

# **WALLACE RESEARCH PROJECT**

## **Project Title**

**A LONGITUDINAL STUDY TO EXPLORE THE RELATIONSHIP BETWEEN THE OCCUPATIONAL PERFORMANCE OF PRE-SCHOOL CHILDREN WITH AUTISTIC SPECTRUM DISORDERS, RECEIVING OCCUPATIONAL THERAPY, USING SENSORY INTEGRATION THEORY AND METHODS, AND HOW THIS AFFECTS MOTHERS' PARENTING STRESS.**

## **Project Objective**

1. To design an outcomes-based assessment tool to determine the occupational performance of pre-school children with ASD, including questions to evaluate the mother's perception of how this affects the family's adjustment in terms of lifestyle and relationships.
2. To use the assessment tool to measure the change in occupational performance of pre-school children with ASD, and the mother's perception of how this change affects family adjustment during one year while the child is receiving occupational therapy using a sensory integration frame of reference.
3. To correlate the change in the children's occupational performance, with change in the mothers' parenting stress levels and changes in the child's sensory processing, over a one year period.

## **Literature Review**

Experts agree that there is an increase in the prevalence of Pervasive Developmental Disorders (PDD) especially in the early diagnosis of the disorder in the pre-school age group, compared with 30 years ago. (Greenspan & Weider, 1998; Fombonne, 2003; Powell Edwards, Pandit, Sungum-Paliwal & Whitehouse, 2000; Allik, Larson, & Smedje, 2006; Rutter, 2005). The increase in the number of young children referred for occupational therapy, with diagnoses which fall into the autistic spectrum in the last 10 years in South Africa has increased considerably. (Venter, 2002). According to Smith-Roley (2005), 95% of children with ASD's have some sensory integration dysfunction, especially in the area of attention, cognition, language, sensory modulation, and particularly tactile processing. In a survey, 95 -97% of occupational therapists working with children with an ASD, reported using a sensory integration based therapy. (Case-Smith & Miller, 1999, Miller-Kuhaneck, 2004)

In the period birth to 2 yrs, sensory perceptual abnormalities may be among the earliest manifestations

of autism.(Baranek ,1998, Dawson & Osterling, 1994, Venter, 2002) with idiosyncratic responses to sensory stimuli (Baranek,: 2002) leading to behavioural difficulties, such as late bowel and bladder control, irregular sleeping patterns, difficulty self-calming once upset, and difficulty dealing with changes in routines, as well as poor spontaneous speech. (Smith-Roley , Blanche & Schaaf , 2001). This condition is often associated with sensory defensiveness, which has been related to rigid or inflexible behaviour patterns, repetitive vocalizations, visual fixations, and abnormal focused attention in children (Baranek, Foster, & Berkson , 1997). Aversion to sensory stimulation impacts on all family members. A child who pulls away or screams when touched, or only likes to be touched if he initiates, is very difficult to handle. As it is not uncommon for one or both parents to have similar issues with interactions demanding physical contact become problematic. (Cermak, Koomar & Szklut, 1998; Ayres& Tickle : 1980, Baranek & Berkson 1994) Sensitivity to noise also causes conflict, as different family members have different requirements in terms of the volume of the TV or stereo, and there is frequently difficulty processing sound of different frequencies, so tolerance of certain voices can be stressful, and manifest in outbursts. Sensitivity to smell may create barriers to relationships and also impact on harmony at mealtimes. People who use certain deodorants, perfumes or after-shaves can be very offensive to a child who is sensitive to smell. Often the child does not know what is bothering him, and is only aware of the agitation or feeling of being out of control, and of not understanding what is happening in their environment. Sensitivity to food smells and textures results in a very limited diet, and frequently makes it very difficult for the family to eat out of their own home environment. (Cermak et al 1998) Konstantareas et al (1989) identified occupational performance delays in their assessment

of ASD children with a mean age of 6 yrs 10 mths. Sleeping problems and self abusive behaviour was prevalent, and more than half were not toilet trained.

Understanding sensory integration and the inter-relationships among diagnosis and the behaviours a child employs to self-regulate is vital in addressing each child's specific sensory needs. (Cermak, et al : 1998) Parent-mediated early intervention for children with ASD, (between 1 year and 7 years) has long been accepted as being helpful, and outcomes where parents were involved were better. (Diggle et al 2003) As part of this intervention, each child's specific sensory needs, the behaviours the child uses to self regulate and their capacity for sensory modulation, need to be understood. (Cermak et al: 1998). Bundy et al (1991) stated that occupational therapy using sensory integration; which provides enhanced sensory experiences within the context of meaningful activities, and results in more

adaptive behaviours e.g. regulation of sleep-wake cycles, feeding, emotional regulation, play and socialisation has been identified as an approach to be used with younger children with ASD, whose nervous systems are still actively developing. SI therapy targets the parts of the brain which register novelty, and encourages other structures within the nervous system to develop. (Mailloux, 2001) The significant differences in Sensory Profile factor scores of 3-6 yr old children with and without autism (Watling, Deitz & White, 2001) supports using it to measure change in sensory processing in this population. Presently, occupational therapists are limited in the information gleaned from, and use structured and unstructured evaluation tools for young children with ASD. In order to determine the underlying causes for the disability, performance skill deficits and occupationally relevant concerns, multiple measures are necessary. These include, but are not limited to standardised measures of sensory discrimination and praxis, parent and teacher reports on sensory modulation, behavioural checklists and performance evaluation measures. Depending on the severity of the ASD characteristics, and the child's ability to cope with structured assessment conditions, certain evaluation tools may not be responsive to the subtle but meaningful changes within the ASD population that clearly affect their occupational functioning, as seen in their occupational performance. Additionally, typical evaluation tools assess only the internal performance components, and do not take into consideration the health and well-being of the family, caregivers, and the context within which the child lives. This is one of the reasons why it is so difficult to demonstrate the efficacy of intervention, (Smith-Roley et al: 2001) although a reduction in sensory defensiveness, especially tactile defensiveness and repetitive behaviour has been reported. (Case-Smith & Bryan : 1999).

Because the range of abilities in this population is so broad, finding the appropriate means for evaluation can be challenging. Many children with this diagnosis cannot tolerate standardized tests, and so it is not possible for testing alone to determine the extent of all aspects of sensory integrative dysfunction. (Smith-Roley et al : 2001), and self-report measures such as the Canadian Occupational Performance Measure (COPM), is not suitable for use with this age or diagnostic group. An outcome measure, which establishes a baseline of the functioning in occupational performance and allows measurement of change in this aspect over time, would be a useful way to measure progress in therapy. A single-case study on young children with ASD who received SI therapy demonstrated improvements in functioning in occupational performance areas including goal-directed play, social interaction, engagement in activities (Case-Smith & Miller 1999), and in their activity level (Linderman & Stewart 1999). This does not include the complexity of all aspects of occupational performance that can be measured.

Literature shows that parents of children with a pervasive developmental disorder, into which ASD falls, have higher rates of psychological distress than those from other groups of children with developmental disabilities. (Fombonne, et al : 2003). Parenting 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 2005). Hastings & Brown (2002) found that mothers reported more anxiety and depression than fathers. Some mothers experienced guilt and uncertainty regarding mothering and they found visual preoccupations, and other sensory seeking behaviours including, smelling, licking and rubbing, inappropriate affect, inappropriate use of the body and objects most stressful. Other stressors included impaired non-verbal communication, extremes of activity, impaired imitation, and resistance to change. The range of specific stressors that father's found most difficult to manage were their child's inability to speak, and their anxiety reactions (Konstantareas et al 1989)

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, fairness and satisfaction with this division, and personal life satisfaction. (Milgram & Atzil 1988). These aspects all relate to parenting stress and the family's ability to function as a unit.

Because of the life-long needs of individuals with an ASD, families need to be prepared to cope with challenges as they arise. If parents are supported, informed, and empowered through an understanding of their child's behaviour and sensory needs in the pre-school years; this helps them to promote organized and goal directed behaviour, in a modified environment. By presenting this goal directed behaviour in terms of changes in occupational performance, evaluated by the individual being able to participate in meaningful occupation, (Mailloux, 2001) parents may understand the effect of this change on their family's functioning and their own stress levels.

## **Protocol**

Researchers and intervention specialists concur, that assessing change in early intervention programs for children with autism is challenging due to the variability in the children. They cannot agree on the type, and intensity of services which produces optimal outcomes for children and their families (Kasari, 2002). Research has not documented the change in the occupational performance of a pre-school child with ASD receiving sensory integration based occupational therapy, because the measures usually used, evaluate progress in sensory processing. There is no measure of outcomes as reflected in the change in the child's occupational performance (Watling, Deitz, Kanny, & Mc Laughlin, 1999)

Although relationship between some of the occupational performance areas like sleep in terms of family life and relationships has been investigated in a number of studies, no study investigates the relationship between the child's sensory profile, the areas of occupational performance in the pre-school child with ASD and the family's adjustment.

Stress in parents, particularly mothers with children with disorders on the autistic spectrum is well documented (Hastings & Brown 2002), but the effect of a change in the occupational performance outcomes in these children the mothers stress level has also not been addressed.

### **Aim of the Study**

To develop an outcome based assessment tool which occupational therapists can use to determine occupational functioning of the pre-school child with ASD, receiving occupational therapy using a sensory integration frame of reference.

The assessment tool will include questions to record the mother's perception of the change in their child's occupational performance and their family's adjustment over a one year period. This will be related to the mother's parenting stress levels by measured using the Parenting Stress Index- Short Form (PSI-SF)( Abidin, 1995), and the child's sensory profile using the Short Sensory Profile (SSP)(Dunn, 1999)

### **Deliverables - What are the expected outputs of this project? [Publications, new techniques]**

Publication of Journal Articles

Questionnaire for Therapists to use clinically to evaluate treatment