

# **Exploring the Diagnostic Ability of the ADOS in Special Needs Schools in the Greater eThekweni Area: A Blinded Study**

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Submitted in partial fulfilment of a Master of Social Science (Research Psychology), in the School of Applied Human Sciences, College of Humanities, Development and Social Sciences, University of KwaZulu-Natal, Pietermaritzburg Campus.

**Declaration:**

I declare that the work presented in this thesis is my own work and that any work that is not mine has been rightfully and properly acknowledged and referenced. This thesis has been submitted in partial fulfilment for the requirements of a Masters in Research Psychology at the University of KwaZulu-Natal, Pietermaritzburg. It has not been submitted before for any degree or examination at any other university.

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Date:

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**Supervisor's approval of this thesis for submission:**

As the candidate's supervisor I have approved this thesis for submission.

Signed:

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B.J. Killian (PhD)

Date: 

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## Abstract

Autism Spectrum Disorders (ASDs) are increasing in prevalence worldwide, including in developing countries like South Africa. If the assumption that ASDs manifests similarly across all cultures, then the Autism Diagnostic Observation Schedule (ADOS), the western gold standard for diagnosing ASDs, will be able to accurately discriminate those children that have ASDs from those that do not. The ADOS was designed to increase the likelihood of children displaying ASD type behaviours to facilitate a diagnosis, but this may negatively impact on scores obtained by African children which are socialised to be respectful as opposed to spontaneous.

This research study formed part of the larger KwaZulu-Natal-ASD<sup>1</sup> (K-ASD) study, and aimed to explore the diagnostic ability of the ADOS in special needs schools in the greater eThekweni area.

The study design used a matched blinded sample comprising of an atypically developing ASD and non-ASD group from Black, White and Indian ethnicities. The sample came from special needs schools. The experimental group thus comprised people with ASD and the control group was a learning disabled group that did not have ASD. This study compared Autism Diagnostic Observation Schedule (ADOS) algorithm scores of a sample of 26 children (6-11 years of age) who were administered modules 1-3 of the ADOS with the clinical diagnoses for each of these children.

Using McNemar's Westlake Schuirmann Test of equivalence it was found that the clinician diagnoses and the ADOS coding algorithm results were statistically equivalent. Thus, no significant difference existed between the two methods of diagnosis. The ADOS showed greater sensitivity in identifying symptoms associated with ASD than did the clinician diagnoses. An ANOVA revealed significant differences in the communication and the reciprocal social interaction algorithm's. This indicates a cultural variation in behaviours, since Black participants behaved in various gestural ways that were significantly different to the manner in which Whites behaved to the ADOS testing.

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## CHAPTER 1

### INTRODUCTION

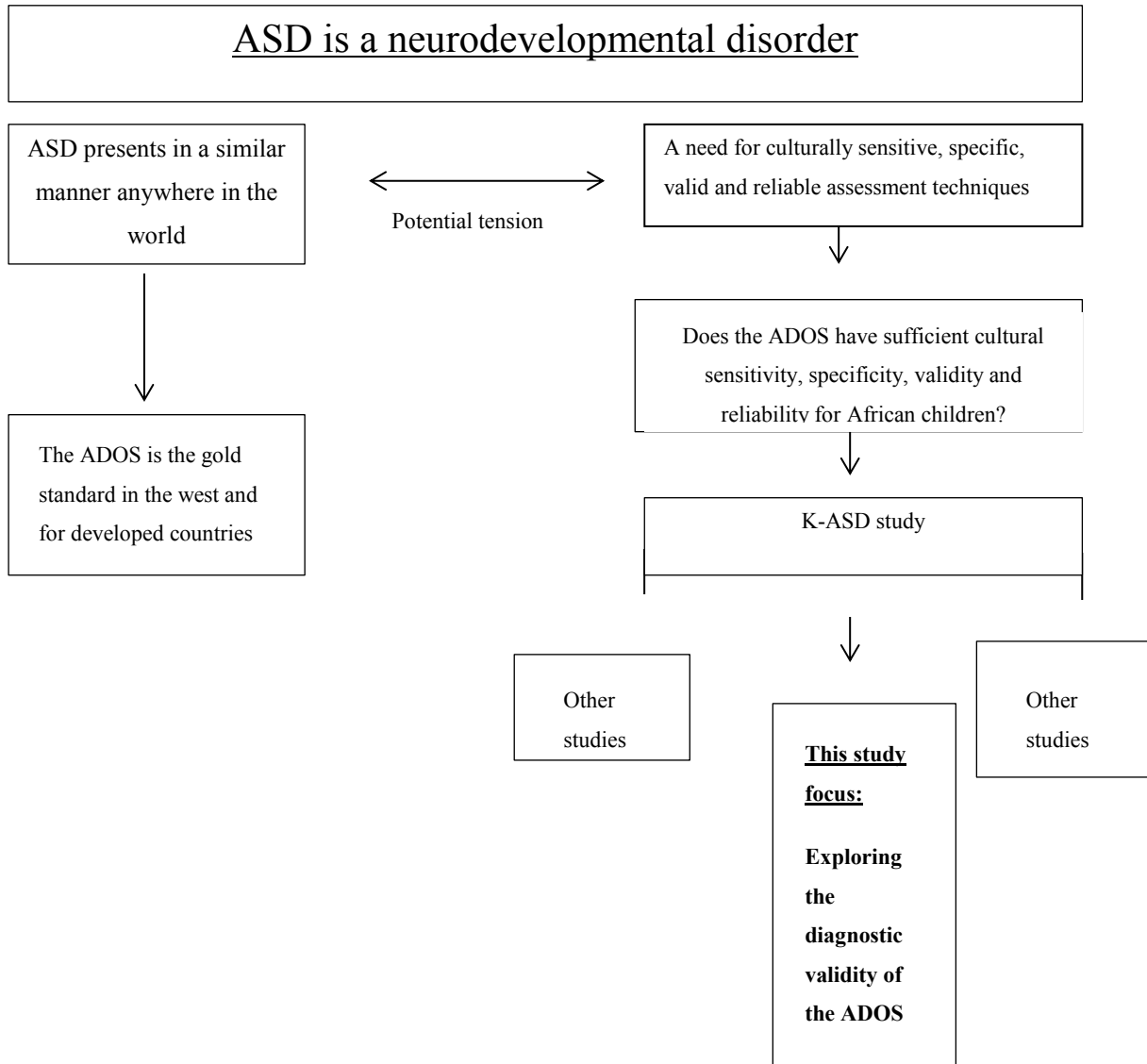
Autism Spectrum Disorders (ASDs) are severe neurodevelopmental disorders that involve social withdrawal, and are accompanied by communication deficits and stereotypical repetitive behaviours (Blaurock-Busch, Amin & Rabah, 2011). Most researchers and clinicians state that they are a disabling continuum of disorders that severely impact on a person's life (Mandell, Listerud, Levy & Pinto-Martin, 2002). Cases of ASDs have been reported world-wide and globally the prevalence rates are on the increase (Moolman-Smook, Vermoter, Buckle & Lindenberg, 2008). This increasing prevalence of ASDs, in atypically developing sectors of the population, makes studying ASDs a priority in South Africa (Durkin et al., 2006). Hence there is a growing societal concern to understand this disorder as it impacts substantially on children and their families (El-Gouroury & Krakow, 2012).

Researchers are beginning to examine whether differences occur between countries and across cultures (Sipes, Furniss, Matson & Hattier, 2012; Chug et al., 2012). There are studies that identify disparities between ethnic groups, arguing that a reason for this is the lack of standardised assessment instruments (Mandell et al., 2002). Hence, the need to have a universal, reliable, culture-fair diagnostic tool (Mandell et al., 2002), such as the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000).

This study forms part of the larger KwaZulu-Natal Autism Study (K-ASD) that aims to standardise and assess cultural relevance of the ADOS in South Africa. The objective of this study was to explore some of the debates surrounding culture and behaviour, in diagnosing ASDs.

The rationale for this study is illustrated diagrammatically in Figure 1 below, where the overarching aim of this study was to explore the diagnostic ability of the ADOS. This study would aid in determining whether the ADOS could be used universally across cultures, and thus could be considered to be the gold standard for ASD diagnosis worldwide (Lord et al., 2000), rather than just in the West and in developed countries. This required an exploration of the specificity of the ADOS in diagnosing ASD, regardless of their ethnic variability.

Figure 1.

*Rationale of this study*

The primary null hypothesis in this study proposed that there was no significant difference in the diagnoses attained on ADOS assessments compared to diagnoses made by trained clinicians for each participant on this study.

The sub-hypotheses in this study aimed to answer uncertainties regarding ethnicity and whether there were significant differences in the ways cultural groups respond to the assessment of the ADOS. This study considered cultural variability in terms of behaviours across Black, White and Indian children. The null sub-hypotheses proposed that there was no

significant difference in the diagnoses attained on behaviours identified on the ADOS of atypically developing South African children from varying ethnic backgrounds who had ASD, compared to those atypically developing children with other special needs who did not have ASD as a developmental disorder. These sub-hypotheses thus considered differential behaviours across cultures for the ADOS subtests. These subtests are communicative behaviours, reciprocal social interaction, imagination and creativity, and stereotyped behaviours and restricted interests.

Special needs schools were targeted and a sample was drawn from these atypically developing children, since this is where ASD children would likely be schooled. ASD and non-ASD children were tested on the ADOS with both the administrator and the co-coder being blinded to the diagnosis of the child, for the purpose of investigating the specificity of the ADOS.

ASD and non-ASD children were tested on the ADOS to ascertain the diagnostic accuracy of the ADOS. The ADOS diagnosis per participant was then compared to the clinician diagnosis for that participant to explore the concordance in diagnoses.

Due to time constraints and limitations in the study design, the sample was fairly small, 26 participants in total. Nevertheless studies in reputable journals have been found with similar sample sizes on the ADOS evaluation (Overton, Fielding & Garcia de Alba, 2008). This study could be considered to be a pilot study where a larger study of a similar nature, with sites all over South Africa, could be very beneficial to ASD research.

The ADOS has not been validated in our context, thus there are reservations regarding its cultural fairness. As a Western diagnostic assessment tool concern exists regarding its applicability in the African context.

### **Outline to the Study**

Chapter one introduces the background and motivation of this research. Chapter two presents the rationale for this research study and considers relevant literature, providing the theoretical background for this research. Chapter three outlines the methodology used for this research including the research design; sampling process; data collection process; data analysis; forms of error in assessment; ethical considerations; and the limitations of the research design. Chapter four considers the results obtained from the analysis of the data using descriptive

statistics and the quantitative techniques of a one – way ANOVA and the specialised version of McNemar’s Westlake-Schuirmann Test of Equivalence. Chapter five discusses the results in relation to the literature on ASDs and the results in relation to the cultural patterns of behaviour that were found to differ across Black and White children with ASD. Chapter 6 concludes this study.

### **Frequently Used Abbreviations**

ADOS	Autism Diagnostic Observation Schedule
ASD	Autism Spectrum Disorders.
DoE	Department of Education
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders (APA, 2005).
ICD-10	International Classification of Diseases
K-ASD	KwaZulu-Natal Autism Study
M-CHAT	The Modified Checklist for Autism in Toddlers
PDD	Pervasive Developmental Disorders
RRBs	Restricted and Repetitive Behaviours
SCQ	Social Communication Questionnaire

### Ethnic categories:

Black	The black group in the sample comprised people of African heritage from various ethnic and cultural groupings including Zulu, Xhosa and Sesotho. Since the study was located in KwaZulu-Natal, most of the children in this ‘Black’ group were Zulu, with some having one parent of another ethnic group.
White	The White group were those of White/Caucasian heritage who were living in South Africa but were presumed to have ancestors of European descent, thus originated from Europe; in most instances the family would have been residing in South African for many generations.
Indian	The Indian group were children in the sample who were living in South Africa yet had a South East Asian heritage and came from various religious groupings including Hindu, Tamil, Gujarati and Muslim. The

countries of their origination include India, Pakistan and Sri Lanka. Again, it is probable that they and their families have resided in South Africa for many generations.

## CHAPTER 2

### LITERATURE REVIEW

#### **2.1 Rationale of Research**

Autism Spectrum Disorders (ASDs) are a very under researched field, especially in South Africa. Children who present with this disorder represent an extremely vulnerable group of the South African population (Chhagan, Karim & Wallace, 2012). They are vulnerable because these children typically isolate themselves socially and struggle to communicate. Their needs are thus not always recognised or even understood. Their needs are different and more acute to those of typically developing children. They require special educational needs to facilitate their development. In addition, ASD children from lower economic circumstances often do not have access to professional health care and often go undiagnosed. Since the ADOS is regarded as the gold standard for ASD assessment in the United States, this study attempted to explore the diagnostic ability of this assessment procedure in the multi-cultural context of South Africa (Lord et al., 2000; Reaven, Hepburn & Ross, 2008). Identifying similarities between countries is important as it points to an ability to generalise diagnostic methods which will in future aid in identifying and treating a greater number of children more effectively.

On-going monitoring of this neurobehavioural disorder is needed, in order to evaluate the impact these disorders have on society. Changes at a national policy level could benefit the future development of children with disabilities in our country. There is the assumption that the state is largely the service provider for individuals with ASDs.

#### **2.2 Theoretical framework of Autism Spectrum Disorders**

ASDs are a group of neurobiological conditions which affect multiple domains of a person's life, making it an extremely complex disorder which is difficult to understand and treat (Le Conteur, Haden, Hammal & McConachie, 2008). The detection of ASDs is a major societal concern, since prevalence rates worldwide have risen in the last decade and a half (El-Gouroury & Krakow, 2012; Bakare & Munir, 2011).

Despite medical advances, no biological markers have been identified that clearly allow for a diagnosis of ASD. Thus, a detailed behavioural analysis involving a diagnosis by a trained clinician and an in-depth consideration of the person's personal history is needed in order to diagnose a person with ASD (Lene & Waldby, 2010).

The Autism Diagnostic Observation Schedule (ADOS) is considered to be the 'gold standard' in evaluating and diagnosing autism (Lord, Rutter, DiLavore & Risi, 2011); especially when the results are verified by trained clinicians using a full neurodevelopmental assessment (Reaven, Hepburn, & Ross, 2008; Lord et al., 2011). Past studies have shown the effectiveness of using the ADOS as a diagnostic tool for identifying ASDs since the ADOS increases the likelihood of participants displaying ASD type behaviours which typify an ASD diagnosis (Lord et al., 2000).

There is an increasing need to explore valid ways of diagnosing ASDs early, which can be used universally. This study explores the use of the ADOS as a diagnostic tool, in the South African context.

### **2.2.1 Historical perspectives of ASD**

Historically, ASD is a new disorder, unheard of one hundred years ago (Firth, 2008). Yet the literature hints to various theorists observing unique behavioural characteristics of ASD, in people during the 1900's (Klinger, Dawson & Renner, 2003). The disorder was not however labelled as ASD for many years.

Carl Gustav Jung identified these unique behaviours which he then categorised as personality types. The label he ascribed to severely introverted people comprehensively describes the behavioural characteristics of autism (Timmi, Gardner & McCabe, 2011). Prior to this, people displaying ASD type behaviours were largely classified as intellectually disabled (Frith, 2008).

In 1911, Bleuler described schizophrenic individuals who displayed catatonic behaviours, as 'autistic'. Thus, this term originally referred to a basic disturbance found in schizophrenic patients, characterised by an extreme withdrawal of oneself from all social life (Klinger et al., 2003).

This finding was supported by two other people in 1940, Leo Kanner, a psychiatrist, and Hans Asperger, a paediatrician. They independently identified children displaying this loss of contact with reality as described by Bleuler, but without the concomitant diagnosis of schizophrenia (Lord, Kim & Dimartino, 2011). Kanner noted shared qualities of social aloofness, language delays and oddities in 11 children at his psychiatric clinic. He suggested that their symptoms formed a unique syndrome which he termed “autistic disturbances of affective contact” (Timmi et al., 2011, p. 55).

At the same time, Asperger noted characteristics of social awkwardness and circumscribed interests in four of his young patients. They displayed strengths in vocabulary and syntactic aspects of language (Frith, 2008). Yet, they were impaired in their conversational skills and the volume of their speech. He noted a high level of original thought and their tendency to become preoccupied with one topic of interest. Thus, the diagnostic label of “Asperger’s syndrome” or “Asperger’s disorder” has since been used to refer to this group of higher functioning individuals (Klinger et al.2003). In 1944, Asperger documented this research in a book entitled “Autistic Psychopathy in Childhood” (Lord et al., 2011, p. 55). He also questioned whether the autistic personality was merely an extreme variant of male intellect, which focuses greater attention on systematising rather than on empathising (Frith, 2008).

Written during World War 2, this book was largely ignored. Suffice to say that these two sets of observations, in different parts of the world at the time, form the conceptualisation of ASD as it is understood today.

In the 1960’s, behaviour therapy and behaviour modification techniques were used on ASD children, based on the principles of learning theory, involving positive reinforcement. Later, Ivar Lovaas developed Applied Behaviour Analysis (ABA), which successfully helped some ASD children to cope (Frith, 2008). ABA is still used as one of the primary forms of intervention in children with ASD.

In 1970, Lorna Wing observed that autistic traits could occur in varying degrees of severity. She thus revisited Asperger’s ideas and her insight resulted in an expansion of the category of autism through the notion of an autism spectrum. Wing, along with Gould in 1979, conducted epidemiological studies and published a paper aiming to investigate how these behaviours related to mental retardation (Lord et al., 2011). These authors described a triad of impairments in social reciprocity, language comprehension and play. Dr Wing’s new direction intersected with Michael Rutter’s work, and the basis for the expansion of the



theory of autism, beyond its original status as a rare and serious condition, associated with multiple impairments, was established (Timmi et al., 2011).

At a similar time, Folstein and Rutter (1978, in Lord et al., 2011) conducted twin studies, comparing identical and fraternal twins with autism. This study connected autism with genetics, with the finding of greater concordance for autism in monozygotic than dizygotic twins. This study also showed that although siblings can both be ASD, there were large discrepancies in their intellectual levels, severity of ASD and their levels of impairment. Later, Michael Rutter developed diagnostic tools for assessing autism (Frith, 2008). He is one of the authors of both the Autistic Diagnostic Interview (the ADI) as well as the ADOS, which has now become the gold standard tool, in the west, for diagnosing people with ASD (Lord, 2011).

### **2.2.2 ASD Defined**

ASD is a heterogeneous group of disorders and the associated behaviours present in variable ways and degrees. This makes defining it extremely challenging. Some children present with learning and language delays while others do not. Some children have restrictive repertoires of behaviour, some engage in self-injurious and aggressive behaviours and others do not. Social deficits and excesses among the ASD group also vary substantially (Matson & Nebel-Schwalm, 2007).

The diagnostic criteria used to define Pervasive Developmental Disorders have also varied over the years and are still changing today. This has affected prevalence statistics and thus the general understanding of these disorders. Today, ASD according to the Diagnostic and Statistical manual of mental disorders (DSM-IV-TR) is a condition characterised by severe and pervasive impairment in several areas of development (American Psychiatric Association (APA), 2005).

ASD is fundamentally a disorder of social relatedness, and serves as an umbrella term for Pervasive Developmental Disorder (PDD) subtypes (Durkin et al., 2010; Roberts, 2010). In all the editions of the DSM, ASD fell within Pervasive Developmental Disorders (PDD). These subtypes range in severity from classic Autism, to Asperger's Syndrome and Pervasive Developmental Disorders - Not Otherwise Specified, as well as the less common Rett's Disorder and Childhood Disintegrative Disorder. These PDD subtypes are classified and defined in the DSM-IV-TR (American Psychiatric Association (APA), 2005) and the ICD-10.

ASD has very specific behavioural patterns that define it. In his initial report in 1943, Kanner noticed that the patients he observed displayed “extreme autistic aloneness”, they found social engagement challenging and he noted that the syndrome lead to language deviance in terms of “delayed acquisition, echolalia, occasional mutism, pronoun reversals and literalness”. He also noted their “obsessive desire for the maintenance of sameness” (Klinger et al., , 2003, p. 409). These ASD children, Kanner believed, due to their good rote learning ability and their normal physical appearance were able to achieve normal cognitive abilities (Klinger et al., 2003).

Asperger, a year later, defined the syndrome in a similar way. He noted their fear of eye contact and social interaction difficulties, as well as their underdeveloped affective expressions. He noted that in speaking, their volume tone may have been slightly abnormal as well as their conversational skills.

Some theorists have noted that this disorder is accompanied by deficits in impulse control, challenging behaviours and psychopathology at much higher levels than occurs in the general population (Matson & Kozlowski, 2011). An analysis of the participants’ personal files in this study may find similar results.

Some ASD children show abnormal attachment relationships with their parents. This may be due to their limited social understanding of people. They struggle to socially imitate what others are doing. In normal development, imitation skills are present shortly after birth (Klinger et al., 2003). Other theorists have documented an “awkward imitation style” in children with ASD (Hobson & Lee, 1999, in Klinger et al., 2003).

Non-verbal behaviours such as eye contact and shared attention through the use of gestures appear to be problematic social communication areas for ASD children (Lord et al., 2011). Other areas ASD children show impairments in are face perception abilities, understanding others emotions and symbolic or pretend play. Given these social impairments, it’s not surprising that language development is delayed, and ASD children often are very literal and concrete in their language expression (Klinger et al. 2003).

Since there is no single primary deficit in autism, rather a collection of impairments that are variable between individuals, defining it is extremely challenging. The unique behaviours and variable presentations of the disorder have led to it being regarded as a spectrum disorder. Some individuals are high functioning, having better language and social skills than most

individuals with autism (Tryon, Mayes, Rhodes & Waldo, 2006). They are thus defined as having Asperger's syndrome such as 'Christopher' in 'The Curious Incident of a Dog in the Night-time' (Haddon, 2003). Others are low functioning, and suffer from classic autism. Regardless of where they fall on the spectrum, (Frith, 2008, p. 24) argues that "autistic children become autistic adults", - it is a disorder, which can be managed to an extent, dependant on where an individual lies on the ASD spectrum.

Nevertheless, people who have ASD, share core similarities. These are outlined in the DSM-IV-TR as impairments in terms of their social interaction, their communication skills, their creativity and their restricted, repetitive and stereotyped patterns of behaviour, interests and activities, and their cognitive impairments (APA, 2005). The development of these areas is intrinsically linked and any impairment in one area during the first two years of life is likely to negatively affect the development of another (Klinger et al., 2003). There can be a range of severities in behaviours associated with each category (Le Couteur, Haden, Hammal & McConachie, 2008).

Considerable paradoxes exist in trying to define children with ASD. Diagnosis requires complex and variable presentations, and accurate, thorough assessment methods (Moh & Magiati, 2012).

One of the aims of this research study was to ascertain whether these ASD specific behaviours are definitive regardless of the child's culture. This concept is particularly complex since behaviours tend to vary across cultures in terms of what is considered appropriate and acceptable.

### **2.2.3 Diagnosis and Classification of ASD**

There is considerable confusion regarding the diagnosis and classification of ASDs. This aspect of ASDs is associated with a long history of debates.

Initially, the diagnostic criteria for ASDs comprised two dimensions for diagnosis; firstly a lack of affective social contact and secondly repetitive, ritualised behaviours (Timmi et al., 2011). Prior to the DSM-IV-TR (APA, 2000), there were only two categories under the pervasive developmental disorders (PDD) class of disorders (autism and PDD-NOS). The DSM-IV then added three additional disorders: Rett's Disorder, Childhood Disintegrative

Disorder, and Asperger's Disorder. Hence, there were five kinds of autism: autistic disorder, Asperger's disorder, Rett's disorder, Childhood disintegrative disorders and pervasive developmental disorders not otherwise specified (PDD-NOS) (APA, 2000). This in itself makes diagnosis confusing and challenging (Klin, Lang, Cicchetti & Volkmar, 2000).

Even before the DSM-IV-TR, clinicians and researchers questioned whether Asperger's disorder was indeed different from high-functioning autism. This confusion was supported by Wing who stated that Asperger's and high functioning autism were very difficult to differentiate (Tryon et al., 2006). Later, the independent research of Rutter, Wing and Gould spoke of the triad of behavioural impairments. These included social relationships, language and communication skills, and restricted imagination (Timmi et al., 2011).

Age of onset of ASD has varied over time and as a diagnostic criterion, age of diagnosis, has been debatable. Early studies implied an age assumption by referring to the syndrome as "early infantile autism" (Timmi et al., 2011, p. 144). Following this, the DSM-III set a specific age limit of earlier than 30 months. The DSM-III-R criteria relaxed this limit stating that age of onset needed to fall between pregnancy and childhood. The DSM-IV then changed the age of onset to occur any time before 36 months. Generally, in the second year of a child's life abnormalities in socialisation become pronounced (Frith, 2008). The emotional development of the child may appear to deteriorate or simply not progress. It has been recorded that 30% of ASD parents noted a gradual developmental decline in their children's development from 18 months. Prior to this time, no regressive or sluggish development was noted (Frith, 2008). The Text Revision version of the DSM-IV retained this age related clause (DSM-IV--TR, APA, 2005).

As a highly debilitating disorder associated with challenging behavioural patterns which affect a person's developmental milestones, early detection, diagnosis and intervention of ASDs has been a vital topic raised in diagnostic debates (Matson, Reiske & Tureck, 2011; Canal-Bedia et al., 2011). Yet studies have shown that of children diagnosed at 24 months, one-third of the cases were not considered autistic on further testing and diagnosis two years later (Frith, 2008., p. 18). As a result, the new DSM-V will see this criterion expanding to include early childhood in general (Matson & Kozlowski, 2011). Regardless of this need for early identification, diagnosis of ASD prior to the first year of life is rare.

Amongst the classification and diagnostic debates, genetic, neuroanatomical and brain function findings have been linked to ASD, as have other biological findings and psychiatric

disorders (Lord et al., 2011). Yet, there are still no clearly defined biological markers or a set of pathology tests that can be conducted, to accurately diagnose people with ASD (Lene & Waldby, 2010).

Accordingly, the diagnostic process is still based on developmental history and behavioural observations made by clinicians (Klinger et al., 2003). This makes ASD's difficult to diagnose as symptoms are variable and manifest differently in each individual and in various combinations, this results in ASD type behaviours being difficult to standardise (Lene & Waldby, 2011). Children with ASD can present with normal and abnormal behavioural patterns (Lord & Luyster, 2006). They often display symptoms which are not easily explained by the diagnosis of ASD alone (Chowdhury, 2009). Rather comorbid diagnoses exist alongside an ASD diagnosis. Medical conditions such as mental retardation and epilepsy are frequently associated with ASD (Chowdhury, 2009) and ADHD is also a common co-morbid diagnosis (Jordan, 2005).

This study used the diagnostic criteria outlined in the DSM-IV-TR as these criteria were the ones used most prevalently by the clinicians and educators who worked with the child subjects on this research. The three domains that specify autism in the DSM-IV-TR are: social reciprocity, communication and restricted repetitive behaviours and interests (Matson & Kozlowski, 2011). Table 1 below explains the behavioural criteria that need to be observed in order for trained clinicians to make an accurate ASD diagnosis. The following criteria, from A, B and C all need to be met, for an accurate diagnosis of ASD.

Symptoms in at least one of the areas that define autism (social development, communication and play) must be present before 36 months. Sub-domains are delineated in each domain, such as non-verbal behaviours and peer interaction, which fall under the social reciprocity domain (APA, 2000). As already stated, individuals must show behaviours that fall into at least two sub-domains in the area of social reciprocity, and one sub-domain in communication and one sub-domain of repetitive and restricted behaviours (RRBs) (APA, 2000; Lord et al., 2011).

This diagnostic classification is a controversial one, with some theorists stating that two domains: social communication and RRBs may better represent the clusters of behaviours that describe autism (Lecavalier et al., 2006).

As research into this disorder has increased the understanding of it, the behavioural symptoms necessary for a diagnosis have been adjusted and altered. This is indicative in the changing diagnostic criteria of the Diagnostic and Statistical Manual (DSM) over the years. One study suggested an elimination of Asperger's Syndrome in the future and rather a classification of high functioning and low functioning autism. High functioning autism is not associated with mental retardation whereas low functioning autism is. Mental retardation, falls on Axis II of the low functioning autism diagnosis thus clinicians need to guard against confusion in diagnosis (Tryon et al., 2006).

Table 1.

*Diagnostic Criteria for ASDs according to DSM-IV-TR (APA, 2000)*

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)

<b>1. social interaction/reciprocity</b>	<ul style="list-style-type: none"> <li>• impairment in nonverbal behaviour's such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction</li> <li>• failure to develop peer relationships appropriate to developmental level</li> <li>• a lack of spontaneous seeking to share enjoyment, interests, or achievements with others</li> <li>• lack of social or emotional reciprocity</li> </ul>
<b>2. communication</b>	<ul style="list-style-type: none"> <li>• delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)</li> <li>• in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others</li> <li>• stereotyped and repetitive use of language or idiosyncratic language</li> <li>• lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level</li> </ul>
<b>3. Restricted, repetitive, behaviours/ and stereotyped interests or activities</b>	<ul style="list-style-type: none"> <li>• encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus</li> <li>• apparently inflexible adherence to specific, non-functional routines or rituals</li> <li>• stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)</li> <li>• persistent preoccupation with parts of objects</li> </ul>

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Other theorists such as Frith (2008) support this notion arguing that Asperger's should be a disorder on its own and suggest that perhaps Asperger's Syndrome should not be considered a part of the ASD spectrum. It should rather be a distinct developmental disorder on its own. Asperger's Syndrome could also be a separate personality type. Grinker (2010, in Lene & Waldby, 2010) agree with this side of the debate.

The DSM-V will also change the classification criteria for ASD. There will be a complete removal of Retts disorder and a collapsing of the remaining four diagnoses into one, namely ASD. They argue that ASD is a better-understood term that reflects autism as best-characterised core syndrome, with a spectrum of other disorders (Lord et al., 2011). Socialisation and communication deficits will be combined into one set of symptoms with the endorsement of all three symptoms (i.e. Deficits in verbal and non-verbal communication during social interactions, lack of social reciprocity, and inability to develop and maintain developmentally appropriate peer relationships) being required for a diagnosis of ASD. Individuals are required to meet two of the required restricted and repetitive behaviours or interests (Matson & Kozlowski, 2011).

Today, as in the past, there is still confusion regarding ASD classification. These debatable diagnostic factors could affect the outcomes of this study, which is largely reliant on the expertise of trained clinicians. In South Africa and other developing countries access to services also affects accurate diagnosis and classification.

Regardless of future changes proposed by the DSM-V, ASD is still diagnosed purely on behavioural presentation and hence the diagnosis of this disorder is a subjective one. Diagnosing an individual as ASD today still requires an acceptance of the diagnostic criteria outlined in the DSM-IV-TR or in the ICD-10. Theorists have questioned the reliability of diagnoses based on these systems, and state that the ADOS, is regarded as the best clinical aid in making the required clinical diagnosis (Klin et al., 2000).

Besides the variable diagnostic criteria, methodologies used in diagnosis of ASD vary. In a multiple clinical site study consisting of 2102 children between the ages of 4 -18 years who met ASD criteria on the Autism Diagnostic Observation Schedule (ADOS), there were variable methods used in the diagnosis of ASD (Moran, 2012). Catherine Lord stated that different sites used variable factors and differed in their cut-offs for the disorder, in terms of IQ or the amount of repetitive behaviours that were deemed exceptional (Lord et al., 2000). Some sites used a client-centred approach in diagnosing and others used a test-centred

approach. The most frequent predictors of ASD across sites were social communication followed by repetitive behaviours.

Lord (2012, in Moran, 2012) suggested a need for future incorporation of dimensional ratings for behaviours associated with ASD, in the revision for the DSM-V, when considering accurate ways of diagnosing. Members of the DSM-V workgroup propose the inclusion of separate severity ratings for the social communication domain and the restricted interests/repetitive behaviours domain. The DSM-V workgroup suggest specifiers of intellectual functioning, age and type of onset, as well as verbal abilities amongst others (Moran, 2012).

In summary, ASDs were only recognised 70 years ago and only became widely acknowledged in the public domain about twenty years ago. ASDs present in variable ways thus diagnosis is challenging which has resulted in contradictory diagnoses between clinicians. (Lene & Waldby, 2010). The present study largely depends on ratings given by researchers dependent on participant behaviours and responses to the ADOS subtests, and the clinician's interpretation of the participants' personal files. These scores are then compared against diagnoses made by clinicians or educators.

It was thus an aim of this study to compare the diagnoses that the ADOS made with those made by trained clinicians for each participant in the sample, to observe whether there was concordance between the two. It is thus understandable that debates still surround the diagnosis and accurate classification of ASD. Indeed the current DSM-IV-TR criteria have already been revised, and the DSM-V criteria have been released for input. The ADOS algorithms will soon be modified to align with the new DSM-V criteria, which are still open to change. It is the DSM-IV-TR and the ICD-10 diagnostic criteria that are used in this study as these criteria were the ones used most prevalently by the clinicians and educators who worked with these child subjects.

#### **2.2.4 Estimated prevalence and Trends**

There are also many controversies surrounding the prevalence rates of ASDs and debates rage over the percentage increases. It seems that prevalence rates of ASDs are increasing globally (Matson & Kozlowski, 2011). In the last three decades rates have at least doubled (Matson & Nebel-Schwalm, 2007; Chhagan, Karim & Wallace, 2012; Durkin et al.,



2006). There has been an increase in prevalence of ASDs in developing countries like South Africa. This may be attributed to the fact that almost 85% of the world's youth live in developing countries (Rutter, 2011). The prevalence of disorders like ASD in children is at least as high as those in developed countries (Rutter, 2011). This study is of paramount importance in contributing to the knowledge of ASDs and how they manifest in a multicultural context like South Africa.

Some epidemiological studies estimating prevalence rates have been conducted (Bakare & Munir, 2011). Recent studies have focussed on the rates that ASDs occur, and little attention has been given to the differences in ASD prevalence across countries and whether the occurrence of ASDs vary across ethnic and cultural boundaries (Zaroff & Uhm, 2012). Thus, there appears to be no research on the effects culture plays in the prevalence of this disorder.

Early estimates of the prevalence of ASDs recorded around 2- 4 per 10,000 people (Wing & Potter, 2002). Current estimates suggest that these results have risen. For example, Rutter (cited in Russell, Kelly and Golding, 2009) stated that the true prevalence of ASD is likely to be within the range of 30-60 per 10,000 people.

Over the period 2002 and 2006, the prevalence rate for ASD rose by 57% across cultures. Nevertheless, exactly how ASD manifests in children has not been fully explained. It represents a complex lifelong developmental disability that typically appears during the first three years of life (Eldin et al., 2008).

A study in 2009 by Kogan and colleagues estimated that ASDs occur at a rate of approximately 110 per 10,000 children in the U.S. (Kogan et al., 2009). Similarly, one 2006 prevalence study found similar rates of ASDs specifically in the UK at a rate of 116.1 per 10,000 suggesting that prevalence rates may be consistent across different geographic regions (Sipes et al., 2011). Perhaps the only unifying feature of ASD prevalence worldwide is that it has been on the increase for the past twenty years. As a result, it is a public health concern.

Theorists have posed a number of reasons for this variability in the past. One significant reason for the variance was the changing diagnostic criteria for ASDs (Kochhar et al., 2010). At one stage the DSM-III-TR criteria were significantly different to those found in the International Classification of Diseases (ICD-10). Countries varied on which system they used to diagnose diseases. The European nations favoured the ICD-10 and the USA favoured the DSM criteria, as did South Africa. Hence differing prevalence rates were recorded. Today

however, these two classification systems are comparable across criteria (Matson & Kozlowski, 2011).

The current prevalence rates that have been documented are still considerably lower in countries outside of North America and Europe. This difference may be due to methodological factors, with very few studies being done on the links between ethnicity and prevalence. Those that have been conducted are confined within the borders of the United States (Zaroff & Uhm, 2012). Hence, the need for a study that considers the relationship between ethnicity and ASDs, and one that explores potential patterns that emerge between ethnic differences and observable behaviours associated with ASDs.

Some theorists state that prevalence rates have increased due to increased awareness and misdiagnosis in the past. A better recognition of the disorder and its variants has resulted in better services for those people with ASD (Frith, 2008; Lord et al., 2000). Other theorists add to this by arguing that new assessment instruments as well as different methodologies that identify prevalence levels, and cultural awareness of the variable ways a disorder may present itself, have resulted in prevalence rates rising (Matson & Kozlowski, 2011).

Others feel that in the past, the standards of normality were broader. Thus ASD behaviours have always been around, they were just more tolerated one hundred years ago (Timmi et al., 2011). Now with mass schooling and a greater focus on individual behaviours, as well as a narrowing of acceptable behaviours, theorists and clinicians have merely attached a label to a pattern of behaviours that always existed. These same theorists state that diagnostic labelling and the use of the DSM, have led to prevalence rates increasing (Timmi et al., 2011).

Along similar lines, some theorists describe an increase in “diagnostic substitution” occurring, where children in the past may have been labelled with learning disabilities are now being labelled with ASDs as this allows them entrance into special needs schools and access to greater resources and social grants (Russel, Kelly & Golding, 2009).

Very few epidemiological studies have been published on autism in Africa, based on a few studies citing autism in African countries; the average male to female ratio calculated was 3.8: 1 (Ametepee & Chitiyo, 2009).

On the global stage, prevalence rates appear similar across countries. Frith (2008) cited a British study involving 57000 children aged 9 to 10 years, and found an ASD prevalence rate of 1%. Of that 1%, 0.2% comprised classic autism and 0.7% Asperger’s syndrome (Baird et

al., 2006). In population numbers this equates to two to three million people in the USA having some form of autism, and approximately 500 000 people in the UK having ASD (Frith, 2008). A study conducted by Heward (2009, in Ametepee & Chitiyo, 2009) stated the autism rates in the USA are 1 in 150 children, with boys outnumbering girls by a ratio of 4:1.

Sinclair (2011) supports these findings. Their study also noted considerable under diagnosis of ASD in children between the ages of 7-12 years, attending mainstream schools in South Korea. This study conducted from the years 2005-2009 cited prevalence rates of 2.64%. This is supported by a recent study on prevalence rates in the past 5 years, which shows rates approaching 2% (Charman, 2011). Another study by Kim et al., (2011, in Lord, 2011) also presented evidence for surprisingly high rates of these disorders – 3.75% in males and 1.47% in females – in school-aged children.

Various theories have been posed regarding reasons for this rise in prevalence rates. Exposure to unknown toxins or viruses, affecting brain development prior to birth, may have caused prevalence rates to rise (Blaurock-Busch, Amin & Rabah, 2011). Other explanations include certain vaccinations such as the MMR (measles; mumps and rubella vaccination) which may have altered the brain development of children (Frith, 2008; Wing & Potter, 2002). The latter explanation has since been discredited but is mentioned in order to highlight the complexity and controversies that have surrounded this disorder (Lancet, 2004).

A further possible proposed cause of ASD onset has been contracting severe malaria in the early years of one's life. However, not one of these environmental causes have been confirmed by an independent scientific investigation. Thus more controlled studies are needed in order to test these hypotheses (Mankoski et al., 2006 in Ametepee, 2009; Wing & Potter, 2002).

Recent studies noted a correlation between the incidence of ASDs in children who were in utero at the time that their mothers experienced chronic stress in migrating from countries in Africa, Latin America and the Caribbean (Psychiatric News Alert, 2012).

In recent years there has been an increased social and cultural expectation for people to be socially competent, and the existence of an ASD phenotype has been debated (Frith, 2008).

When one throws ethnicity into the prevalence equation, the results are very different. As stated earlier, few studies have been conducted linking ethnicity and prevalence. Those that have been done in the United States have shown that children of Hispanic descent have

considerably lower prevalence rates of ASDs than white children (Zaroff & Uhm, 2012). This study cited methodological factors, socioeconomic variables and bias, as the reasons for this variability (Zaroff & Uhm, 2012). Disparities have also been recorded concerning the age of diagnosis between races (El-Ghoroury & Krackow, 2012).

Another noteworthy factor to consider in reviewing ASD literature is the increased awareness of this disorder in the media, which may have precipitated parents seeking medical assistance in diagnosing difficult behaviours noted in their children (Matson & Kozlowski, 2011).

Suffice to say that the past research studies that focussed on prevalence cannot be compared to the current ones as the diagnostic criteria have changed so much over time, regardless of the variable methodologies that are also used. Thus, some theorists feel that researchers cannot claim that prevalence rates are increasing (Matson & Kozlowski, 2011).

There is thus an urgent societal need for standardised assessment instruments like the ADOS world-wide. Since it is considered the most reliable and valid instrument for ASD diagnosis in the West, this study aims to explore the diagnostic ability of the ADOS in the South African context also. In so doing, meaningful future comparisons could be made.

### **2.2.5 Aetiological Issues**

The pathophysiological aetiologies which precipitate ASD symptoms remain elusive and controversial in many cases, both a neurodevelopmental component and environmental factors have been implicated (Blaurock-Busch, Amin & Rabah, 2011; Matson & Kozlowski, 2011). Rutter (2011) concurs, arguing that ASDs are multifactorial in nature thus not only are genetic factors at play in causation, but environmental factors also.

Initially it was thought that neglectful and rejecting parental styles caused autism (Kanner, 1943 in Klinger et al., 2003). However, this theory has been refuted and is no longer considered to have any scientific validity.

The greatest emphasis on aetiology in the last 20 years has been genetics (Russell, Kelly & Golding, 2009). Kanner and Asperger said aspects of their patients' behaviours are observable in the parents of their child patients. Kanner and Asperger proposed thus that a broader autism phenotype may run in some families (Kanner, 1943; Lord et al., 2011).

Conversely, Timmi et al., (2011) have a controversial perspective on autism as a diagnosis and ASDs in general. They feel that a person's biological and genetic make-up are secondary causes of ASDs as opposed to the cultural practices of the time and the economy that they feel had a greater role to play in defining someone as autistic.

Other research shows that certain risk factors result in a greater propensity for developing ASD. As already stated, being a male places one at greater risk of developing ASD, than being a female. On comparative studies of male and female personality differences, Baron-Cohen et al., (2001, in Frith, 2008) raised the theory that the male hormone, testosterone, may in part be responsible for ASD development and thus prevalence patterns.

Certain viral infections of the mother during pregnancy, such as Rubella, are thought to be a risk factor (Frith, 2008). Unknown effects of certain drugs are also risk factors. For example, it was found that Thalidomide and Valproic acid (an anti-convulsant used as a mood stabiliser or to treat migraines) use, have been linked to autism (Klinger et al., 2003).

Neurological studies have recognised abnormalities in the autistic brain which are difficult to explain. It was the experimental work of Beate Hermelin and Neil O'Connor who neurologically linked ASD behaviour to the brain (Frith, 2008).

There appear to be a reduced amount of Purkinje cells in the cerebellum and cells in the frontal cortex in ASD people are 'smaller and more spread out' (Frith, 2008, 59). In the limbic system, cells appear to be denser than that found in a normal functioning brain. The long-range connecting fibres are sparser in ASD brains also (Frith, 2008).

Frith (2008) noted that observations carried out by Leo Kanner stated that larger heads have been observed in children with autism than in other children. This observation has long been ignored in the past. Frith further states that although ASD types share core social features, their basis in the brain may vary (Frith, 2008, p. 48).

A study by Johnson et al. (2010) found a higher incidence of neurodevelopmental disorders, including ASDs, in children who were born prematurely, than in the general population.

Research provides evidence that genetics plays a significant role in ASD aetiology. Twin studies found that of identical twins with ASD, there was a 90% chance that both twins experienced this disorder. In comparing non-identical twins with ASD, it was found that only

10 % of the twins were concordant for ASD. This supports a genetic cause for ASD rather than an environmental one (Rutter, 2006, in Frith, 2008).

Some theorists state that ‘It is extremely rare that Autism is caused by an external agent’ (Frith, 2008, p. 16), and diagnosis is invariably based on behaviour which can only be made in hindsight. This has been countered by other theorists who note environmental and emotional stresses linked to migration, have resulted in increased occurrence of ASD in some African countries South American and the Caribbean (Psychiatric News Alert, 2012). This results in ambiguity in terms of diagnosis. Advocacy groups have called for more studies on environmental factors, yet studies as cited in the Psychiatric News, are merely interesting leads at this stage. In conclusion, theorists are divided on whether external factors cause the development of ASDs or whether it is the genetic internal factors that are responsible.

This research study briefly considers the way children respond to the ADOS from various ethnic backgrounds, since children appear to respond differently across ethnic boundaries. What is considered normative behavioural responses in one culture is not considered normal in another (Canal-Bedia et al., 2011). Hence, American children who have English as their home language, may behave differently to South African children who also have English as their home language, since cultural responses may vary across borders.

## **2.3 Assessment, differential diagnoses and comorbidities**

### **2.3.1 Assessment**

Generally, ASD’s are difficult to categorise and symptoms are heterogeneous. This variability leads to complications in assessment (Matson & Nebel-Schwalm, 2007). The classifications of ASDs are made more complex again by a variety of assessment approaches and diagnostic tools used amongst professionals (Lene & Waldby, 2010). Various techniques and instruments have been used in the past in an attempt to diagnose and classify people accurately. Diagnosis has always been based on behavioural presentations and a full clinical history, which includes a neurodevelopmental assessment (Baird et al., 2003; Lord et al., 2005).

The use of standardised instruments is becoming of paramount concern, as this will increase accuracy which in turn increases accuracy in estimating prevalence rates, gender ratios and in turn provides insights into the aetiology and progress of ASDs. Hence the need for a study

like this which considers the way South African children respond to the ADOS, the gold standard instrument for ASD diagnosis in the West.

While the DSM aids the clinician in determining whether the patient is on the spectrum, the ADOS as a diagnostic tool, produces standardised scores that measure the individual severity of each patient and counts the number of symptoms that are manifest (Lene & Waldby, 2010). Standardising the ADOS worldwide will greatly increase accuracy of assessment of this disorder.

In a study conducted by Le Couteur et al. (2007) the use of the ADOS and the Autism Diagnostic Interview Revised (ADI-R) proved effective in diagnosis. In fact, many studies have cited the effectiveness of the ADOS as a diagnostic tool, yet no studies have been found to explore its diagnostic ability in an African context (Reaven, Hepburn & Randal, 2008; Lord et al., 2011).

Matson et al. (2011) state that scales in assessment need to be developed that are specific to young children, following research stating that early detection is paramount. Further, instruments need to go beyond measuring core symptoms of autism. Rather, instruments need to assess behaviours more broadly considering variable behaviours across age groups. The ADOS meets these criteria, in that there are specific modules for certain age groups, beginning at preschool, which consider variable gestural responses that are age appropriate.

The literature suggests that a multi-disciplinary assessment process with access to information from different sources and settings is needed (LeCouteur et al., 2007). Lastly, multi-disciplinary and multiple scales are needed to establish concurrent validity of assessment and diagnosis (Matson et al., 2011). Hence, the methodology for this study follows these guidelines. Information regarding the participants in this study is gleaned from the ADOS, Behaviour during assessment form and Biographical information accessed from their personal files. Thus, the Behaviour During Assessment form will be used concurrently with the ADOS as will an analysis of the personal files of the participants in order to check the validity of the study, and ensure reliability in categorising behaviours that are presented.

### 2.3.2 Diagnoses

Lord et al., (2011) state that the diagnosis of autism of whatever subtype, can be made with sensitivity and specificity. Sensitivity is the ability to successfully identify all the people with a disorder, and specificity is the ability to identify only persons with the disorder and not persons with other disorders (Lord et al., 2011). The ADOS ranges from .80 to 1.00 for sensitivity of diagnosis and from .68 to 1.00 for specificity (Lord et al. 2000). These two factors are measurable. Sensitivity and specificity rates are higher and more accurate when clinicians use combinations of instruments.

Another argument in the diagnostic equation was articulated by Paul Meehl over 50 years ago and still has relevance today. Meehl was an esteemed clinical psychologist who stated that there is considerably more value in having well designed tests in comparison to having opinionated clinicians (Meehl, 1956; Morera & Dawes, 2006). His argument raised issues of diagnosing false positives and false negatives by clinicians or tests. Meehl analysed 20 studies that compared clinical and statistical prediction in decision making and concluded that the judgements of a statistical model, like the ADOS in this study, outperformed trained expert opinion (Morera & Dawes, 2006). He debated this issue in a famous text that he published in 1954, entitled *Clinical versus Statistical Prediction: A theoretical analysis and review of the evidence*. In response to Meehl's argument, other theorists concurred, stating that Meehl's debate over "actuarial judgement was won". Tests prove superior to clinician diagnoses (Morera & Dawes, 2006, p. 410). Meehl further argued that in determining human outcomes, an aggregation process correlated better with gold standards than do clinical judgements. Rutter (2003) supported this diagnostic suggestion in his statement that dimensional and categorical measures be used in the future.

ASD, while treatable, has a lifetime course as do all the associated problems and comorbid factors. Occasionally, children present with a variety of behaviours and symptoms appear to represent a variety of disorders superimposed on each other in the same individual, in a comorbid fashion. This begs the question as to which label is the most appropriate.

For accurate diagnosis it is important that clinicians acknowledge co-occurring problems that people may present with. "Some of these high co-occurring problems include immune factors, epilepsy, and intellectual disabilities, which are physiological" (Matson et al., 2011, p. 1320). Also various forms of psychopathology and challenging behaviours frequently co-occur for persons with autism.



It is difficult to distinguish between various forms of ASD. Some cases present with comorbid disorders as well as ASD, thus behavioural patterns are not easily explained by the diagnosis of ASD alone (Chowdhury, 2009; Frith, 2008). The diagnosis of classic ASD with no comorbidities is more easily made than diagnosis of other types of ASD such as PDD-NOS and Asperger's (Lord et al., 2011). This pattern supports the proposal of autism as being a single category in the DSM-V with dimensions of severity and impairment in it. It has been found that the most common differential diagnoses for ASD vary with the age of the child or adult (Chawarska, Klin, Paul & Volkmar, 2007).

Hence, for this study the sample will comprise children between the ages of 6-11 years of age, since the ADOS is most suited for administration to children within these ages. The ADOS and Behaviour during Assessment form shall be used. Descriptively, one should consider the specificity of the ADOS in identifying participants on the spectrum in comparison to clinician diagnoses. Gleaning information from the personal files will improve the reliability of the study.

### **2.3.3 Comorbidities**

Many children with ASDs have comorbid disorders too, these further add to the complexity of diagnosing ASDs as they present in such variable ways (Amr, Raddad, El – Mehesh, Bakr, Sallam & Amin, 2011). Some studies state as much as 70% of the children diagnosed with ASDs have comorbid disorders (Matson & Nebel-Schwalm, 2007, Strang et al., 2012).

Common comorbid disorders with ASD in older children are Attention-Deficit/Hyperactivity Disorder (ADHD) or anxiety disorders, often coupled with other difficulties such as oppositional defiance disorder or learning difficulties. In these cases factors such as eye contact and facial expressions may be more important for diagnosis than peer interactions (Matson & Nebel-Schwalm, 2007; Jordan, 2005).

Most common in children are mistaken diagnoses of speech and language delays or non-specific behavioural problems with delayed developmental milestones. Language delay is not a requirement for autism. Yet many children are first suspected as having ASD due to language delays (Lord et al., 2011). However, increasingly, more children who have met their normal language milestones are being diagnosed with ASD (Lord et al., 2011). Thus, clinicians need to be extremely cautious in diagnosing ASD. Children presenting with behavioural problems show social deficits and often display an inability to share attention or they may present with repetitive sensory or motor behaviours (Chawarska et al., 2007).

Similarly, not everyone is completely socially competent, they may be naturally introverted. This does not mean that they fall into the autism spectrum. Some adults struggle with intonation and use of idiosyncratic phrases, the ability to hold a conversation, yet are not on the spectrum (Lord et al., 2011).

Only 10% of all people diagnosed with ASD are intellectually superior, a large majority have IQ scores of below 70, thus present with co-occurring intellectual disability (ID). The degree of mental retardation (MR) is a complicating factor in diagnosing ASD (Chowdhury, 2009; Timmi et al., 2011). It is sometimes difficult to differentiate these two disorders especially with severe MR, since the symptoms become more identical with that of autism (Ahmad & Mahmood, 2011).

A Californian study reveals a considerable decrease in mental retardation recorded and a corresponding increase in ASD incidents recorded over a 10-year period, spanning 1987-1994 (Frith, 2008). This can largely be accounted for by the change in diagnostic criteria.

Some studies have found that depression is a comorbid condition with autism, being diagnosed in 2% of the children studied by Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin (1998). More recently researchers have stated that depression is one of the most common disorders associated with autism (Strang et al., 2012). Few studies have been conducted on fears and phobias being comorbid with ASDs; suffice to say that there is considerable debate in this area. Some researchers feel that ASDs may be separate from fears, phobias, depression and anxiety; others differ in their understanding (Matson & Nebel-Schwalm, 2007).

This study considered the comorbid disorders in the ASD sample group. These findings, gleaned from the personal files of each participant were plotted on a bar graph and shall be addressed in the discussion chapter.

#### **2.4 Gender, Culture and Socialisation**

ASD is a challenging group of disorders to understand and treat, and numerous factors compound diagnosis (Klinger et al., 2003). The spectrum of behaviours associated with the subtypes complicates diagnosis, as does gender, age, categorisation, comorbidity and cultural differences.

### **2.4.1 Gender**

ASD does not manifest itself in equal proportions across gender. Frith (2008) stated that one in one hundred children born, are autistic with a greater prevalence in boys than in girls. In Kanner's initial observations of 11 children in 1943, eight were male and three were female (Timmi et al., 2011). Some statistics reveal that the disorder is at a minimum four times more prevalent in boys than in girls (Lemon, Gargaro, Enticott & Rinehart, 2011). Frith (2008) argues that at the more able end of the autism spectrum gender ratios may be as great as 8:1. It has been theorised through observations that girls are able to mask ASD symptoms better than boys and this may account for a part of the unequal ratio (Dworzynski, Ronald, Bolton & Happe, 2012). Gender can be either a protective factor or a risk factor in terms of developing ASD (Frith, 2008).

Lemon et al. (2011) found that there are fewer behavioural issues with girls that are ASD than boys. They also appear to have greater social and communication abilities and have fewer and more typical special interests. Thus, it is possible that there may be neurobehavioral gender differences in ASD that can account for clinical manifestations of core symptoms.

### **2.4.2 Culture**

ASD has been observed in a variety of countries from the Americas, to Europe, the Middle East and countries such as Japan and Korea (Sipes et al., 2011). However, a lack of research exists on ASD in Africa (Ametepee & Chitiyo, 2009).

Large ethnic disparities in the diagnosis of ASDs have recently been identified (Matson et al., 2011; Chung et al., in Sipes, 2011). There is thus a need to be culturally informed, so as to recognise cultural differences in diagnosing and assessing ASDs.

Some studies found that early detection time spans varied between ethnic groups. Black, Hispanic and other ethnic groups were less likely to be diagnosed early with ASDs than were Caucasian children. On average Caucasian children were diagnosed at 6.3 years and the other ethnic groups averaged 7.9 years (Mandell et al., 2002.) These inconsistencies may be due to differences in help-seeking between cultures, and possibly different clinician behaviours (Mandell et al., 2002).

The deficits that these children display, in terms of their socialisation, communication and restricted interests and repetitive behaviours may manifest themselves in variable ways due to their cultural differences (Matson et al., 2011). Cultures influence patterns of behaviour since there are behaviours that are considered normative and acceptable in certain cultures and not necessarily in others. Certain skills are valued in some cultures compared to others. In African cultures the young show respect for their elders by avoiding direct eye contact, yet in Western cultures, looking at someone directly in the eye is considered respectful (Ostrosky-Solis, Ramirez & Ardila, 2004). In fact, little research has been done on the behavioural characteristics of children from different cultures (Bernier, Mao & Yen, 2010). One recent study by Chung et al. (2012) compared characteristic challenging behaviours associated with ASDs across cultures. These behaviours, such as aggression, self-injury, disruptive behaviours and stereotypies, are exhibited in about half the people who have ASDs (McTiernan, Leader, Healy & Mannion, 2011). The study by Chung et al. (2012) found few differences between children in the frequency of these symptoms in South Korea, the United States and Israel. However, when behaviours were compared between children in the United States and the United Kingdom, they differed on nearly half the behavioural items.

Cross-cultural studies have questioned whether scores obtained on tests are comparable amongst different cultural groups (Fischer, 2004). Numerous authors have cited variable response patterns between cultures (Clark, 2000 as cited in Johnson et al., 2005; Bachman, O'Malley & Freedman-Doan, 2010, Scarborough & Poon, 2004 in Chung et al., 2012). Some noted differences between American and Greek student samples (Chun et al., 1974) while other studies comparing the same cultural groups residing in different areas of the globe, showed differing response styles (Suzuki, 1973, as cited in Chun et al., 1974). The cultural qualities responsible for response variability are still largely unexplored (Johnson et al., 2005).

In South Africa cultural differences stem from ethnic identity, informed by ideologies from Colonialism and Apartheid (Durrheim, Mtose & Brown, 2011), although ethnic differences may also be affected by other factors that are cultural or ethnic in origin. For example, western children tend to be socialised to ask for things they need and to speak up for themselves in socially appropriate ways. On the other hand, African children are socialised to be respectful, to be able to wait to have their needs met and to not use gestures too much.

ASDs are diagnosed on observable behaviours which include gestural behaviours. The latter are not universal and vary according to societal norms of behaviour (Archer, 1997). In the Zulu community socially acceptable behaviours are termed social ‘hlonipha’ actions. These are respectful actions that are fundamental to Zulu life. To illustrate this point, on entry into the test venue the researcher makes conversation with the child and considers their use of gaze and eye contact. Zulu culture considers direct eye contact to be a sign of disrespect. This is a ‘hlonipha’ action. Further, some of the subtests of the ADOS considered eye contact between the child and the researcher. The construction task, shared enjoyment and joint interaction sub categories that made use of the puzzle, car/bunny and the family of dolls respectively, all required an assessment of eye contact.

Generally, people are taught to behave in respectful ways, dependant on social variables such as age, status and gender (Rudwick, 2008). These respectful behaviours may appear as submissive, subdued actions, as in the case of some of the Black children who were tested on the ADOS.

Since Black, White, Coloured & Indian people in South Africa come from different cultures, it is highly likely that there are differences in their response patterns on assessment tools. Thus, different ethnicities may respond differently to the ADOS sub-categories when comparing behaviours across cultures.

One cannot assume homogeneity of behaviours across different cultures and racial groups, since culture shapes behaviours and what is considered acceptable behaviour is determined by culture (Norbury & Sparks, 2012). For example, poor eye contact, which is typical amongst ASD individuals, may be interpreted differently depending on the societal norms of that culture (Sipes et al., 2011). While the White culture may view direct eye contact as socially appropriate, other cultures, such as the Black people, may view direct eye contact as disrespectful (Rudwick, 2008). Likewise, some cultures value social interaction and as a result, the development of social skills are paramount. They may thus more quickly recognise autistic-like behaviours in children and thus seek an accurate diagnosis fairly early in the child’s life, compared to other cultures. Having said this, “studies have shown that children with autism in both the West and Africa generally exhibit almost similar behaviours” (Ametepee & Chitiyo, 2009, p.10; Klinger et al. , 2003).

One study conducted by Lotter (1978) countered this finding. This early study that relied on different diagnostic criteria compared symptoms of ASD between children living in Britain

and those living in Africa. 1300 children were seen from five different African countries. Their symptom patterns in terms of their restricted, repetitive, stereotyped behaviours varied. The African children showed movement peculiarities where they banged things or twisted objects and played with items more repetitively. The British children that were studied engaged more in hand flapping, self-aggression and detailed repetitive play.

People do respond differently to stimuli in the environment and cultures dictate behavioural norms. The way a person is taught to socialise within their culture, greatly affects their behaviours, and since behavioural observations are what largely determine the diagnosis of ASD or not, one surmises that culture and socialisation have a significant role to play in the prevalence rates of ASD and in the diagnosis. This highlights the need for assessment tools to be culture-fair. Although some researchers claim that cultural influences at the macro and micro level affect diagnosis, treatment and outcome of ASDs, limited research has been done on this topic (Bernier, Mao, & Yen, 2010).

Culturally, some theorists have generalised that African parents tend to focus on the physical development of the child and Western parents value social engagement as a developmental marker (Amentepée & Chitiyo, 2009). Mankoski and colleagues' (2006, in Amentepée & Chitiyo, 2009) found that certain stereotypical behaviours such as hand flapping, self-aggression and rocking, which are common in Western children with ASD, were uncommon among the African sample that he studied. This suggests that there may be differences in the manifestations of autistic behaviours between Western English speaking children and South African children.

The diagnostic procedure for diagnosing ASDs in children could be enhanced using tests such as the ADOS, but such tests need to have cultural validity. The International Test Commission's guidelines state that all assessment tools and procedures must be culturally fair (Foxcroft, Roodt & Abrahams, 2008). It thus stands to reason that cultural diversity must be acknowledged and accounted for in assessing and diagnosing ASD.

A study conducted by Wallis and Pinto-Martin (2008) recognised the challenge of screening for ASD in a culturally diverse society like the United States, thus in the South African context with 11 official languages, culture cannot be ignored. Thus, a study like this one, which explores the diagnostic ability of the ADOS, needs to document the variable effects that culture may have on behaviour. Given the lack of research on symptom expression across cultures, this is certainly an area for future exploration and study.

### 2.4.3 Socialisation

Socialisation not only affects peoples' behavioural patterns, it also affects peoples thought processes (Bernier et al., 2010). Thus the way researchers and clinicians are socialised also affects their diagnoses and thus ADOS outcomes. An acceptable behaviour in one culture may not be acceptable in another. As already mentioned eye contact between a child and an adult in the Zulu culture would be deemed disrespectful (Grinker et al., 2011). Yet eye contact is one of the criteria considered in a diagnosis of ASD. This makes the concept of socialisation and culture a thorny, sensitive issue that needs consideration in the diagnosis and classification of ASD.

Similarly, in the Japanese culture an obsessive attention to detail is considered a valuable attribute to have. This may be misinterpreted as a restricted, obsessive behavioural pattern, if observed and coded by a clinician who does not understand the Japanese worldview (Kunihira, Senju, Dairoku, Wakabayahi & Hasegawa, 2006).

Social myths and beliefs also affect behavioural patterns. African cultures fear frogs and believe that lightning spits out frogs mouths causing harm, therefore need to be avoided at all costs (Olupona, 2008). A frog in the ADOS assessment kit may spark an unusual behavioural pattern that could be misinterpreted, hence for the Black children in the sample it was substituted for a car and a piece of cylindrical wood.

Responses to questions on assessment tools and individual behavioural responses also vary across cultures. This was highlighted in a study conducted by Grinker et al (2011) which showed the need for back translations of assessment tools due to variable interpretations of questions asked, between English and Zulu speakers.

Some theorists' have opposing and controversial ideas on the interaction between society, culture and ASDs. They feel that Western socialisation has caused 'new age illnesses' such as ASDs. Timmi et al., (2011, p. 236) define the increased prevalence of ASDs as an "autism epidemic". They state that the political, economic and social changes seen in the last few decades in the West have resulted in this epidemic. The focus on smaller families, smaller social networks, the decreased time parents afford children, increasing divorce rates, aggressive consumerism and increased stimulation via media and gaming for children and greater involvement by professionals in child rearing activities, have all created negative social and economic shifts. Coupled with the changing gender relationships, and gender

politics, as well as the western culture's categorisation of certain behaviours as a disorder, we now have this "autism epidemic".

Timmi et al., (2011) pose a Marxist perspective on ASD diagnosis. They state that the ruling, wealthier classes, who are the clinicians and professionals, have both the material and intellectual force of society. They act on behalf of the state to maintain power and influence parents regarding their children's behaviours. These theorists argue that in the early 1900's when children were removed from the labour force in the UK in particular, schooling focused on their intellect through intelligence testing. Today, the focus is on being socially and emotionally competent and able to work in a service economy. They feel that ASDs are Western disorders and people who may have physical deformities or other reasons for decreased participation, may be ostracised from communities and thus may display autistic-type behaviours. These theorists feel that prevalence of ASDs runs concurrently with increases in internet usage and being able to identify with websites and people who personalise the disorder as "my autism". These theorists criticise the fact that ASDs have a vocabulary all of their own such as 'perseverate', 'stimming' and 'sensory overload'. These views appear radical, yet are worth taking into consideration to illustrate the complexities surrounding this disorder.

### **2.5 Autism Diagnostic Observation Schedule (ADOS)**

In ASD assessment procedures, instruments can either be used for screening purposes such as the M-CHAT (Robins, Fein, Barton & Green, 2001) and the SCQ (Rutter, Bailey & Lord, 2003) or they may be specialised diagnostic instruments such as the ADOS. Regardless of their processes, all assessment techniques need to meet required standards in terms of validity, reliability, sample error, specificity and sensitivity.

The Autism Diagnostic Observation Schedule (ADOS) is considered as the gold standard for ASD diagnosis in the West (Reaven et al., 2008). The ADOS is a semi-structured, play and activity based assessment that increases the likelihood that a child with ASD will display behaviours that typify disorders on this spectrum (Lord et al., 2000). The test authors have claimed from their initial steps in developing the ADOS, ranges from .80 to 1.00 for sensitivity of diagnosis and from .68 to 1.00 for specificity (Lord et al., 2000). The ADOS has been cited in other studies as being extremely accurate in differentiating children with ASDs from children with non-spectrum disorders (for example, Overton, Fielding & Garcia de Alba, 2008).



The ADOS test takes the form of an observational interview of participants when there is a possibility of making a suspected ASD diagnosis (Reavan, et al., 2012). The ADOS provides, through various ‘social presses’, standard contexts for observation of aspects of social behaviour, communication, play and restricted or repetitive behaviours in individuals suspected of having a possible ASD (Le Couteur et al., 2007; Lord et al., 2011). The various activities allow the researcher/examiner to observe the specific behaviours that are identified as important to the diagnosis of Autism Spectrum Disorders.

The ADOS consists of four modules, each with variable protocols for use with participants, who are at particular developmental and language levels, from non-expressive or receptive language, through to verbally fluent individuals (Le Couteur et al., 2007; Lord et al., 2011). The modules are designed for differing expressive language levels and differing ages, from non-verbal preschool children to verbally, fluent high functioning adults. Studies reveal that the expressive language level of participants is the strongest predictor of outcome for ASD, in individuals beyond the preschool level (Kobayashi, Murata, & Yoshinaga, 1992, in Lord et al., 2011). The ADOS is designed to test for ASD in individuals no matter where they fall on the spectrum.

The ADOS aims to provide information about the participant’s social and communication abilities, beyond mere expressive language delays (Lord et al., 2011). This allows the instrument to control for language ability as a possible confounding variable in diagnosing ASD. The raw scores obtained by an ADOS administration can be understood to indicate the severity of the ASD that the child has (de Bildt et al., 2011). The ADOS yields a diagnostic algorithm using scores from social and communication domains and provides error cut-off scores for two diagnostic categories: Autism and ASDs (Reaven et al., 2012). The current algorithms are based on the DSM-IV-TR and ICD-10 (used in the current study) and are in the process of being modified to accommodate the changes introduced in the DSM-V.

Only one module is administered to a participant at any one time. The decision about which Module to administer is based on the clinician’s judgement of which module is most suited to fitted the expressive language abilities of the child, as well as some consideration of developmental level.

### **2.5.1 Standardisation**

This study forms part of the larger K-ASD study, which attempts to standardise and assess cultural relevance of the ADOS in South Africa. Thus, one has to ascertain its reliability and validity and the normative data surrounding behaviours and gestures used by the participants.

Reliability of the ADOS is beyond the scope of this study, yet, to a degree it is accounted for. Reliability considers the consistency of the instrument, and requires scorers to be consistent in their scoring procedures and their interpretations. Independent scoring was conducted by the scorers, followed by collaboration and consensus on the final scoring attained. Thus the study attempted to meet the criteria for consensus screening rather than inter-scorer reliability. This was based on the fact that although the examiners were trained in the coding procedure, they were relatively inexperienced.

The questions asked by the researchers/scorers, and the wording used, needed to be standardised, as were the 'presses' used in the different subtests. The researchers were required to participate in sufficient training through attending seminars, viewing training DVD's designed by the ADOS developers themselves, observing the ADOS in practise at the Asenze site, scoring individually then collaborating with fellow researchers, to ensure consistency and reliability of administration.

Part of standardisation required consistency in terms of the administration of the ADOS. The ADOS needed to be administered under carefully controlled, standardised conditions in order for results to be reliable, valid and unbiased. Thus, the same room in each school was used for administration purposes every time to ensure consistency. The researchers were trained in administration of the ADOS, in accordance with the manual's instructions. The ADOS needs to be culture fair if it is to be a source of scientifically standardised information (Foxcroft & Roodt, 2004). This aspect of the ADOS investigation is being completed by the members of the K-ASD study.

### **2.5.2 Theoretical Considerations**

The categorisation of autism subtypes as outlined in the DSM-IV-TR is problematic. There is a similarity between high functioning Autism and Asperger's syndrome. Often people are diagnosed in late childhood /early adulthood when it is difficult to decide if there was a language delay in the early years. Thus, it is argued that language delay is not a reliable indicator of ASD in late diagnosis (Swedo, Thorsen & Pine 2008, in Roberts, 2010).

Comorbidity, as already discussed, makes diagnosis a challenging process. In this study, using the ADOS in conjunction with the behaviour during assessment form; as well as an analysis of personal files, hopefully provided a comprehensive picture for each child being tested. Safeguarding against errors in diagnosis; limiting confounding variables in the study; and ensuring a more valid diagnosis were all taken into account as much as possible.

There are limitations in using the ADOS, since it only provides information of the participant's current behaviour and diagnosis was based on one observation. Thus, the study considers the participants' history through accessing the personal files to substantiate the diagnosis on the ADOS and highlight any possible comorbidities.

### **2.5.3 A Western tool within the South African Context**

The ADOS is a Western tool and this study primarily aimed to explore the diagnostic ability of it in the South African context. As mentioned, cultures and related behaviours are variable. In conducting the assessments in South African schools where the majority of the participants are Black, one needed to try to reduce behavioural variances related to culture.

Assessment tools such as the ADOS are subject to cultural biases (Norbury & Sparks, 2012). Hence, every effort was made to standardise the ADOS to the South African context without changing the assessment procedure. Some adaptations were however necessary. For example, the pictures on the original ADOS kit are Americanised and represent activities many South African children are unfamiliar with. Due to concern regarding un-relatedness and lack of understanding, the Westernised pictures were substituted for scenes that are more African. Namely, a picture including activities such as water skiing, paragliding, playing tennis and sailing, were replaced with illustrations of a rural home environment with people flying home-made kites, corn growing in the garden and chickens running around with a pet dog on the scene, since these are features that were more likely to be familiar to most Black African families.

Similarly, dolls in the form of a Caucasian family with children and grandparents, were substituted for an African family with brown skins. Likewise the doll used in the birthday party task was replaced with a brown-skinned doll.

The reason for these minor adjustments was to ensure equivalence across races in administration of the ADOS and thus avoiding bias. According to Van deVijver and Leung (1997) attaining equivalence is the most central issue in cross cultural research.

Further, the demonstration task was simplified to a dish and the soap, without too much focus on hot and cold taps. If children were unable to perform the demonstration gestures simultaneously with verbal comments, they were provided a bar piece of soap and a face cloth with which to demonstrate the task. If this task was unsuccessful, the child was asked to show and describe how they brush their teeth, using imaginary tooth paste and tooth brush.

Although the ‘birthday party’ routine was not problematic, a more culturally accepted alternative of ‘bathing the baby’ is provided in the manual.

Further, the frog was also not used as a toy in the ADOS subtest as many Black children fear frogs. This was noted in the Azenze study which forms part of the larger K-ASD study. Here researchers tested normal developing African children’s responses to the ADOS subtests. It was found as a general rule, that Black children were culturally scared of frogs. The DSM IV acknowledges specific phobias associated with frogs, termed Ranidae phobia. Frogs also superstitiously represent bad omens in the Zulu culture (Gordon, n.d.; Psychiatry speciality board review for the DSM IV, 1996). The ‘Tuesday’ book tells the story of flying frogs. Attempts were made to introduce a more culturally appropriate book for storytelling and the children were given the choice of which book they wanted to read.

Changing the tasks to be more culture fair was relatively simple. The larger challenge lies in recognising the culturally embedded verbal and non-verbal behaviours that relate to the spontaneity in play, use of gestures, and in the asking and showing of objects in an interactive way with adults. Especially, adults who are unfamiliar white adults, namely the researchers. Finding appropriate translations of ADOS instructions and commands can also be challenging. The translation and back-translation processes were conducted under the auspices of Western Psychology, the distributors of the ADOS, in conjunction with members of the K-AD research team.

Thus, an attempt was made to make the ADOS more culture-fair. Allowing the participants to identify more with the objects and elicit free conversation and imaginative play more easily.

The adaptations made included:

1. Translation, back-translation and re-translation of the ADOS prompts into isiZulu.
2. Substituting the Americanised pictures for ones that portray scenes more familiar to South African children.
3. Dark-skinned dolls were added to modules 1, 2 & 3 of the ADOS for both task two and the birthday party.

These adaptations aided in bridging the obvious cultural and social gaps that existed in using the ADOS in a Western context as opposed to the South African context. The aim was to aid the children who were being assessed to more easily identify with the tasks of the ADOS in order to facilitate an accurate diagnosis. These adaptations were not done independently by the researcher, rather an expert panel of psychologists (across race), and paediatricians on the larger K-ASD study made adjustments relative to their findings in the broader study.

Since ASDs affect multiple domains of a person's life and are a very under researched field in South Africa, it was hoped that this study might contribute to our understanding and management of this disorder. Hopefully, changes at a national policy level could improve the provision of services and needs to children with disabilities in our country.

## CHAPTER 3

### METHODOLOGY

#### 3.1 Research Design

This design was supported by the paradigm of logical positivism, with an objective epistemology in which the researcher adopted the role of a detached observer. The methodology involves hypothesis testing and is experimental in nature (Neuman, 2006; Terre Blanche, Durrheim & Painter, 2009).

Using a quantitative, blinded experimental design, the researcher was unaware of whether the children being assessed had been given an ASD or non-ASD diagnosis. An attempt was made to match all children assessed on the basis of age, gender and ethnic origins. A comparative assessment was carried out using the ADOS, in an attempt to explore the diagnostic ability of the ADOS across ASD and non-ASD participants.

This study used the diagnostic framework of the DSM-IV-TR (APA, 2005) to explore the diagnostic ability of the ADOS with regard to the way in which South African children present with ASD. The DSM-IV-TR is currently the diagnostic framework most frequently used in diagnosing this sample in special needs schools.

Since ASDs are a heterogenous group of disorders that present in variable ways in individuals, a child-centred approach to diagnosis was adopted. The literature supports the fact that children are socialised differently and thus have variable response patterns and gestural behaviours. Since ASDs are diagnosed based on behaviour patterns presented during assessment, the unique characteristics each child brings to an assessment process should not be ignored. A test-centred approach would have ignored these fundamental differences that influence an ASD diagnosis.

The primary aim of this study was to explore the diagnostic ability of the ADOS. This was done by observing whether concordance existed between the diagnoses made by the ADOS and those made by the trained clinicians per participant in the study.

The primary null hypothesis states that:

There will be no significant difference in the ADOS diagnosis and a clinician's diagnosis for each atypically developing participant in the sample with Zulu or English ancestry, including those children diagnosed with ASD and those children with other special needs.

The alternative hypothesis thus is:

There will be a significant difference in the ADOS diagnosis and a clinician's diagnosis for each atypically developing participant in the sample with Zulu or English ancestry, including those children diagnosed with ASD and those children with other special needs.

The sub-hypotheses focus on the different sub-categories embedded in the ADOS and questions whether different ethnicities respond differently to the various sub-categories. The hypotheses therefore consider if there are significant differences between ethnic groups on each algorithm. They are worded as follows:

**H01:** There is no significant difference between children of Black, White or Indian ethnic origin with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.

**Ha1:** There is a significant difference between children of Black, White or Indian ethnic origin with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.

**H02:** There is no significant difference between children of Black, White or Indian ethnic origin with ASD and those with other special needs based on the sub-group coding for Reciprocal Social Interaction on the ADOS.

**Ha2:** There is a significant difference between children of Black, White or Indian ethnic origin with ASD and those with other special needs based on the sub-group coding for Reciprocal Social Interaction on the ADOS.

**H03:** There is no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Imagination/Creativity on the ADOS.

**Ha3:** There is a significant difference between children of Black, White or Indian ethnic origin with ASD and those with other special needs based on the sub-group coding for Imagination/Creativity on the ADOS.

**H04:** There is no significant difference between the children of Black, White or Indian ethnic origin with ASD and those with other special needs based on the sub-group coding for Stereotyped Behaviours and Restricted Interests on the ADOS.

**Ha4:** There is a significant difference between the children of Black, White or Indian ethnic origin with ASD and those with other special needs based on the sub-group coding for Stereotyped Behaviours and Restricted Interests on the ADOS.

## **3.2 Data Collection Procedure**

### **3.2.1. Sampling and Measures of recruitment**

In identifying a suitable sample for this study, Special Needs Schools in the greater eThekweni region were first identified. However access to schools is authorised through the Department of Education and so permission was first sought through them.

The gatekeepers for this research study were the Department of Education and the Principals of the special needs schools. This study forms part of a wider KwaZulu-Natal ASD study. Initially three Special Needs Schools in the greater eThekweni area were identified. The principals were contacted telephonically, and followed up with an e-mail that provided a brief outline of the study, to ascertain whether they were prepared to participate in the study. Two agreed to participate and one school declined.

Following this initial contact, a formal meeting was held with the principals of the schools explaining the study, followed by a letter outlining the detailed nature of the study and explaining how the ‘blinding’ was to be organised (Appendix A). The letter explained the role key people needed to fulfil in the school in terms of setting up the sample frame, obtaining parental informed consent and child assent, and maintaining anonymity in the initial phase of the study. This was necessary to ensure that the researcher was blind to the diagnosis of a child while administering and coding the child’s performance on the ADOS. Participation was on a voluntary basis and there were participant drop-outs.

This sample is considered to be a vulnerable population thus part of sampling required letters of informed consent to be obtained from parents/legal guardians of potential participants in the study (Appendix B). Once a parent had signed and returned consent for their child to participate, the relevant staff members at the schools scheduled the assessment times. The



one school was only able to provide a matched sample of 8 children in total; the other school targeted a total matched sample of 40 participants who participated in the study. However due to ‘screen-outs’ - samples not being correctly matched according to age and gender, or being unable to engage with the tasks - ultimately only 18 participants in total were able to be used from the second school. In total the experimental group in the sample comprised 13 atypically developing children with ASD and 13 atypically developing children with other special needs who constituted the control group, thus 26 in total (see Table 2). In terms of gender, the sample comprised eight females in total. Four females with ASD and four females who had other special needs and were Non-ASD participated in this study. There were 18 males in the sample; nine were ASD and nine were Non-ASD. Studies suggest that considerably more males have ASD (Lemon et al., 2011). This was consistent in the current study that had 8 females and 18 males in the sample.

Table 2.

*Gender differentiation across ethnicities in each school*

		ASD		NON-ASD	
	Ethnicity	Female	Male	Female	Male
School 1	African	0	5	0	5
	White	0	1	0	1
	Indian	2	1	2	1
School 2	African	0	0	0	0
	White	2	2	2	2
	Indian	0	0	0	0
<b>Total</b>		<b>4</b>	<b>9</b>	<b>4</b>	<b>9</b>

### 3.2.2 Participants

Non-probability purposive sampling was used in this study. In order to have a representative sample, this is the most viable method to use (Kerlinger 1986, in Terre Blanche et al., 2009). Special Needs Schools in the greater eThekweni area were approached and a matched atypically developing sample was obtained. Two Special Needs Schools were used as sites in this study from which the sample was drawn. The sites, although independent of each other, were similar in terms of the methods of recruitment used and the strategies used in the collection of the data.

Forty children between the ages of 6 and 11 years were initially recruited to provide some standardisation and so as to avoid misdiagnosis. Ultimately, only 26 were used in the final sample. One group of participants ( $n = 13$ ) consisted of atypically developing, clinically diagnosed ASD children. This group comprised the experimental group. Following DSM-IV-TR diagnostic criteria, participants in this group met the requirements for an ASD diagnosis and prior to our study, had been diagnosed by clinicians either in their schools or privately.

The second group ( $n = 13$ ) consisted of children who did not fall on the autism spectrum, but were in Special Needs Schools for various other reasons; thus, they too were atypically developing children. This group served as the control group. The experimental and control group were matched according to gender, age and ethnicity or ancestry to reduce confounding factors.

The majority of children in this group had learning delays; some were further challenged by having ADHD, mental retardation, cerebral palsy, chromosomal disorders and so forth. Pure cases of ASD are found in some people and others present as co-morbid ASD with epilepsy, ADHD and anxiety disorders (Frith, 2008). These patterns were noted in some of the children used in this study sample.

### ***3.2.2.1 Inclusion and exclusion criteria***

All the children in both groups spoke English as their language of instruction. This was an inclusion criterion. Those who spoke Zulu as their home language had an isiZulu interpreter present during the administration of the ADOS. The samples were from Indian, Black and White ancestry.

Each participant had to be between the ages of 6 and 11 years old. This age group was selected since modules 1, 2 and 3 of the ADOS in previous studies conducted by Lord et al. (2000) and Lord et al. (2005) showed diagnostic accuracy. Having age limitations also provided standardisation in the study. Each child that was ASD was matched according to age, ethnicity and gender with another child that was non-ASD. This matched sample was co-ordinated by a school staff member without participation by the researcher. Thus, the entire sample consisted of 10 paired White children, 6 paired Indian children and 10 paired Black children (see Table 3.).

Participants were excluded from the study if they failed to complete the full ADOS assessment, or were unable to engage with the tasks.

### 3.2.3 Ethical considerations

This study followed the ethics guidelines for research with human subjects outlined by the Health Professions Council of South Africa (HPCSA) and the UKZN- College of Humanities codes for research. In both schools a staff member had to facilitate the organisation of the sample. In the one school the occupational therapist performed this task and in the other, the head of the autistic unit, performed this duty. Considerable time and effort went into matching the sample and organising the completion of the written informed consent and assent forms (Appendix A & B). The researchers worked in a collaborative partnership with these key people (Wassenaar & Mamotte, 2012). On-going respect and professional integrity was maintained in this partnership.

Table 3.

#### *Profile of Participants*

Years in School	Age	Gender	ASD			Non-ASD		
			Black	White	Indian	Black	White	Indian
4	10	F						Y
4	10	F			Y			
3	9	F					Y	
3	9	F		Y				
3	9	F					Y	
5	11	F						Y
6	12	F			Y			
3	9	F		Y				
5	11	M				Y		
4	10	M			Y			
4	10	M						Y
1	7	M	Y					
1	7	M				Y		
2	8	M	Y					
2	8	M				Y		
3	9	M				Y		
3	9	M	Y					
5	11	M	Y					
3	9	M					Y	
3	9	M		Y				
2	8	M					Y	
2	8	M		Y				

4	10	M				Y		
4	10	M	Y					
2	8	M				Y		
5	11	M					Y	

On occasions participants failed to come to school or the work schedule at school clashed with the assessment process, and researchers were required to reschedule and return at a more convenient time for the participants (Wassenaar & Mamotte, 2012).

Participants and parents were assured that all data would be kept confidential and would only be used for research purposes. A separate external hard drive was purchased to store all the videos in a confidential manner and ensure moral sensitivity towards participants' in the study. This study involved minimal risks and no potential harmful tasks were involved. The participants' parents benefitted from this research in that it shed more light onto the nature of their children's disorders. Other ancillary core obligations were identified, that is, other needs that the participants may have had that were not able to be met by this study, were documented and a report was given to the parents advising them of further assessments needed for the benefit of the participants (SARETI lecture notes, 2012). The participants were permitted to withdraw at any stage during testing. No one chose to withdraw although a few participants requested a toilet break or required a rest from the activities and went for a short walk during the assessment process.

Although this is a small study with limited participant numbers, it will contribute to a greater understanding of ASDs in South Africa, and will hopefully add to the broader knowledge of this disorder on the African continent and so benefit society.

Principals and parents were given written feedback regarding their child's performance during the assessment (Appendix C). This was in accordance with the initial letter informing them of the study and requesting the child's participation.

### **3.2.4 The Assessment Process**

The methodology followed in the assessment process was rigorous. A child-centred approach to assessments was adopted in this study rather than a test-centred approach. The latter required that the researcher rigorously adhere to the methodology outlined in the ADOS manual and handbook. The researcher rather chose the child-centred approach where one had

to be acutely aware of the child's behaviour and responses in the assessment process. The aim was to establish rapport and to allow the child freedom to engage with the test procedure in a flexible, positive manner. The actual testing was extremely time consuming and labour intensive. It took place at the participants' schools.

Prior to commencing, the researchers had to undergo intensive preliminary training sessions. There were 2 x 3 hour training sessions with Dr Bev Killian, where the characteristics of ASD were discussed and the ADOS was introduced. General administration procedures were explained and observed using DVD's designed by the developers of the ADOS assessment tool. The manuals on the ADOS were studied individually and further DVD training on the coding and scoring of the ADOS followed. This second process took about ten full days of training.

The ADOS instructions or prompts had to be translated and back-translated for the isiZulu participants. These instructions also had to be standardised before commencement of administration. This ensured a standardisation in the administration of the tool. This process was undertaken by the larger K-ASD study in collaboration with Western Psychology, the publishers and distributors of the ADOS.

The instruments of relevance to this study were:

- The Behaviour during Assessment Form (Appendix C)
- The ADOS and,
- Biographical Forms (Appendix D).

When used alone they are not reliable in diagnosing ASD. All three assessment measures are dependent on the accurate completion of the assessment by the researchers. The Behaviour during Assessment form and the Biographical Form were developed in a collaborative manner.

A room was assigned to us at each school and the ADOS and video camera were set up. For the purposes of this study, modules 1, 2 and 3 of the ADOS were used.

As per the manual instructions, module 1 was used on participants who displayed minimal speech, bar simple phrases. Module 2 is intended for participants who are verbally fluent and can use flexible three word phrases. It was the assumption that low functioning participants from the Special Needs Schools would be assessed using this module, some however required

module 1. Higher functioning special needs participants, with a greater command of language, were most likely assessed using module three.

There was rigidity in the assignment of modules, in accordance with the ADOS module specifications, thus ensuring a rigorous design. If, during the assessment, the module of use proved inappropriate for the language level of the participant, then the module was substituted for the more appropriate one. Participants unable to engage with the tasks were excluded from the sample.

The ADOS was administered at a comfortable table for modules 2 and 3. Since module 1 began with activities on the floor, a flat blanket was placed on the floor with the toys on top. The researchers tried to keep the room quiet and free of distractions, however in a school environment with an intercom system, this was not always possible. Interestingly, the intercom and other distractions did not appear to upset the participants as much as the researchers.

Each ADOS administration lasted between 45 minutes to 1 hour. Children were randomly brought to the assessment venue. The allocation of “who to test” was performed by a key member of staff at the school who was not blinded. Thus, they knew who those with ASD were and who were non-ASD in the study; they ensured that the sample was matched.

At least two researchers participated in each ADOS administration. A person conducted the assessment on the ADOS and another ensured that the video footage was being captured, they changed the cards in the camera when necessary, and they filled out the Behaviour during Assessment form for the child (Appendix C).

The ‘Behaviour during Assessment’ form (Appendix C) was specifically designed for this study to more accurately code the participant’s behaviours during assessment. It is a questionnaire aimed at recording the child’s emotions, gestures and general responses to the researcher and the ADOS activities, in a qualitative way.

The intent was to observe and document impairments associated with ASD and to observe the child’s general response to the testing situation, especially communication impairments, social interaction behaviours, creativity limitations, and restricted behaviours (Eldin et al., 2008). It comprises yes/no dichotomous data, and functions to compliment and confirm the ADOS diagnosis as well as note more general response patterns.

The rationale behind this form is that using more than one tool ensures that the various ASD-type behaviours are sufficiently covered in testing and are adequately assessed. It is assumed that diagnosis will be more accurate in that it reduces false positives.

Notes were taken during the administration of the ADOS module by both researchers for each participant tested. The child's behavioural responses and overall appearance were recorded under the following headings on the Behaviour during Assessment form (Appendix C):

- Body size
- Grooming and hygiene
- Facial expressions
- Nature of eye contact
- Energy levels
- Attitude to the examiners
- Behavioural characteristics (introverted, stereotypical, tactile defensive etc.)
- Speech and language patterns (echolalia, odd imaginative comments)
- Concentration and attention span
- Fine and Gross motor co-ordination
- Attitude to toys and assessment
- Cognitive processes
- Mood and affect
- Their behaviour after assessment

The information gleaned was largely consistent with a mental status examination used to assess individual children. It provided additional information that could briefly alert the researchers to potential areas for further investigation.

A few participants had imaginary friends and one imaginary friend in particular was observing the whole ADOS administration procedure from behind a nearby pillar! Odd speech was recorded, such as "Americanised phrases". In terms of behaviour, repetitive hand or finger flicking or odd twitches were recorded.

After the administration of the ADOS, the researchers present independently rated the participant on the ADOS subtests and then, by consensus, decided on the most appropriate scores for each subtest. The items in the ADOS are generally scored on a three point scale from 0 (no evidence of abnormality related to autism) to 2 (definite evidence). Some items include a code of 3 to indicate abnormalities so severe as to interfere with the observation. For all interpretations the scores of 3 were converted to 2 (Lord et al., 2000). The scores were then used to formulate a diagnosis through the use of the diagnostic algorithm provided for

each module. A conclusion was reached on whether the participants fell into the autism spectrum or not.

The procedure was videotaped and observed by relevant professionals involved in the study to ensure accuracy in the coding of the behaviour exhibited by the participants during the assessment. All participants' scores on the ADOS, as well as their age, gender and race, were entered into an Excel-spread sheet database. Once all the participants at a particular school were assessed, their personal files were accessed and analysed by a trained clinician, Dr. Beverley Killian. Based on the information found in the personal files, biographical information on each participant was recorded using the Biographical forms (Appendix D). The following information was recorded from the personal files:

- Family history of psychological and medical disorders
- Learning difficulties
- Paediatric reports recording comorbidities
- Psychological and occupational reports
- Speech therapist reports
- Audiologist reports
- Remedial reports

Most importantly, the diagnosis of the child based on clinical reports was noted. This information was further categorised and placed in a spread sheet format.

Neither the Behaviour during assessment form nor the biographical data forms were formally included in the analysis. The information obtained on these forms is neither standardised nor validated. They were intended simply to make the recordings relating to the child more intensive. They were helpful in preparing the feedback reports to the principals.

### **3.2.5. Forms of error in assessment**

There is always a certain amount of error in measurement (unsystematic and systematic) even if the ADOS is consistent and reliable; it does not guarantee the test's validity (Roodt, 2009). "The utmost care was taken in the standardisation of assessment conditions, the administration procedures, and the clarity of instructions, so as to avoid ambiguity" (Roodt, 2009, p. 51). This reduced unsystematic error (Finchilescu 2002, in Tredoux & Durrheim, 2002). Thus, allowing for a more accurate explorative test of validity of the ADOS in this study.



Systematic error could occur if the ADOS were measuring something other than ASD. This systematic error is reduced in the ADOS by the test comprising multiple sub-categories, thus high or low scores on any one category would have cancelled out due to the test having comprehensive multiple sub-categories (Durrheim & Painter, in Terre Blanche, Durrheim and Painter, 2009). The overall random error of this study is reduced by increasing the sample size. Due to time constraints, the lengthy process of individual assessment, and the need to have a reliable administrator within the school that would ensure a blinded, matched sample, the sample size was limited.

Systematic errors are problematic. They originate from two sources, namely respondent error and administrative error.

In terms of respondent error, if a participant becomes emotionally upset during the assessment or is too upset prior to assessment for responses to be accurate, then respondent error has occurred (Durrheim & Painter, (2009). During the ADOS administration, a participant may fail to complete or participate in a section of the ADOS and thus, they cannot be coded. This also constitutes an administrative error. There were some study 'drop-outs' from the original administration of the ADOS.

This study would not be valid if a matched sample was not an accurate sample. Thus, the study ensured that all participants included in the experimental and the control groups met criteria of inclusion which were gender, age and race matches.

Use of the ADOS is largely dependent on the researchers/examiners clinical experience, how they subjectively score each participant and their experience with the instrument.

Thus, two or more researchers scored each participant on the ADOS. They then discussed their individual scores with the aim of reaching consensus on the most accurate score to be allocated. Thus, examiner variance, as a source of error variance, was limited in this study (Roodt, 2009). Inter tester reliability was not considered in this study. The researcher felt that due to their own inexperience with the ADOS, consensus scoring would be more beneficial for the child concerned and more in line with the aims of the study.

Since the assessments were conducted in a school environment, excess noise outside the assessment venue would have contributed to a systematic and administrative error.

Reliability of the ADOS required that the questions asked of the participant were clear and unambiguous for all cultures, if not, then a systematic error had occurred. Careful measurement design hopefully reduced this systematic error (Durrheim & Painter, 2009). This was achieved through a collaborative effort on the part of all the researchers involved, whereby the comments for each sub-category of module two and three were standardised under the direction of the study co-ordinator, using the ADOS manual as the guide.

Thus, all the observed scores ( $X$ ) or codes on the ADOS are comprised of the true score ( $T$ ) and an error score ( $E$ ).

$$X=T+E$$

The true score is however a theoretical concept and as the researcher, one will never know the true score of any participant on the ADOS. In this study, the process of assessment required observing the way participants responded to the questions asked and the tasks presented during the ADOS assessment. These were then coded by the researchers independently and were scored in various sub-sections. Algorithms were then calculated to obtain diagnostic cut-off scores. The cut-off scores allowed for a degree of error in measurement and are based on the current DSM-IV TR (APA, 2000).

### **3.3.6 Limitations in the Research Design**

The matched, blinded study design was necessary to ensure that researchers were uninfluenced by prior diagnoses of participants who participated in the assessments. However, it proved to be problematic in many ways.

The researchers at the outset had to accept the professional judgements made by the staff at the schools in matching the sample. Although the key staff members at each school understood the study design, errors occurred which compromised the ultimate size of the sample. This could not be checked for errors during data collection as the researcher was blinded and it would have been unethical. As a result, after all the assessments were completed, errors were discovered and 9 participants had to be excluded from the study.

- WP 12 – 6 years, had no accurate match
- WP 16 – 7 years, had no accurate match, gender was inaccurate.
- WP 3 – 14 years, too old for inclusion
- WP 21 – 14 years, too old for inclusion

- WP 23 – 16 years, too old for inclusion and no match.
- WP 24 – 12 years, too old and no accurate match
- WP 27 – 10 years, no accurate match
- WP 14 - 7 years, no gender match
- WP 22 – 13 years, too old for inclusion in this study.

As already stated, this compromised the study in terms of the sample size. The original aim was to have a minimum of 25 paired, matched participants. After checking inclusion criteria, we were left with 18 paired, matched participants.

Another factor that compromised the sample size was the unwillingness of schools to participate in the study. Eventually two schools were prepared to assist in this study. It took considerable time to identify and commit key people in the schools to co-operate with the research study. Then the task of obtaining the completed consent and assent forms was a time consuming and tedious process for them. They then had to match the sample and keep the researcher blinded. They had to set up interview times with class teachers in collaboration with researchers in order for us to administer the ADOS. Great care was taken to ensure that participants did not miss important and fun lessons as well as other activities.

The key staff members in each school stated that it took a considerable amount of their time to perform the administrative tasks needed for this study. Getting completed forms, vetting calls from curious and concerned parents whose children were on the study etcetera. It was time taken from their busy teaching schedules and perhaps this is why some schools were not co-operative.

From the researcher's point of view, standardising the language for each module took time, the design of the behaviour during assessment forms also was a collaborative time consuming effort. Considerable time was spend collaborating via email and telephonically and in travel to and from the schools.

The administrative logistics of co-ordinating translators with days that suited the schools for assessment was challenging. It was a costly, time-consuming method of data collection, more than anticipated. Often children were absent from school so additional assessment days had to be scheduled. This incurred further costs for transport and the fees of the translator.

Some of the personal files had scant information while others were comprehensive, so the amounts of personal information gleaned, varied between participants and schools.

In terms of race, the study found no coloured children that could have been included in the study hence Black; White and Indian participants were used. In this study Black referred to children of African origin, mainly the Zulu ethnic group, although some had one parent who was Zulu and the other parent was from a different ethnic group; e.g. Xhosa.

The two schools were vastly different in terms of the students that they attracted. The one school attracted middle to upper class families since the fees were fairly high. They also had stringent entrance criteria. This school only provided the sample with White males and females. Their personal files were comprehensive since parents were able to afford the necessary assessments.

The other school was prepared to take any special needs children that needed educating. Their entrance criteria were more relaxed and fees were reasonable. This school contributed Black, White and Indian participants to the sample. Their personal files were not always comprehensive as the social economic status of the parents limited their access to professional assessments. In this regard, the ADOS administrations greatly contributed to the well-being of the children. Reaching consensus of an ASD diagnosis of a child where two clinicians come from separate worldviews on a few occasions in the data collection process was problematic. Socialisation experiences affect the behavioural patterns of people and also affect their thought processes, thus researchers think differently and often observe behaviours, which are then interpreted, in variable ways (Bernier, Mao, & Yen, 2010). This makes consensus on ADOS scoring sometimes challenging. To overcome this, a third researcher or clinician was called in during these instances and was asked to code the child in question using the video recording, and ultimately consensus was reached.

### **3.4 Data Analysis**

All the data collected was organised into Excel tables. The data set comprised of an experimental ( $n = 13$ ) and a control group ( $n = 13$ ). Namely, an ASD group of participants and a Non-ASD group of participants. Some data was nominal data and some interval data.

#### **3.4.1 Gender and ethnicity in the sample**

Descriptive analysis of the sample ( $n = 26$ ) considering the percentages represented by gender and ethnicity, were calculated. Patterns that emerged in the data were represented in pie charts.

### 3.4.2 Concordant diagnoses

The comparison of the concordant diagnostic ability of the ADOS diagnoses per participant, and that of the trained clinician diagnoses were recorded as nominal, dichotomous data.

#### 3.4.1.2 Descriptive statistics

Initially graphs were drawn using Excel to observe whether concordance between the diagnoses could be visually made.

#### 3.4.1.3 Statistical analyses

Further, comparisons were made using a specialised version of McNemar's Test called the Westlake-Schurmann Test of Equivalence for two dependent samples. The McNemar's inferential statistic is used with nominal or categorical data when evaluating a hypothesis about the distribution of data into two dependent populations (Sheskin, 2007).

The Westlake-Schurmann Test, an equivalence testing hypothesis as opposed to the zero-difference hypothesis used in analysis of variance (ANOVA), was also used in this study.

The aim of using this test was to see whether two dependent samples represent different populations. It aims to evaluate whether the ADOS diagnoses of the 26 participants is equivalent to the clinical diagnoses given to each of these 26 participants. The McNemar Test (McNemar, 1947) is a nonparametric procedure for categorical data employed in a hypothesis testing situation like this study, where the design comprises two dependent samples.

In this sample ( $n$ ) of matched subjects, a dichotomous (Yes=1/No=0) dependent variable is used. Where Yes=1 shows that a person has ASD and No=0 means that they do not have ASD. A significant result allows the researcher to conclude that there is a high likelihood that the two groups represent two different populations.

The McNemar Test is based on the following assumptions:

1. The sample of  $n$  subjects has been randomly selected from the group that it represents (Due to time constraints children with or without ASD were selected from special needs schools willing to participate in the study. They were blindly assigned to the researcher so they never knew the clinical diagnosis of each participant when the ADOS was administered to them)
2. Each of the  $n$  observations in the contingency table are independent of all other observations (Each child was individually assessed independently of other observations).
3. The scores of the subjects are in the form of dichotomous categorical measures involving two mutually exclusive categories.

4. Most sources state that McNemar's Test should not be employed with extremely small sample sizes (Sheskin, 2007). Due to the small sample size in this study, some sources recommend the use of a correction for continuity (Sheskin, 2007). This shall be done to counter the fact that  $n=26$ .

### **3.4.3 ADOS sub-category analyses**

The ADOS sub-categories of each group were also compared according to ethnicity and scores were entered as numerical values. The sub-categories were:

- Communication
- Reciprocal Social Interaction
- Imagination/creativity
- Stereotyped behaviours/ restricted interests

Thus, each ethnic group was compared on each algorithm to note whether diagnosis on the ADOS varied across ethnic lines. Hypotheses were formulated in this regard (see page 43 and 44 of this thesis).

#### **3.4.3.1 Statistical analyses**

For all statistical decisions made in this study, an alpha level of  $p = 0.05$  was used.

The different ethnicity scores across all ADOS sub-categories were compared using one-way analyses of variance (ANOVA), to observe whether there was a systematic difference was present in the sample (Durrheim, 2002). In this regard the specific question was 'Do variable ethnic groups within the sample responded differently to the ADOS sub-categories in a statistically significant manner?' 'This one-way ANOVA was a suitable design for this study as it comprised one categorical independent variable, ethnicity, which had three distinct categories (Black, White and Indian) and one continuous variable which is ADOS scores on each sub-category (Pallant, 2001).

A Levene's Test was initially run to test for homogeneity of variance, as the populations from which the data was sampled should have the same variance. This was one of the assumptions of an ANOVA (Sheskin, 2007; Durrheim, 2002). The other assumption was that populations represented by the data should be normally distributed (Sheskin, 2007; Durrheim, 2002).

An F-statistic was then calculated and if significant, a systematic difference was found. Which means that the null hypothesis stating equal means between groups could be rejected (Durrheim, 2002). This meant that the ethnic groups responded differently to the ADOS in a significant manner as the scores on the sub-categories varied significantly from each other.

Post-hoc tests were used to reveal where the significant patterns of difference between ethnic groups lay (Durrheim, 2002). They systematically compare each ethnic group to another, in pairs, to indicate whether there is a significant difference in the means of each (Pallant, 2001). More specifically it indicated the sub-categories on which the ethnic groups varied significantly (Pallant, 2001).

#### **3.4.4. Analysis of personal files**

After the ADOS had been administered to the whole sample and scores had been completed, the personal files of each participant on the study were analysed by a trained clinician. The comorbid factors and other variables were also recorded as Yes/No, dichotomous data. The race variable was coded categorically as Black = 1, White = 2, Indian = 3.

For each participant tested on the ADOS, the following data was extracted from their personal files kept at the schools and transcribed in a spread sheet format using Excel:

- Race
- Home language
- Date of Birth
- Gender
- ADOS Module administered
- Subtest algorithm scores on the ADOS
  - Communication
  - Reciprocal Social Interaction
  - Imagination and Creativity
  - Stereotyped behaviours/ repetitive Interests
  - Diagnosis ASD/Non-ASD
- Speech and Language delays
- Mental retardation
- ADHD
- Neurodevelopmental disorders
- Hearing Impairment
- Pre-birth and congenital history
- Early and middle childhood developmental difficulties
- Pervasive developmental disorders
- Oppositional defiance disorders
- Aggression
- Sexual abuse

#### ***3.4.4.1 Descriptive statistics***

The information from the personal files were analysed and compared considering patterns that emerged in the data. The frequencies of Mental retardation, ADHD and other comorbid factors with ASDs were noted. Percentages were calculated and presented in a bar graph.



## CHAPTER 4

### RESULTS

#### 1.1 Introduction

This study was a quantitative study that made use of the McNemar's Westlake-Schuirmann Test of Equivalence, one – way ANOVAs, and descriptive statistics, to explore the diagnostic ability of the ADOS in the South African context; and to more specifically answer the hypotheses posed in this study.

The first stage of data analysis involved an examination of descriptive statistics of the sample. This analysis allowed for a description of the gender and ethnic spread in the sample.

#### 4.1.1. Gender and ethnicity in the sample

Descriptive analysis of the sample ( $n = 26$ ) considering the percentages represented by gender and race, were calculated (Figure 2). Patterns that emerged in the data were represented in pie charts and bar graphs.

Figure 2.

*Pie chart showing percentage representation per gender*

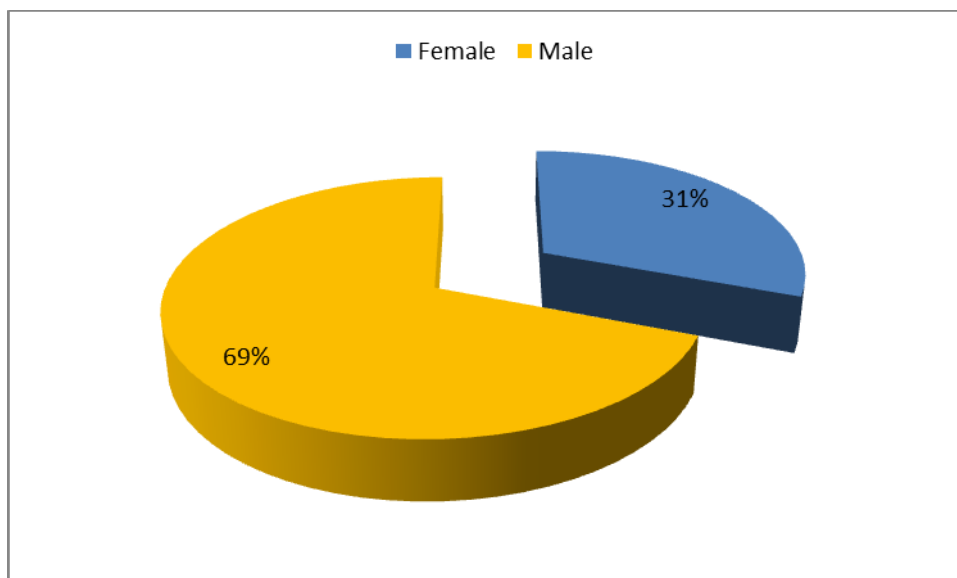


Figure 2 shows that 69 % ( $n = 18$ ) of the sample were males and 31 % ( $n = 8$ ) of the sample were females.

Figure 3.

*Pie chart showing percentage representation per ethnic group.*

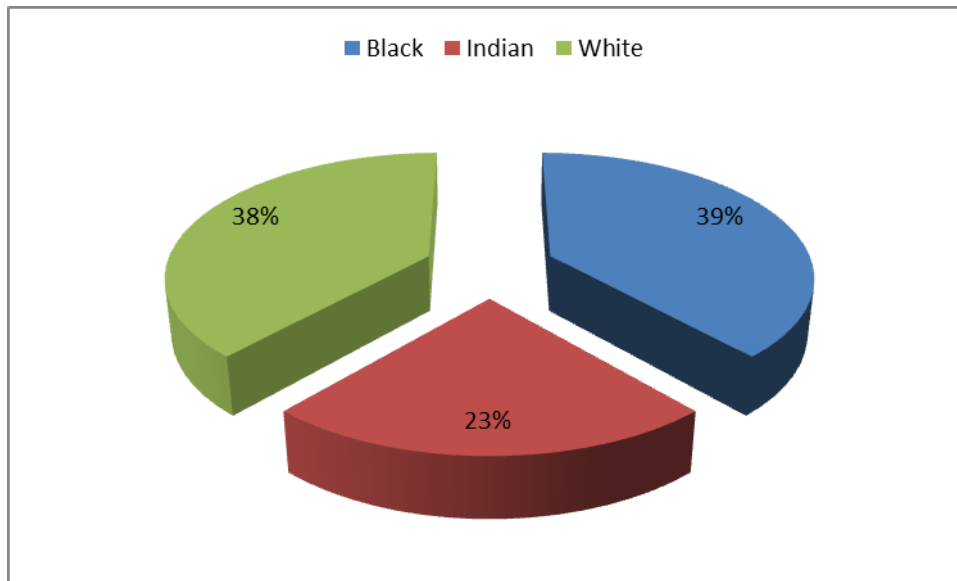


Figure 3 shows that 39 % of the sample comprised Black participants, 38 % comprised White participants and 23 % comprised of Indian participants.

Figure 4.

*Ethnicity and gender*

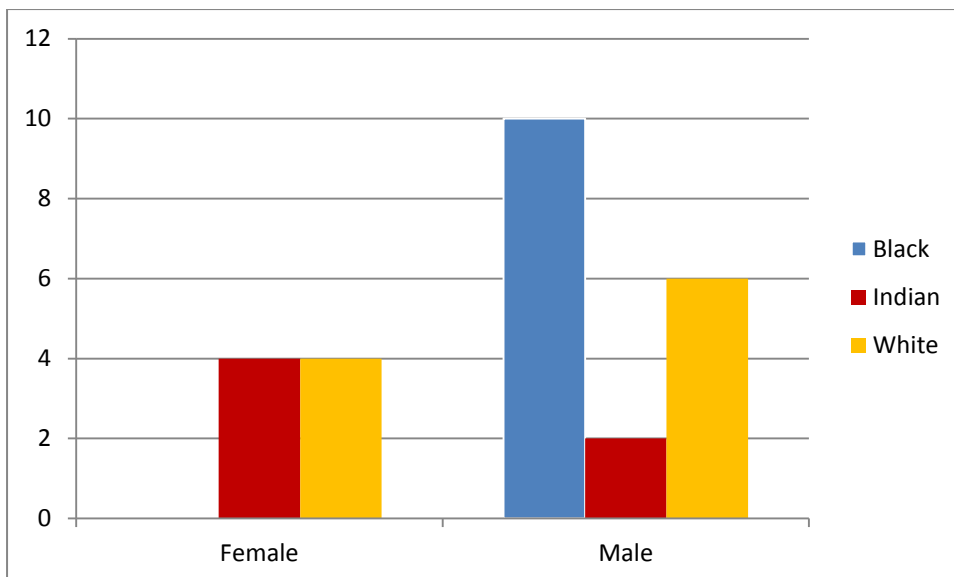


Figure 4 considers ethnicity and gender. It is noted that no females were Black. There were 4 Indian females and 4 White females. The sample comprised 2 Indian males, 10 Black males and 6 White males.

#### 4.1.2 Concordant diagnoses

Initially descriptive graphs were drawn per ethnic group to observe whether patterns in diagnosis between the ADOS and that of trained clinicians could be identified. This was followed by statistical testing.

##### 4.1.2.1 Descriptive statistics

For each graph below concordance between the clinician and the ADOS codes per participant is observed by a double bar. Where the two differed in their diagnostic outcome, only one bar is observed above that participant's case number. The absence of an upper graph thus indicates that the final diagnosis for that particular person was not the same for the clinician and the ADOS scores. One would have diagnosed the participant as ASD and the other would have diagnosed the participant as Non-ASD.

Figure 5.

*Black ethnicity: comparing ADOS diagnosis with clinician diagnosis per participant*

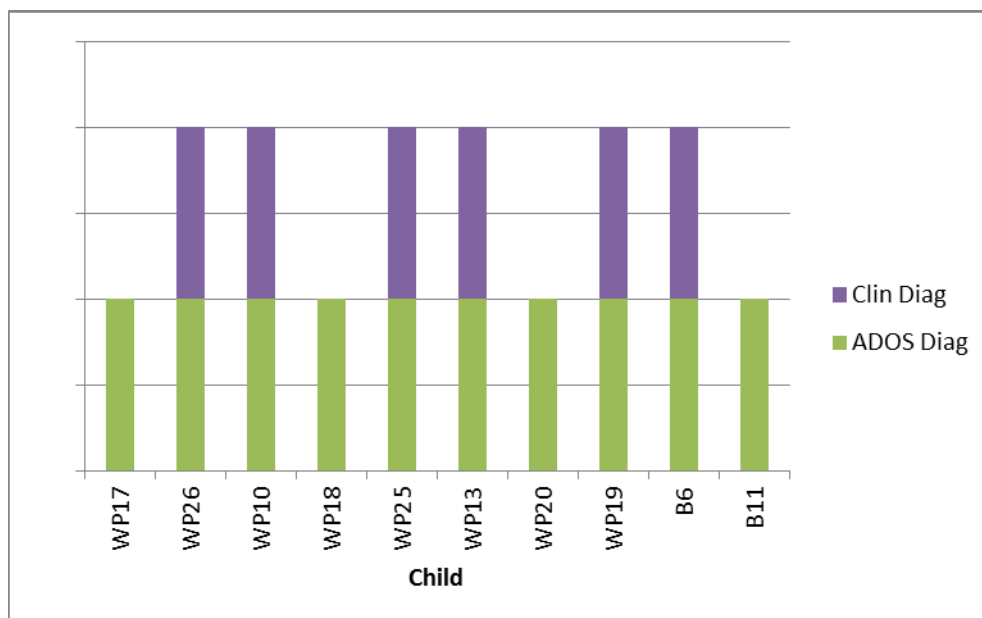
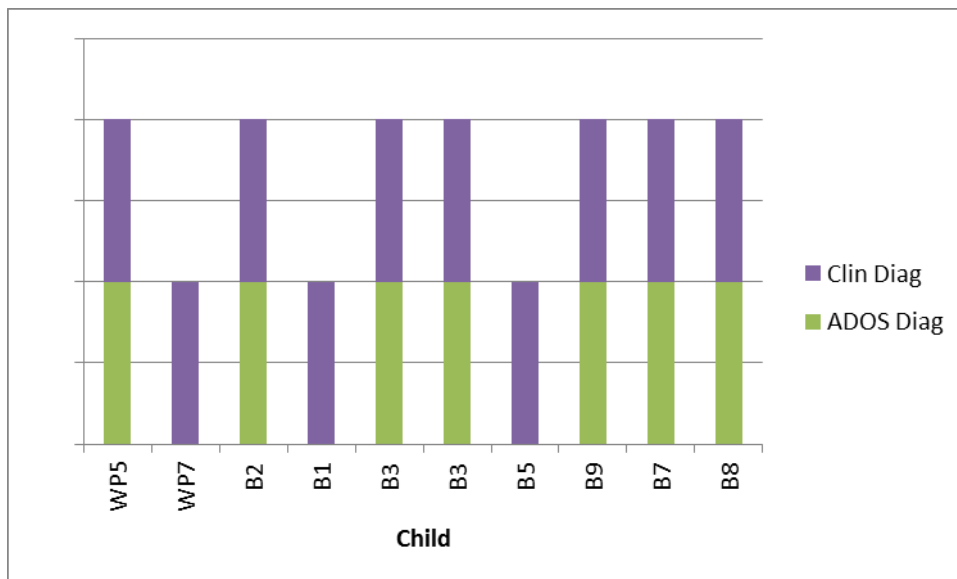


Figure 5 shows that of the 10 Black participants in the sample, there was concordance in the diagnoses between clinicians and the ADOS for 6 participants. Namely, WP26, WP10, WP25, WP13, WP19 and B6. This means that in 60% of the African participants, the ADOS final scores and clinical diagnoses obtained from the files were in agreement.

Figure 6.

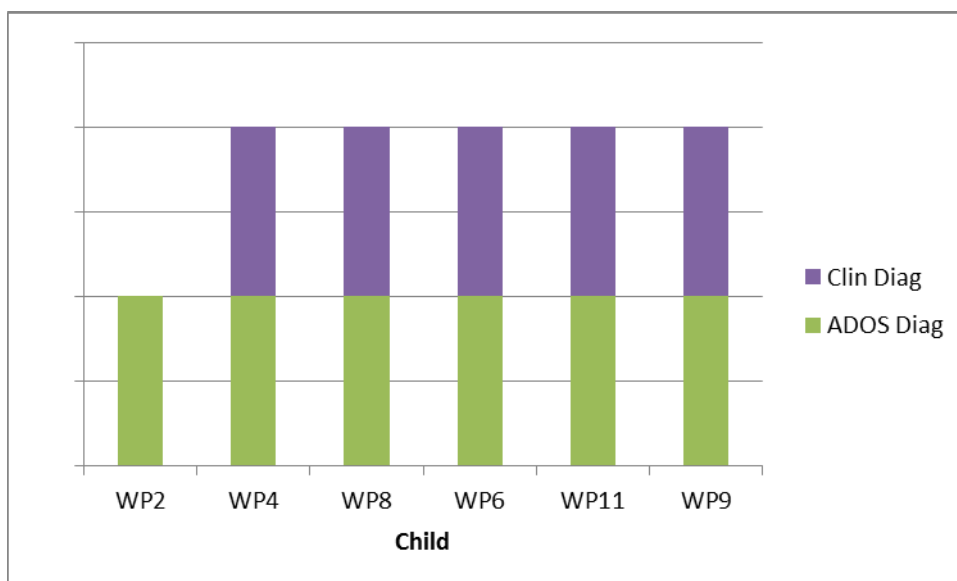
*White ethnicity: comparing ADOS diagnosis with clinician diagnosis per participant*



For the 10 White participants in the sample, there was concordance of diagnoses for 7. This means that in 70% of the White participants, the ADOS finding scores and the clinical diagnoses obtained from the files were in agreement.

Figure 7.

*Indian ethnicity comparing ADOS diagnosis with clinician diagnosis per participant*



Of the Indian participants in the sample, there was diagnostic concordance between the clinician and the ADOS for 5 of the 6 participants. This means that in 88% of the Indian

participants, the ADOS final scores and clinical diagnoses obtained from the files were in agreement.

#### *4.1.2.2 Statistical Analyses*

The McNemar Test was manually calculated to determine whether there was a statistically significant similarity between the ADOS diagnoses and the clinician diagnoses for all 26 participants in the study. It thus tested concordance between diagnoses made by trained clinicians compared to the ADOS scores which also gave a diagnosis, for each child on the study. Further, the specialised McNemar calculation, the Westlake-Schuirman Test of Equivalence was calculated to observe whether the two diagnoses could be regarded as equivalent.

Due to the unanticipated small sample size, it was decided that the Black children would be considered in one category, while the Indian and White children were placed in the English category. The rationale for this is based on several assumptions:

1. There would be greater similarity in the way in which White and Indian children were socialised with regard to the use of gestures, eye contact, social interaction and reciprocal conversation. Likewise, in line with the literature on Afrocentric parenting, Black children were more likely to be socialised to place respect as a high priority and thus would be less likely to socially interact with the examiner.
2. Having conducted the assessments it seemed that Indians and White participants were more alike, while African children responded differently in relation to spontaneity and creativity.
3. The Indian and White children had English as their home language, whereas the Black children in this sample had isiZulu as their home language and thus had a Zulu ancestry.

The hypotheses were thus stated as follows:

The primary null hypothesis states that:

There will be no significant difference in the ADOS diagnosis and a clinician's diagnosis for each atypically developing participant in the sample with Zulu or English ancestry, including those children diagnosed with ASD and those children with other special needs.

The alternative hypothesis thus is:

There will be a significant difference in the ADOS diagnosis and a clinician's diagnosis for each atypically developing participant in the sample with Zulu or English ancestry, including those children diagnosed with ASD and those children with other special needs.

The Chi-Square distribution is generally employed to evaluate the McNemar Test statistic (Sheskin, 2007).

		<b>ADOS diagnosis on the ADOS</b>		
		YES	NO	
YES	A= 11	B= 2	13	
<b>Clinician diagnosis</b>	C= 5	D=8		
NO			13	
		16	10	<b>26</b>

For McNemar's Test the cells of interest are B and C, since these two cells indicate those subjects who were diagnosed differently by the ADOS and by a trained clinician. Cell B indicates the number of cases that were incorrectly diagnosed as Non-ASD but were in fact ASD. Thus of the sample there were 2 false negative diagnoses made by the ADOS. Cell C shows the number of false positives that were diagnosed by the ADOS in the sample. Thus 5 participants were diagnosed as having ASD by the ADOS, but clinician diagnoses did not concord with this result. Cells A and D show concordance between the clinician diagnoses and the ADOS diagnoses.

It is assumed that the two categories of ADOS diagnoses and clinician diagnoses are represented by the following proportions:

$\pi_b$  = Population b

$\pi_c$  = Population c

$$\pi_b = \frac{b}{(b+c)} \quad \text{and} \quad \pi_c = \frac{c}{(b+c)}$$

If there is no difference between the two groups, the following would be true:

$$\pi_b = \pi_c = 0.5$$

With respect to the sample data, the values  $\pi_b$  and  $\pi_c$  are estimated with the values  $P_b$  and  $P_c$ :

$$P_b = \frac{b}{(b+c)} = \frac{2}{(2+5)} = 0.285$$

$$P_c = \frac{c}{(b+c)} = \frac{5}{(2+5)} = 0.714$$

Employing the above information, the null and alternative hypothesis can now be stated as:

Null Hypothesis

$$H_0: \pi_b = \pi_c$$

Alternative Hypothesis

$$H_a: \pi_b \neq \pi_c$$

The test statistic for the McNemar Test, which is based on the Chi-Square distribution, is computed as:

$$\chi^2 = \frac{(b-c)^2}{b+c}$$

Where b and c represent the number of observations in cells b and c. substituting the appropriate values the  $\chi^2$  is:

$$\chi^2 = \frac{(b-c)^2}{b+c} = \frac{(2-5)^2}{2+5} = \frac{9}{7} = 1.285 = 1.29$$

Since the obtained Chi-Square value = 1.29 is less than the tabled critical two-tailed values

$\chi^2$  at 0.5 = 3.84 and  $\chi^2$  at 0.1 = 6.63, one accepts the Null hypothesis that both groups are equal and rejects the alternative hypothesis of  $H_a: \pi_b \neq \pi_c$  at both the 0.5 level and the 0.01 level of significance.

It can thus be concluded that the diagnosis that the ADOS gave to the subjects significantly matched the diagnosis given to the same subject by trained clinicians. Therefore, the ADOS does accurately differentiate between those who are on the spectrum and those who are not.

Since the McNemar Test employs a continuous distribution to approximate a discrete probability distribution, some sources recommend that a correction for continuity be employed in computing the test statistic (Sheskin, 2007). Due to the sample size being small, it is recommended that a correction for continuity be made, as illustrated below:

$$\chi^2 = \frac{(|b-c|-1)^2}{b+c} = \frac{(|2-5|-1)^2}{2+5} = 0.571$$

$$Z = \frac{|b-c|-1}{\sqrt{b+c}} = \frac{|2-5|-1}{\sqrt{2+5}} = 0.75592$$

Using the continuity correction one can see that the  $\chi^2$  value is lower, providing a more conservative test of the null hypothesis than does the uncorrected analysis.

In this instance, the decision that the researcher made regarding the null hypothesis was not affected by the correction for continuity. Since the values  $\chi^2 = 0.571$  and the  $Z = 0.75$  are both less than the relevant tabled critical one-tailed and two-tailed .05 and .01 values.

Thus the Null hypothesis of  $H_0: \pi_b = \pi_c$  is supported at both the 0.5 and 0.01 levels of significance. Therefore, it has been established that the two groups are statistically similar to each other and that there is no significant difference between them.

To further establish whether the decisions of diagnosis made by the ADOS are equivalent to those made by trained clinicians for each participant in the study, additional analysis was needed. For this, the researcher employed a criterion of equivalence. That is, the diagnoses of the ADOS administrations needed to be 90% accurate, thus they needed to match those diagnoses made by the clinicians 90% of the time. Therefore, there needed to be no more than a 10% difference in the outcome diagnoses between the ADOS and the clinicians.



10% expressed as a proportion is equivalent to .10, thus the value  $\zeta = .1$  was employed in the test of equivalence.

The Null and alternative hypotheses for a two-tailed, non-equivalence analysis, were as follows:

#### Null Hypothesis

$H_0 : \theta \leq -.10$  or  $H_0 : \theta \geq .10$

#### Alternative Hypothesis

$H_a : \theta \geq -.10$  or  $H_a : \theta \leq .10$

The notation  $\theta$  represents the difference between the two proportions in the underlying populations. It was assumed that the estimate of that difference was based on subtracting the proportions of accurate ADOS diagnoses, that concurred with those of clinicians (YES = 1; No = 0) from the accurate clinical diagnoses (Yes = 1; No = 0) that concurred with the diagnoses on the ADOS. Namely, cells A and C in the Chi-Square table. Thus, for the null hypothesis, the difference in the overall diagnoses between the ADOS and clinicians was less than or equal to -0.10 or was greater than or equal to 0.10.

This was termed the hypothesis of non-equivalence. Hypotheses for this test were not 'zero-difference' hypotheses as in the case of the ANOVA used in this study; the latter wanted to show that there was a difference between groups. The West-lake Schuirmann hypotheses aimed to show that two groups were the same, within a certain confidence interval range.

Thus the question the hypotheses aimed to answer was:

Is there an unacceptable difference between the two data sets? In this case, between the ADOS diagnoses and the clinicians' diagnoses (Lung, Gorko, Llewelyn & Wiggins, 2003).

For the alternative hypothesis, in the underlying populations that the samples represented, the difference between the two diagnoses was greater than - 0.10 or less than 0.10. This is known as the hypothesis of equivalence. This is a reverse way of arguing for tests of equivalence, thus can be confusing.

$$Z = \frac{(P_1 - P_2) - \zeta}{\frac{\sqrt{(a+d)(b+c) + 4bc}}{n^3}}$$

$$P_1 = \frac{a+b}{26} = \frac{11+2}{26} = 0.5$$

$$P_2 = \frac{a+c}{26} = \frac{11+5}{26} = .615$$

Employing the above Z equation, the  $H_0: \theta \geq 0.10$  and  $H_a: \theta \leq 0.10$  was evaluated first. Here  $\zeta = 0.10$  was employed in the numerator of the equations since we were evaluating the right boundary of equivalence.

$$Z = \frac{(0.5 - .61) - (.10)}{\frac{\sqrt{(11+8)(2+5) + 4(2)(5)}}{(26)^3}} = \frac{-0.14}{11.53266} = 0.121$$

Since the obtained absolute value  $Z = 0.121$  was less than the tabled critical one-tailed value of  $Z_{0.5} = 1.65$ , the null hypothesis ( $H_0: \theta \geq .10$ ) designating non-equivalence could not be rejected. Thus the groups (ADOS diagnoses and Clinician diagnoses) were equivalent within an acceptable range. In analysing Z tables, this meant that 12% of the time, there was a difference between the two groups at that acceptable level of difference. The differences between statistical significance and clinical significance are discussed in the next chapter (Meehl, 1956).

Employing the correction for continuity  $\frac{-1}{n}$  was employed, hence  $\frac{-1}{26} = 0.038$  and this was subtracted from the numerator of the above Z equation. The result was that the Z value was still below the 0.5 value that was pre-stipulated for alpha.

In order to declare equivalence of ADOS diagnoses with clinical diagnoses, both Z tests had to be statistically significant; the two Z values computed needed to have opposite signs.

Evaluating the second null hypothesis designating non-equivalence, we once again employed a one-tailed test which evaluated the following null and alternate hypotheses:

$$H_0: \theta \leq -.10 \quad \text{and} \quad H_a: \theta \geq -.10$$

This analysis employed the same values as the previous equation except for the value

$\zeta_1 = -.10$ , which was employed in the numerator as we were evaluating the left boundary of equivalence.

$$Z = \frac{(P1-P2)-\zeta}{\frac{\sqrt{(a+d)(b+c)+4bc}}{n^3}}$$

$$Z = \frac{(0.5-0.615)-(-.10)}{\frac{\sqrt{(11+8)(2+5)+4(2)(5)}}{(26)^3}} = \frac{-0.015}{11.53266} = -1.30065$$

Since the obtained value  $Z = 1.3$  was less than the tabled critical one-tailed  $Z_{.05} = 1.65$ , the null hypothesis ( $H_0: \theta \leq -0.10$ ) designating non-equivalence, could not be rejected. Thus they were equivalent within the designated margin of error. The slight variations between groups could be due to chance variations also. If the correction for continuity was made once again,  $\frac{-1}{n} = -0.038$ , the results would not have affected the outcome.

So, the second of the null hypotheses designating non-equivalence cannot be rejected. Thus, since both null hypotheses cannot be rejected, we conclude that the ADOS diagnoses are equivalent to the clinician diagnoses. The lower range of the 90% confidence interval falls below the minimum tolerable difference between the diagnoses of the two groups. Both null hypotheses would have had to have been statistically significant at the 0.05 level, and if the latter had occurred, the lower limit of the confidence interval would have been some value greater than 0.10 and -0.10 for the tests to be non-equivalent. The results therefore support the main null hypothesis of this study.

#### 4.1.3 ADOS sub-category analyses

The ADOS sub-categories of each group were compared according to race, and scores were entered as numerical values. The sub-categories were:

- Communication
- Reciprocal Social Interaction
- Imagination/creativity
- Stereotyped behaviours/ restricted interests

Thus, each ethnic group was compared on each algorithm to note whether diagnosis on the ADOS compares across ethnic lines.

An analysis of variance (ANOVA) was run using SPSS (version 19) to consider whether significant effects existed between ethnic groups regarding their responses on the ADOS algorithm scores. This statistical procedure was used to answer the following hypotheses:

Ho1: There is no significant difference between children of White, Black or Indian cultures with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.

Ha1: There is a significant difference between children of White, Black or Indian cultures with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.

Ho2: There is no significant difference between children of White, Black or Indian cultures with ASD and those with other special needs based on the sub-group coding for Reciprocal Social Interaction behaviours on the ADOS.

Ha2: There is a significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Reciprocal Social Interaction behaviours on the ADOS.

Ho3: There is no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Imagination/Creativity behaviours on the ADOS.

Ha3: There is a significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Imagination/Creativity behaviours on the ADOS.

Ho4: There is no significant difference between the children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Stereotyped Behaviours and Restricted Interests on the ADOS.

Ha4: There is a significant difference between the children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Stereotyped Behaviours and Restricted Interests on the ADOS.

Table 4.

*Homogeneity of variance*

Test of Homogeneity of Variances				
	Levene Statistic	df1	df2	Sig.
Communication	.302	2	23	.743
Reciprocal Social Interaction	.699	2	23	.507
Imagination/Creativity	1.281	2	23	.297
Stereotypical Behaviours/Restricted Interests	.961	2	23	.397

In the Levene's Test above, the F-value is not significant since all values are greater than  $p = 0.05$ . Thus, suggesting that we cannot reject the null hypothesis of equality of variance. Thus, the assumption of homogeneity has not been violated.

Table 5.

*ANOVA summary table for analysis of data*

ANOVA						
		Sum of Squares	df	Mean Square	F	Sig.
Communication	Between Groups	31.405	2	15.703	3.607	.043
	Within Groups	100.133	23	4.354		
	Total	131.538	25			
Reciprocal Social Interaction	Between Groups	106.128	2	53.064	6.621	.005
	Within Groups	184.333	23	8.014		
	Total	290.462	25			
Imagination/Creativity	Between Groups	5.785	2	2.892	2.247	.128
	Within Groups	29.600	23	1.287		
	Total	35.385	25			
Stereotypical Behaviours/Restricted Interests	Between Groups	.328	2	.164	.134	.875
	Within Groups	28.133	23	1.223		
	Total	28.462	25			

In studying the summary table, significant effects were found. It was noted that the source of variance in the data was between ethnic groups and lay in the sub-categories of communication and reciprocal social interaction. Since their significance values were  $p = .043$  and  $p = .005$  respectively. These values were less than the alpha level of  $p = 0.05$  indicating statistical effects in the data.

Further multiple comparisons in the form of post hoc tests needed to be run so as to identify where the precise difference between means lay (Durrheim, 2002). This study used Tukey's Honestly Significantly Difference test (HSD), since it was the test used most widely in the Social Sciences (Durrheim, 2002).

Tukeys HSD tests (Table 6.) of multiple comparisons confirmed that the significant differences were found between groups in the communication and reciprocal social interaction sub-categories. More specifically, differences were noted between the Black and White/Indian ethnic groups. For the communication sub-category the significance value was 0.034 at the significance level of  $p = 0.05$ . For Reciprocal Social Interaction the significance value was 0.004 at the significance level of  $p = 0.05$ . The other sub-categories of imagination/creativity and stereotyped behaviours/restricted interests had significance scores greater than  $p = 0.05$ , thus no significant differences in behavioural responses on the ADOS were found between Black, White and Indian participants for the sub-categories of imagination/creativity and stereotypical behaviours/restricted interests.

Table 6.

*Multiple comparisons using Tukey's (HSD) test results*

**Multiple Comparisons**

Tukey HSD

Dependent Variable	(I) Ethnicity	(J) Ethnicity	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
Communication	Black	White	2.500*	.933	.034	.16	4.84
		Indian	1.067	1.077	.590	-1.63	3.77
	White	Black	-2.500*	.933	.034	-4.84	-.16
		Indian	-1.433	1.077	.393	-4.13	1.27
	Indian	Black	-1.067	1.077	.590	-3.77	1.63
		White	1.433	1.077	.393	-1.27	4.13
Reciprocal Social Interaction	Black	White	4.600*	1.266	.004	1.43	7.77
		Indian	2.033	1.462	.362	-1.63	5.69
	White	Black	-4.600*	1.266	.004	-7.77	-1.43
		Indian	-2.567	1.462	.207	-6.23	1.09
	Indian	Black	-2.033	1.462	.362	-5.69	1.63
		White	2.567	1.462	.207	-1.09	6.23
Imagination/Creativity	Black	White	.700	.507	.368	-.57	1.97
		Indian	-.500	.586	.674	-1.97	.97
	White	Black	-.700	.507	.368	-1.97	.57
		Indian	-1.200	.586	.123	-2.67	.27
	Indian	Black	.500	.586	.674	-.97	1.97
		White	1.200	.586	.123	-.27	2.67
Stereotypical Behaviours/Restricted Interests	Black	White	-.200	.495	.914	-1.44	1.04
		Indian	-.267	.571	.887	-1.70	1.16
	White	Black	.200	.495	.914	-1.04	1.44
		Indian	-.067	.571	.993	-1.50	1.36
	Indian	Black	.267	.571	.887	-1.16	1.70
		White	.067	.571	.993	-1.36	1.50

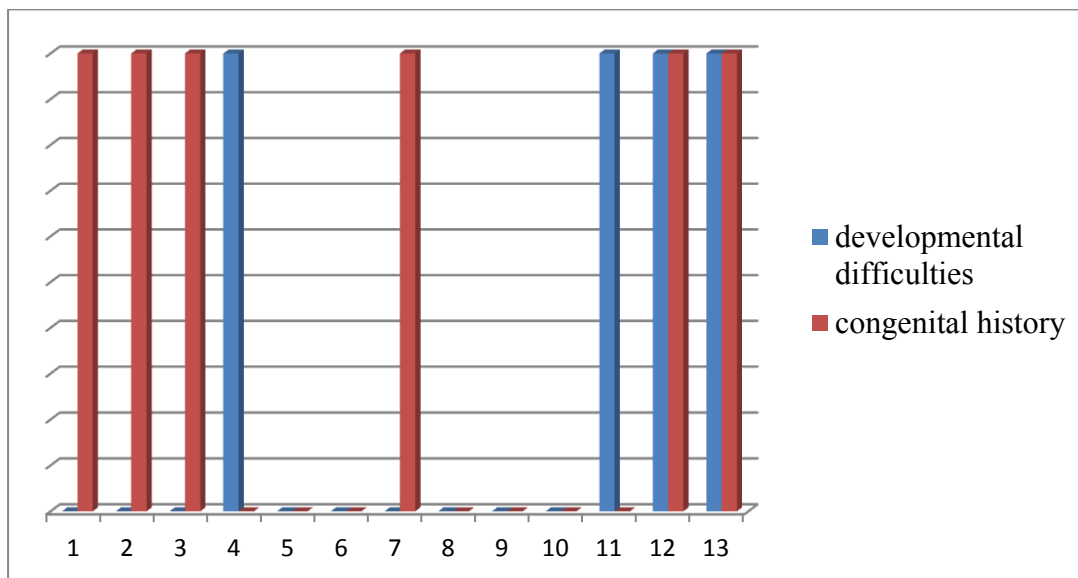
\*. The mean difference is significant at the 0.05 level.

#### 4.1.4 Analysis of Personal files

Although not a prime focus of this study, bar graphs were drawn, using Excel, illustrating the comorbidity patterns in the data. The information was gleaned from the personal files of those participants on the study who were placed into the experimental ASD group. Thus those children who were clinically diagnosed as ASD and who were allotted to the experimental group of this study, were used. Figure 8 was used to illustrate patterns that exist in the ASD group for pre-birth and congenital history complications and early to middle childhood developmental difficulties. Of the 13 participants with ASD, only two experienced both congenital and pre-birth complications and developmental difficulties. Five of the thirteen (38 %) experienced neither congenital history nor developmental difficulties. Four of the 13 (30%) of the ASD participants experienced developmental difficulties, and 6 of the 13 (46%) had a challenging pre-birth and congenital history.

Figure 8.

*Bar graph showing pre-birth and congenital history and developmental difficulties*



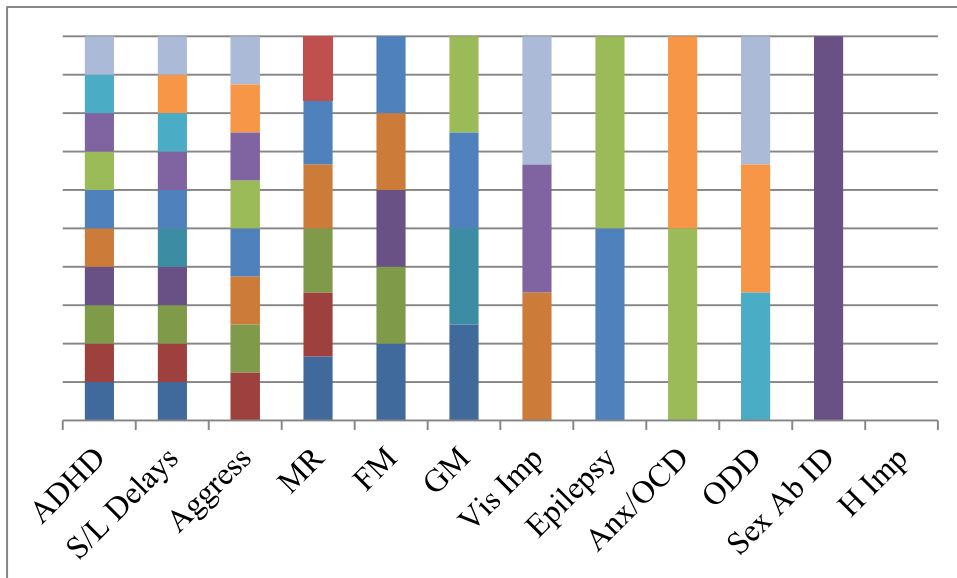
It was of interest to examine the possible comorbid patterns that presented themselves in the ASD experimental group, hence Figure 9 examined these. In considering comorbid factors, every participant that was ASD ( $n = 13$ ) had at least one comorbid disorder. For this bar graph, each colour in every vertical bar represents a participant on the study who experienced that particular comorbid factor. For example, in the first bar, representing ADHD, there are ten colours, therefore ten of the total thirteen had comorbid ADHD with their ASD diagnosis.



Thus, 78% ( $n = 10$ ) of the sample experienced speech and language delays and ADHD as well as ASD. 61% ( $n = 8$ ) had aggressive tendencies, 46% ( $n = 6$ ) of the ASD participants also presented with mental retardation. Fine motor delays were found in 38% ( $n = 5$ ) of the participants. 31% ( $n = 4$ ) of the ASD sample experienced gross motor delays. 23% ( $n = 3$ ) were visually impaired and suffered from Oppositional Defiance Disorder comorbidly. 15% ( $n = 2$ ) ASD participants experienced anxiety problems and obsessive compulsive tendencies and only 15% ( $n = 2$ ) suffered from epilepsy comorbidly. Lastly, only 8% ( $n = 1$ ) had a history of sexual abuse that was clinically identified and no participants in this sample experienced hearing impairment problems.

Figure 9.

Comorbidity bar graph

Key:

S/L Delays	Speech and language delays.
MR	Mental Retardation.
ADHD	Attention Deficit/Hyperactivity Disorder.
Vis Imp	Visual Impairment
H Imp	Hearing Impairment
ODD	Oppositional Defiance Disorder
Aggress	Aggression
GM	Gross Motor Delays
FM	Fine Motor Delays
Epilepsy	Epilepsy
Sex Ab ID	Sexual Abuse that has been clinically identified
Anx/OCD	Anxiety or Obsessive compulsive disorder

## Chapter 5

### Discussion

#### 5.1 Introduction

This study aimed to explore the diagnostic ability of the ADOS by administering it on a special needs blinded and matched sample of ASD and Non-ASD participants between the ages of 6-11 years of age. This sample represents an extremely vulnerable sector of our multi-cultured South African population (Chhagan, Karim & Wallace, 2012). As a developing country, we have some of the 85% of the world's youth which reside in developing countries (Rutter, 2011). ASDs affect the individual, family and the larger community. This pathology extends the responsibility of an accurate diagnosis of this disorder to the national and international community at large.

If one were to be solely reliant on parental initiative and support for diagnosing and treating people with ASDs, the disorder would go unchecked and the livelihood of many youth will be sorely affected. As a study which spanned two very different socio-economic communities in the greater eThekweni area, it was obvious that access to resources in terms of clinician expertise and assessments, were not evenly weighted. The one school servicing a more affluent community was able to have comprehensive personal files and assessment results at the researcher's disposal. Whereas the other school in a low income area struggled to have their learners adequately assessed.

The increasing prevalence of ASDs in developing countries like our own, makes a study like this relevant and useful for mental health professionals working in South Africa (Durkin et al., 2006). In relation to the theory, this chapter has documented the study findings by first considering gender and ethnic group patterns, then discussing the concordant clinician and ADOS diagnoses and lastly enlarging on patterns that emerged in the ADOS sub-categories in relation to ethnicity.

##### 5.1.1 Gender and ethnicity in the sample

Descriptive statistics in the form of graphs and pie charts were first done on the sample to establish gender and ethnicity patterns.

In terms of gender, ASD does not manifest itself in equal proportions across males and females (Rivet & Matson, 2011). This was observed in our sample ( $n = 26$ ), where 31% of the sample (8 participants) were female and 69% (18 participants) were male. This was a ratio of 2.25:1, thus for every one girl with ASD there were 2.25 boys in this study with ASD. Some studies cite boys outnumbering girls by a ratio of 4 to 1 (Ametepee & Chitiyo, 2009). Frith (2008) argues that in high functioning ASD categories, these ratios may be as high as 8:1. Dworzynski et al (2012), reason that these disparities may indicate that females are better able to adapt and compensate for this developmental disorder. It is also probable that males are more readily identified, or consistent with most childhood disorders, since boys are at greater risk in developing such disorders (Rutter, 2011).

It was the intention that the sample characterise various ethnicities in our country. However, only participants from Black, White and Indian ethnic groups were represented. 39% were Black, 38% were White and 23% were Indian. Of those, all the Black participants were males. There were 6 White males and 4 White females in the sample and the Indian ethnic group was the only one that had more females (4 participants) than males (2 participants) being represented.

The latter ratios and percentages found in the sample are not representative of those cited in the literature. It is assumed that the small sample size largely accounted for this disparity.

### **5.1.2 Concordant diagnoses**

The primary null hypothesis that this study aimed to test was that there was no significant difference in the ADOS diagnosis compared to the clinician diagnosis for each participant in the sample comprising atypically developing children from Zulu and English ancestry, diagnosed with ASD and children with other needs for special education. To answer this hypothesis, descriptive statistics and a specialised non-parametric test, the McNemar's Westlake-Shuirman Test of Equivalence was conducted..

#### **5.1.2.1 Descriptive statistics**

In considering the descriptive graphs illustrating concordance between the ADOS diagnoses and those made by trained clinicians per participant in the sample, there was an overall pattern of similarity in diagnostic outcomes. Of the 26 participants on the study, there were 19 cases of diagnostic concordance between the ADOS and the clinicians. For the Black participants there was a 60% concordance, a 70% concordance for the White ethnic grouping

and an 83% concordance for the Indian ethnic group. Thus, overall there was a 71% concordance in diagnosis for the ADOS and the clinicians.

In order to statistically affirm these patterns a McNemar Test of Similarity in scores between ADOS diagnoses and clinician diagnoses were run.

#### *5.1.2.2 Statistical analyses*

The study accepted the main null hypothesis that stated that there was no significant difference in the ADOS diagnosis and a clinician's diagnosis for each atypically developing participant in the sample.

This result warranted a further analysis using the Westlake-Shuirmann Test which tested for equivalence, within chance and within an acceptable range, for the ADOS diagnoses and the clinician diagnoses. This showed concordance between the ADOS diagnoses and the clinician diagnoses.

On closer analysis, the ADOS diagnosed more people with ASDs than the clinicians did ( $P_1 = 0.5$  and  $P_2 = .615$ ). The ADOS diagnosed five false positives, which intimates that it was possibly more sensitive in picking up cases of ASD than the clinical diagnoses were. Studies cite that the ADOS does increase the likelihood of participants displaying ASD type behaviours, this may account in part for the false positives (Lord et al., 2000). These false positives showed the sensitivity of the ADOS and in arguing for this, it is better for the well-being of the child to be overly cautious in diagnosing and thus having false positives than underdiagnosing and having false negatives. This assumption only holds in countries where the diagnosis enables access to services and interventions. This is however debatable in South Africa which has an under resourced context.

Paul Meehl (1956) added to this argument by articulating that there is considerably more value in having well designed tests in comparison to having opinionated clinicians (Morera & Dawes, 2006). Thus sensitive tests are better and more accurate than clinician intuition. He concluded that the judgements of a statistical model, like the ADOS in this study, outperformed trained expert opinion (Morera & Dawes, 2006).

Meehl also argued that in determining human outcomes, an aggregation process correlated better with gold standards than do clinical judgements. This aggregation process is noted in the use of the ADOS. This assessment tool has 4 sub-categories with 17 subsections for module 1, 15 subsections of coding for module 2 and 16 subsections for module 3. These

subsections fall under these four sub-categories and clinicians coded the participants on observed behavioural patterns that define this disorder for each one of the subsections (Matson & Nebel-Schwalm, 2007).

Further to this study, the four sub-categories each had algorithm scores per participant and these were subjected to an ANOVA to consider ethnic variances in behaviours on each of the sub-categories.

### 5.1.3 ADOS sub-category analysis

This study tested a sample of atypically developing participants with ASD and Non-ASD using the ADOS. The sub-category tasks formed part of the administration of the ADOS. Children with ASDs have generally shown weaknesses in social reciprocity, communication and repetitive behaviours (Strang et al., 2012). It has been found that the ADOS increases the likelihood that a participant will display ASD type behaviours which typify an ASD diagnosis (Lord et al., 2000).

The ADOS, in previous studies, revealed extreme accuracy in diagnosing those who are on the autism spectrum and those who are not (Overton, Fielding & Garcia de Alba, 2008). As already mentioned, there were more false positives in this study than false negatives revealing the sensitivity of the ADOS in identifying ASD type behaviours.

Some studies have highlighted disparities across ethnic groups in diagnosing ASDs (El Goroury & Krackow, 2012). Thus in South Africa's multicultural context it was relevant to ask the sub hypothesis of whether different ethnicities respond differently to the various sub-categories on the ADOS resulting in significant differences existing between ethnic groups on each algorithm. With four sub-categories the hypotheses were worded as follows:

- **H01:** There is no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.  
**Ha1:** There is a significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for communicative behaviours on the ADOS.
- **H02:** There is no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Reciprocal Social Interaction on the ADOS.

**H<sub>a2</sub>:** There is a significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Reciprocal Social Interaction on the ADOS.

- **H<sub>o3</sub>:** There is no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Imagination/Creativity on the ADOS.

**H<sub>a3</sub>:** There is a significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Imagination/Creativity on the ADOS.

- **H<sub>o4</sub>:** There is no significant difference between the children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Stereotyped Behaviours and Restricted Interests on the ADOS.

**H<sub>a4</sub>:** There is a significant difference between the children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group coding for Stereotyped Behaviours and Restricted Interests on the ADOS.

This study explored and documented the way participants behaved on the ADOS sub-categories across Black, White and Indian ethnicities. Since diagnosis of ASDs is based on observable behaviour patterns, cultural variations across cultures may account for various diagnoses, and may result in possible false positives (Klinger, Dawson & Renner, 2003).

Limited research has been conducted comparing behavioural differences of children across cultures; however it is highly likely that there are variable response styles (Bernier, Mao & Yen, 2010). Some authors have documented variable response patterns across cultures (Clark, 2000 as cited in Johnson et al., 2005; Bachman, O'Malley & Freedman-Doan, 2010, Scarborough & Poon, 2004 in Chung et al., 2012).

As part of the K-ASD study, this study formed part of an initial exploration for cultural variations, although the focus in this study was in concordance of clinician and ADOS diagnoses. The ADOS sub-category algorithm scores were recorded and compared in this study using an ANOVA to ascertain whether there was a statistically significant variance or difference between the way Black, White and Indian participants were coded and thus responded on the ADOS sub-categories.

It was found that a significant variability existed between Black and White participant scores on the sub-categories for communication ( $p = 0.34$ ;  $\alpha = 0.05$ ) and reciprocal social interaction

( $p = 0.04$ ;  $\alpha = 0.05$ ). Thus, the researcher was able to reject the null hypothesis ( $H_{01}$ ) for communication and the null hypothesis ( $H_{02}$ ) for reciprocal social interaction. The study also resulted in the researcher accepting the third and fourth null hypotheses which stated that there was no significant difference between children of Black, White or Indian cultures with ASD and those with other special needs based on the sub-group codings for Imagination/Creativity and Stereotyped Behaviours and Restricted Interests on the ADOS.

This result can be interpreted to mean that Black participants behaved in various gestural ways that were significantly different to the manner in which the White participants behaved. These differences were picked up on the ADOS and affected the individual scores significantly.

There are various explanations for these differences. It could be argued that the children from Zulu ancestry may have misunderstood the instructions on the ADOS that they were given in English, even though their medium of instruction is English, but this was compensated by the presence of a translator.

Another reason for the variability could be culturally normative behaviours. What is considered acceptable in one culture may not be acceptable in another (Ostrosk-Solis, Ramirez & Ardila, 2004).

It was observed that the Black children were very reticent to spontaneously communicate with the researcher, in a verbal or a non-verbal gestural manner, such as pointing. In one task where they are encouraged to choose from sweet biscuits or savoury crisps, the Black children behaved in a shy, reserved way; never asking for additional treats. The White children were more likely to request more. They appeared more confident and out-going. This behaviour would be considered disrespectful in Zulu culture.

In Zulu culture, due to age, gender and status the researcher was elevated in status (Rudwick, 2008). As the researcher was an adult, the children would have behaved in a more respectful manner towards them, and due to her being a White researcher more status and thus more respect was granted to the researcher by the children. If the researcher were a male as opposed to a female, the researcher would have an even more elevated status.

These reservations were also noted when the participants were scored on their attempts to get the researcher's attention, their ability to engage with the researcher in asking questions and directing the researcher's attention to objects of interest for the participant. It appears that



Black children are culturally not encouraged to engage with strangers or visitors in a verbal manner. It has been observed that children do not socialise in the company of adults. Yet, on the ADOS the children were scored on their attempts to get the researcher's attention and to socially and verbally engage with them.

The study did attempt to modify the ADOS in consideration of cultural norms and superstitions so as to facilitate a fairer administration across ethnic groups. As previously stated, the descriptive pictures that were used to encourage free conversation were substituted for more culturally fair and appropriate African scenes that all children could relate to.

The reciprocal social interaction sub-category also considered verbal and non-verbal responses and behaviours. More specifically it considered the quality of eye contact that the participant had with the researcher throughout the ADOS administration. Poor eye contact, which is typical amongst individuals with ASD, may be interpreted differently depending on the societal norms of the cultural group in question (Sipes et al., 2011). In Zulu culture children may be considered disrespectful if they gaze into an adult's eyes while they are being spoken to (Rudwick, 2008). In a White culture, it is considered rude to avoid eye contact with a person with whom one is communicating with. Attention and reflection on the quality of eye contact was given for the entire duration that the administration of the ADOS occurred. This allowed for initial reticence and shyness until rapport was established between the participant and the examiner.

These variances may have affected the scoring on the algorithms and resulted in significant differences in the ADOS scores. Alternatively they reflect actual cultural differences.

Reciprocal social interaction as a sub-category also considered the normality of facial expressions that the participant directed to the examiner. The quality of the participant's social overtures and variable responses were considered. That is, were the social interactions appropriate to the test context and were they variable? This included a researcher's judgement call on how comfortable the interaction was and the degree of difficulty in establishing rapport.

People are influenced by their environments and learn how to socialise within their culture, and this largely affects how people behave (Grinker et al., 2011). Since ASD diagnoses rely heavily on observable behaviours, people's responses to social interactions and their gestural behaviours greatly influence prevalence and incidence rates (Bernier et al., 2010).

Researchers need to recognise cultural behavioural differences, defined by a society's norms, in diagnosing ASDs across cultures. Gestures and behaviour patterns are not universal (Archer, 1997). Uninformed researchers make errors in their diagnostic coding, resulting in inaccuracies in diagnosis (Grinker et al., 2011).

#### **5.1.4 Personal Files**

Very few articles have been written on comorbidity in the assessment of ASDs. Many children diagnosed with ASDs however, experience comorbid disorders (Matson & Nebel-Schwalm, 2007). Some studies cite as many as 70% of ASD children present with comorbid disorders, while other studies estimate that comorbid disorders affect ASD sufferers 100% over their lifetime (Rosenberg, Kaufmann, Law & Law, 2011; Strang et al., 2012). Hence it was interesting and of relevance to discover the comorbidities in our sample of participants with ASD. The experimental ASD group ( $n = 13$ ) was used in this analysis.

Of the sample ( $n = 13$ ) who were concordantly diagnosed as ASD on the basis of clinician diagnoses, 10 participants experienced speech and language delays, that is 76 % of the sample. Although speech and language delays are not a requirement for an ASD diagnosis, a fair amount of ASD sufferers experience these delays, this was affirmed in this study (Lord et al., 2011). It's a common error that clinicians may misdiagnose speech and language delays as being indicative of ASDs (Lord et al., 2011). This may account for the couple of false positives that the clinicians identified yet the ADOS diagnosed as Non-ASD.

A study by Ahmad & Mahmood (2011) stated that 10% of all people with ASDs are intellectually superior with the majority of ASD cases having IQs below 70. In our sample 46% of the participants were intellectually disabled, a considerably large percentage. Features of mental retardation are very similar to those of ASD. This can be a complicating factor in ASD diagnosis and may also account for the partial disagreements that this study observed between the ASD diagnoses and the clinician diagnoses (Ahmed & Mahmood, 2011; Timmi et al., 2011).

Of the ASD sample group, 10 participants had ADHD, this equates to 76% which is considerably large also. Numerous theorists have documented results stating that a large percentage of people with ASDs have higher than expected rates of ADHD symptoms of higher than 50% (Matson & Nebel-Schwalm, 2007; Kachhar et al., 2010, Gadow, Devincient & Pomeroy, 2006; Lee & Ousley, 2006). This study confirms this finding. Current classification systems (DSM-IV-TR, ICD-10) do not allow for a comorbid diagnosis of ASDs

with ADHD. Conceivably, these disorders appear to be diagnostic opposites in terms of social interaction and communication. Despite these diagnostic rules many research studies have documented coexistence and this is becoming widely accepted by clinicians (Kochhar et al., 2010).

Other authors have stated that oppositional defiance disorder is also a common comorbid disorder (Jordan, 2005; Charwarska et al., 2007). However, in this study only 3 participants of the 13 showed this pattern, thus for this study sample it was not a common comorbid disorder. The sample size may account for this lack of representation.

Interestingly, six of the 13 participants with ASD had pre-birth or congenital challenges. The personal files revealed premature births' (28 weeks), and stressful births involving oxygen deprivation, foetal distress and constricted blood flow to the brain. These problems may result in various difficulties including intellectual disability, which, as already stated, can be confusing in diagnosing ASDs (Timmi et al., 2011; Chowdhury, 2009).

Another mother in this sample suffered from severe trauma when her baby was three months in utero. Since ASDs are multifactorial in nature, some environmental factors are likely to be implicated in causation (Rutter, 2011). Hence, this intense stress may have provided the condition where it would be easier for genetic abnormalities to occur, especially if there was a predisposition for this in the family. Research has cited pathogenic gene mutations being responsible for the development of autism in 1% of the ASD cases (Persico & Bugeron, 2006).

Twin studies have linked genetics to ASD and have shown that ASDs have a heritability of about 90% (Rutter, 2005b in Rutter, 2011). In our sample four participants with ASD had a history of ASDs in the family. One participant had a father with Williams's syndrome. ASDs have been associated with such chromosomal abnormalities in at least 10% of time (Ritter, 1994).

The sample also showed a high percentage of aggressive tendencies with 61% of the sample experiencing this comorbidity.

This study found that gross and fine motor delays also appeared comorbidly with ASD, although the percentages were only 30% and 38% respectively.

Literature does cite that epilepsy is often comorbid with ASD, with some estimating that a quarter of all individuals with autism develop epilepsy (Belhadj, Mrad & Halayem, 2006; Volkmar & Nelson, 1990). Although in our sample of ASD participants only two experienced this.

There was one case where sexual abuse had been identified by a clinician. This particular participant had no history of ASDs in their family and the mother experienced a normal birth. Rutter (2001, p. 399), talks of some people having signs of what he terms, “Quasi-Autism”. The implication is that autistic like behaviours may develop and be observed in people who have experienced an external environmental trauma. It may appear as a developmental regression in some cases. He does however conclude that it remains to be determined whether abuse can have some effect. Future studies need to try and answer this concern as there is currently limited evidence supporting this. One wonders how many sexual abuse cases there were that were unidentified. Lastly, two of the thirteen participants suffered from anxiety and obsessive compulsive disorder comorbidly. Recent studies have shown that rates of anxiety symptoms are elevated among individuals with ASDs (Strang et al., 2012).

Some studies found that 58.3% of the sample experienced comorbid anxiety (Amr et al., 2012). These high percentages were however not reflected in this study, the small sample size may have resulted in the findings in this study not reflecting what has been found in other studies of a similar nature.

Since these variant comorbid disorders impact on an ASD person’s life in an increasingly challenging and negative way, it is important that comorbid disorders are highlighted in literature. There is scholarly debate over whether these comorbid diagnoses should be considered as separate categories as has been discussed in this study, or whether they should rather be viewed as symptom clusters of ASD (AACAP, 1999). These comorbid disorders add to the many subtypes that exist on the spectrum.

Further studies are needed, with larger samples, to test and validate the specificity of the ADOS and to further analyse comorbid patterns associated with this extremely complex disorder.

### **5.3 Limitations and future research possibilities**

This quantitative study investigated the diagnostic ability of the ADOS; it proved to be an interesting journey. The researcher has gained much practical, clinical and research

experience from this research. It was fascinating to note the diverse ways in which ASDs manifest across cultures, and it was interesting to witness how observable behaviours differ across ethnic groups. This area of ASDs is such an under researched field in South Africa, this study has illuminated many possible future studies that could build on from this one.

This study was time consuming and challenging. There was considerable expense and time involved in travel and administration, which was underestimated. Future studies which may include multiple sites all over the country will need to consider applying for funding to ensure research feasibility.

As a researcher, more training on the ADOS would have been beneficial along with more knowledge on the different models that can be used for administering tests. This study adopted the child-centred approach to testing and the researcher was acutely aware of how the child was responding to the ADOS tasks and the testing situation in general. A test-centred approach to administration requires a more rigid adherence to the manual instructions and prompts. This was not advocated in this study.

One of the greatest limitations in this study was the sample size. Although forty children were assessed for inclusion in this study, only twenty-six were ultimately included. There were various reasons for this which were previously been discussed in this thesis. For the future, a larger sample size would ensure more valid results.

The matched blinded study design dictated the inclusion and exclusion criteria. On the one hand, one may view the design as a limitation and the researcher has contemplated this fact considering the possibility of future studies using a matched design but not being blinded. On the other, for a study to have such a design is a strength. It provided an objective, unbiased, positivist base from which to explore the results. It may also be feasible to not have a blinded study. Rather, choosing a matched design that was unblinded would ensure a greater number of participants.

Some factors such as maternal age at birth were not addressed in this study that future studies would do well to include. Studies cite that mothers over the age of 35 years have 30% increased risk of ASDs. One particular study which made this conclusion included 25,687 cases of ASDs and over 8.6 million control subjects (Sandin, Hultman, Klovzon, Gross, MacCabe & Riechenberg, 2012). However, maternal age as a variable was not documented in

all the personal files of the participants. Too many files with missing data resulted in this study having to ignore this possible correlation being shown.

Depression has also been cited as a common ASD comorbidity yet this study did not consider this variable (Simonoff et al., 2008 in Strang et al., 2012). It will be worth considering depression as a comorbid factor in future studies.

This study addressed differences in behaviours on the ADOS sub-categories across Black, White and Indian cultures, and observed significant differences on certain sub-categories. However, the sample failed to find any coloured children. It also only included children whose medium of instruction in school was English. Given these findings, and knowing that there are eleven official languages in South Africa, future research should further examine differences between cultures across different languages. It would be of future benefit to replicate this study across multiple sites in South Africa. This will increase sample size, thus increase the power and make results more generalizable.

## Chapter 6

### Conclusion

This study has addressed the very under-researched area of ASDs in South Africa (Bakare & Munir, 2011). The aim was to explore the diagnostic ability of the ADOS in special needs schools in the greater eThekweni area. As the gold standard for ASD assessment in the West, this tool needs to be validated and examined in the South African context. The use of a standardised tool-based procedure, like the ADOS, for early ASD diagnosis is a widely recognised recommendation, since it will reduce diagnostic delay and facilitate early intervention (Canal-Bedia et al., 2011). South Africa needs a specific ASD-case detection tool like the ADOS which is easy to use in a paediatrician's or psychologist's office. This study formed part of a broader research project (K-ASD) that aimed to standardise and assess cultural relevance of the ADOS in South Africa.

This study found that the ADOS diagnoses were concordant with and equivalent to the clinician diagnoses. One could thus extrapolate that the ADOS can accurately and specifically diagnose those that are ASD in our multicultural context. In fact, this study found that the ADOS tended to be more sensitive to diagnosing ASD type behaviours than the clinicians were. The sub-categories of this instrument cleverly encouraged participants to respond and behave in ways that made an ASD diagnosis easier, than a mere clinical judgement (Lord et al., 2000).

Making use of the information gleaned from the personal files the equivalent of a mental status exam was conducted on each participant. It provided additional information that alerted the researchers to potential areas for further investigation and highlighted the complexity of ASDs through identification of comorbid factors associated with ASDs in the sample. Comorbid disorder patterns with ASDs are a very under-researched area and often lead to confusion in diagnoses (Rutter, 2011). This study considered these patterns in the ASD group and found high comorbidity with speech and language delays, ADHD and aggression. This was followed by gross motor and fine motor delays.

There is a lack of research on gestural behaviours and expression variances between cultures. It is a fact that gestural behaviours are not universal (Archer, 1997). This study found

behavioural variations that were statistically significant between the Black and White ethnic groups, on the communication and reciprocal social interaction sub-categories of the ADOS. This supported the fact that cultural differences in behaviours are evident (Rudwick, 2008). What is considered normative in one culture is not necessarily a norm in another (Ostrosk-Solis et al., 2004). Although Black, White and Indian children in this study had English as their medium of instruction at school, their home languages differed. Black children spoke either isiZulu or isiXhosa at home and were more likely socialised to be respectful and obedient. In comparison, the White and Indian children spoke English as their home language and appeared to be socialised in similar ways. The variable perspectives on what is considered respectful behaviour may have accounted of this (Rudwick, 2008). This may have accounted for the disparity in the ADOS sub-category results.

The enormity of familial, communal and individual distress incurred by the pathology of ASDs extends the responsibility of an accurate diagnosis of this disorder to the international community at large. One cannot rely solely on parental support to do this. Many people in South Africa do not have access to services affiliated with ASDs nor do they have the means to have lengthy expensive assessments done on their children. This was obvious in the second school used in the study which had a lower social economic status of parents than the first school. The personal files at times were quite scant in terms of assessments.

Decisions need to be taken at a national level to ensure the wellbeing of South Africa's children. This is supported by Munir and Bakare (2011) who stated that "Africa needs more policy making attention directed at child and adolescent mental health service provision, especially regarding the issues of childhood developmental disorders and intellectual disability" (Munir & Bakare, 2011). Hopefully this research has added to the knowledge of the magnitude of the problem of ADSs; provided information on how ASDs present in South Africa across certain ethnic groups and posed that the ADOS can be used as a valid diagnostic tool for ASD assessments in our multi-cultured country.



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## APPENDICES

### Appendix A: Letters to the Head Masters of Special Needs Schools

Details blanked to preserve anonymity

3<sup>rd</sup> December 2011

Mr [REDACTED]  
The Principal,  
The [REDACTED] School

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Per electronic transmission: [REDACTED]

Dear [REDACTED],

#### KwaZulu-Natal Autism Study

#### Seeking permission to conduct research at your school during 2012.

We are requesting your permission to use [REDACTED] as a site for data collection in 2012, beginning in the first term of 2012, if at all possible. We understand that you and your staff are extremely busy and are sensitive to the extra work this may require. It is however, a large study involving the standardization of the Autistic Disorders Observation Schedule (ADOS) for South African children. You are possibly aware that the ADOS is now regarded as the gold standard for the diagnosis of the Autism, and so we hope to be able to standardize this assessment schedule for children in our country and on our continent. The Principal Investigators in this study are Dr Shuaib Kauchali (Dept. of Paediatrics & Child Health, University of KwaZulu-Natal), Dr Beverley Killian (School of Psychology, University of KwaZulu-Natal) and Dr Meera Chhagan, (Maternal & Child Health, University of KwaZulu-Natal).

We would require the collaborative efforts of key staff members on the study. This is an experimental design, thus we ideally would like to assess two groups of children, who will be matched according to age, race and gender. One group being those children with Autism spectrum Disorder, who will be matched to a control group of children without this disorder and who have other needs for special education. The aim is to assess the children using the ADOS screening test and to ascertain whether it accurately screen for ASD or whether it shows false positives/negatives among SA children. We intend to conduct a double blind study meaning that at the time that the ADOS is administered, we want the researchers not to know the diagnosis of the child concerned.

It will require the collaboration with key staff members who will allocate the two researchers 6 children a week to assess. The researchers' involved namely Aurene Wilford and Michelle Dixon, are teachers themselves and between them have twenty years of experience. They will be assisted by other masters' students who will video record the administration of the ADOS in the child's home language.

We ideally would like to test 20 students who present with ASD in varying degrees, across race, age and gender and compare them to 20 students who are matched according to race, age and gender, yet do not present with ASD. Each assessment session will take between 40 minutes - 1 hour.

We understand the ethical ramifications of testing children, and will thus require written informed consent from each parent whose child is involved as well as the consent of the child concerned. Should you agree to our using [REDACTED] as the site for this research, we will provide you with copies of the informed consent form. We shall draw up the form, but it will require some administration work on the part of the staff involved. Every session shall be recorded for research purposes. Ethical approval for this study has already been granted by the UKZN ethical review committees.

Should your psychologists and other staff be interested, we are willing to train them in the use of this assessment tool. We would also like to make a meaningful contribution to both the parents and staff of the school in terms of their understanding of ASD.

We understand the pressures of school life and the probability that you are inundated with requests for research studies, which place added stress on your staff members. Nevertheless, we realize the uniqueness of your school learner profiles.

If you have any questions regarding this study you can contact Dr. Beverley Killian, can be consulted on her email at [Killian@ukzn.ac.za](mailto:Killian@ukzn.ac.za).

Thank you for taking the time to consider our proposal.

Yours faithfully,

Bev Killian (PhD)



3<sup>rd</sup> February 2012

Mr [REDACTED]  
The Principal,



Per electronic transmission: [REDACTED]

Dear [REDACTED]

KwaZulu-Natal Autism Study

Seeking permission to conduct research at your school during 2012.

Thank you for taking time out of your busy schedule to meet with us. These are the details of our study. We are requesting your permission to use [REDACTED] as a site for data collection in the first term of 2012, if at all possible. We understand that you and your staff are extremely busy and are sensitive to the extra work this may require. It is however, a large study involving the standardization of the Autistic Disorders Observation Schedule (ADOS) for South African children. You are possibly aware that the ADOS is now regarded as the “gold standard” for the diagnosis of autism, and so we hope to be able to standardize this assessment schedule for children in our country and on our continent. The Principal Investigators in this study are Dr Shuaib Kauchali (Dept of Paediatrics & Child Health, University of KwaZulu-Natal), Dr Beverley Killian (School of Psychology, University of KwaZulu Natal) and Dr Meera Chhagan, (Maternal & Child Health, University of KwaZulu-Natal).

We would require the collaborative efforts of [REDACTED] on the study. This is an experimental design, thus we ideally would like to assess two groups of children, from 6-11 years of age who will be matched according to age, race, language and gender. One group being those children with Autistic Spectrum Disorder, who will be matched to a control group of children without this disorder and who have other needs for special education. The aim is to assess the children using the ADOS screening test and to ascertain whether it accurately screens for ASD or whether it shows false positives/negatives among SA children. We intend to conduct a double blind

**Child and Family Centre  
School of Psychology**

Golf Road, Scottsville,  
Pietermaritzburg  
Private Bag X01, Scottsville, 3209,  
South Africa  
Telephone (033) 260-5166 Fax (033)  
260-5363  
Email: savagem@ukzn.ac.za



## **Appendix B: Parent Consent and Child Assent forms**

### Informed Consent for Parents and Child

To whom it may concern,

We are conducting a research project towards our Master's Degree in Psychology, at the University of KwaZulu-Natal, under the direction of Dr. Beverley Killian. This research is part of an international study, funded by 'Autism Speaks'.

Autism spectrum Disorder (ASD) tends to be very difficult to diagnose and international research literature suggests that the ADOS is the current gold standard in assessing ASD. This assessment tool has however not been tested in the South African context, and the purpose of the study is to find out how we can best use the ADOS to identify young children who have communication difficulties. These tests are made up of questions and observations by trained health professionals, additionally the ADOS has been used widely in children in countries like the USA, but we have yet to establish the relevance of their use in our context.

The school psychologist will assist in the running of this study. We are asking for your consent for both you and your child to participate in our research project. Your child may or may not have a diagnosis of ASD; however we need to assess both children who have this diagnosis and children who do not.

Your child's involvement in the project will require that he/she participate in a detailed evaluation, to be conducted at your child's school, which will last approximately 1 hour. The assessment will take the form of some communicative questions posed to your child and joint attention tasks, involving play activities.

With your permission, the assessment will be video recorded and may be viewed only by relevant professional's involved in this study.

There will be no remuneration in cash or kind for participation in the project, but it would be a privilege for us to participate with your child. The identity of your child will be kept confidential and no identifying information will be included in the completed research reports. A coding system will be used to ensure your child's confidentiality. You may withdraw from this study at any time and you will experience no adverse effects from such withdrawal or refusal. Any concerns or questions are welcome and we will be of assistance whenever and wherever possible.

Sincerely,

Michelle Dixon

Aurene Wilford

Dr. Beverley Killian

Masters student

Masters Student

Supervisor

**Please complete this form and return it to the school.**

**Section A:** CONSENT OF PARENT OR CAREGIVER

I \_\_\_\_\_ (Full name of parent/ caregiver) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to my child taking part in the assessment process.

\_\_\_\_\_

Signature of parent

\_\_\_\_\_

Date

**Section B:** ASSENT OF CHILD

As parent/ caregiver, I have explained the nature of this research to my child in the most understandable way possible.

\_\_\_\_\_

Name of child

\_\_\_\_\_

Printed name/ signature or thumbprint of child.

**Section C:**

ADDITIONAL CONSENT/ASSENT TO VIDEO RECORD ASSESSMENT.

I hereby agree to the video recording of the ADOS assessment. I understand that no personal identifying information or recording will be released in any form.

\_\_\_\_\_

Signature of Parent

\_\_\_\_\_

Signature of child

## Appendix C: Behaviour During assessment form

### K-ASD study: behaviour during assessment

Child Tag: ..... Stud nuc: .....

Name: ..... Date of birth: ..... Gender: ..... Home Language: .....

Descriptions	NAD	Code
<b>1.Body Size</b>		X
1.1 Underweight	X	
1.2 Overweight	X	
<b>2.Grooming &amp; Hygiene</b>		X
2.1 Poor	X	
2.2 Excessively neat	X	
2.3 Unusual appearance	X	
<b>3.Facial expression</b>		X
3.1 Unusual	X	
3.2 Mimicking of facial expressions	X	
3.3 Wooden (no changes in facial expression)	X	
3.4 Other: specify		
<b>4. Eye contact</b>	X	X
4.1 Eye contact made within a few secs	X	
4.2 Sustained eye contact	X	
4.3 Eye contact sought as a means of establishing contact	X	
4.4 Seems to avoid eye contact out of respect	X	
4.4 No eye contact	X	
4.5 Fleeting eye contact	X	
4.6 Peripheral vision only	X	
4.7. Looks past examiner	X	
<b>5. Energy levels</b>		X
5.1. Fatigue evident from beginning	X	
5.2 Fatigue evident towards end of session	X	
5.3.Other: specify		

<b>6. Attitude to examiner</b>		X
6.1. Talkative		
6.2.Unwilling to answer questions or cooperate	X	
6.3.Does not smile in response to examiner	X	
6.4 Unable to share or take turns	X	
6.5 Resistant to accompany examiner	X	
6.6. No social interaction	X	
6.7. Unable to ask questions	X	
6.8. Other		
<b>7. Behaviour (Appropriate behaviour to context)</b>		X
7.1. Intimidated or overwhelmed	X	
7.2 Shy apprehensive	X	
7.3 Very inquisitive	X	
7.4 Unable to sit still	X	
7.5 Stereotypical behaviour	X	
7.6 Tactile defensiveness evident	X	
7.7 Other		
<b>8. Speech</b>		X
8.1 Hardly audible (abnormal volume)	X	
8.2 Loud (abnormal volume)	X	
8.3 Formal or monotone speech	X	
8.4. High pitched		
8.5. Sing song tone		
8.6. No speech		
8.7. Flat- robot like		
8.8. Pronunciation difficulties	X	
8.9. Stutter or stammer	X	

## K-ASD study: behaviour during assessment

Child Tag: ..... Stud nuc: .....

Name: ..... Date of birth: ..... Gender: ..... Home Language: .....

8.10. Immediate echolalia	X		aggression, etc) Specify		
8.11. Delayed echolalia	X		11.5 Frequently asks to take toys home	X	
8.12. Uses sounds to communicate	X		11.6 Unable to focus on available toys as distracted by box of toys	X	
8.13. Frequently reverts to one topic	X		11.6 Unable to focus on available toys as distracted by others things in room	X	
8.14. Other			11.7. Lines up toys	X	
<b>9. Concentration and attention</b>		<b>X</b>	11.8. Takes toys without asking	X	
9.1 Unable to focus on a task	X		11.9. Other specify		
9.2 Highly distractible	X		<b>12. Cognitive process</b>		<b>X</b>
9.3 Distracted by peripheral objects	X		12.1 Seems below average in cognitive functioning	X	
9.5 Hyperactive	X		12.2 Seems above average in cognitive functioning/and or general knowledge	X	
9.6 Day dreams	X		12.3 Curious and ask questions	X	
9.7 Remains focussed on a special interest area	X		12.4 Above average fund of knowledge (not related to special interest)	X	
<b>10. Motor-coordination (Fine and Gross)</b>		<b>X</b>	12.5. Slow to process or understand instructions	X	
10.1 Difficulties with fine motor coordination	X		12.6 Other: specify	X	
10.2 Repetitive fine motor movements	X		<b>13. Mood and affect</b>		<b>X</b>
10.3 Gross motor difficulty: specify	X		13.1. Anxious	X	
10.4 Stereotypical behaviour impacts on other movements (e.g. flapping)	X		13.2. Seems sad/depressed	X	
10.5. Low muscle tone (slumps over the desk, or can't sit up straight)				X	
10.6. Clumsy				X	
10.7. Rocking (whole body)			<b>14. Behaviours after assessment</b>		<b>X</b>
<b>11. Attitude to toys and assessment</b>		<b>X</b>	14.1. Extremely happy to reunite		
11.1. Seems nervous to touch toys	X		14.2. Shows no evidence of reuniting happily		
11.2 Rough with toys	X		14.3. Behaviour changes upon reuniting: Specify		
11.3 Frequently checks verbally or nonverbally if permitted to touch toys	X		14.4. Other: Specify		
11.4 Toys evoke potential contextual concerns (bullying, interpersonal	X				



**K-ASD study: behaviour during assessment**

Child Tag: ..... Stud nuc: .....

Name: ..... Date of birth: ..... Gender: ..... Home Language: .....

<b>15. Areas of strength identified</b>	<b>X</b>	<b>X</b>
Specify:		
<b>16. Contextual issues of concern</b>		
16.1 Domestic violence		
16.2 Child being beaten at home		
16.3 Child exposed to excessive drunkenness		
16.4 Financial stress		
16.5 Food insecurity		
16.6 Illness or death in family		
16.7 Child is being bullying		
16.8 Child feels discrimination against self		
<b>17. Vision</b>		
<b>18. Hearing</b>		
<b>19. General health status</b>		

Examiners:.....

.....

---

**Appendix D: Biographical Form****Biographical Information and Medical History Obtained From Personal Files:**

Child's Name: \_\_\_\_\_ Code: \_\_\_\_\_

Child's age: \_\_\_\_Y \_\_\_\_m Child's Birth Weight: \_\_\_\_\_ &lt;2kgs (1) &gt;2kgs (0)

Ethnicity: White  Black  Indian  Coloured  Asian  OtherHome language: English  Afrikaans  isiZulu **1. Family History****Marital status:** Married 1 Divorced/Single 0 Widowed**Parental Age:** Mother: \_\_\_\_\_ Father: \_\_\_\_\_**Age at child's birth:** (0-38 years) 1 (38+) 0 (**Occupation:** Mother: \_\_\_\_\_

Father: \_\_\_\_\_

**Number of siblings:** \_\_\_\_\_ **Number of older siblings:** \_\_\_\_\_**Do siblings have ASD/autism or learning difficulties:** Yes 1 No 0**2. Family history of disorders:**

Psychological disorders: Mother Yes 1 No 0 \_\_\_\_\_

Father Yes 1 No 0 \_\_\_\_\_

Medical conditions: Mother Yes 1 No 0 \_\_\_\_\_

Father Yes 1 No 0 \_\_\_\_\_

Medical conditions at time of pregnancy: Mother Yes 1 No 0

Father Yes 1 No 0 \_\_\_\_\_

**Learning difficulties:** Literacy: Mother Yes 1 No 0

Literacy: Father Yes 1 No 0

Numeracy: Mother Yes 1 No 0

Numeracy: Father Yes 1 No 0

---

### **3. Formal Assessments:**

**a) Paediatrician report:** Yes 1 No 0

Comorbidities:

ADHD: Yes 1 No 0

ADD: Yes 1 No 0

Epilepsy: Yes 1 No 0

Mental retardation: Yes 1 No 0

Other: \_\_\_\_\_

\_\_\_\_\_

**b) Psychologist report:** Yes 1 No 0

**IQ:** \_\_\_\_\_ **Tests administered:**

(20 – 25 to 35 - 40) 0      (35 – 20 to 50 - 55) 1      (50 – 55 up to 70) 2

Severe mental retardation      Moderate mental retardation      Mild mental retardation

Other: \_\_\_\_\_

\_\_\_\_\_

**c) Occupational therapist report:** Yes 1 No 0

Fine motor difficulties: Yes 1 No 0

Gross motor difficulties: Yes 1 No 0

Other: \_\_\_\_\_

**d) Speech Therapist report:** Yes 1 No 0

Language difficulties: Yes 1 No 0

Speech difficulties: Yes 1 No 0

Other: \_\_\_\_\_

**e) Audiologist report:** Yes 1 No 0

Hearing difficulties: Yes 1 No 0

Other: \_\_\_\_\_

Visual difficulties: Yes 1 No 0

Other: \_\_\_\_\_

**e) Remedial report:**

Literacy difficulties: Yes 1 No 0

Numeracy difficulties: Yes 1 No 0

Memory difficulties: Yes 1 No 0

Dyslexia: Yes 1 No 0

Other: \_\_\_\_\_

## Appendix E: Ethics clearance



7 September 2012

**Mrs Aurene Wilford 891143299**  
**School of Applied Human Sciences – Psychology**  
**Pietermaritzburg Campus**

Dear Mrs Wilford

**Protocol reference number: HSS/0351/012M**  
**Project title: The Validation of the ADOS for atypically developing South African children, between the ages of 6-11 years, in special needs schools – a double blind study.**

### EXPEDITED APPROVAL

I wish to inform you that your application has been granted Full Approval through an expedited review process.

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)**

/px

cc Supervisor Dr Beverley Killiam  
 cc Academic leader Professor JH Buitendach  
 cc School Admin. Ms Nondumiso Khanyile

**Professor S Collings (Chair)**  
**Humanities & Social Sc Research Ethics Committee**  
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Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville



INSPIRING GREATNESS

## Appendix F: College of Humanities plagiarism pledge

### COLLEGE OF HUMANITIES

#### DECLARATION - PLAGIARISM

I, Aurene Wilford declare that

1. The research reported in this thesis, except where otherwise indicated, is my original research.
2. This thesis has not been submitted for any degree or examination at any other university.
3. This thesis does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
4. This thesis does not contain other persons' writing, unless specifically acknowledged as being sourced from other researchers. Where other written sources have been quoted, then:
  - a. Their words have been re-written but the general information attributed to them has been referenced
  - b. Where their exact words have been used, then their writing has been placed in italics and inside quotation marks, and referenced.
5. This thesis does not contain text, graphics or tables copied and pasted from the Internet, unless specifically acknowledged, and the source being detailed in the thesis and in the References sections.

Signed

