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Development of a questionnaire to determine change in the occupational performance of pre-school children with autistic spectrum disorders receiving occupational therapy - sensory integration

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Chapter 2

REVIEW OF LITERATURE

This review of the literature will consider ASD and the assessment of constructs of sensory processing and parent stress related to occupational performance both in terms of the child with ASD and the family. The role occupational therapists play in intervention and the use of outcome measures and occupation based outcome measures with this population will also be considered.

2.1 Introduction

Autistic Spectrum Disorder consist of a number of conditions including pervasive developmental disorders (PDD) and Autism which are neurobiological disorders of development that cause discrepancies in the way the brain processes information. This affects the child's ability to understand language, communicate with people, understand and relate in typical ways to people, events and objects in the environment. It also affects the child's ability to learn and think in the same way as typically developing children (Schaaf, et al. 2007). There is no cure for autism, but as soon as a diagnosis of ASD is suspected, early intervention services need to be recommended. In the pre-school years a supportive educational environment with related services appears to be the most beneficial management strategy in assisting individuals with a disability to lead meaningful lives (Schaaf et al. 2007).

Experts agree that there is an increase in the prevalence of ASD , especially in the early diagnosis of the disorder in the pre-school age group compared with 30 years ago (Allik, et al. 2006; Rutter, 2005; Fombonne, 2003; Powell et al. 2000). The number of young children with diagnoses that fall into the autistic spectrum in the last 10 years in South Africa has increased considerably (Jacklin, 2006).

2.2 Factors Affecting Occupational Performance in the Child with an Autistic Spectrum Disorder

In OT a wide variety of internal and external performance components (Kielhofner, 2002) supporting the activities carried out in occupational performance for both children with

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ASD and their parents, have been researched and are assessed. These include motor and process skills, communication and interaction skills, and the effects of the environment in facilitating participation (Case Smith, 2005).

The developmental perspective is one of many frames of reference used by occupational therapists to frame their assessment of a child's occupational performance and to identify dysfunction in relation to developmentally normal milestones or age appropriate behaviour (Case-Smith, 2005; Stewart-Lord & Kotkin, 1998). The sensory integration (SI) frame of reference is commonly used by occupational therapists treating children with ASD (Case-Smith et al. 1999). Therapists therefore consider both the developmental level and sensory processing in the child with ASD as well as parent stress in terms of family functioning in their assessments and therapy (Diggle et al. 2003; Case-Smith & Miller, 1999). All these factors are necessary for a holistic approach to therapy, as parents want therapists to understand their family's values and aspirations for their children, and they want to understand and be part of the therapy process, and learn strategies to cope (Cohn & Cermack, 1998)

Inclusion of the SI frame of reference allows the therapist to identify dysfunctional internal components in the child with ASD which cause dysfunction in occupational performance. The atypical motor development which includes low muscle tone, repetitive motor movements (Baranek, 2002) and dyspraxia affect the child's endurance and ability to imitate and learn resulting in developmental delay. (Rogers, Hepburn & Wehner, 2003; Mailloux, 2001; Radomski, 18995; Ayres, 1972). Poor oral praxis adversely influences the development of speech and thus the ability to communicate (Oetter, Richter & Frick, 2001). Baker, Lane, Angley & Young (2007), reported the presence of sensory processing difficulties in children with ASD, which affect their ability to understand and respond to sensory stimuli in typical ways which results in problems with their social, emotional and behavioural functioning needed for everyday activities. Children with ASD show these abnormal sensory responses to both social and non-social stimuli in the absence of known peripheral dysfunction like hearing acuity or visual deficits (Ben-Sasson et al. 2007; Hilton, Graver, & LaVesser, 2007).

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2.2.1 The relationship between Occupational Performance and Sensory Processing in the Child with Autistic Spectrum Disorder

Literature reports that 80%–90% of children with ASD have poor sensory processing (Ornitz, Guthrie & Farley, 1977), which sets them apart from children with global cognitive impairments (Dahlgren & Gillberg, 1989). Using the Diagnostic Interview for Social and Communication disorders (DISCO) at least a 90% frequency of sensory symptoms was found, in both the low and high functioning ASD groups, in taste, smell, touch (Leekam et al. 2007). Occupational therapy literature reflects a similar picture using Dunn's (Dunn, 1999) Sensory Profile (Kientz & Dunn, 1997) and the Sensory Processing Measure (Miller-Kuhaneck, Henry, Glennon & Mu, 2007).

Jasmin et al. (2009) found a relationship between daily living skills measured on the Functional Independence Measure (FIM) and the sensory processing in pre-school children with ASD who present with atypical sensory responses, motor difficulties and difficulties with daily living skills. Poor functional independence in daily living skills is related to and caused in part by their atypical sensory responses and fine motor difficulties (Stephens & Tauber, 2001; Parham & Mailloux, 1996). In a recent pilot study of 22 children with an ASD daily living skills, and behavioural responses correlated moderately with sensory processing difficulties on the Short Sensory Profile (SSP) (Baker et al. 2007).

Children aged three and six years with ASD show the greatest differences in the under-responsive/seeks sensation, auditory filtering and tactile sensitivity scores when compared with an age matched typically developing control group (Tomchek & Dunn, 2007; Kern, Trivedi, Garver, Johnson, Andrews, Savla, Mehta & Schroeder, 2006). Children with ASD frequently demonstrate mixed patterns: hyper-responsivity to auditory and tactile stimuli, and hypo-responsivity to proprioceptive and vestibular stimuli have been consistently reported in the same children (Kientz & Dunn, 1997). It has been hypothesised that the behavioural features of this reported sensory hypo-responsiveness are connected to sensory gating, discrimination, attention and motivation systems across social and non-social contexts (Davies & Gavin, 2007) resulting in an inability to relate socially and to communicate. The severity of hyper-responsiveness to environmental stimuli makes it difficult for children with ASD to adapt to novel situations, affecting their exploration and participation in new activities. Hypersensitivity to auditory and tactile stimuli and hyposensitivity to proprioceptive stimuli result in vision being the preferred

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sensory channel used to interact with the environment in this population (Dzuik, Gidley-Larson, Apostu, Mahome, Dinckla & Mofstovsky, 2007; Mailloux, 2004; Williamson & Anzalone, 1997). These sensory patterns of hyper- and hypo-responsiveness and the associated behavioural manifestations therefore affect the ASD child's occupational functioning at home, at school and at play (Baranek, Boyd, Poe, Watson, 2007; Baranek, David, Poe, Stone & Watson, 2006). The relationship between occupational performance areas and different aspects of sensory processing is discussed further under the various occupational performance areas.

2.2.1.1 Personal Management

Although there is scant literature describing the performance of children with ASD in terms of daily living activities, children with ASD obtain lower scores in daily living skills than do children matched by age and non-verbal IQ on psychological tests (Liss, Saulnier, Hare, Fein & Kinsbourne, 2002). Konstantareas & Homatides, (1989) identified occupational performance delays in the assessment of ASD children with a mean age of six years ten months. Sleeping problems and self-abusive behaviour were prevalent, and more than half were not toilet trained.

Disrupted sleeping patterns, intense difficulties that arise during the transition to bedtime, calming for sleep, staying in bed, falling asleep and remaining asleep throughout the night were commonly described problems (Miller-Kuhaneck, 2004). Sleep issues and irregular sleeping patterns are frequently part of the ASD child's sensory and arousal dysregulation and parents frequently use sensory strategies to assist their children to fall asleep in an a attempt to diminish the effect of disrupted sleep on family members (Weiss, 1991). Developmental norms indicate that by the age of three years sleep-wake cycles should be well regulated, with an uninterrupted 10½-hr night-time sleep (Miller-Kuhaneck, 2004; Stewart-Lord & Kotkin, 1998).

Sensory processing difficulties also result in sensitivity to food tastes, smells and textures so the child with ASD eats a very limited diet, which frequently makes it very difficult for the family to eat out of their own home environment (Cermak, Koomar & Szklut, 1998). Other difficult behaviours, associated with sensory issues, like rigid feeding routines, limited diets, intolerance for a variety of food tastes and textures, difficulty with sucking, chewing and swallowing, disruption of meal times and a short attention span all affect family harmony at mealtimes even at home (Dunn, 1999). Feeding idiosyncrasies were

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used to evaluate the eating behaviour of children with ASD as normally developing toddlers should be eating a wide range of healthy food as part of a balanced diet by the age of three years (Miller-Kuhaneck, 2004).

Behavioural difficulties like late bowel and bladder control have also been linked to sensory processing difficulties (Smith Roley, Blanche & Schaaf, 2001). Limited independence in many hygiene tasks, especially extreme difficulty with toilet training, are frequently issues in children with ASD (Case-Smith, 2005; Miller-Kuhaneck, 2004). The effects of the social environment at home and at school are factors that influence the child's independence in toileting routines (Case-Smith, 2005). Anxiety evoked by unfamiliar environments appears to result in an inability to pay attention to interoceptive cues and an inability to plan the motor response required to void the bladder or bowel, provided that specific bowel and bladder problems have been excluded (Wheeler & Kranowitz, 2007).

In this aspect children usually gain control by three years (Stewart-Lord & Kotkin, 1998) thus problems in all of the above occupational performance areas in children with ASD between four and six years could be considered as related to their condition, if other specific bowel and balder problems have been excluded.

2.2.1.2 Social Interaction

Social interaction is one of the triad of impairments that defines autism which includes communication and cognitive impairments, as originally described by Wing in 1981 and the American Psychiatric Association (2000). Difficulty in processing more than one stimulus simultaneously is the factor that appears to impair social interaction in individuals with ASD, as they struggle to orient to social stimuli (Williams, 1994; Grandin 1986). The child with ASD has extreme difficulties with self-calming once upset which frequently manifests as aggressive behaviour, not coping in unfamiliar settings and struggling to deal with transitions and change in routines. Parents often find they have to deal with tantrums or self-stimulatory behaviour (Cohn & Cermak, 1998). Therapists need to be able to monitor the frequency of these behaviours, as self-regulation is a pre-requisite for peer and group interaction.

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Parents want their children to fit in socially and to participate with same-aged peers, with siblings and with other children. The child with an ASD finds using and reading non-verbal cues very difficult. Poor attention in group settings, as well as difficulty with sharing, imitation and turn taking makes it very challenging for them to form friendships. As a result children with ASD tend to remain on the fringes of their peer groups. Group participation is a prerequisite for coping in a pre-school and school environment (Weiss, 1991).

Due to dysfunction in social interaction the inclusion of the pre-school ASD child in group activities like family gatherings, birthday parties, shopping expeditions and eating in public places presents a very real challenge for parents (Schaaf & Miller, 2005; DeGrace, 2004).

2.2.1.3 Communication

Communication is one of the major impairments in ASD (Wing, 1981). Information processing, particularly auditory processing, makes understanding of language and communication difficult and affects the child's ability to relate in typical ways to people, events and objects in the environment (Dominick,Davis, Lainhat, Tager-Flusberg, Folstein, 2007; Schaaf et al. 2007). The child with ASD's concrete perspective on the world makes the lack of development of a sense of humour and socially inappropriate behaviour a concern (Miller-Kuhaneck, 2004).

Communication that enables children to have their needs met and follow instructions were frequently expressed parental goals. This included requesting, signing, gesturing and asking for help using language or augmented communication strategies. Fathers particularly found the communication challenges to be most stressful (Esdaile & Greenwood, 2003),

2.2.1.4 Play

Play is one of the three primary occupational roles addressed in the theoretical foundation of occupational therapy (Couch, Deitz & Kanny, 1998). Play is the primary occupation of children (Bundy, 1993). All children have an innate drive to develop physically and mentally. They use play to master each new level of development and to foster development and maturation of the central nervous system. Play, using toys and activities provide the child with opportunities to communicate, to practise specific motor

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and functional skills and to promote sensory processing, perceptual abilities and cognitive development. As children endeavour to respond to greater challenges through child-directed play, integration of increasingly complex sensory experiences and adaptive responses occurs (Fisher, Murray and Bundy, 1991).

Children engage in different types of play depending on their circumstances and particular needs. Types of play vary from passive observation to participation in group play, which requires planning and co-operation. It is important to understand how typically developing children develop play skills, in order to understand the differences we see in the population of children with ASD. Solitary play with e.g. push button toys, opening and closing doors is common (Case-Smith, 2005). Children with ASD frequently get stuck on repetitive cause and effect play sequences (Watson, Baranek & DiLavore, 2003). The social-emotional component of play is a deficit in children with ASD, and the emergence of object permanence and associated enjoyment of "peek-a-boo" games are important in determining this aspect (Case-Smith, 2005).

With the development of mobility, spatial and temporal concepts develop, which gives rise to packing and unpacking, pushing, pulling and pouring, and children begin to manage to classify according to form, size and colour concepts (Watson et al. 2003; Stewart-Lord & Kotkin, 1998).

Pretend play is evidenced when toddlers begin to imitate adults in their world. They enjoy pushing and pull along toys, imitating daily living activities, and playing "pretend" games with cars or dolls. When children start to substitute objects in play sequences we know that they can suspend reality and that the child is at the stage of representational play. Substitution of objects in play sequences is a sure sign that this is developing (Watson et al. 2003; Greenspan & Weider, 1998). Typically developing toddlers of three years of age are able to deal with complex emotional thinking, can differentiate what is real and what is not, and pretend play has a logical structure, with ideas that are connected (Greenspan & Weider, 1998).

The level of play in children with ASD varies tremendously, although to an extent the child's developmental level will determine play. Some children with ASD have a high sensory need for movement or touch whereas others are sensory avoidant (Dunn, 1999). The result is that restrictive, repetitive and sometimes destructive play predominates.

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Frequently one observes repetitive banging, shaking, poking or mouthing which the child uses to gain optimum feedback in order to learn from the sensory experience (Case-Smith, 2005; Watson et al. 2003).

Some children with ASD have difficulty in choosing appropriate toys or games, and tend to resort to toys that would appeal to a much younger child, or display perseverative play routines, so that their repertoire of play becomes circumscribed. Many children with ASD need adult supervision in order to optimise their attention span. Some are unable to play alone, whereas others struggle to cope with parallel play. Playing alongside ones's peer is a milestone seen in normal development at around 24–30 months, (Solarsh, Katz & Goodman, 1990) due to difficulties with attention and imitation (Miller-Kuhaneck, 2004).

2.2.1.5 Schooling

The child's developmental level, the severity of symptoms with regard to impairments which characterise ASD (Wing, 1982), and the child's level of independence in the realms of occupational performance; would determine the goodness of fit with various educational options. The social/emotional/sensory nature of ASD impacts on this with both sensory hypo and hyper-responsiveness affecting their ability to tolerate the structured situation presented at most schools (Greenspan & Weider, 1998). The child with ASD will not manage to learn in noisy environments with distractions, as they cannot focus on the interactions that do matter. Tactile sensitivities and poor verbal and receptive communication make learning from verbal instruction difficult. Most school or educational institutions present complex sensory environments. Thus the unpredictable individualized reactions of each child with ASD as a result of different sensory processing disorders make successful participation at school difficult for both the child, the teacher and other children (Baranek, 2002).

2.2.2 The relationship between Occupational Performance in the Child with Autistic Spectrum Disorder and Parent Stress

Parenting of children with developmental disabilities is associated with impaired mental health, higher levels of stress, tiredness and exhaustion, feelings of intense anger, guilt, depression and anxiety most of the time (Allik et al. 2006). Literature shows that parents of children with ASD have higher rates of psychological distress than parents of children with other developmental disabilities (Fombonne, 2003). The older and lower functioning

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the child, the higher and more chronic is the parent's stress level. This stress was associated with fears regarding their child's future (Konstantareas & Homatides, 1989).

Atypical behaviours leading to a lack of occupational performance in young children with ASD are common issues faced by parents (Cermak et al. 1998). Studies making use of the Parent Stress Index (and the PSI-SF respectively; also reported excessively high levels of Parenting stress (Fisman, Wolf, Ellison & Freeman, 2000; Wolf, Noh, Fisman & Speechley, 1989), with all three domains elevated. The child with ASD has difficulty in participating as a family member and as part of a community. This affects family adjustment. The result of this family stress is highlighted in research on the everyday occupations and factors related to family functioning in families with a child who has ASD. (Miller-Kuhaneck, 2004). These aspects all relate to parenting stress and the family's ability to function as a unit (Zhan, 1992) and include a number of aspects:

2.2.2.1 Family Time

Family time is depleted by rigid therapy regimes and dealing with professional and support services (Wilson, Kaplan, Fellowes, Gruchy & Faris, 1992). Insufficient information about care for the child and the constant need for supervision were rated as specific factors creating the most extreme stress for the caregivers (Konstantareas & Homatides, 1989). Families felt "robbed" of time; they felt that family celebrations, birthday parties and holidays, which were the essence of being a family, were often not worth the effort, and resulted in marital strain (DeGrace, 2004).

Due to the time-consuming task of attending to the ASD child's special therapeutic and educational needs, mothers are frequently unable to pursue their careers or interests (Donovan, van Leit, Crowe, & Keefe, 2005; Tunali & Power, 2002). The child's prolonged dependence on their parents and unusual habits frequently cause family members anxiety and distress (Weiss, 2002; Weiss, 1991).

2.2.2.2 Atypical Behaviour in the Child with Autistic Spectrum Disorder

Allik et al. (2006) conducted a study on Health-Related Quality of Life (HRQL) in parents of children with Asperger's Syndrome (AS) and High Functioning Autism (HFA), using a 12 Item Short Form Health Survey (SF-12), measuring physical and mental wellbeing. A correlation was found between maternal wellbeing and child behaviour characteristics. Pre-school children with autism showed the highest level of behaviour problems, and

mothers of these children reported more parenting stress than other groups (Eisenhower et al. 2005)).

The difference between the father's and the mother's experience of parenting stress was examined using Abidin's Parenting Stress Index (Abidin, 1995) in families where there was a pre-school child with a disability, including families with a child with ASD. The range of specific stressors that fathers found most difficult to manage was their child's inability to communicate and their anxiety reactions (Konstantareas & Homatides, 1989). Fathers rated the child's acting out (Davis & Carter, 2008), self-abusive behaviour (Konstantareas & Homatides, 1989) and delays in language development as being their major stressors. Mothers, whose role in child-care and parenting was greater, found a low level of adaptive behaviour and a high frequency of distressing symptoms the most stressful. Some mothers experienced guilt and uncertainty regarding mothering. Most stressful for them were the child's visual preoccupations and other sensory seeking behaviours, including smelling, licking and rubbing, inappropriate affect, the inappropriate use of the body and objects typically seen in ASD (Ornstein-Davis & Carter, 2008).

Research (Hastings & Brown, 2002; Moes, Koegel, Schreibman & Loos, 1992) found that mothers reported more anxiety and depression than fathers and their stress levels were predicted by their child's behaviour problems including hyperactivity and conduct problems, rather than by adaptive behaviour problems or ASD per se (Hastings, Kovshoff, Ward, Epinosa, Brown & Remington, 2005). Other stressors included their child's extremes of activity, impaired imitation, and resistance to change. When the behaviour problems were profound, mothers who were less optimistic reported lower scores on measures of wellbeing than mothers who were more optimistic (Baker, Blacher & Olsson, 2005).

2.2.2.3 Social Support and Life Satisfaction

Because of the lifelong needs of individuals with ASD, families need to be prepared to cope with challenges as they arise over the individual's lifetime. However, if parents are supported, informed and empowered through an understanding of their child's behaviour and sensory needs in the pre-school years, they find it easier to promote organised and goal-directed behaviour, in a modified environment. (Hastings & Brown, 2002)

However, research illustrated the additional stressors experienced by these parents resulted in fewer opportunities for interacting within their communities or even sociability within their own homes, thus decreasing their support systems (Esdaile & Greenwood, 2003). This may be related to the stigma associated with maladaptive behaviour in children with ASD as well which results in siblings struggling to maintain peer relationships (Hastings, 2003), and families feeling isolated due to the restriction in the child's ability to cope in a variety of settings (Miller-Kuhaneck, 2004).

Stress was also related to overall parenting difficulty, the number of parenting tasks performed primarily by each parent, division of the burden between the parents, the perceived fairness of and satisfaction with this division, and personal life satisfaction (Milgram & Atzil, 1988). Families where there was a greater emphasis on spousal support and those who had more understanding of their child's behaviour were better adjusted (Tomanik, Harris & Hawkins, 2004). Those parents who placed less emphasis on career success, and believed that mothers of young children should not work outside the home, spending more leisure time with their extended family, as opposed to individual leisure pursuits, placed less emphasis on the opinions of others of their child's behaviour. These mothers who were able to make sense of situations beyond their control were found to have greater life satisfaction (Donovan. van Leit, Crowe & Keefe, 2005; Tunali & Power, 2002).

Research on the effectiveness of treatment in children with ASD has considered change in underlying performance components of sensory processing (Touch, taste, smell, visual, auditory, proprioception and movement) (Rogers & Ozonoff, 2005) and the effect on the family stress, rather than changes in child's occupational performance areas (feeding, sleep, toilet training, play and socialisation) (AOTA, 2004a; Watling, Deitz, Kanny & McLaughlin, 1999).

2.2.3 Outcome Measures for Sensory Processing and Parent Stress

Two of the outcome measures used in occupational therapy to measure sensory processing and family function are Sensory Profiles (SSP) (Dunn, 1999) and Abidin's Parenting Stress Index (PSI-SF) (Abidin, 1995). Both have been successfully used in studies of children with ASD where internal components and family perspectives were

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under investigation. Occupational therapists view goal-directed behaviour in terms of changes in occupational performance by measuring the individual's ability to participate in meaningful occupation (Mailloux, 2001). OT's also help parents understand the effect of change in occupational performance on their family's functioning and their own stress.

It would be of assistance to include:-

1. a sensory processing measure as an outcome, to measure the change in sensory processing during the time the pre-school child attends OT-SI, in order to evaluate the efficacy the treatment of internal performance components.
2. The use of a parenting stress measure as another outcome, to measure the change in parenting stress during the same time period, would be of assistance in evaluating the efficacy of family-centred treatment. Although it is virtually impossible to ensure there are no other variables; by delineating stress related to the child with ASD and the parent/child relationship; from internal parental distress i.e. stress outside of the parent/child dyad, the researcher endeavoured to minimise extraneous parent variables. The treatment effect could be measured by recording change in parenting stress related to the child over time.
3. It would be useful to correlate both sensory processing and parenting stress with the occupational performance outcome measure.

2.2.3.1 The Short Sensory Profile (SSP)

The use of sensory profiles as a measure of change and adaptive ability in the ASD population, have been reported occupational therapy research literature (Baranek et al. 2006). Studies with children who have various disabilities including ASD have shown that children with these disabilities have significantly different patterns of sensory processing from their peers. Although there is significant individual variability in sensory processing in this population, in the areas of tactile processing, attention, cognition, language, and sensory modulation consistent trends have been noted (Schaaf & Miller, 2005) when using Dunn's (1999) Short Sensory Profile (SSP).

The SSP is a caregiver questionnaire, for children 3-10 years of age, which measures children's responses to sensory events in everyday life. It contains 38 items and is used for screening and research purposes. The child's caregiver completes the questionnaire by reporting how frequently their child responds using a five point Likert scale (Dunn, 1999).

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In a recent study by Miller Coll & Schoen (2007) the SSP was shown to have construct validity and occupational relevance. Thus, behaviour assessed on the SSP could be associated with the personal management, social interaction, play and schooling items on the OPQ.

2.2.3.2 Parenting Stress Index – Short Form (PSI-SF)

The PSI-SF is commonly used to assess stress in the parent-child system (Abidin, 1995). Esdaile & Greenwood (2003) showed that this instrument is sensitive to stress in parents of children with severe disabilities. The PSI-SF provides a "Total Stress" score as well as three subscale scores for "Parental Distress" (PD)," Difficult Child"(DC) and "Parent-Child Dysfunctional Interaction"(P-CDI). Each subsection, which comprises 12 items, can be rated from 1 (strongly disagree) to 5 (strongly agree). The higher the score on the PSI, the greater is the level of parental stress that is experienced. The PSI-SF can be used with children who are typically developing, or children with special needs. The internal consistency of the PSI-SF was found to be very good for the three factors in the Pervasive Developmental Disorder (PDD) population group (Abidin, 1995; Weiss, 2002).

2.3 Role of the Occupational Therapist in Children with Autistic Spectrum Disorder

Until knowledge gained through research on ASD allows for prevention, appropriate intervention will remain of utmost importance (Miller-Kuhaneck, 2004). With respect to intervention, occupational therapists have reported providing services that focused on the child's ability to process and integrate sensory information thus forming a basis for improved independence and participation in daily, personal management activities, play and school-related tasks (Schaaf & Miller, 2005). Sensation is an organiser of behaviour and arousal and because sensory processing is invisible, therapists need to observe behaviour and put together a working hypothesis on what they are achieving by evaluation behaviour in occupation based functioning (Schaaf et al. 2007).

Research has demonstrated that structural, molecular and cellular changes in neural functions are possible, also that lifestyle redesign including meaningful sensorimotor activities can be mediators of plasticity and improve functional outcomes (Schaaf &

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Miller, 2005; Diamond & Hopson, 1998; Field, Lasko, Mundy, Herleff, Kabal et al, 1997; Ornitz, 1974). This entails modifying existing circuitry and creating novel circuitry by facilitating synaptogenesis and dendritic arborisation (Buonomano & Merzenich 1998; Greenough, Black, & Wallace, 1987). Thus sensory integration therapy has the potential to address the underlying mechanisms of behaviour (Kraemar, 2001). Research indicates that 25%–38% of individuals with ASD have increased serotonin levels. Research also suggests that serotonin has a generalised inhibitory effect on defensive behaviour, filtering of sensory signals, social attachment and perception. Hyperserotonemia may lead to a reduction in the drive for social attachment. There is also evidence of increased cortisol and dysregulation of the hypothalamic-pituitary axis in ASD (Chamberlain & Herman 1990). In addition, by measuring heart rate variability, Toichi and Kamio (2003) found that individuals with ASD were more stressed, experiencing autonomic hyperarousal in a resting state, compared with when they were performing repetitive mental tasks.

Key principles of the OT-SI approach to influence these underlying neural dysfunction include (Parham, Cohn, Spitzer, Koomar, Miller , Burke, Brett -Green, Malilloux, May-Benson, Smith-Roley, Schaaf, Schoen & Summers, 2007; Parham & Koomar, 2006; Ayres, 1972):

- "the Just Right Challenge", where the therapist creates playful activities with achievable challenges;
- "The Adaptive Response", whereby the child adapts their behaviour with new and useful strategies;
- "Active Engagement", whereby the therapist's artful creation of challenging, yet playful, sensory rich environments entice the child to participate actively in play;
- "Child Directed Play", where, by reading the child's behavioural cues and following the child's lead or suggestions, the therapist creates interesting, sensory rich activities within a therapeutic environment designed to tap into the child's inner drive to play.

The purpose of OT-SI methods therefore is to assist the child to organise their responses to incoming sensory information by providing controlled tactile, proprioceptive and vestibular input, which increases or decreases the state of arousal. Helping the child attain and sustain the "quiet-alert" state in a variety of natural settings is the optimal goal of intervention. This enables the child to attain an appropriate level of attention and

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orientation for interaction with people and in the environment critical for the development of personal management, communication, social interaction, play and learning (Bundy, Shia, Qi & Miller 2007; Ingersoll, 2003). Focussing on relevant stimuli enables the child to respond in a more appropriate manner. OT-SI is fundamental to motor planning, which is inherent in everyday activities typical of pre-schoolers (Case-Smith & Bryan, 1999).

In addition to direct intervention with the child, the occupational therapist collaborates with parents, teachers and other professionals involved with the child to help them to understand the child's behaviour from a sensory perspective. The therapist assists them in adapting the child's natural environments and in creating sensory and motor experiences (DeGangi, 2000). These experiences are planned throughout the child's day, to meet sensory needs. The "Sensory diet" ensures that there is carry-over of gains made in therapy enabling the child to be more functional in activities of daily living. Therefore OT-SI must always be embedded in the context of an OT programme, as was originally described by Ayres (Schaaf & Miller, 2005), as it is not a "stand alone" therapy. Home-based intervention (Diggle et al. 2003) needs to be grounded in typical family occupations, and therapeutic activities need to be embedded in the child's regular daily routines. Intervention has limited impact, unless there is carry-over into family life by incorporation of therapeutic activities in daily routines. Practice in school environments has also presented the need to consider meaningful interventions in the classroom and on the playground.

2.3.1 Effectiveness of Occupational Therapy using a Sensory Integration Frame of Reference with Children with Autistic Spectrum Disorders

The status of the research in SI-OT has presented a dilemma for occupational therapists who strive to provide evidence-based, family-centred practice. Therapists observe an improvement in the quality of life of the children and their families after intervention, yet definitive research to support their practice based on OT-SI principles is lacking (Parham et al. 2007). Research on the validity of the OT-SI outcomes has been threatened by weak fidelity with regard to therapeutic process and weak methodologies.

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2.3.1.1 Fidelity to Treatment Measure for Occupational Therapy using a Sensory Integration Frame of Reference

There is a lack of a clear model delineating the critical factors that constitute OT-SI and this needs definition in a manner that will make all OT-SI replicable. A fidelity instrument to measure which elements of sensory integration treatment are crucial to allow for standardisation of OT-SI so that the outcome of treatment can be compared (Parham et al. 2007). In order to ensure this standardisation of OT-SI, using the "Fidelity to Treatment Measure" (Parham et al. 2007) a task group identified core SI intervention elements through expert review and nominal group process. Elements were classified into structural (equipment used, therapist training) and therapeutic process categories as described by Ayres (1972). Thirty-four SI intervention studies were examined for consistency of intervention descriptions with these elements. Ten core elements that are critical to the SI intervention process were identified (See Appendix D) (Parham et al 2007).

2.3.1.2 Methodologies used in Research on Occupational Therapy using a Sensory Integration Frame of Reference

To date, studies measuring the effect of OT-SI on pre-schoolers with ASD are few and far between.

- Methodologically sound randomised controlled trials must be used to answer questions of best practice in the scope of OT-SI in behavioural and educational (Baranek, 2002) and family-centred practice (Cohn & Cermak, 1998).
- Controlled evaluation studies of SI treatment were beset by limitations including heterogeneous samples, (Kaplan, Polatjko, Wilson & Faris, 1993) and lack of control for normal maturational changes because of the issues surrounding recruiting for a no-treatment control group.
- External validity in studies on OT-SI has been limited, due to small sample sizes and the inability to generalise from single subject designs (Polatajko, Law, Miller & Wilson, 1991).
- The design of case studies used, also presented confounding variables during the treatment phase using OT-SI (Linderman & Stewart, 1999). Other limitations include the lack of description of treatment and therapist variables; rarely do they link in both systematic and measurable ways (Baranek, 2002).

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Therefore a clear definition of the subject population: age, gender, severity of dysfunction and socio-economic criteria is vital. Developmental issues can be more closely explored by keeping chronological age and mental age bands narrow, and by separating subjects with low and average IQ. A stringent research design that controls for maturation, tester bias and treatment variability amongst therapists and subjects is essential.

- Identifying appropriate outcome measures that are reliable, and can be used to link the occupational performance issues faced by the child and their family with the neurobiological substrate, is a logistical challenge faced by researchers in OT-SI outcomes research (Cermak & Henderson, 1990).

In spite of the fact that there are now more than 80 studies that support the effectiveness of OT-SI therapy (Miller, 2003); longitudinal studies that measure occupational performance outcomes and link these to the internal components addressed in SI-OT treatment have not been addressed.

OT-SI intervention for children with ASD usually lasts more than a year (Vargas & Carmilli, 1999) and occupational therapists need to be accountable for functionally significant changes, so an outcome measure that can connect the change in occupational performance behaviour related to occupational therapy is needed (Cermak et al. 1999, Meisels & Fenichel, 1996) to ensure that OT services are measured according to the individual's functioning in meaningful activities.

2.4 Occupational Performance Outcomes

Sensory or motor treatments are often used within the context of a more holistic intervention plan in OT-SI where the occupational therapist provides interventions aimed at improving or compensating for a child's functioning in occupational performance e.g. personal management, play, school and social functional skills (Baranek, 2002).

No instruments that evaluate and reflect the change in occupational performance related to sensory patterns and the behavioural manifestations in children with ASD are reported in the literature. The norm-referenced behavioural and developmental assessments available were not suitable, as researchers have voiced concern over whether "typical

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development" can be used as a baseline measure with the autistic child. This concern is due to the continued developmental implications of sensory dysfunction, in terms of delay in language acquisition, social communication, perceptual, cognitive and general functioning which continues into later childhood. These children cannot respond to tests with verbal instructions requiring motor output and verbal responses (Leekam et al. 2007; Volkmar & Cohen, 1986). These children therefore cannot be judged against their typically developing peers, as they have not had the opportunities to experience the tasks that formal assessment instruments use (Meisels & Fenichel,1996).

Occupational therapy paediatric practitioners are therefore hampered by the lack of an occupation-centred standardised assessment tools when dealing with children with ASD (Coster, 1998). A "score" on any assessment measure is meaningful only if it provides information about the child's current abilities, facilitates the documentation of growth over time, and suggests the skills and processes that should be incorporated into the child's treatment plan (Meisels & Fenichel, 1996). Outcome measures for children with ASD should reflect changes in scores as a result of growth or change made by individual children, rather than comparing the child with any norm group. These scores are referred to as growth or ability-scaled scores. Six-monthly and annual evaluations should complement ongoing monitoring. They should be used to compare the child's progress with some standard or expectation for progress. This is in keeping with the trend towards Rasch analysis (Andrich, 1988) in occupational therapy, where the child is his own control, rather than using the developmental trajectory of typically developing children (Meisels & Fenichel, 1996).

2.4.1 Review of Occupational based Tests

Several occupation based outcome measures have been designed for use with young children with significant motor disabilities. The Pediatric Evaluation of Disability Inventory (PEDI) provides a comprehensive clinical assessment of performance on key functional and occupational performance tasks by children aged six months to seven years. Although it is most suitable for children with physical disabilities due to the subtests which measure mobility, caregiver assistance, modifications and adaptations; sections on self-care and social functioning may apply to the ASD population (Feldman, Haley & Coreyell, 1990).

A second measure is the Australian Occupational Performance Model (OPM) which has been adapted for school-aged children with underlying sensory integrative dysfunction related to learning disabilities (Steer, 1996). The unpublished paediatric version is known as the Parent and Teacher "Sensory Integration Rating Scales". A five point Likert scale is useful in measuring change in occupational performance at home and at school. Although a pilot study measuring the efficacy of OT-SI was done by Steer in a group of school going children with motor, learning and behaviour difficulties (Steer, 1996) this outcome measure does not deal with preschool children.

The Canadian Occupational Performance Measure (COPM) has an open-ended parent interview format. It is widely used in physical paediatric rehabilitation to assist in goal setting with school-aged children. Productivity/work, self-care aspects, play and socialisation are covered. The COPM is helpful in identifying and prioritising intervention goals from the perspective of parents (Stamm, Cieza, McHold, Smolen & Stucki, 2006).

An adapted version of the COPM, the Modified COPM (M-COPM) was used to study a group of pre-school children with ASD, to identify whether parents' expectations in terms of therapy had been met. They identified three to six goals, which were assigned to the domains of communication/behaviour (instead of productivity/work, which is applicable to school-aged children), play/leisure, self-care, and social interaction (Rodger et al. 2004). These occupational performance goals were further broken down into observable behaviours to guide the evaluation of changes that had occurred. Parents identified the effect of inappropriate and concerning behaviour like tantrums, self-stimulation and screaming as being of paramount importance. Issues associated with daily routines and transitions were also identified as important. In the occupational performance area of play, parents identified the ability to play on their own, playing alongside and with others, (both at home and in early childhood settings), and expanding play preferences by encouraging play activities the child avoided as goals they would like the child to achieve. Social interaction behaviours identified included were: making eye contact, sharing, taking turns, joining in conversations with another adult or child and family socialisation. In the area of self-care which encompassed eating, toileting, and grooming routines, sensory hypersensitivity or communication of needs often appeared to be priority issues, (Rodger et al. 2004).

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2.5 Conclusion

The literature review illustrates the progress that researchers in the field of occupational therapy have made in identifying the critical factors required in producing reliable, valid research. The need for a stringent research design with homogeneous subject selection with strict inclusion and exclusion criteria has been highlighted. With the ASD population longitudinal studies are essential to investigate treatment efficacy. Appropriate outcome measures to determine change need to include a measure of the child's proximate sensory behaviours as well as considering the family-centred aspects like parent stress.
An occupation-based outcome measure, which establishes a baseline of the child's ability to function and can measure change in these aspects over time, is not available for this age or population group. Linking change in functional occupational behaviour with systematic change in other measurable constructs assessed as an outcome of treatment with the ASD population would be a useful tool to evaluate the efficacy of occupational therapy in this area (Baranek, 2002).

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