of responsibility and policy disconnect between health and education was raised in two provinces (WC and KZN). There was a concern that some children get lost in the system when referred between departments. Children older than six years should receive therapy in educational settings, but due to limited access to school placement, remained within the health system for much longer.

*O: “as the manager of the paediatric services, I think the advocacy role comes in where we link with the Department of Education, so we’ve been trying to almost get an understanding between the Department of Health and the Department of Education in terms of who are the children that we will be able to accommodate within our health services...how should the referral process be working...reinforce the fact that there isn’t enough schools and placement opportunities for these children”*

*H: “... I got a call from some irate person there, “we are education and you’re health and you should not be referring to me... now we refer to the school principal who refers them to SNES (special needs educational services) ...they determine whether the child should go to special school and then that process starts up...there used to be the Joint Service Providers Forum, where we used to meet... education and health therapists, and we would discuss these issues and cases and follow up... but that fell away a long time ago”*

In one SNS, advocacy involved accessing resources.

*R: “our role as an OT here is to advocate for assisted technology”*

OTs in hospital and PP sectors predominantly lobby for educational placement, whilst OTs in SNSs seemed less active on the advocacy front. School OTs may need to advocate for parent involvement in IEP development in line with a call for therapists to take up advocacy roles (Struthers, 2005).

## 4.4 EDUCATION AND TRAINING FOR OTS

### 4.4.1 UNDERGRADUATE TRAINING

All participants except one, felt that undergraduate training did not prepare them for working with ASD. Their comments ranged from OT E “pathetic” to OT F “even qualified OTs feel threatened by ASD”. The perception of the majority of OTs in the study, concurs with those of various SA professionals including OTs, that undergraduate training is inadequate for ASD (Geertsema, et al., 2011).

OT G was exposed to ASD at undergraduate level but poor supervision and support made it a negative experience. SI achieved taboo status at undergraduate level at some universities, making entry into the field of ASD daunting for newly qualified OTs. Some OTs felt that a lack of sensory integration knowledge excluded them from working with ASD. Discouraging comments such as ASD is a “specialised area” that requires specialist skills made OTs reluctant to treat ASD if they were not SI trained.

*L: “I mean when we were students, you didn’t say the word ‘sensory’ - “don’t even, you’re not qualified”...”*

*G: “especially if you’re at x university, you don’t hear the word SI...they’re like ‘you’re not qualified, don’t do it’, so we...knew nothing...”*

*G: “I was the only therapist there (on SI course) from a government hospital and I explained to them... We are seeing more SI kids than you, like research is showing SI problems are more prevalent in a lower socio-economic status in any case... how can we help now, because if you’re coming out of university you’re not really knowing what to do”*

Whilst the more recently qualified OTs had exposure to ASD at undergraduate level, older graduates had no exposure to ASD even on a theoretical level at university. The SI qualification courses have recently introduced SI for ASD, as a lecture topic on an introductory level. One university has introduced more SI theory in the undergraduate curriculum. Some OTs in private practice, have developed an

introductory course on SI for fourth year students at their local universities. These OTs felt that there was a need for further SI knowledge before graduation.

*G: “ at the University of x, they’re making sure that the students leave with at least knowing how to treat on a modulation level”*

*P: “ I do a three-day workshop for the fourth years.”*

This led onto discussion on what curriculum advice participants would offer to training institutions, to better prepare new graduates for work in the field of ASD. Whilst acknowledging a full syllabus with diseases such as TB and HIV AIDS taking prominence, the majority felt that ASD belonged in the programme. ASD is a condition new OTs would face in their practice. It was recommended that ASD be specifically taught within the paediatric syllabus, echoing the view of other medical professionals (Mubaiwa, 2008).

*S: “ saying there’s not time and leaving it (ASD) out when it is such a growing epidemic, I think is doing a disservice to your patients and to the OT students, because I am yet to meet a Comm Serve OT who has never come across an autistic kid- and they didn’t know what on earth to do.”*

Eight OTs felt strongly that more SI should be introduced at an undergraduate level. They felt that understanding sensory systems, processing, and modulation would equip new graduates to work with ASD. They would be able to assess and comment on sensory processing and treat modulation at a basic level. Participants also emphasized that SI information is useful for all populations across the age and diagnosis spectrum, and was not limited to paediatrics.

Understanding the sensory component of ASD may demystify the condition for OTs and reduce any negative perceptions around treating ASD. Community service OTs, who are most likely to encounter ASD will then at least be able to treat with basic skill.

*P: “ ...they must understand over- and under-responsiveness in the sensory system and they must understand how to regulate the child.”*

*D: “ I've never, ever, really understood why its regarded as being so, um, complex or elitist...because actually its so, so fundamental and so basic... I do understand that the curriculum is enormous... but I think that sensory integration pervades every person from the time they're born until the time they die, every single diagnostic, category that we treat and I think that it's a big chunk that's missing”*

Behaviour modification and how to handle challenging behaviour was another recommendation for undergraduate training, by three OTs. Managing challenging behaviour was also among the recommendations by SA OTs surveyed regarding aspects to be included in a potential training programme for ASD (Geertsema, et al., 2011). OT D felt that an introduction to the DIR framework would benefit undergraduates. One OT felt that play needed more teaching time whilst another felt communication needed to be taught. The importance of understanding child development was also emphasized. OT I emphasized the relevance of the MoCA model and its application to paediatrics in the undergraduate programme, as it equipped OTs with practical treatment ideas.

*O: “ behavioural modification kind of techniques – what can you and can you not do as an occupational therapist.”*

*Q: “ people like underplay it but in fact making the student understand the importance of play...and also development. I think with those two skills I think undergrads they can manage...”*

#### **4.4.2 POSTGRADUATE STUDY**

All OTs except one, felt strongly that some form of postgraduate study in the field of ASD would have benefits. One OT mentioned that ASD is a niche area that lends itself to specialisation. Two OTs felt that ASD was best suited to post graduate study due to its complexity. A post-graduate programme they felt, should include multidisciplinary input and research collaboration. Another OT raised the lack of availability of postgraduate courses within the profession, and that such a specialisation would expand opportunities for professional growth in an area of

critical need. OT I felt strongly about the ethical obligation to provide appropriate intervention for ASD, which a specialist OT would be able to fulfil. The current lack of experts compounds this ethical dilemma, as there are few persons sufficiently skilled to provide the service or possibly even mentor other OTs. OT D emphasized the necessity of an alternate training channel for SI, without having to progress through the current programme, parts of which are irrelevant for ASD. Most participants agreed that SI training would be a necessary part of a postgraduate training programme for OTs.

OT G felt that a disadvantage of postgraduate study, was the perception it would create that OTs need to have special qualifications to treat ASD. This would further discourage OTs from engaging with ASD. The other disadvantage raised by two OTs was the possibility of a scope of practice register, which would then limit an OT to working in the field of ASD only. There are no concrete plans for such a register for OT, by the Health Professions Council (HPCSA).

*M: "it would be almost beneficial to have it like a medical degree where you had to do something general and then specialise afterwards..."*

*G: "therapists are already scared of the autistic kids, they're already saying...we don't know what to do. If you're going to add the speciality they're already going to step even further back by saying "I don't have that speciality"... they're just going to immediately say, hands off, I'm not qualified... not even giving it a try...so I don't think it should become that specialised."*

Four OTs questioned whether a postgraduate degree would necessarily make one a skilled clinician. A title or knowledge without practical application and skills development was of limited value, they argued. A specialist should embody theoretical knowledge as well as clinical expertise. OT J suggested an alternate to postgraduate study would be a professional support group and mentorship programme. Three OTs recommended the value of mentorship and work experience in improving clinical skills.

*P: "you can have all the titles, but it does not make you a good therapist."*

*L: "first line of defence OTs... They're Com Serves...we need experts but more so, if you had to make me choose, I'd say we need the...first line of defence"*

*J: "start a professional support group...there are support groups... for parents, but that's not really helping us with treating the kids."*

The majority of OT participants concurred with the international literature on the need for OT specialists in the field (Mcgee & Morrier, 2005). South African caregivers and professionals also highlighted the need for local specialists in ASD (Geertsema, et al., 2011; Hooper, 2009). Most OTs were in agreement with a two-tier structure, of clinicians with a special interest in ASD, and OT specialists. They agreed that not all OTs who wished to work with ASD needed to specialise, but that specialist OTs would be useful in a number of roles.

#### **4.4.2.1 Benefits of OT specialisation**

Two OTs felt that specialists could provide guidance to other OTs or schools as consultants, possibly in an outreach multidisciplinary team. Specialisation opportunities would allow for professional advancement of OT in the field, and ensure the profession kept pace with developments and research. Specialist knowledge one OT felt was required to significantly impact on intervention for ASD.

*J: It would be nice to have a consultant, you know a specialist that's a consultant to other therapists... where you go in and you sort of help, support, give input..."*

*F: " You know what would work well, if you had specialists but they must be able to almost be drawn to different places...a multi-disciplinary team that actually goes to a school and helps them set up...a specialist group would be the answer really, in almost each region."*

*Q:" OTs mustn't be behind...in the medical field there's just so much that has been developed... so we can't afford to be behind."*

*I: “ To just be a general private practitioner you will really find it difficult to have a deep impact on a child with autism, so you do need a specialist or specialised knowledge.”*

*J: “ sensory integration therapists, just out of necessity, do eventually end up autistic specialists. Not because we want to but because there is no one else.”*

The majority of OTs were in support of further education and training at both undergraduate and post-graduate level for OTs, which concurred with a SA multidisciplinary survey study (Geertsema, et al., 2011). The need for local specialists was strongly supported.

#### **4.5 CHALLENGES TO FAMILIES AND CHILDREN WITH ASD IN SA**

These were divided into challenges around awareness of ASD, availability of educational and social facilities and services, as well as social challenges faced by families.

##### **4.5.1 Issues around Awareness**

Nine OTs identified a lack of awareness of ASD as a developmental disability within the general public. The stigma associated with having a child with ASD as well as the cultural misconceptions about ASD within African communities, and possibly within other cultural groups was raised. Two OTs were specifically concerned about ignorance within the medical health professions. They raised the non-referral from general practitioners and nurses, of children who should have been identified as at risk for developmental disorders. The limited knowledge of professionals together with conflicting professional opinions were among the top five challenges identified by caregivers in a South African study (Hooper, 2009).

*S: “Stigma. They get called bewitched”*

*D: “there are not enough trained professionals...I don’t think our medical professionals are at all well-equipped to begin to identify and refer...the clinic sisters need to be better informed”*

#### **4.5.2 Lack of Facilities and Services**

Seventeen OTs mentioned a lack of schooling facilities and placement opportunities for children with ASD. They also identified the lack of a full range of facilities such as early learning centres, day care centres, training centres as well as work opportunities. They stressed the need for a variety of facilities that catered for different levels of ability of children on the spectrum. A few OTs spoke of the need for more autism units at schools. OT I in PP, found that support for inclusion policies was not available at school institution level for it to work successfully. On an institutional level, two OTs raised concern regarding the lack of accountability in private SNSs, which they felt required monitoring and accreditation. The lack of appropriate facilities and lack of services were the top two ranked challenges for caregivers of children with ASD in urban SA (Hooper, 2009), thereby validating the opinions of the OTs in this study.

*C: “ schooling. For me that’s huge at the moment. I’m lost for what to tell parents on that”*

*O: “Actually, any kind of placement...if they’re not high functioning enough to go to school, they at least need to be able to go to some kind of special care centre.”*

*E: “ASA needs to quality control the (private) schools that are coming up, and they need to re-licence them every two years or whatever, and they need to look at the quality of staff. You can do so much of nothing with these kids.”*

Ten OTs were concerned about insufficient access to therapy. Six OTs identified the impact of transport cost factors in accessing services in the public health sector. This was also a finding in the SA caregiver survey study (Hooper, 2009). Eight OTs felt that inadequate access was also due to human resource challenges, a shortage of qualified professionals and lack of ASD specialists. Two OTs acknowledged

growing waiting lists at hospitals to access therapy. A few OTs expressed concern that services that do exist, such as SNSs and healthcare centres were under resourced in terms of equipment and especially staff. OT I expressed concern about rural areas of SA where resources would be more restricted than urban centres.

*C: “ the amount of service and the regularity of therapy that they’re getting is a challenge for them, so the affordability to attend therapy”*

*S: “The grant goes just to...the child’s transport and to nothing else”*

Another need identified by four OTs was that of practical training for parents, teachers, facilitators and other professional staff involved with ASD. One OT felt that a one-stop multidisciplinary screening service centre would be valuable.

#### **4.5.3 Social challenges**

Fourteen OTs stressed the difficult social challenges faced by families. These were identified as social isolation of the family across all cultural communities, divorce and financial strains. Two OTs noted that access to intervention information that lacked clarity could be overwhelming for parents and further contributed to stress. Long term, the variety of services required by a child with ASD was a financial strain. The vulnerability of these children to abuse was another concern raised by one OT.

*R: “a lot of friends judge them until they know the diagnosis, ok, they’re not a bad parent, the child’s just got this disorder.”*

*M: “...so much hocus-pocus out there in terms of managing autism...there’s so much confusing information for parents...”*

*P:”... protection of the child – I mean also these children are open to abuse”*

## 4.6 SCHEMATIC VIEWS OF KEY FINDINGS IN EACH AREA

A schematic view of key findings in each section will precede the conclusion.

Figure 4.6.1: Schematic view of key Assessment Findings

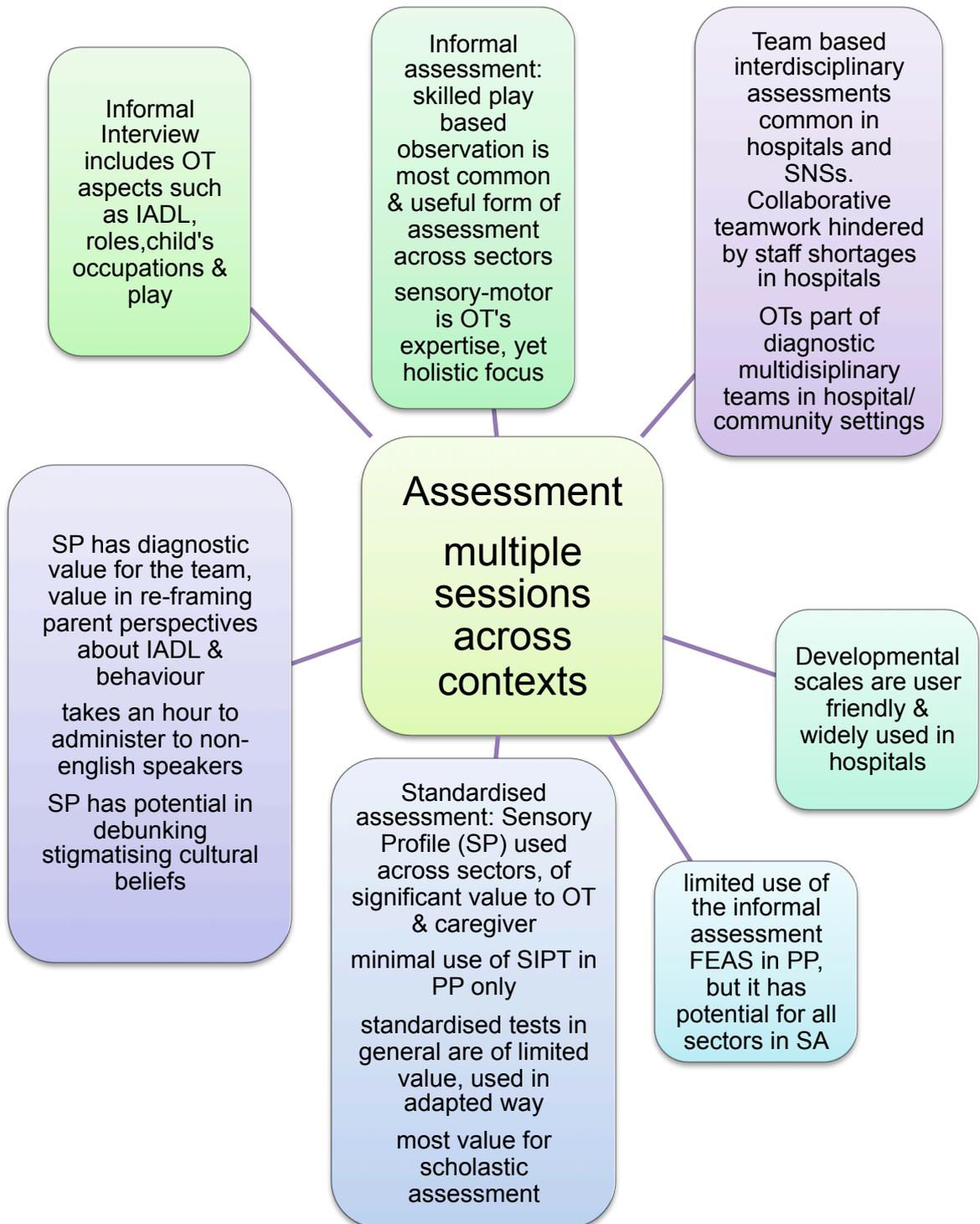


Figure 4.6.2: Schematic view of key Direct Intervention Findings

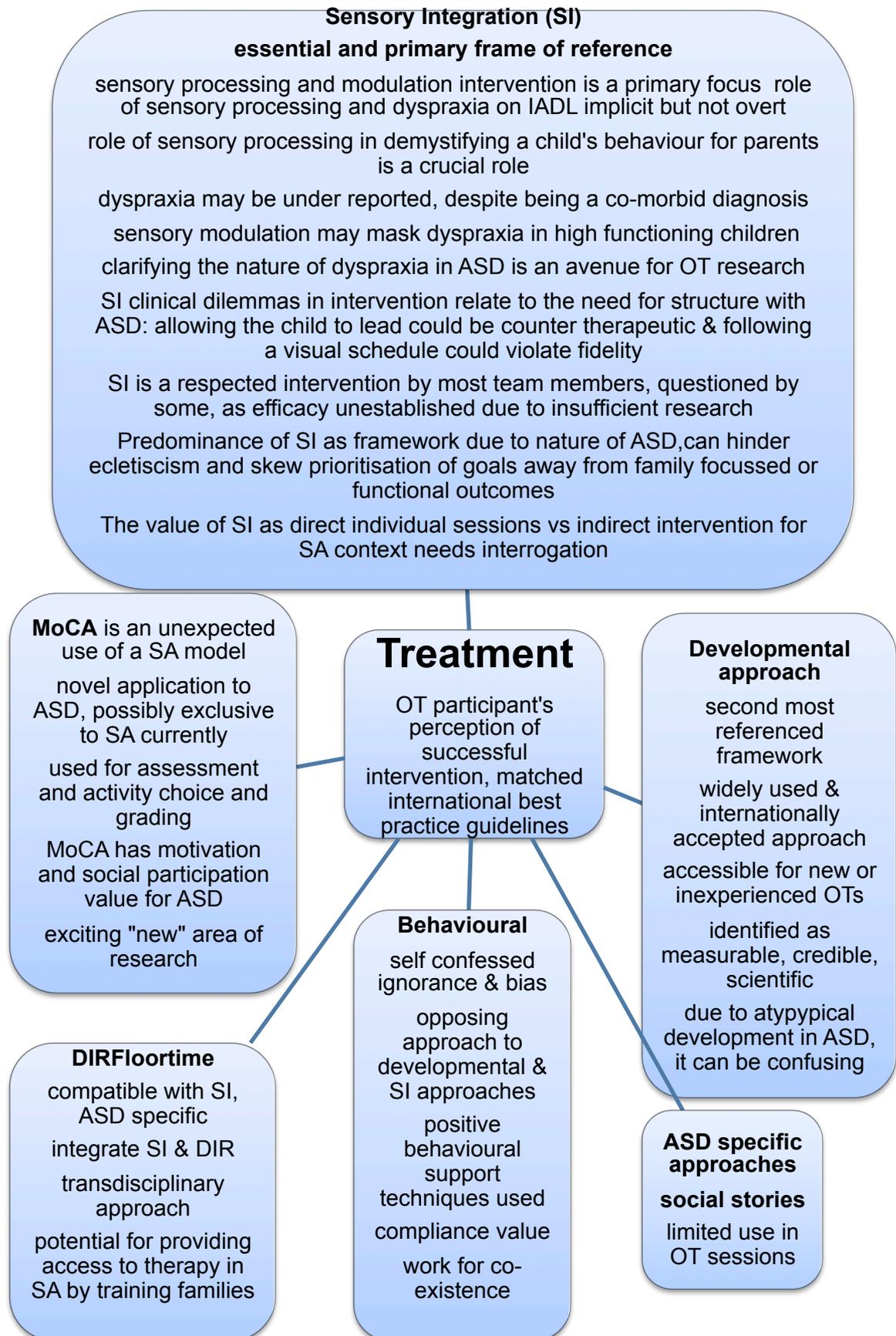


Figure 4.6.3: Schematic view of key findings for service provision models and team collaboration in sectors

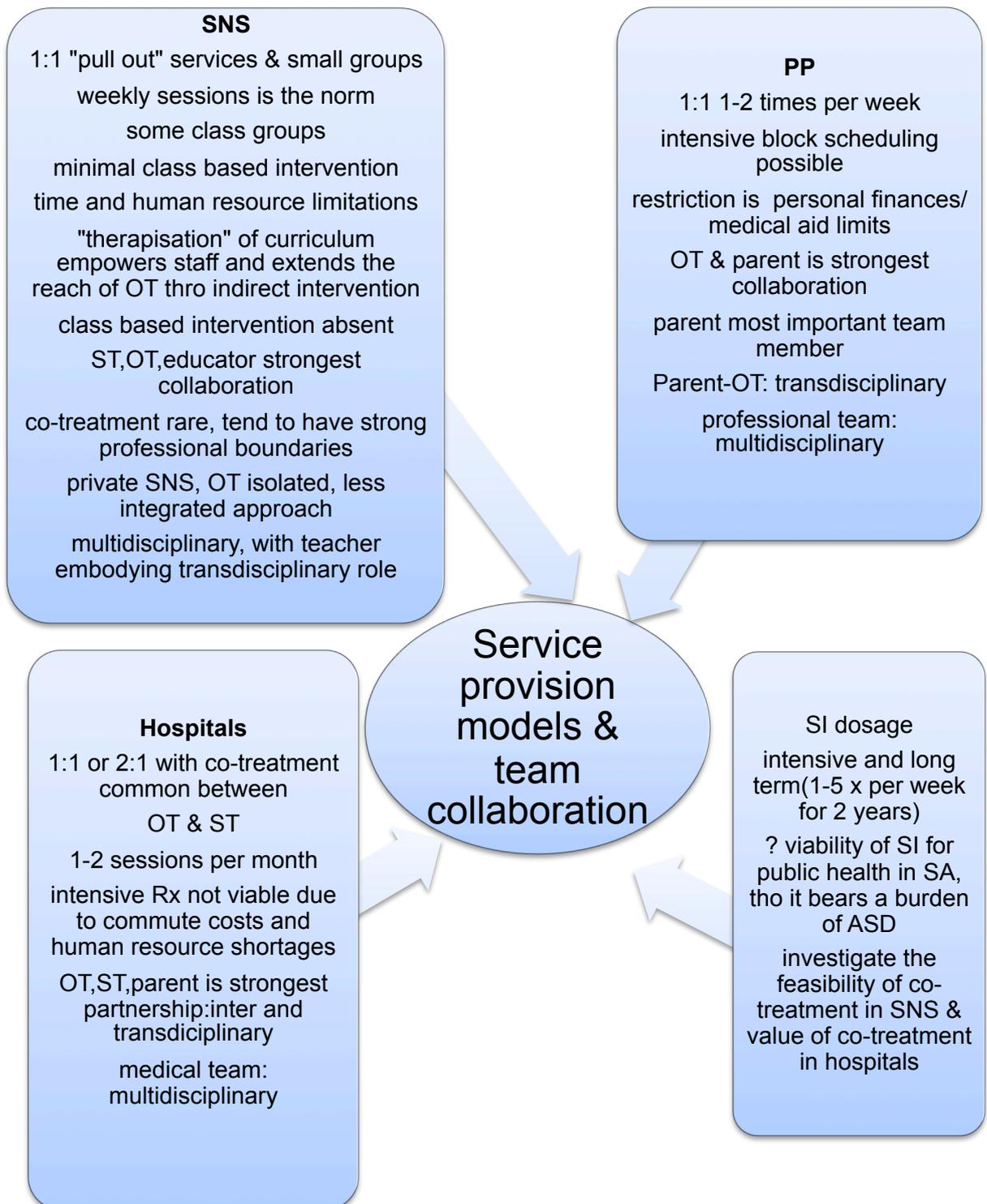


Figure 4.6.4 Schematic view of key findings on family collaboration

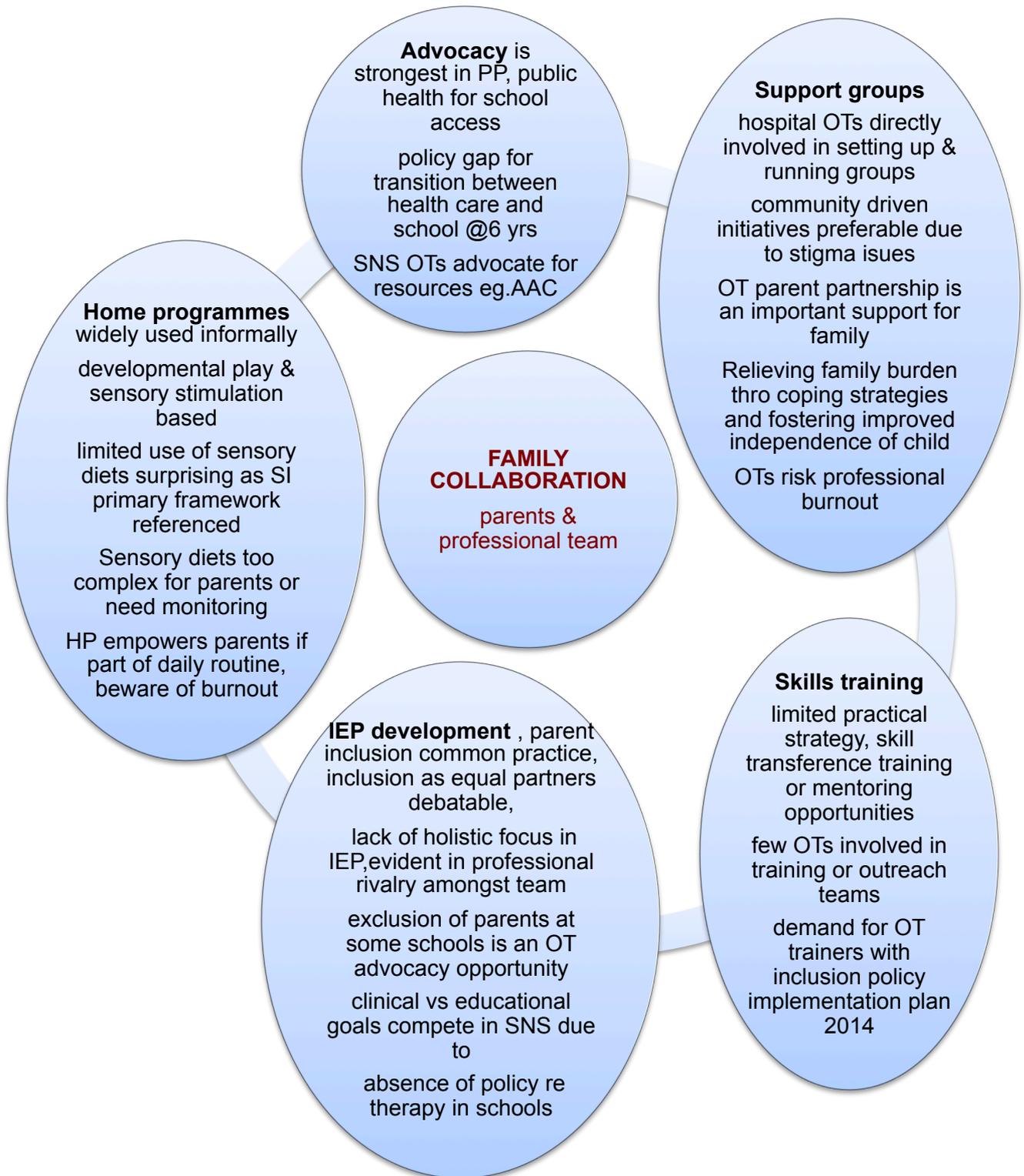
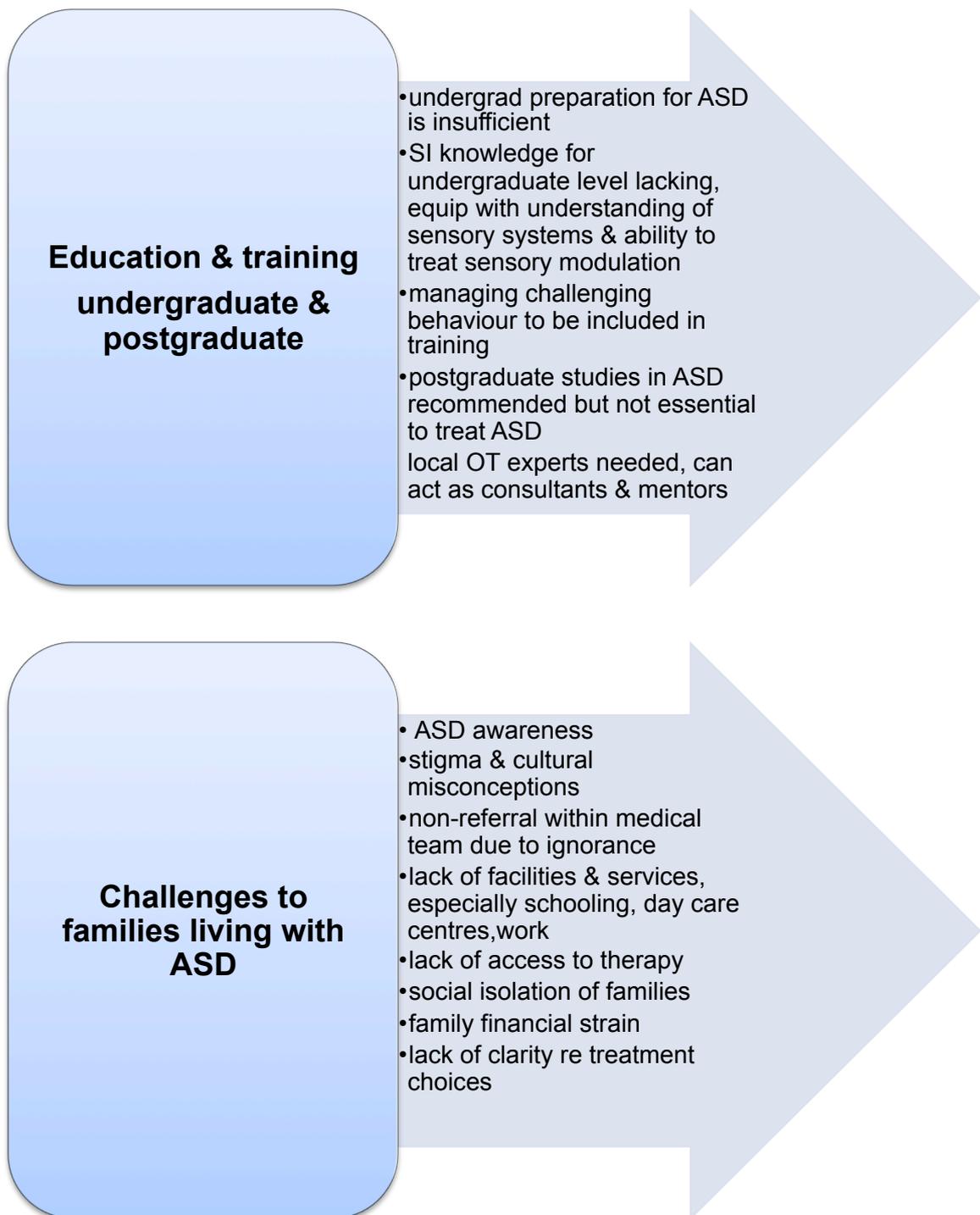


Figure 4.6.5: Schematic view of key findings related to education and training and challenges to families



## CHAPTER FIVE

### 5.1 CONCLUSION

An outline of conclusions drawn from the results and discussion of this study will precede recommendations and limitations of the study. This study explored OT practice in SA across sectors of public health, special needs education and private health care. It outlined OT assessment and therapy practices, indirect intervention practices through collaborative engagement with families and team members, service provision models, opinions on undergraduate and postgraduate training for ASD and challenges for SA families as well as perceptions of OTs around OT practice in SA. Similarities and differences in practice across the three sectors were highlighted.

SA practice is similar to international practice in a number of areas, despite unique challenges due to social conditions of poverty, infrastructure, cultural stigma, limited access to services and limited availability of services. Similarities to international practice are format and content of assessment practices, including the preference for informal assessments and limited use of standardised tests. Common standardised tests were used in both countries. OT components assessed and treated in direct intervention are largely sensory processing and sensory integration based, with one on one therapy common practice. After SI, the developmental approach was the second most popular framework referenced by both American and SA OTs. Collaboration between OT, SLT and educator was the strongest professional partnerships locally as well as internationally. Possibly unique to SA practice is the use of the MoCA model to assess and plan treatment for children with ASD at institutional and private practice level.

Sensory processing was a predominant focus in assessment and treatment, with functional developmental aims also prioritised. Skilled observation and an understanding of core deficits of ASD were important components of successful evaluation, together with multiple opportunities for observation across contexts where possible. Assessment and treatment practices utilised play, the child's interests or obsessions, with a strong SI and family occupational focus. OTs were the experts in sensory and motor assessment, while remaining holistic, by being

able to conduct assessments that were comprehensive. A sensory history was a significant component of the initial interview, with most OTs across sectors utilising the standardised Sensory Profile (SP; Dunn, 1989), to determine sensory modulation difficulties common in ASD. The SP with non-English language speakers takes up to an hour and depends on the availability of a translator or OT fluent in an indigenous language.

Standardised tests seem to hold most value for private practitioners and OTs in the SNS sector. The use of standardised tests to assess sensory integration and sensory motor skills despite on a limited basis, occurred most in private practice. The SIPT (Ayres, 1989) was seldom used and only used in PP. The limited clinical utility of standardised tests in SA was due to a number of factors besides those attributable to ASD as a condition. Tests were not designed for ASD specifically, internationally standardised tests lacked suitability across SA multilingual, multicultural populations and were expensive to purchase and in some cases administer. Other factors included the child's level of severity of ASD, as well as the length of administration and scoring of the test itself. Perhaps the use of a standardised sensory profile has the most value in reframing parent perspectives and may even play a role in dispelling cultural myths linked to behavioural idiosyncrasies.

A standardised sensory processing instrument such as the (SP; Dunn, 1989), which is able to differentiate children with ASD from those without REF, also has diagnostic value for the medical team. This is especially relevant, as OTs in some hospitals collaborate on diagnosis within multidisciplinary teams. Standardised assessments also have value on a scholastic level (visual perceptual tests) and for research purposes. Informal assessments may have better cross cultural clinical utility for SA, especially in community health settings. SA developed developmental checklists were commonly used, and are valuable for new graduates with limited SI knowledge or those new to the field. The FEAS (Greenspan, 2001) is an ASD specific informal assessment being used on a small scale in PP. The FEAS (Greenspan, 2001) as an informal assessment tool that involves the caregiver, may have clinical value across all sectors in SA.

OTs primarily referenced therapeutic frameworks with a developmental philosophy, such as SI, developmental skill facilitation, DIRFloortime and MoCA. SI was the primary frame of reference for the majority of OTs, due to the inherent nature of sensory issues in ASD. OTs emphasised sensory processing in intervention for modulation difficulties, whether they were SI certified or not. OTs felt that intervention for sensory modulation was a key starting point to creating a calm alert state in the child, and a suitable environment for learning. SI is respected amongst the team, but open to critique regarding efficacy due to insufficient research evidence. SI clinical practice lacked clarity in terms of fidelity, due to the unique requirements of greater structure for ASD. There may be a tendency for OTs to prioritise SI to the detriment of other valuable frameworks, due to the sensory features of ASD. This was evident in the prioritisation of goals, which could contradict functional and family priorities. The perspective of SI as operating within functional and family centred practice frameworks is critical to ethical practice. Whilst integral to ASD intervention, the value of SI within the SA context needs interrogation in terms of service provision challenges across sectors.

The second most referenced developmental framework is a widely accepted international approach that is accessible to new or inexperienced graduates. It was identified by participants as a measurable and credible approach.

DIRFloortime is often practiced together with SI due to similar philosophical roots. It was being used primarily in PP on a small scale. MoCA was an unexpected framework referenced for ASD, which may be a uniquely South African practice. MoCA's value for ASD is an avenue for further exploration, especially as it relates to facilitating motivation and social participation in the child. MoCA held value for OTs in assessment as well as treatment planning in terms of activity choice and grading.

The behavioural approach was less popular due to its contrasting philosophy to OT favoured approaches. Despite this, a number of its behaviour management principles and techniques were used by OTs. Behavioural challenges whilst often stemming from a sensory processing difficulty, may need more than an "SI" approach to reduce inappropriate behaviour and promote acquisition of new social skills. Positive behavioural support strategies were commonly used in OT sessions. There was a fair measure of resistance from participants to ABA versus more

naturalistic behavioural interventions. Participants admitted bias and ignorance, with few OTs viewing it as complementary to OT approaches. There exists self confessed bias and ignorance on the part of OTs towards behavioural intervention. There is a need to create awareness and improved collaboration between the behavioural and OT favoured approaches.

The use of ASD specific integrated approaches seemed to be influenced by the degree of inter and transdisciplinary teamwork. The use of eclectic approaches, including ASD specific approaches such as AAC and TEACCH was more common in education and public health. These ASD specific approaches need to be consciously integrated into OT sessions so that intervention is comprehensive and generalisation across contexts can be facilitated.

Motor skills are also an area of unique OT practice, specifically regarding the role of dyspraxia in ASD. Assessment of dyspraxia was often based on clinical evaluation, and dyspraxia was not always distinct from sensory modulation difficulties in some children on the spectrum. The nature and manifestation of dyspraxia in ASD compared to a child with traditional SI difficulties is an avenue for further investigation. The clarification of assessment and intervention for dyspraxia in children with ASD according to the DSM V's three levels of support required may be useful for clinical practice.

IADL is inextricably tied to the identity of OT as a profession as well as to sensory processing difficulties. Surprisingly, the role of sensory issues and dyspraxia was not highlighted but implicit in the intervention plan for IADL. This link between sensory processing and IADL was most beneficial in reframing parental understanding of challenging behaviours related to self-care routines. IADL was largely addressed through a consultation model. The role of sensory processing difficulties and dyspraxia on function in children with ASD was evident during parent consultation. However, the extent to which it impacted daily function and IADL may not be sufficiently emphasised during the counselling process.

In the majority, OTs were less directly involved in the use AAC and social stories than other team members. Social stories were most often, written by SLTs, teachers and parents. The need to integrate various approaches within the OT session,

including the use of AAC in particular, needs to be encouraged. The need for vigilance in the use of SI, so as not to exclude other relevant evidence based approaches is paramount to ethical practice. An eclectic and ASD specific family focussed approach is recommended. OT opinions on successful intervention for ASD compared favourably with best practice guidelines, which is extremely positive for a developing country such as SA.

Intervention in the form of direct therapy, for OTs across all sectors, was in the majority, individual therapy sessions. Co-treatment occurred most in hospitals and in some SNS's. The ability to respond to intensity of intervention had different challenges for each sector. In public health, transport costs hampered intensive block therapy due to services located outside of communities. Intensive blocks of therapy in private health, was hampered by financial cost to parents. SNSs had limited resources to provide more frequent services, to the level they would have preferred.

SNSs were still utilising direct "pull out" services, with less emphasis on class based and indirect intervention through consultation and "therapising" of the curriculum. Research has proven the success of class-based intervention, which can reach more pupils, while maintaining an occupation-based focus. The distinction between class based intervention and class run groups needs to be clarified and explored in school settings. This form of direct intervention is especially important for ASD, as the generalisation of skills across contexts is a challenge. The move to consultation and indirect services remains a policy level recommendation of White paper 6, which has not filtered into clinical practice.

Home programmes were a means of contributing to the twenty hours per week of active engagement, advocated for intensity of intervention. Home programmes were informal, utilising play, developmental goals and limited use of SI (sensory diet) activities. While sensory processing was a large component of direct intervention, it was surprising that sensory diets were not utilised as widely in home programmes. OTs were actively involved in co-ordinating support groups in hospitals. There were limited formal skills training opportunities for parents and professionals, especially in hospital and private health sectors. This is an identifiable gap in education and support to parents and professionals. The need for more OTs to serve on outreach

and training teams is needed, especially in the light of the 2014 inclusion policy implementation plan (Department of Basic Education, 2011). It requires staff in SNSs to be adequately trained to work with learners with ASD.

The viability and effectiveness of SI in public health and to a lesser extent in SNSs, remains questionable due to infrequent sessions. Rather than infrequent direct services, perhaps services should be directed to functional class or home activities through adaptation of the curriculum, family activities, routines and the environment. This is in line with international recommendations of learning to adapt behaviour in natural environments as they occur (National Research Council, 2001).

Private practice and hospital sectors shared a family centred approach with direct regular contact between OT and parents to collaborate on goals. Parents partnered with OTs in implementing intervention in therapy settings as well as in carrying over intervention into the home environment. Some SNSs did not embrace family centred policies such as parental involvement in IEP development. This goes against current recommendations and best practice. There was a strong allegiance to family centred practice amongst all OTs with evidence of this in their personal practice. The need for OTs to advocate this philosophy in the workplace to advance the rights of families is an ethical challenge.

OTs in SNSs and hospitals, share the benefits of regular contact with the multi-disciplinary team and opportunities for collaboration on assessment and intervention. PP has a strong SI focus, is multidisciplinary, with strong OT- parent collaboration. Co-treatment is used in hospitals and may serve SNSs well too. OTs and SLTs collaborate most strongly in hospitals. Teamwork is largely multidisciplinary in private practice, and more interdisciplinary in hospitals. SNSs were either multidisciplinary or interdisciplinary. A transdisciplinary model of intervention may have value in early intervention community settings, though the challenge will be to find sufficient numbers of skilled therapists to comprise intervention teams.

This study supports findings of other studies for the development of a postgraduate programme in ASD. SI would be an essential part of that programme, though the need for an alternate training channel was raised. The qualification process as is,

has the SIPT training component that is irrelevant for ASD. The value of specialist OTs who serve as part of ASD multidisciplinary teams, can offer support to clinicians, advise institutions on policy as well as advocate with and for persons with ASD. Undergraduate training OTs felt was insufficient to prepare OTs to work with ASD, a condition they are likely to encounter in their community service year. The inclusion of basic SI training in the undergraduate curriculum is the most popular suggestion from participants. Basic SI skills were considered necessary, in equipping graduate OTs to deliver intervention to persons with ASD. Other areas to include were managing challenging behaviour and the use of MoCA applied to paediatrics.

OT's perceptions of the challenges facing families matched those of SA caregivers (Hooper, 2005), indicating an understanding of local realities. A lack of facilities and services, especially schools and access to services were top priorities identified. Social awareness of ASD across cultures and poor knowledge and awareness amongst health professionals were also common issues. Access to therapy in public health, aside from the cost of transport, was also due to long waiting lists, under resourced facilities and lack of OT specialists. The situation in rural SA was presumed to fare worse.

## **5.2 RECOMMENDATIONS**

The following recommendations are made for future research and practice.

### **5.2.1 Research recommendations**

#### **Future research should:**

- Explore the most valuable and contextually appropriate standardized and informal tests for SA, across all sectors
- Explore the role of OTs in diagnosis especially in areas of sensory processing, motor skills and play skills
- Develop a pilot study on the use of a transdisciplinary assessment and intervention model in a community setting. This will contribute valuable

information to developing appropriate service provision models for South Africa

- Explore the value of an informal assessment such as the FEAS for clinicians and families in the South African context
- Translate and standardize the Sensory Profile (Dunn, 1999) in an indigenous SA language
- Explore the value of a sensory processing questionnaire for reframing African cultural perceptions around ASD
- Explore the value of co-treatment in SA health and education sectors
- Investigate the effectiveness of greater indirect services of consultation, “therapising” the curriculum and adapting learning environments versus direct therapy services in SA SNSs
- Explore the value of class based intervention and block scheduling in SNSs as alternate models to “pull out” intervention
- Pilot a multidisciplinary team of ASD specialists to consult with and provide support for staff on inclusion, at full service schools or SNSs with new ASD units
- Contribute towards the science or evidence base of SI by SA OTs, with a focus on the SA context
- Explore the value and application of Vona duToit’s MoCA model for ASD
- Explore parent perspectives on the value of OT for ASD, as this important perspective is lacking in the research
- Instigate greater interdisciplinary research collaboration on assessment and intervention for ASD in SA.
- Explore the issue of social stigma of ASD across SA cultures
- Explore issues of intensity of intervention and dosage solutions for public health in SA
- Explore the use and value of sensory diets with ASD, in schools and in families as home programmes
- Follow up this qualitative study on a quantitative level to ascertain the breadth of SA practice for young children with ASD

### 5.2.2 Recommendations for practice

- Postgraduate training in the form of a structured multidisciplinary programme in ASD is recommended, as SA needs specialists
- Undergraduate training should include lectures on ASD, basic SI theory and treatment principles for sensory modulation disorder as well as skills needed to work in collaborative teams. Interdisciplinary undergraduate training in some modules will foster skills needed in practice, particularly for complex disorders like ASD
- Greater availability of CPD seminars and mentoring opportunities for developing and improving skills in ASD intervention. The use of social media platforms may be useful online discussion and mentoring avenues
- Professional bodies need to respond to the clinicians need for information by providing greater clarity on practice issues and latest research information that is practical, especially as it relates to SI for ASD
- Practical skills and strategies training by a multidisciplinary team, for parents, health professionals and educators
- Mentoring for therapists in the field of ASD and setting up of a professional interest group
- Class based intervention and block scheduling of intervention need to be explored as alternate or parallel programmes within SNSs
- A one stop ASD specialist centre for a full range of assessment services
- OTs should partner with community organisations, to engage in advocacy roles for improved services
- Encourage the use of small group intervention for social skills development, together with individualised one on one therapy
- Develop a SA checklist for assessment together with suggestions for an assessment kit.
- Guidelines for a “starter kit” for therapy intervention will be also useful for OTs new to the field and for those in schools starting ASD units
- Develop resources and workshops for clinicians on eclectic and comprehensive treatment approaches, utilising ASD specific approaches such as AAC, TEACCH, social stories and positive behavioural support

- Development of a SA policy on therapy in education
- Development of SA guidelines for OT intervention for ASD

### **5.3 LIMITATIONS OF THE STUDY**

The depth of information or thick description, for aspects of the study was lacking. Limited information on fine motor skills for example, was gleaned. This was due to the broad scope of the study, covering all aspects of intervention from assessment to direct as well as indirect intervention. As an initial study, the breadth of OT intervention was explored with limited opportunity to probe all aspects covered. This study can form the basis from which further investigation on specific aspects can occur. Focus groups could have been used instead of interviews, with a possibility of divergent views emerging through interaction between participants. An inherent feature of qualitative research is its lack of generalizability. The extent and nature of OT practice for ASD in SA could not be determined.

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# APPENDICES

## APPENDIX A



Research Office, Govan Mbeki Centre  
Westville Campus  
Private Bag x54001  
DURBAN, 4000  
Tel No: +27 31 260 3587  
Fax No: +27 31 260 4609  
ximbap@ukzn.ac.za

12 March 2012

Mrs Aneesa Ismail Moosa (8523148)  
School of Audiology, Speech-Language Pathology and Occupational Therapy

Dear Mrs Moosa

**PROTOCOL REFERENCE NUMBER: HSS/0060/012M**  
**PROJECT TITLE: Exploring Occupational Therapy (OT) intervention for young children with Autism Spectrum Disorder (ASD) in South Africa (SA)**

In response to your application dated 5 March 2012, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

.....  
**Professor Steven Collings (Chair)**  
**Humanities & Social Science Research Ethics Committee**

cc Supervisor Gurayah Thev  
cc Karim Saira Banu  
cc Ms Phindile Nene



Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

## APPENDIX B

### Consent form

Regarding “Exploring occupational therapists perspectives on Occupational Therapy Intervention with Children with ASD” to be conducted by **Aneesa Moosa**, registration no: 8523148, as a requirement for her Masters in **Occupational Therapy** at the University of KwaZulu-Natal:

I have been adequately informed about the above research and hereby give the researcher permission to use the information that I am willing to provide during the interview. I understand this information will be kept in a private and confidential storage facility and that my identity will be kept anonymous in the reporting process. I have been assured that audio recordings will be destroyed within 5 years of completion of the study. Furthermore, I understand that there are no risks to my participation in the research. I thus willingly give consent to participate in the interview and this study, and reserve the right to withdraw at any point. I understand this information will be used for research and may be published.

Full Names: ..... Date: .....

School /hospital /private practice name:

Work tel no:

Work address:

Province:

Cell:

Email address:

(This form will be in duplicate so you will be able to keep the copy)

Aneesa Moosa

Occupational Therapist

Masters student at UKZN

Postal address:

P.O.Box 734, Westville, 3630

Cell: 082 480 8813

Email: [aneesasresearch@gmail.com](mailto:aneesasresearch@gmail.com)

for further information contact A.Moosa, or her supervisor,

Ms T. Gurayah (tel: 031 260 7310

or her co-supervisor, S Karim on 031-2607550)

Research Ethics Committee of UKZN: Faculty of Health Sciences, Westville  
Campus, P/Bag X 54001, Durban 4000

## APPENDIX C



June 2012

The Occupational Therapist

### REQUEST FOR PARTICIPATION IN A RESEARCH PROJECT

I am a postgraduate student currently registered for my masters degree in Occupational Therapy at the University of Kwa-Zulu Natal. I am conducting research in the field of autism, with my focus being Occupational Therapy intervention with children with ASD (Autism Spectrum disorder).

I need to interview occupational therapists who are working with children with ASD aged 2-12 years in school and private practice settings in Kwa-Zulu Natal, Western Cape and Gauteng provinces. I would like to request your participation in the study. You would need to participate in a single interview of approximately 90 minutes, with myself at your school or workplace.

The interview will be audio recorded for interpretation at a later stage. The recording will be used for this purpose only and will not be disclosed to another person.

The interview date and time will be scheduled for your convenience. In order to participate in this study:

1. You must be a registered OT working with children with ASD between the ages of 2 and 12 years

2. You must have clinical experience of 2 or more years working as an OT with ASD
3. You may have additional training such as sensory integration
4. Your OT intervention should be developmental or sensory integration in nature and not primarily or exclusively vocational or social skills training

Please be informed that participation in this study is on a voluntary basis and that you are at liberty to withdraw at any stage without any repercussions. You can be assured that your identity together with others that participate in this study, will remain strictly confidential. If you would like to participate in this study, please return and complete the attached consent slip to Aneesa Moosa at [aneesasresearch@gmail.com](mailto:aneesasresearch@gmail.com)

You will then be contacted telephonically to schedule an interview and clarify any concerns you may have.

Your participation in this study will be highly appreciated. If you have any queries, please contact me on 082 480 8813 or my research supervisor on 031-2607310

Yours sincerely

Aneesa Moosa

B. Occupational Therapy (UDW)

Occupational Therapy Masters student

Thev Gurayah

Lecturer

Department of Occupational Therapy  
Westville campus, University of Kwazulu-Natal, Durban

Tel: 031-2607402

e mail: [gurayaht@ukzn.ac.za](mailto:gurayaht@ukzn.ac.za)

## APPENDIX D



PRIVATE BAG X54001 DURBAN

4000 SOUTH AFRICA  
TELEGRAMS: 'ÚDWEST'

TELEX: 6-23228

The Principal

Dear Sir/Madam

### REQUEST : PARTICIPATION FOR OCCUPATIONAL THERAPY MASTERS RESEARCH PROJECT

I am a postgraduate student currently registered for my masters degree in Occupational Therapy at the University of Kwa-Zulu Natal. I am conducting research in the field of autism, with my focus being Occupational Therapy intervention with children with ASD (Autism Spectrum disorder).

I plan to interview occupational therapists who are working with children with ASD, aged 2-12 years in schools, hospitals and private practice. The OT s who choose to participate, will be interviewed once for approximately 90 minutes, by myself at your school. The study has received ethical clearance from the university of Kwa-Zulu Natal's Ethics committee (HSS/0060/012) and from the Kwa-Zulu Natal department of Education.

The interviews will be scheduled outside of therapy times and other school commitments, at a time convenient to the OT and the school. The interview will take place in her school department or office. The school and participant's identity and details will remain confidential during the data gathering process as well as in the research report.

The study's documentation of OT practice will be useful to OT s in the field as well as to policy makers and training facilities.

It would be highly appreciated if you would grant me permission to approach OT s working with children with ASD at your school. Further information for OT s will be forwarded to you upon receipt of a reply from you.

In order to meet research deadlines, I would appreciate a prompt reply. If you have any queries, please contact me on 082 480 8813 or my research supervisor on 031-2607310

Yours sincerely

Aneesa Moosa

B. Occupational Therapy (UDW)

Occupational Therapy Masters student

082 480 8813

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Ms Saira B. Karim

Lecturer

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## APPENDIX E

# University of KwaZulu-Natal



PRIVATE BAG X54001 DURBAN

4001 SOUTH AFRICA  
TELEGRAMS: 'UDWEST'

TELEX: 6-23228

DEPARTMENT OCCUPATIONAL THERAPY

WESTVILLE CAMPUS

July 2012

The Hospital Superintendent

### REQUEST : PARTICIPATION FOR OCCUPATIONAL THERAPY MASTERS RESEARCH PROJECT

I am a postgraduate student, currently registered for a Masters degree in Occupational Therapy at the University of KwaZulu-Natal. I am conducting research in the field of Autism Spectrum Disorder (ASD), with my focus being Occupational Therapy intervention with children with ASD.

I plan to interview occupational therapists working with children with ASD aged 2-12 years in schools, hospitals and private practice. The OTs who choose to participate, will be interviewed once for approximately 90 minutes, by myself at your hospital. The study has received ethical clearance from the University of KwaZulu-Natal's Ethics committee (HSS/0060/012M). Permission has also been received from the DoH (see attached approval letter). The KZN Department of Health requires permission from the institutions directly before granting approval, hence this request. I have identified the OT department at your institution as a viable research site.

The interviews will be scheduled outside of therapy time and other work commitments, at a time convenient to the OT. The interview will take place in her department or office. Participant's identity and details will remain confidential during the data gathering process as well as in the research report.

The study's documentation of OT practice will be useful to OTs in the field as well as to policy makers and training facilities.

Permission has been granted by the KwaZulu-Natal Department of Health for the hospital, upon your approval to participate in the study (see attached letter from. It would be highly appreciated if you would grant me permission to approach OTs working with children with ASD, at your facility. Receipt of your approval will be forwarded to G. Khumalo at provincial department of health for final approval. Once provincial department approval is received, further information for OTs will be forwarded to you.

In order to meet research deadlines, I would appreciate a prompt reply, within the week of 2012/07/23. If you have any queries, please contact me on 082 480 8813 or my research supervisors on 031-2607310/031-2607550/031-2607402

Yours sincerely

Aneesa Moosa

B. Occupational Therapy (UDW)

Occupational therapy Masters student

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**APPENDIX F**

**INTERVIEW SCHEDULE**

**Interview no:**

**Participant:**

**City/Province:**

**Work Setting:**

**A. BIOGRAPHICAL DETAILS**

Age:

Race:

Number of years of experience as a practicing OT:

Number of years you have worked with children with ASD:

Further training in OT or ASD related skills: eg. Sensory Integration (SI),  
DIRFloortime, auditory integration training (AIT)

---

---

**Describe your work setting:**

---

---

---

**Describe the range of children with ASD with whom you work: ages and  
severity, social background**

---

---

**Before we begin, is there anything you would like to share at the outset about your work with children with ASD ?**

---

**Describe your KEY role in providing intervention to children with ASD**

---

*Probe: Assess, diagnose, therapy, consultation, advocacy*

---

**B. ASSESSMENT in ASD**

**Tell me about your assessment of children with ASD ?**

---

*Probe (what areas assess, why assess these aspects, where assessment happens- environment), how-format, what tests used, who- multi-disciplinary team, referral)*

---

**Describe the content of a typical assessment (performance components and areas assessed)**

---

<ul style="list-style-type: none"><li>○ Gross motor co-ordination</li></ul>	<ul style="list-style-type: none"><li>○ Social/communication</li></ul>
<ul style="list-style-type: none"><li>○ Play</li></ul>	<ul style="list-style-type: none"><li>○ Activities of Daily Living</li></ul>
<ul style="list-style-type: none"><li>○ Sensory processing</li></ul>	<ul style="list-style-type: none"><li>○ Behaviors</li></ul>
<ul style="list-style-type: none"><li>○ Fine motor co-ordination</li></ul>	<ul style="list-style-type: none"><li>○ Cognition</li></ul>
<ul style="list-style-type: none"><li>○ Praxis</li></ul>	<ul style="list-style-type: none"><li>○ Visual perception</li></ul>
<ul style="list-style-type: none"><li>○ Oral motor control/praxis</li></ul>	<ul style="list-style-type: none"><li>○ other</li></ul>

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**Elaborate on your role as an OT in the assessment of a child with ASD**

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*Probe: unique OT contribution, role in diagnosis, differs in settings? Educational vs medical*

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**Tell me about the specific tests or assessments you use and why?**

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*Probe: standardised, non-standardised , sensory profile(Dunn)*

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### **C. THERAPY-DIRECT**

**Describe a typical therapy session with a child with ASD**

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*Probe: duration, content, environment,*

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**Tell me about the most important frames of reference you use in therapy**

*Probe:*

<i>Sensory Integration</i>	<i>Motor Learning Approach</i>
<i>Ecological adaptation</i>	<i>Applied Behavioural Analysis (ABA)</i>
<i>Developmental skills</i>	<i>DIRFloortime</i>
<i>Neuro-Developmental Therapy</i>	<i>Creative Participation</i>
<i>Biomechanical</i>	<i>Motor Learning Approach</i>
<i>Cognitive, visual perceptual</i>	

- *Reasons for the choice of these frames of reference*
  - *Applicability in private practice/school settings*
  - *Evidence based practice / success*
  - *SI controversy, use as therapy or framework, environmental management*
-

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**Tell me about any other approaches you use in your practice?**

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*Probe: ABA/Discrete trial training*

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*Computer technology - iPad*

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*Auditory Integration Therapy*

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*Hippotherapy*

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*TEACCH*

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**Describe other therapy techniques that you may use in therapy with children with ASD**

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*Probe: facilitation-hand over hand, SI tech of proprioception, NDT tech of proprio, weight bearing, alignment*

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**Tell me about the service provision model you use, with children with ASD eg. the pull out model in school, one on one or group therapy**

*Probe:*

- Pull out (1-1 or group)
  - Class / ecologically based
  - Team
  - Home/ community based
- 
- 
- 

*Probe: why this approach?*

*Dictated by context/policy*

#### **D. INDIRECT INTERVENTION**

**Tell me about your indirect intervention programmes in OT**

*Probe:*

- *Team consultation*
  - *Supervised therapy or Home programmes*
  - *Parent meetings*
  - *Parent training*
  - *Advocacy (inclusion)*
- 
- 

*Probe: value of, proportion of time spent on,*

#### **E. TEAM WORK**

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**I d like to explore the concept of teamwork in your practice. Tell me more about team collaboration.**

*Probe: value of, extent of, level of collaboration*

*Type of collaboration*

- *Multi-disciplinary; discipline specific, maintain individual roles*
- *Inter-disciplinary: knowledge and skills across disciplines*
- *Trans-disciplinary: one team member fulfils all roles on behalf of team (role release)*

*Experience of, opinion of each model*

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**Who are team members with whom you have the most contact?**

*Probe: Dr, teacher, ST, audiologist, psychologist, parent, other*

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*Discuss further - how, why*

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**Tell me about the difference if any, in working in a team for children with ASD as compared to teamwork for children with other disabilities ?**

*Probe: transitions, importance of environments, behaviour*

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## **F. WORKING WITH FAMILIES**

**Talk to me about your experiences with working with families of children with ASD**

*Probe: positive-early intervention, negative-poor co-operation*

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*Education, training, support, specific skills training eg SI*

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**Tell me about your (OT) role when working with the family**

*Probe: ed, training, support, specific skills eg SI in daily routines*

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**G. EDUCATION and TRAINING**

**What is your opinion on undergraduate training in preparing OT s to work with children with ASD?**

*Probe: adequate, suggestions re skills needed?*

*Solution to coping with future demand?*

**Discuss your confidence levels in implementing intervention for children with ASD**

*Probe: due to skills, experience, training, peer validation*

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**What is your opinion, about the need for OT specialists in the field of ASD intervention**

*Probe: literature indicates this- appropriate solution for SA?*

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**H: What in your opinion, are the challenges for children with ASD and their families in SA?**

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*probe: diagnosis, therapy (OT services), education, work, family life, support, economic, awareness*

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**Elaborate on “successful intervention” for a child with ASD?**

**Any closing comments**

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