

EXAMINER'S COPY

**Exploring How Black African Children Respond During
the Administration of the ADOS: A Pilot Study**

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**Submitted in partial fulfilment of the requirements for the
Degree of Master of Social Science (Research Psychology)
in the School of Applied Human Sciences, College of Humanities,
University of KwaZulu-Natal,
Pietermaritzburg Campus**

May 2014

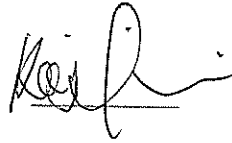
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Acknowledgements

I would like to express my sincere gratitude and appreciation to the following people, for their support and contribution to this study:

- First and foremost I would like to thank God for the divine mercy and grace showered upon me during all phases of this dissertation;
- My supervisors for their time and expertise during the process of completing this research project;
- My family, fiancé and friends for their support, guidance and prayers;
- The participants who selflessly gave of their time; and
- My fellow colleagues for all their input and support during this time.

Foreword

Precautions in interpreting the findings and recommendations of this study

In ensuring appropriate and non-offensive representation of the racial groups being compared, as well as to ensure that the integrity of the ADOS remains intact, the author would like to express suggestive pronouncements, declarations, and recommendations in working with the data presented. The purpose of this study was to fulfil the course requirements of a Research Master's degree, as a result, my supervisor at the time allowed to be a part of a larger study that she was working on. This meant that I was not the Principal Investigator, but a very junior member of the team. There were many limitations associated with this, such as control over the use of translated versions of the ADOS, the extra persons present in the testing situation and the training given to those responsible for administering the ADOS. The stance that this thesis aims to serve as a preliminary pilot test in uncovering possible areas of further investigation needs to be emphasised and used as the lens through which to view the data and subsequent analysis.

It is therefore important that the readers heed the following precautions;

Firstly, the recommendations put forward can never substitute for a trained clinician's conscientious attempts in understanding the sample or target group that they are administering the test to. The researcher acknowledges that any person who wishes to uncover and relay culturally relevant psychological test taking information must have undergone specialized training in the test being used and have substantial experience in working with the groups they hope to serve. To assume that reading over relevant literature and observing test taking behaviour of different races makes one culturally competent would be the height of ignorance. The researcher acknowledges this and appeals to the reader to bear this in mind.

Secondly, the future research recommendations are aimed at serving as guideposts that stimulate and inform further investigation into the specific areas of concern. The researcher openly acknowledges that uninformed application of the conclusions reached and suggestions put forward have the potential to result in offensive, inappropriate, unbeneficial and unethical

behaviour toward the racial groups being compared. In addition, the researcher has used a dimensional analysis of cultural differences based on the ideas of Brown and Levinson (1987) such as power, social distance, and the degree to which face threatening acts require mitigation. Further to this, claims of cultural differences can be read as racist or as invoking stereotypes but the failure to investigate cultural differences may mean that tests may well be biased and inaccurate.

Thirdly, these recommendations and conclusions should not, in any way, be rigidly applied without taking into consideration the impact of individual differences, sub-cultural group variations, and factors specific to the state of the child during assessment, as well as the inaccuracy of data collection, as per ADOS recommended standards. Adherence to these standards was the domain of the Principal Investigators and the researcher of this study was a junior member of the research team. This study will point out most carefully where adherence to the standards of the ADOS have not been met.

In this instance, drawing inferences without further robust investigation would prove to be more harmful than helpful.

Lastly, while aiming to provide the reader with insightful and novel conclusions, the author acknowledges the absolute shortfalls in the undertaking and execution of this study and thereby attempts to highlight, identify and provide the reader with possible areas of concern that might arise should a study of this nature be undertaken properly in the future.

Abstract

This study is a preliminary attempt to explore how (Black) African children respond to the administration of the Autism Diagnostic Observation Schedule (ADOS) within the prescribed categories of Communication; Reciprocal Social Interaction; Play; and Stereotyped Behaviours and Restricted Interests. Cultural factors are used as the point of exploration in determining whether or not they are a contributing factor in receiving elevated scoring in the ADOS, thereby placing children at risk of receiving false positive diagnoses of Autism Spectrum Disorders (ASD). This study is therefore aimed at exploring how African children communicate and behave socially, in accordance with their respective normative patterns. This is then compared to their Indian and White counterparts within the context of the ADOS administration as it took place in the present investigation, even though the present investigation falls short of the expected standards for the administration of the ADOS.

The methodology used to inform the results of this study is based on video recordings and observations of children who the ADOS was administered to. This sample included African children from a rural area and a sample of African, Indian and White children from special needs schools in KwaZulu-Natal, South Africa.

Results from this study show that in the behaviour categories of communication (verbal and non-verbal) and reciprocal social interaction, Black African children differed more significantly when compared to Indian and White children, based on literature. This is hypothesised to be due to cultural differences on some dimensions common to all cultures and not a lower level of communication and social interaction ability. The category of play indicated that African and Indian children scored similarly and collectively differed to that of White children. In stereotyped behaviours and restricted interests, all race groups being compared were shown to score similarly, thereby indicating the accuracy of the ADOS in identifying cases of ASD in the presence of culturally derived systems of behaviour.

The objective of this study was to investigate the presence of culturally derived behaviours elicited by specific tasks in the ADOS, in an attempt to highlight possible areas of further investigation in future endeavours of test adaptation.

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Preliminary Comments

Frequently used abbreviations and acronyms and terms

Throughout the text of this study the following abbreviations and acronyms have been used for the sake of brevity:

ASD: Refers to Autism Spectrum Disorders

ADOS: Refers to Autism Diagnostic Observation Schedule

DSM: Stands for Diagnostic and Statistical Manual of Mental Disorders

ICD: Stands for International Classification for Diseases

SES: Refers to Socio-economic status

Chapter 1

Introduction

Autism Spectrum Disorders (ASD) are a set of neurodevelopmental disorders that are considered to occur across all cultures. Whilst the aetiology of these disorders remains unknown, there are many culturally based theories surrounding the factors which are viewed to cause autism and other ASD (Ennis-Cole, Durodoye & Harris, 2013).

It is understood that ASD is presented in terms of deficits in communicative and social development in children, thereby making it different in appearance when compared to other mentally pervasive disorders (Ennis-Cole et al., 2013). Furthermore, there may also be environmental factors which are contributing to the increasing incidence detection of this spectrum of disorders (Wing & Potter, 2002). While accepting that ASD presents in children across all cultures, a study conducted by Hussein, Taha and Almanasef (2011) yielded results suggesting that there may be minor variations in symptom manifestation across different cultural groups (Hussein et al., 2011). There is a general shortage of studies on African children, although some more recent studies have focussed on African children with ASD (Hussein et al., 2011).

The diagnostic criteria used are western based, with the DSM-IV-TR (APA, 2000), and the soon to be introduced DSM-V, or the International Classification of Disorders, 10th Edition (ICD 10) being used to diagnose autism and other ASD. Although recent studies may suggest there are biological markers, there are no currently accepted biological markers for this disorder, therefore careful observations of the child's behaviour with a detailed neurodevelopmental history, are used to diagnose individual children. The DSM-TR-IV defines the main diagnostic categories as based on *inter alia* the absence of communication skills and reciprocal social interaction, plus the presence of stereotypical interests and complex mannerisms (APA, 2000). In other words, patterns of social behaviour and the degree to which they deviate from the child's chronological and social developmental stages are used to diagnose autism. This suggests that it may be important to consider other influences on the patterns of social behaviour exhibited by a child before diagnosing autism.

Given that social interaction and patterns of communication are critical aspects of the way in which ASD is diagnosed, and that culture shapes the manner in which people interact (Holdstock, 2000), it is crucial to explore how culture may be affecting the manner in which African children communicate and socially interact, especially when interacting with adults. The rationale behind emphasising behaviour when interacting with adults is due to the fact that when being diagnosed, tested or even participating in a screening process, children would need to interact and respond to an adult administrator or practitioner.

All cultures value respect and obedience, but they differ in the degree to which they place importance on this value. African parents (just as European parents of 200 years ago did) tend to place high importance on respect, for example. This would certainly affect the way in which an accurate diagnosis of ASD can be made in African children who may be more respectful and compliant, and less spontaneous and questioning than their Western counterparts. This study sets out to explore the ways in which Black African children respond to tasks in the Autism Diagnostic Observation Schedule (ADOS) and how the different behaviours elicited could be further investigated in future research, in an attempt to standardise this psychometric test.

The Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, DiLavore & Risi, 2008) is currently regarded as the international gold standard to assist in the diagnosis of Autism Spectrum Disorders (ASD) (Sikora, Pettit-Kekel, Penfield, Merkens & Steiner, 2006). As such, it is being translated and adapted for use in various countries and across different cultural groups. The ADOS comprises of a series of tasks and behavioural “presses” which are presented to the child in the form of activities during the administration phase, their behaviour is then coded onto an algorithm which is used to make the diagnosis. The algorithms used in this study are the ones aligned to the DSM-IV and the ICD 10. The algorithms constitute summed scores for various codes that fall into the following categories of Communication, Reciprocal Social Interaction, Play, and Stereotyped Behaviours and Restricted Interests. These categories of behaviour are not used specifically for the purpose of this study but are prescribed behaviour categories as per the ADOS manual. Cut-off scores for the diagnosis of autism and ASD are provided based on the summed scores within the Communication and Reciprocal Social Interaction categories. The higher scores are indicative of behaviour considered to be aligned with ASD (Lord et al., 2008).

This study is a preliminary attempt in exploring how Black African children respond to the administration of the Autism Diagnostic Observation Schedule (ADOS) within the prescribed behaviour categories. The impacts of cultural factors are explored in an attempt to determine whether or not they are a contributing factor in children receiving elevated scoring in the ADOS. This is viewed as an important indicator of elevated scoring as it places children at risk of receiving false positive diagnoses of Autism Spectrum Disorders (ASD). This study is therefore aimed at exploring how Black African children communicate and behave socially, in accordance with their respective normative patterns; these behaviour patterns are then compared to Indian and White children within the context of the ADOS testing environment. Conclusions reached are then proposed to serve as guideposts for potential “danger spots” when interpreting scores and to inform areas of discrepancies that may arise when trying to standardize the ADOS. It is proposed by the researcher to use the areas of concern mentioned to inform further investigation before making claims about the acceptability of the ADOS in the South African context.

Recommendations for areas of further investigation are based on careful observations of children to whom the ADOS was administered. Video recordings of a range of urban and rural African children and a sample of children from special needs schools in KwaZulu-Natal were used in this study.

The present study forms part of the KwaZulu-Natal ASD (K-ASD) Study which is located in the Paediatrics Department at the University of KwaZulu-Natal. The principal investigators, Dr. Kauchali and Prof. Chhagan, together with a team of researchers and research assistants, aim to examine ASD in Black children. The K-ASD Study has multiple focal areas amongst which is the exploration of how ASD manifests, and how it can best be identified, in South African children in the KwaZulu-Natal region specifically.

The process of adapting a test for cross-cultural purposes is based on the assumption that the test is both culturally sensitive and culture fair (Foxcroft & Roodt, 2009), to ensure the constructs being measured are relevant and meaningful in that particular culture and context. However, there is not yet any clarity about whether or not the constructs are relevant or meaningful in this African context. The ideas upon which the ADOS is based hold implicit norms about children’s behaviour with regard to patterns of Communication, Reciprocal Social Interaction, Play, and Stereotyped Behaviours and Restricted Interests. These are the same constructs upon which a

diagnosis of ASD is based (Lord et al., 2008). Yet, little is known about how African children communicate; reciprocally socially interact; their normative range of imagination and creativity; or if there are restricted interests due to factors other than the presence of ASD. Thus, before conducting a formal cultural adaptation of the ADOS, it is necessary to first explore the relevance and meaning of these behaviour eliciting activities for African children.

As a result, this thesis aims to serve as a pilot test in uncovering the problems that might occur when trying to assess the applicability of a psychometric test to a Black African population. It is acknowledged that due to the dearth of information, research aimed at eliciting appropriateness and applicability of tests to Black African populations is in high demand, and this study aims to be a precursor to much more rigorous research of this kind.

1.2. Thesis outline

In the next chapter, Autism Spectrum Disorders will be described in terms of the guidelines and criteria set by the DSM IV. The main race group of interest in this thesis is Black African children, so the next focal area of the literature review will be on African cosmology, parenting values and patterns of behaviour that may develop as a consequence of Zulu ancestry values. The literature review will then discuss ways in which culture may impact on the manner in which children present themselves in testing situations, as well as the many ways in which this psychometric test could be adapted for different cultural contexts.

Chapter 3 of this dissertation sets out to focus on the methodology used in this study. This includes detailing the chosen research design and exploring the sample population, as well as the sampling methods used in analysing the data collected. Ethical considerations are then explored and outlined as to the way in which they are addressed in this study. The results are presented in Chapter 4 followed by a chapter in which the results are later discussed in relation to the literature in Chapter 5. Chapter 6 is the concluding chapter which outlines the implications for this research as well as researcher reflexivity; in addition it will consider the impacted limitations of the current study and make suggestions about future research endeavours. Since the ADOS is one of the primary areas of concern for the South African context, suggestions will be made about how moving forward, researchers can investigate potential stumbling blocks and inform

future interventions in an effort to adapt the ADOS for effective use in the South African context.

Chapter 2

Literature Review

This study forms part of a larger research programme – the KwaZulu-Natal Autism Spectrum Disorders (K-ASD) Study which aims to gain an understanding about the manner in which Autism Spectrum Disorders (ASD) manifest themselves in African children. Various focal areas of investigation have been identified as central to accomplishing this basic aim. The present study is concerned with the question of how Black African children respond to the administration of the ADOS, in comparison to Indian and White children. The impact of their culturally normative behaviour patterns on the behaviour exhibited during the testing phase is explored and potential areas of concern are highlighted as points of further exploration. Whilst the ADOS has been developed in Western contexts, its applicability in Africa remains to be investigated. It must be noted that although this study makes reference to “Black African” children and “African” culture, the diversity within these groups must be acknowledged. This study refers primarily to the Zulu ancestry subgroup of the Black African sample.

The careful observation of children forms an essential component of all psychological assessment procedures. These observations are normally incorporated into the report under a special heading entitled “behaviour during assessment”, as it is these observations that enable the reader to gain insight into the child, as well taking into consideration the reliability and validity of the assessments that were conducted. Although the descriptions of the child’s behaviour during assessment are individually-based observations, the practitioner takes into consideration normative behaviours for a particular context and culture. While the manner in which behaviours are considered normative is usually contextually based, little evidence has been gathered to describe normative behaviours among African children (Austen, 1986). Indeed, culture is a significant variable that may impact on a child’s behaviour during assessment, but how this affects the behaviour of a Zulu child has not been well articulated nor understood. In the absence of such descriptions, many of the norms generated from predominantly Western contexts are used to understand children within the African context.

There are a number of ideas and stereotypes about the typical behaviour of Zulu ancestry children in relation to authority figures and how a child is expected to show respect (Kotchick & Forehand, 2002). For example, Ogbu (1981, in Kotchick & Forehand, 2002) asserts that African

children are raised with a paramount focus on being respectful. This respectful attitude may take the form of children hesitating to ask or not asking questions at all during an assessment, in addition, waiting to be offered something instead of requesting it, or purposely avoiding eye contact in a display of respect to the adult.

The ideas of Brown and Levinson (1987) explain the notion of negative face and positive face, and indicate that all cultures share these ideas, but differ in the relative importance assigned to them. Specific cultures may change the relative assigned importance over time. Zulu cultures are historically found to place high importance on negative face (as does the Japanese culture, etc) meaning that children must be taught to be respectful if they are to avoid giving offence. Historically, White and Indian cultures have progressively given negative face less importance (though it is viewed that it will unlikely be the case that they give it no importance). This approach highlights the point that this study is avoiding merely asserting stereotypes but trying to provide a theoretical description of culture, as it pertains to social interaction (Terkourafi, 2004).

Although this point is viewed as acceptable, it must be questioned as to whether the doctrine of respect and submission to authority figures stems from survival means of past doctrines and became embedded into the culture or if it is intrinsic to the cultural practices, belief in the afterlife and conducting one's earthly life in a manner that is pleasing to the elders who have passed away (Kotchick & Forehand, 2002).

In relation to the example, it is known that within many African cultures, including the Zulu culture, that children are generally raised in households which hold respect in high regard, with said children being raised to be respectful to their elders (Kotchick & Forehand, 2002). It is acknowledged that all cultures place an emphasis on respect and African cultures are no exception. Respect is considered to be the cornerstone of all behaviour and interaction in Zulu culture and the notion of respect being held in high regard spans across most African communities and is central to African cosmology (Super & Harkness, 1999).

This proves to be increasingly apparent in the testing situation due to the common behaviour of submission to authority figures, which, as mentioned, is emphasised in the Zulu culture. As a result, participants may be inhibited in their responses and may not meet all the requirements set

out in the Autism Diagnostic Observation Schedule coding sheet used during the administration. In particular, this undertaken study will focus on patterns of social interaction and reciprocal social interactions as described in the ADOS as well as other behaviours that are observed during the administration of the ADOS to (Black) African, Indian and White children in the age range of 6 – 11 years. The sites for this study comprised of a rural and peri-urban area in KwaZulu-Natal, which is a previously disadvantaged lower socio-economic area.

The ADOS is currently regarded internationally as the “gold standard” (Sikora et al., 2006) to test for the diagnosis of Autism and other pervasive Autism Spectrum Disorders (ASD) alongside a clear and detailed developmental history. It can be characterised as a structured observation schedule that provides “presses” to elicit behaviours that relate to communication, reciprocal social interaction, imagination/creativity, and the presence of stereotypical behaviours and restricted interests. As the “gold standard” (Sikora et al., 2006) for the diagnosis of ASD, the ADOS assesses the absence of certain communication and social reciprocal interaction behaviours and the presence of stereotypical behaviours and restricted interests. There is a clear assumption by the developers of the ADOS that behavioural gestures and responsiveness to the social cues that arise during the administration of the ADOS are universally occurring phenomena amongst children. As such, the ADOS is generally hailed as an important method to identify ASD in Western children, although the cross-cultural sensitivity and applicability of this test has yet to be fully investigated.

This study will therefore explore the problems that might arise when trying to investigate the cross cultural applicability of the ADOS and suggest areas which are in need of further exploration, as well as key areas of concern that should be taken into account when attempting to assess cross cultural applicability.

The ADOS, perhaps more than many other psychometric techniques, relies on culturally and socially embedded constructs to elicit the behavioural manifestations of ASD. For example, the make-believe celebration of a doll’s birthday party is used in the administration of Modules 1 and 2 of the ADOS. The purpose is to provoke certain behaviours that may be characteristic of ASD: for example, flicking of the doll’s eyelids, self-stimulatory behaviour (stimming) or over-excitement in reaction to feelings of excitement or fear, inability to use gestures and imaginative thought processes, lack of social interaction, and so forth. Thus, the tasks provide a series of

“presses” that are intended to elicit behaviours characteristic of ASD. Note that birthday parties would tend to be occasions for positive politeness in the Western world, but the testing situation as a whole would most probably be an occasion for negative politeness (respect) in the cultural world of Zulu speakers. In addition to the test being culturally sensitive, it is necessary for the test administrator to be familiar with the cultural practices and routines so that s/he can judge variations from the norm. However, the problem is that, while common behavioural assumptions exist about how Zulu ancestry children respond to various social interactions, little empirical research has described normative and atypical responses among Zulu ancestry children. For example, it is widely believed that historically Zulu ancestry children avoided eye contact with people in positions of authority, but it is not known how widely practiced this sign of respect is seen amongst children today. This practice may also differ in degree of adherence between urban and rural children.

2.1 Autism Spectrum Disorders

2.1.1 Basic Description of Disorder

According to the DSM-IV-TR, the fundamental features of ASD include the presence of significant abnormal impairment in the development of communication and social interaction and a markedly stereotyped and restricted range of interests. The progression of this disorder and the manner in which it manifests itself in children varies greatly with the chronological age of the child and their developmental level (APA, 2000).

The underdevelopment and lack of reciprocal social interaction is thought to be maintained throughout the administration with the child, as opposed to momentary scenarios lacking in reciprocal social interaction between the child and administrator. A marked weakness in non-verbal behaviour is also observed with a child having ASD. Impairment in behaviour such as eye contact, facial expression and gaze is found to be lagging with chronological age expectancies and developmental expectancies in ASD children. In children with ASD, a failure or difficulty in making friends at similar developmental levels or ages is evident and younger children are found to have a significant lack of interest in establishing friendships or seeking peer relations. Older children, on the other hand, may have a desire to engage in friendships and relationships, but lack the foundational understanding or knowledge of social interaction to make this possible. In

ASD children there is a marked deficiency in spontaneity and spontaneous shared enjoyment, interest or achievements; they are likely to show a marked disregard for other individuals around them and are found to be content in their individual play (APA, 2000).

A marked weakness in communication skills is also found in ASD children. This impairment is found to be sustained and filters into both verbal and non-verbal language and communication used, there is often a developmental delay in language production and in some cases a complete lack of spoken language (APA, 2000).

With the children who do have language production, a significant impairment in the ability to spontaneously engage in and sustain a conversation with another individual/s is noticed. A preoccupation and restricted range of interests in topics of communication or a stereotyped and repetitive use of language and or idiosyncratic use of language is also noted in ASD children (APA, 2000).

A restricted, repetitive and stereotyped pattern of behaviour, interests and activities is noted in individuals with ASD. ASD individuals are found to have a significant preoccupation with one or more restricted and stereotyped interests which are found to be abnormal in either intensity or focus; a rigid obedience to specific non-functional routines and/or rituals; stereotyped and repetitive motor mannerisms; and a persistent preoccupation with detailed components of toys or objects (APA, 2000).

ASD individuals often have a blinker mentality with a narrow vision in terms of interests, for example a child with ASD may have a preoccupation with dates and phone numbers, or line up the same toys in the exact same manner repeatedly, or mimic an advert or actor impersonation repeatedly without having a social goal; behaviour is predominantly insulated with limited social interaction. A marked resistance and significant distress is noted when their surrounding environment goes through a change. These individuals find it difficult to transition between changes, even as minor as the changing of utensils at the dinner table.

Stereotyped body movements can be categorised as including hand mannerisms, which often include flapping, clapping, and finger flicking, as well as a full whole body rocking motion (whole body or torso) swaying and dipping. Abnormalities in posture, which include walking on tip toes, odd body posture and hand movements are also noted. Individuals with ASD are found

to show a persistent fascination and preoccupation with detailed parts of objects and movements of the objects, such as spinning the wheels of the car as opposed to playing functionally with the car (APA, 2000).

2.1.2 Prevalence Rates

The median rate of ASD, according to the DSM IV-TR, has been found to be five instances of ASD per ten thousand individuals (APA, 2000). In addition to this, rates ranging from two to twenty instances per ten thousand individuals were also reported (APA, 2000). It is unclear, however, if the difference in rates are a result of differences in methodology in the respective studies or not, or if in fact there is an increase in the incidence of the condition frequency (APA, 2000).

The Centre for Disease Control and prevention have reported that many studies investigating the prevalence of Autism and other ASD show that approximately one in eighty-eight children have been diagnosed with either autism or other ASD (APA, 2000). ASD and autism have been shown to occur in all socio-economic, ethnic and racial groups; however the manifestations are interpreted differently. According to the studies conducted at the CDC, autism and other ASD are found to occur more frequently in boys (1:54) than in girls (1:252) (Centre for Disease Control and prevention, 2012).

2.1.3 Diagnostic Criteria

The diagnostic criteria set by the DSM-IV-TR to diagnose ASD are made up of three main areas;

- 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):
 1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
 - b. Failure to develop peer relationships appropriate to developmental level.

A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interests). Lack of social or emotional reciprocity (APA, 2000).

2. Qualitative impairments in communication as manifested by at least one of the following:
 - a. 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);
 - b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
 - c. Stereotyped and repetitive use of language or idiosyncratic language; and
 - d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level (APA, 2000).

3. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
 - a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
 - b. Apparently inflexible adherence to specific, non-functional routines or rituals;
 - c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements); and
 - d. Persistent preoccupation with parts or objects (APA, 2000).

- 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 used in social communication, or (3) symbolic or imaginative play (APA, 2000).

- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder (APA, 2000).

2.1.4 Ways of Making a Diagnosis

Unfortunately there are no standard medical tests available to make a diagnosis of Autism. Doctors, psychiatrists and psychologists mainly rely on behavioural assessments which are designed to elicit typical autistic behaviour from patients (Autism Speaks, 2012).

The Modified Checklist of Autism in Toddlers (M-CHAT), which was also used in this study, is often used to gather information from the caregiver about the child to ascertain whether or not they are in need of further evaluation and assessment by a psychiatrist, neurologist or psychologist, for example.

In order to diagnose autism, children should be screened from birth to approximately three years and parents should watch diligently for the completion of milestones at appropriate developmental stages (Autism Speaks, 2012).

As mentioned above, there is no single medical test to diagnose autism and other ASD, the diagnostic evaluation is very much multi-disciplinary, including the input of psychologists, paediatricians, and occupational therapists, and in some cases, teachers and speech therapists (Autism Speaks, 2012).

2.1.5 The Autism Diagnostic Observation Schedule (ADOS)

The Autism Diagnostic Observation Schedule (ADOS) is characterised as a semi-structured, standardized assessment of communication, social interaction and play for those individuals who have been referred for assessment due to possible autistic or other pervasive developmental disorders, which are referred to as Autism Spectrum Disorders (ASD) (Lord et al., 2008).

The ADOS consists of standardized and specific activities which enable the examiner to observe behaviour patterns which are considered as symptomatic of autism and other ASD at the different developmental levels and chronological ages of the individual (Lord et al., 2008).

The ADOS uses planned social events which are referred to as “presses” (Murray, 1938, in Lord et al., 2008) to illicit particular behavioural patterns associated with the specific social event. The structured activities and tools used to create the scenarios provide a standardised means of measuring social interaction, communication, play and typical behaviour patterns associated with autism (Lord et al., 2008).

The ADOS comprises of four modules which are all administered in an average of thirty to forty-five minute sessions, depending on the individual. Each module in the ADOS has a schedule of activities which are designed for the purpose of accommodating individuals of all developmental levels ranging from verbally fluent to non-expressive or receptive language. One module is administered at a time, although if the individual is found not to be adequately coping, the examiner may downgrade to a lower module. The examiner chooses which module to administer based on the chronological age and developmental level of the individual (Lord et al., 2008).

Coding sheets corresponding to the modules in the ADOS are completed during the administration and overall ratings are assigned and coded after the administration of the test. These ratings are used, in the algorithm, to inform the diagnosis of the individual (Lord et al., 2008).

All four of the modules of the ADOS provide a social-communicative sequence of structured and semi structured interactions which result in the “presses” of the various social behaviours (Lord et al., 2008).

The goal of the ADOS is to provide standard contexts in which social-communicative interaction can occur. The standardization of this test is provided in the level and order of the behaviours exhibited by the examiner in the various situations in each module task, and the types of behaviours considered when assigning overall ratings.

2.2 Understanding Zulu Ancestry under the umbrella of African Culture

2.2.1 Parenting and Socialising of Children

Children are a product of their environment. They are shaped and socialised by what they see, hear and experience, both directly and non-directly. Culture is viewed as a “prime mover” (Jenni & O’Connor, 2005, p.204) in the development of a child and is further argued to be more influential on a child’s development than biology (Jenni & O’Connor, 2005). This is an important statement as it illustrates the importance of culture on the development of children. With regards to children, culture in addition to biology are considered to be the two main influential gateways of human progression and continuity (Jenni & O’Connor, 2005).

Jenni and O'Connor (2005) argue that through the evolution of research in the field of culture and children, the adopted definition of what culture is takes into account more than what the 'developmental niche' refers to, in that a child's behaviour is conditioned and regulated (Jenni & O'Connor, 2005).

The developmental niche, as argued by Super and Harkness (1999) refers to reducing the cultural perspectives of the respective cultures down to the level of the individual child and their experience of their environment (Harkness, Moscardio, Bermudez, Zylicz, Welles-Nystrom, Blom, Parmer, Axia, Palacios & Super, 2006). The developmental niche can be conceptualized into three fundamental components.

Firstly, it takes into account the physical and social settings of the child in their everyday life. This includes taking into consideration the context of their living environment from the physical structure and expanding it to the social context, in terms of who they live with and the influential voices within the particular household (Super & Harkness, 1999). Secondly, the developmental niche is conceptualized in terms of the culturally regulated traditions and child rearing. This refers specifically to the customs within the specific culture and the child-rearing based on the core principals of the customs.

This is an important consideration because child-rearing is said to be based on the principle advocated for most within the specific culture (Super & Harkness, 1999). For example, a child waiting to be offered something by an adult, instead of spontaneously requesting it from the adult. In terms of Brown and Levinson's ideas, if negative face is given high importance then spontaneous requests are only permissible with socially close people (Terkourafi, 2004).

Lastly, the developmental niche can be conceptualized in terms of the psychology of the child-minders. This is an important factor in child rearing as the psychological states of the care-givers directly impact on the manner in which they rear the child and the context of the child-rearing (Super & Harkness, 1999).

According to Jenni and O'Connor (2005), culture is not an individual entity associated with the individual patient who enters the therapy room; but rather, is an encompassing social entity which involves us all in a cross-cultural, interchangeable web (Jenni & O'Connor, 2005).

Culture should not merely be viewed as values, languages, religions, family structure, political and economic structures, healthcare resources and many other social entities, rather, all of these entities should be viewed as particular elements of culture. It is also important to take into consideration that cultures are partial, to an extent, and subjective as they cater for certain human preferences and change or omit others, the basis of these “changes” are a product of the different worldviews associated with the various cultural groups (Jenni & O’Connor, 2005).

This gives rise to the notion of acculturation. By definition, acculturation refers to the natural process of cultural and psychological transformation preceding intercultural interactions (Berry, Phinney, Sam & Vedder, 2005). Urban and rural distinctions are an equally important factor and influence; given that this thesis attempts to draw comparisons between different race groups and subsequent cultures, it is imperative to take into account the notion of acculturation. Although culture has been viewed as a generational preceding entity, it has also evolved and changed through the generations and the subsequent social environment experienced at the time. Although overlooked in many culturally explorative texts, acculturation may stand as an equal contender to the household, in both the changing and sustaining of a particular culture.

Based on their study, it is further argued by Makhmalbaf and Yi-Leun (2007) that the household is a significant influential factor ensuring cultural longevity because it was found that even though children spend a significant amount of their time at external facilities such as day care, schools, family houses, they still recognise their own home as their “permanent space” (Makhmalbaf & Yi-Leun, 2007, p.2), and much of what they may be exposed to outside the home is dependent on the household as to whether it becomes a fixed structure for the child or not.

Politeness and acquiring other social normative behaviour is found to have its roots in the environment most exposed to the child during their developmental years (May, 2001). The same principle was emulated in a study conducted by Hyun (1998) illustrating that the make-believe play behaviours of children were shown to be representative of their ethnic and cultural household practices (Hyun, 1998). A study conducted by May (2001) on the understanding of specific cultural politeness cues by a person outside of the cultural group, showed that the fundamental principle of politeness is to maintain harmony in the interaction and to convey a

sense of positive intentions and regard for the speakers involved in the exchange (May, 2001). This underlying principle is found to be universally applicable to all cultural groups. The difference comes about with regard to the specifics of acting out these intentions during the interaction (Hyun, 1998). May (2001) holds that as a result of the different environmental, social and power structures found in various countries and cultures, each culture and language system has developed specific politeness mechanisms to convey positive regard and respect for the other person and to allow for optimal functioning in that specific society. This highlights an earlier argument pointing out that characteristics such as politeness are not representative of one specific culture, but are emphasised in a multitude of cultures and are merely manifested differently.

These social rules are formed in order to facilitate successful interaction and avoid any conflict (May, 2001). This is important with regard to autistic children, as they are found to be deficient in how they interact socially and as a result, it is argued that one needs to assess deviations from the norm against some understanding of the normal rules of politeness in a particular society/culture.

May (2001) goes on to argue that in order to achieve this assessment, one needs to be mindful of the fact that in decoding these markers of politeness, especially in an exchange between speakers of different cultural backgrounds, the mechanisms of politeness themselves may be compromised by the speaker and accepted or interpreted in a different way by the listener. This may add a misrepresentation of intentions and prove to be invalid in terms of the meaning extracted from the interaction (May, 2001; Tek & Landa, 2012), as is argued to be the case in psychometric test assessments in the South African context. The administrator of the test is further reminded of the importance of being mindful of the cultural behavioural norms when administering and interpreting results from psychological assessments. With particular regard to interpreting results from this study, the sound understanding of the patient's cultural behaviour pattern is an area that should be researched further when trying to assess the applicability of the ADOS, in addition, it is the author's view that this area should have been taken into consideration to a greater degree when conducting this study.

The impact of culture on children, with particular reference to this study, should be fully acknowledged. Research has shown that the cultural background of a child directly impacts on

the detection and decisions around treatment made by the families of autistic children. In their review of literature on how different cultures detect ASD and the subsequent treatment routes they opt for, Mendell and Novak (2005) argue that the meanings parents attribute to the symptoms displayed by their child are culturally derived. This means that symptoms are most commonly interpreted in the context of the cultural background, more so than within a medical psychological context. The parents' associated system of belief which they compare symptom manifestation and subsequent cause to, directly impacts on the prognosis of the child (Mendell & Novak, 2005). This article highlights a limitation to this specific study and others like it in putting forth the fact that culture is commonly associated with race, ethnicity and nationality, which is not always the case. Many generalizations are drawn under those labels when in fact within them, there are a multitude of sub groups and cultures. This applies directly to the South African context, given the array of different cultural systems and psychologists' attempts at making instruments applicable to the various cultural groups.

Based on the review of studies conducted, it is argued by many researchers that due to the impact which cultural differences have on identifying ASD, there is a need to move from traditionally conceptualizing ASD symptoms on a continuum approach to developing a set of behavioural phenotypes for disorders within the ASD spectrum (Mendell & Novak, 2005). It is acknowledged that this cannot be applied across the spectrum in a single move, it is argued that for appropriate disorders within the spectrum, if a phenotype of behaviours could be used, then it would prove to be easier for parents and medical practitioners to identify them, without the impact of cultural symptom interpretation. This would be beneficial for a South African context, given the diversity of cultural systems and general lack of information and awareness of ASD within the community.

That fact that culture is viewed to be an integral factor in interpreting the symptoms of ASD and deciding on the subsequent treatment route, highlights the absolute need for future studies, such as the foundation of this thesis, to be conducted within the South African context specifically.

This is supported by a recent study attempting to examine the impact of culture on the detection of autism. In their study, Ennis-Cole et al. (2013) identified that culture is an influential factor in the primary detection of autism and the subsequent treatment strategies adopted by the parents. Although it is accepted that cultural background influences the speed of detection, it still remains

that early detection and treatment are of prime importance in the successful management of ASD. It is therefore imperative that all cultural groups be aware of the signs and symptoms of this disorder, and associate it with ASD immediately, as opposed to creating cultural justifications for the symptoms (Ennis-Cole et al., 2013). It is argued that, based on this reasoning alone, the need for further research into the degree of the impact which culture has on ASD detection is needed. Minority and lower socio-economic status (SES) groups may interpret lack of communicative and social skills as something that will develop and improve over time and miss the subtle ASD signposts, thereby delaying a proper course of action. This in no way implies that minority and lower SES groups are more prone to having ASD children, but being from one of these groups does, however, impact on the early detection of ASD (Ennis-Cole et al., 2013).

2.2.2 Critiques of measurement by African Psychologists

At the onset it is known that Zulu ancestry children are born and subsequently socialized into a richly traditional environment. Cultural belief systems are embedded into the minds and behaviours of Zulu ancestry children and are not easily overrun. These belief systems are found to be vastly different when compared to those of a Western child (Lassiter, 1999).

Research investigating any of these aspects among others in Africa has been found to be faced with many opposing political assumptions and standards with regards to what is deemed as valid evidence. This had become an on-going struggle in early research of cross-cultural psychology as research methods and test adaptations were not carried out and implemented at that stage; however this soon changed as theorists began to see the need for these Western constructs to be adapted to various cultural needs in order for valid and reliable results to be yielded (van Leeuwen, 1976).

Methodology can be viewed as a significant factor hindering psychology as a discipline in Africa as there is a lack of methods of analysis and scales available to test various constructs within the vast array of African cultures (Abdi, 2007). Psychology in Africa is said to be handicapped by these inadequate theoretical constructs and designs, and a lack of proper, valid and reliable methodological designs (Abdi, 2007). It is based on this critique that African-centred research should be aimed at addressing these methodological gaps and producing well accomplished findings which provide alternate designs.

Contributing to the methodological dilemma is the fact that the extent of cultural diversity is overlooked in Africa. Researchers from the Western world view Africa as a whole and assign “African culture” to the whole of Africa, when in fact within Africa is a host of various cultures and belief systems. This makes it even more difficult to adopt Western scales of measurement as one cannot generalize findings throughout the population because of the diversity. Further to this, African theoretical constructs are not properly defined or understood, and are incongruent with European theoretical constructs, therefore when adopting the same scale, unreliable and invalid results are a definite outcome (Abdi, 2007). Nsamenang (2007) reiterates this point and argues that socially derived behaviours are difficult to compare against different cultures, in addition to a test normalised on a different culture, as they do not operate on the same social mechanisms and cues (Nsameneng, 2007).

This provides an area of conflict because although the diversity of cultures is recognised, so is the need for psychometric tests in order to facilitate early detection and treatment. A compromise is required where a consensus of normative behaviour traits of the most common culturally influenced behaviours are attained and this list of behaviour’s is used in the adaption of Western tests in the South African context, as argued earlier by Mendell and Novak (2005).

Opposite to the individualistic orientation of the Western world, Zulu ancestry society is more centred toward interpersonal relationships and dynamics. *Ubuntu* refers to the interconnectedness between one’s environment and oneself, spanning from the physical people to nature and the supernatural realm. *Ubuntu* is taught to advocate and represent humaneness, compassion, care, respect and empathy, and is viewed to be central to African psychology (Schuster, 2005). The notion of *Ubuntu* is important in relation to the ADOS and ASD detection as it is centred on the social aspect of daily living and social engagement of one’s surroundings, as opposed to individual functioning. This social aspect is tested for in the ADOS and viewed to be a tell-tale sign of ASD.

As discussed in Schuster (2005), the concept of *Ubuntu* in Zulu ancestry culture has often been compared to the personal centred approach by Carl Rogers; this comparison is drawn as *Ubuntu* is referred to as a function of being, and this was viewed as a similar goal of Rogers’, however the execution and implementation of his principle became centred around and remained restricted to the professional area (Schuster, 2005).

The two main problematic factors are, firstly, “indigenization and integration” (Nsamenang, 2007, p.23). This is still limited significantly to the level of academia and the fact that further research is needed in program development in this area, as the knowledge generated has not been translated into practise and execution of the principles generated have been shown not to have adequate practice modalities (Nsamenang, 2007).

The second problematic factor is the fact that the indigenous psychology of Africa is undeveloped, unformed and non-programmatic. It can be viewed as being in the conceptual stage of development, as the ideology, conceptual models and procedural modes of developments which are supposedly sensitive to South African cultural needs are not yet available for use and execution (Nsamenang, 2007).

2.2.2.1 The African Context of Child-Rearing

As with all cultures, the importance of respect, especially toward elders is stressed in the Zulu culture. Communication as a basic example is viewed to be undertaken with great caution, children are viewed as subdued and minimal in their communication style when interacting with adults (Chandler, A’Vant & Graves, 2008). In Brown and Levinson’s (1987) ideas, the negative face is given high importance so that people in authority must be respected and actions that could threaten negative face, such as asking questions, must be avoided or mitigated (Terkourafi, 2004). The elders in the Zulu culture are held in high regard in the family and it is the child’s duty to serve and adhere to the guidelines set by them (Holdstock, 2000).

Holdstock (2000) identified many principles on which African child-rearing is based. The main premise is that nothing exists in isolation, this has direct reference to the previously discussed notion of *Ubuntu* where the child is not only taken care of by his/her parents but by the whole family and community. Life is considered as sacred and a community of souls which is not limited to the physical world, it is cyclical and the actions carried out on earth directly impact on the quality of life one has after death. Children are brought up in this context and are made aware of the consequences of their actions. This is related to the reason why adults are revered as much as they are, because children are taught that blessings from the elders and pleasing Ancestors (who are relatives who have passed away) will result in a successful life on earth and in the afterlife (Holdstock, 2000). In addition, the style of interaction could make a child appear autistic even though the child is not, if the person conducting the psychometric test did not realise that

the child's interaction arises from very different rules. In this context, the child is brought up in a social environment so it is assumed that social deficits would be more easily noticed, however within the same environment, they are also brought up to be submissive and not as vocal with elders, therefore making an underdeveloped communicative ability difficult to detect, especially when it is encouraged in some cases (Ennis-Cole et al., 2013).

Children are raised with the importance of respect ingrained in them from birth and grow up with this conditioning which impacts on the way they interact and develop socially, emotionally and physically (Holdstock, 2000). According to Brown and Levinson's (1987) theory of politeness, all people have two kinds of faces that they want acknowledged by others in social interaction. With respect to strangers or non-family members people have negative face – their claim to be respected, to have their goods and actions respected, and to be able to do what they want without interference from others. People with little power often do not have their negative face respected (Terkourafi, 2004). On the other hand all people have a desire (face) to be acknowledged as part of a group, as belonging, as loved and valued for themselves. This is positive face and in most cultures positive face is mainly of importance with family and with friends. Some cultures (e.g., American) tend to stress positive face and positive politeness (even though American's still have negative face). However, Zulus, the Japanese and traditional European societies placed much more emphasis on negative face (even though these people still have positive face needs) (Terkourafi, 2004).

Western parenting ideas, including attachment theory, have received much criticism with regard to their Eurocentric bias and proposed lack of cross-cultural applicability (Mkhize, 2004). The attachment theory is based on the appropriateness and promptness of the parent's response to the proximity and contact in seeking the signals given by the child. It primarily focuses on the mother as the primary caregiver (Morton & Browne, 1998). This may not be the case in traditional South African households, as in most instances the grandmother or elder member of the family may take on the parenting roles; it is not limited to the maternal and paternal parent. In addition, different family and community members may tend to the child at different intervals and therefore the attachment which the child develops is not limited to the mother only (Bozalek, 1997).

It has been argued that ideas of parenting and childhood are social constructs which cannot be divorced from the historical period, culture, class and ethnicity within which they emerged (Holdstock, 2000). Attachment theory, for example, developed in the post-World War Two context in which traditional family roles were greatly esteemed, largely in response to the family ruptures that had occurred during the war (Bozalek, 1997). Therefore, based upon the specific contexts in which parenting theories emerged, it cannot be assumed that they apply on a universal level. One of the main criticisms of attachment theory in relation to its applicability in the South African context is the fact that the attachment theory was also based on the nuclear family, whereas the African family is more communal in nature (Bozalek, 1997).

The development process through child rearing and the journey of self-definition is thought to connect the individual's sense of personal identity to a sense of community (Nsamenang, 2007). Within the context of child rearing, the child is viewed to individuate by being interconnected to others in the community and environment, both living and dead, human and nature.

Nsamenang (2007) concludes on this point by arguing that collectivism research has focused on the basic communitarian values, and limited their reporting on the basic communitarian values advocated for and used in child rearing (Nsamenang, 2007).

Traditional South African teachings acknowledge all humanity and great reverence is placed on the spirituality of all human beings, both living and dead (Nsamenang, 2007). Children are taught to respect people who are living and to respect the spirits of those who have died. Protective qualities are assigned to those who have passed on and children are taught to follow the right conduct set by cultural norms and ideology, in order to receive the protection of those who have passed, and for their blessing to ensure success in life (Nsamenang, 2007).

Based on the fact that African, and specific to this context, Zulu ancestry children are exposed to the presence of unseen entities from an early age, it implies that they already have a solid foundation in the conceptualization of abstractions and imaginative play (Nsamenang, 2007). This links directly to the ADOS which has specific activities designed to elicit any indication of ability to understand objects symbolically, in addition to literally, as well as to gain an understanding of the imaginative capacity of the child through play.

2.2.3 Socialising of African Children

Thus far, the argument has referred to the “child” in a general sense as in most Western cultures; gender differences do not play as significant a role as they do in African cultures. Shiraeev and Levy (2010) mention in their article that parents do in fact assign children to particular roles and prohibit them from others, the criteria of assignment to the respective roles are found to be based on cultural influence and dictations about what is deemed appropriate behaviour for the respective genders (Shiraeev & Levy, 2010).

Shiraeev and Levy (2010) hold that in more traditionally cultured societies, girls are often kept closer to home and are involved in more household and childcare activities as this is the culturally promoted role of a female (Whiting & Edwards, 1988, in Shiraeev & Levy, 2010). On the other hand, boys are permitted to be outdoors, with the men and involved in less limited activities when compared to girls, as the various traditional cultures promote the quintessential strong and manly role for males (Shiraeev & Levy, 2010).

This illustrates the impact both biology and culture have on children, as the gender of the child dictates the manner in which they are treated and the basis or reasoning behind this treatment is all culturally derived. One could go further to say that biology has laid the groundwork for cultural practices and norms to further reinforce gender inequality in society (Shiraeev & Levy, 2010).

As mentioned, Shiraeev and Levy (2010) reiterate the point that in predominantly collectivist cultures, parents practice more authoritarian parenting styles as therefore children are exposed to that environment more than in the parenting style of individualistic cultures. A consequence of this style of parenting may result in the child hesitating or completely disengaging in a reciprocal interaction with an adult, in addition, the child may refrain from asking questions or engaging in spontaneously getting the attention of an adult. In the context of the ADOS administration, this may prove to hinder the child’s scoring. The livelihood of culture is dependent on its principles being passed down from one generation to the next, so the very essences of its principles have become the norms of that culture and, according to Shiraeev and Levy (2010), once a norm has been established, it is then able to be passed down from generation to generation (Shiraeev & Levy, 2010).

Culture is found to work in conjunction with external environmental and social factors as well; studies have shown cross-cultural differences between pretend play in children with results showing that pretend play is more developed in children from higher socio-economic conditions when compared to children from lower socio-economic levels (Shiraeve & Levy, 2010). The socio-economic background of the child was found to directly impact on the degree of social interaction exhibited by the child, as children of higher socio-economic backgrounds were found to have higher levels of creativity and imagination in their play, as opposed to the very practical themes found in the play of children from lower socio-economic backgrounds (Shiraeve & Levy, 2010).

Although cultural differences are vast among communities and societies, cultural psychologists must also take note not to discount the fact that people are all intrinsically humanly natured and have similar tendencies at the core of their humanness.

Studies conducted have shown that culture cannot be viewed as a separate entity from other environmental factors, but rather as a factor amongst other environmental factors all working together to help shape a child and prepare them with the necessary tools specific to their environment in order for them to survive and live effectively, but also commonly enough for them to still be able to interact with peers and members of differing social and cultural backgrounds.

2.2.3.1 Cross-Cultural Perspectives on Parenting and Child Behaviour

The body of knowledge acquired and research conducted in the area of parenting has been predominantly gathered from Western countries, as many of the theories and foundational principles of the field of psychology have been passed down from Western cultures' founding fathers. It is only in recent years that the research in the area of parenting is becoming more culturally and ethnically diverse. The recent investigations into other cultures and their parenting practices have led to an otherwise unknown awareness of underlying belief systems of other cultural groups (Chaudhuri, 2006).

Parental intrusiveness, or the amount of parental control exercised on the child during parenting, is one of the main factors or attributes of parenting that is found to be culturally specific and this

area is where significant differences can be seen with regard to various parenting practices and cultural beliefs (Chaudhuri, 2006).

A further aspect of parenting practices that appear to differ among cultures is known as “parental warmth” (Chaudhuri, 2006, p.14). Cultural contexts have been shown to control the norms and degrees of parental warmth shown during parenting, as communities place different levels of emphasis on physical affection or non-verbal affection and praise. In communities where the emphasis of parenting is placed on prioritizing the care and education of children instead of the physical and emotional demonstration of affection, parental warmth is viewed to be demonstrated by providing education and taking care of the child (Chao, 2000, in Chaudhuri, 2006). In other communities, physical gestures of appraisal and emotional demonstrativeness are valued and the parents in those communities are found to exercise parenting styles accordingly (Chao, 2000, in Chaudhuri, 2006).

As mentioned earlier, cultural practices arose from a specific environment in an effort to ensure survival of the next generation; in other words, to ensure that effective socialization is achieved. According to Chaudhuri (2006), parent’s socialization goals are comprised of their cultural beliefs, attitudes toward parenting and their expectations for their child.

“Socialization goals and cultural ideology” (Chaudhuri, 2006, p.16) have been shown to differ most among cultures on the concept of interdependence and independence. It is these two constructs which prove to be useful in understanding why various communities and cultures differ in their socialization goals. The construct of interdependence or collectivism is defined by the emphasis placed on the interconnectedness between all individuals in the community, while independence, or individualism is defined by the emphasis placed on the individual autonomous being and self-actualization. Chaudhuri (2006) argues that these factors guide parenting perspectives and practices in mainstream Western cultures (Chaudhuri, 2006).

Building on Chaudhuri (2006), Lamm and Keller (2007) view these socialization goals to consist of two main components which includes firstly, individual agency with two poles of autonomy and heteronomy, and secondly interpersonal distance with the two poles of relatedness and

separateness (Lamm & Keller, 2007). It must be noted that ASD children cannot be expected to attain these outcomes.

In their article are three main parenting cultural models which are based on the two main components of agency and interpersonal development. Firstly is the model of independence, which is characterised by emotional autonomy and economic independence (Lamm & Keller, 2007). In this model, the child or individual is considered and viewed as separate from others and defined by their individual quality and traits, as opposed to being defined by a collective trait or quality. In this model, self-confidence and competitiveness are viewed as vital socialization goals and are seen as essential in order to attain social and economic success. This model is shown to be more readily and commonly adopted in Western industrialized and post-industrialized societies, and more specifically suited to urban, educated families (Lamm & Keller, 2007).

Lamm and Keller (2007) go on to discuss the next model which is identified with emotional relatedness and economic interdependence. This model is known as the “cultural model of interdependence” which illustrates that the individual is primarily regarded as part of a group within the family and not as an individual agent. This model is found to be more prevalent in traditional rural subsistence-based communities. Although this point suggests equality and in the above mentioned literature inequality is stressed with regards to the notion of respect - it is important to acknowledge that within the vast number of African cultures, there is a degree of equivocation inherent, as all African cultures themselves are not equal societies in relation to each other (Lamm & Keller, 2007).

The final model mentioned in Lamm and Keller (2007) is known as the “model of autonomous relatedness”, this model combines aspects from both the model of independence and the model of interdependence. In this model, emotional interdependence is viewed to be used in combination with economic independence (Lamm & Keller, 2007). The socialization aims in this model focus on the development of autonomy as well as integrating lower level family structures into higher levels. The model of autonomous relatedness is found to be adopted largely by urban, educated middle-class families who belong to communities with an interrelated cultural heritage (Lamm & Keller, 2007).

As researchers, it is important to note the varying degrees of parenting strategies within specific cultural groups. This directly impacts on the manner in which parents interpret their child's presentation of ASD. This further advocates for future research into the mechanics of parenting in different cultures as to inform the detection and treatment interventions needed for the management of autism and ASD.

Lamm and Keller (2007) argue that in terms of parenting practices and the influence of culture; culture is viewed as a uniformed and single entity, and little or no light is shed on intercultural variation in parenting practices. The parenting model adopted is shown to depend largely on the socio-economic status of the parent, both economically and educationally (Lamm & Keller, 2007).

Building on the example of respect mentioned above, respect for elders is promoted so diligently by parents to their child as the culture holds that by having respect the Ancestors will reward the child with success in life (Kotchick & Forehand, 2002). It can be ascertained that from this, in the testing environment children will treat the adult with respect and this respect will be exhibited in the form of less eye contact, lack of asking, lack of spontaneity and reciprocal social interaction, for example. These behaviours have the potential to cause the child to score lower in the ADOS and receive an inaccurate diagnosis.

Parenting styles, according to Kotchick and Forehand (2002), are determined by the availability of resources in the immediate environment which can be used to facilitate the development of the various attributes valued by the culture. They are based on the many cultural myths and legends which dictate customary parenting practises which are viewed to be successful in producing culturally and socially satisfactory child behaviour (Ogbu, 1981, in Kotchick & Forehand, 2002).

Socio-economic status is also a contributing factor to parenting and has always been one of the influential factors in parenting styles (Kotchick & Forehand, 2002). According to Kotchick and Forehand (2002), poverty has been identified as having a significant influence on the parenting styles of parents and the children's behaviour (Kotchick & Forehand, 2002). Parents are preoccupied with the financial functioning and survival of the family, leading parenting demands to move to a lower priority because tasks such as feeding and providing shelter for one's family take precedence (Kotchick & Forehand, 2002). The financial strain negatively impacts on the

mental wellbeing of the parent and that directly impacts on the manner in which the parents interact with their child. This, in turn, impacts on the child's interactional behaviour. They are found to be reserved and may not be as socially developed as children from higher socio-economic backgrounds (Kotchick & Forehand, 2002).

Moving beyond the immediate effects of poverty on parenting, economic classes have been shown to have different parenting styles within themselves. Among middle class families, the parenting styles have been found to be more democratic and accepting, while lower class families tend to be more concerned with advocating obedience and conformity (Kotchick & Forehand, 2002). The rationale behind this is that lower socio-economic class families foster obedience and conformity in an effort to ensure protection of their children from the possible dangers in their environment (Kotchick & Forehand, 2002). In other words, if this does affect style of social interaction, there is another variable besides culture that may play a role in the behaviour witnessed in this study – namely socio-economic status.

2.2.3.2 Cross-Cultural Parenting Models

Parenting in itself is a complex process and adding cross-cultural influences to it further magnifies the complexities within parenting models and styles.

According to Shiraeve and Levy (2010), parents are found to typically have their own developmental expectancies of their children at different developmental stages where they are expected to portray specific characteristics such as walking, talking, and reasoning, and centre their parenting around achieving these developmental milestones (Shiraeve & Levy, 2010).

Arguably one of the most used accounts of parenting styles for the last twenty five years is based on the account of Baumrind (Darling & Steinberg, 1993). Baumrind has produced a concise and consistent description of parenting in the effort of effective socialization of children. She holds that the authoritarian model associated with parental attributes fostering and giving “emotional support, high standards, appropriate autonomy granting and clear bio directional communication” (Darling & Steinberg, 1993, p.487) has been shown to give children the competency in balancing both individual and societal needs and responsibilities. This view is based on socialization in mainstream America (Darling & Steinberg, 1993). However, this is found to be flawed, not only because it was founded on such a specific sample but because

adoption of the authoritative style has been shown to yield different outcomes in culturally different groups (Darling & Steinberg, 1993). For example, authoritarian type parenting which was used in European American families resulted in timid, fearful girls whereas when used in African American families, was associated with assertiveness in girls. The variation in results is not accounted for or explained by the parenting model (Darling & Steinberg, 1993).

Although there has been much written in theory about certain parenting models being used in certain cultures and the extent to which various parenting styles may impact on child development, there is limited empirical evidence to support such claims or to test the alternate hypothesis on which the same parenting styles may differently effect the child's development. An obvious example of this predicament is the consequence of researchers' lack of understanding about the authoritativeness model and the impact which ethnic and cultural factors have on it in child development (Darling & Steinberg, 1993).

Hamilton (2012, p.68) holds that parenting models must be looked at in the context of the family in which they are carried out. "Competent families" are more urban families who are not exposed to high community violence occurrences and who experience low maternal distress with moderate to high levels of warmth and control dimensions to parenting. The second type is referred to as "struggling families", who are commonly from lower socio-economic areas and who are exposed high levels of community violence, and who also showed high levels of maternal distress, with lower levels of functioning throughout parenting practises (Hamilton, 2012, p.68).

"Competent" and "struggling" families have shown to adopt mostly authoritative and authoritarian parenting models and styles, respectively. "Competent" parents are shown to adopt the authoritative model with regards to high levels of parental warmth and low levels of punitive discipline, although they are viewed to move away from the authoritative model by encouraging independence and moderate use of inductive reasoning (Hamilton, 2012). "Struggling" parents, on the other hand, showcase low levels of parental warmth, indirect control practises, low levels of parental hostility and low levels of severe discipline (Hamilton, 2012).

These differences in parenting styles have been found across both cultural groups as well as differing socio-economic groups (Chaudhuri, 2006), showing that the type of parenting models adopted depend on the socio-economic level of the parent as well as the cultural background of the parent.

According to Chaudhuri (2006), class differences in parenting models adopted for child rearing are connected to the socialization goals of the parent for their child. Parents who belong to and come from a long line of professionals encourage qualities and behaviors such as reasoning, negotiation, autonomy, and skills, which are associated with success in the professional business world (Chaudhuri, 2006).

As past research has shown, there are undeniable links between race, ethnicity and income, and in some instances minority cultural background has been shown to overlap with these. This must be taken into consideration when trying to understand and evaluate parenting models, beliefs and practices between diverse populations. With regards to the present study, the above mentioned factors are of prime importance when drawing conclusions from the results presented. One must view all outcomes in light of the various confounding variables that may have impacted on the end result, as to view these purely as they stand would be the height of ignorance.

2.3 The importance of Mental State Examinations and Culture Fair Testing

In any form of assessment, it is accepted that a Mental State Exam is a part of the process and is done routinely at the beginning of the assessment process. Ouvrier, Goldsmith, Ouvrier and Williams (1993) found that there is limited information about and options for mental state examinations in children and started a pilot study on the use of the Mini Mental State Exam in the paediatric division. The results indicate that although there is a long training process required for the administrator to undergo, the MMSE can be used on children with learning difficulties from the age of four years and upwards (Ouvrier et al., 1993).

In the South African context, problems arise in that that much of the literature is based on research done in the Western world and the norms generated from these are based on Western ideology and constructions of childhood. Although in recent years much literature has been

generated on the testing process in South Africa, such literature remains limited with regards to taking into account the diversity of African culture and ideology. The tests are merely directly adapted and this negatively affects the validity and reliability of the tests within the South African context in which a different process of parenting and childcare may occur (Foxcroft & Roodt, 2009).

Foxcroft and Roodt (2009) hold that tests must be adapted to ensure culture fairness and to be culturally sensitive. There is no doubt that, in general, both the validity and reliability of a psychometric test will decrease when a person is not tested in their home language, but in either the second or third language of the person (Foxcroft & Roodt, 2009). It is further argued that the results generated should be viewed in the context of the environment and not primarily on the test score sheet itself. There are three main contexts in which assessment result must be viewed (Foxcroft & Roodt, 2009).

Firstly, the biological context; chronological age is by far the most obvious factor according to Foxcroft and Roodt (2009), due to the subsequent developmental factors associated with each chronological level, physical impairments should also be taken into consideration as they directly impact test performance. Screening for impairments such as hearing, history of stroke or narcoleptics must also be taken into account when reviewing and administering tests. In addition, disabilities need to be taken into consideration when adapting tests, for example, if a child is hearing impaired, the necessary precautions need to be adapted to the test in order to conclude with valid and reliable scores (Foxcroft & Roodt, 2009).

The social context also needs to be taken into consideration when adapting tests and reviewing scores. Foxcroft and Roodt (2009) mention schooling, language and environmental factors, and emphasise the importance of culture. According to Foxcroft and Roodt (2009) culture is an integral part of a person's behaviour and directly influences how they respond to certain situations (Foxcroft & Roodt, 2009). Therefore, as a result of cultural orientation, the child may not make any spontaneous disclosures with the person administering the test and if the tester does not take into consideration the cultural significance of this behaviour they may assign an inaccurate score.

Foxcroft and Roodt (2009) also argue that intrapsychic contexts need to be taken into consideration in addition to biological factors, as one cannot separate people's feelings and experiences about themselves from their test scores; the reason why the factor of reflexivity will be included in this research.

Foxcroft, Paterson, le Roux and Herbst (2004) argue that a disadvantage in psychological testing in South Africa lies with regards to the fact that comprehensive studies on the test-use patterns and needs of the various psychological assessments have never been done in South Africa. As a result, it has proven difficult to establish an effective framework regarding development, adaptation and the updating of psychological tests in an effort to adapt and make changes to tests and to ensure the test remains reliable and valid (Foxcroft et al., 2004).

Although tests are designed to be used on a certain population, chosen on the assumption that they display common symptoms associated with the disorder the test is trying to measure, it is advantageous to take into account the fact that value is added to the test when it is used in a culture fair and ethically sound manner (Foxcroft et al., 2004). The need for culture fair testing arises from both the absolute need and appeal for the practitioner to use fair and ethical practices, and from a legislative point of view where policies and laws instruct specific rules and regulations, and standards of use regarding psychological test-taking and administering (Foxcroft et al., 2004).

In their study, Foxcroft et al. (2004) found that due to the fact that many psychological tests cannot be used across cultures, practitioners were moving away from using only tests in assessments and were trying to incorporate other methods of assessment which were more culturally apt, such as play therapy or drawing. Although psychological tests still form the foundation of the assessments, adding other means of assessments in addition proved to be beneficial (Foxcroft et al., 2004).

In order to ensure culture fair testing, practitioners are required or are encouraged to administer the test in the language of the patient/client/participant (Foxcroft et al., 2004). Although this sounds like a reasonable requirement, it may prove to be idealistic in a context such as South Africa, due to the diversity of home languages. In addition, many, if not the majority, of the psychologists trained in South Africa are fluent only in their home language and a second

language; it would be most unlikely to have a large group of psychologists fluent in all eleven official languages. Practitioners interviewed acknowledged as well that they often face difficulty in deciding which language is best to assess the client in (Foxcroft et al., 2004).

The promotion of culture fair testing is not limited to African contexts, international literature confirms the point that cultural and linguistic differences hinder the cross cultural use of psychological tests. When tests are taken from one cultural context and imported to another cultural context, all persons involved should pay attention to the quality of translations, the ability of the translator, linguistic equivalence, length of items, inappropriate items, cultural equivalence, psychometric equivalence, procedural and normative equivalence, and lastly, the cross cultural validity of the adapted measures and constructs (Sue & Chang, 2003, in Foxcroft et al., 2004).

Given the multicultural and multilingual context of South Africa, equivalence, rigorous and bias tests are required to be conducted in order to decide which test can be used on which population group and yield significant, valid and reliable results (Foxcroft et al., 2004). The theory behind and in favour of culture fair testing provides guidelines which should be followed during psychological assessments.

In addition to what has been mentioned above, the concern of test bias is also of prime importance in the usage of psychometric tests. According to Reynolds and Suzuki (2012), the complications of using a psychometric test for either diagnostic or standardization reasons on a minority population is becoming increasingly problematic among clinicians and clients in the field. Some of the concerns surrounding test bias are with regard to clinicians over diagnosing clients, misdiagnosing clients and, in the long term, unfairly disadvantaging clients due to bias in the construction and standardization of the test. Van de Vijver and Tanzer (2004, in Reynolds & Suzuki, 2012) argue that there are three main categories of test bias to be aware of when administering a psychometric test on minority populations such as Hispanic, Black, Indian and Asian Americans. This racial distinction proves to be applicable to the ADOS in the context of this research.

Firstly is the issue of construct bias, which refers to the overlapping or ambiguity of the construct being measured across cultures. The construct may take on one meaning in a White household

but take on a different meaning in a Black African household. The notion of appropriateness is also intertwined in this overlap and, as a result, has the potential to cause a degree of offensiveness to the cultural group being tested (Van de Vijver & Tanzer, 2004, in Reynolds & Suzuki, 2012). In the context of the present study, the issue of construct bias is relevant with regards to the way in which behaviours are assessed; many of the behavioural requirements to perform well are viewed as taboo in Zulu culture - such as the uninhibited interaction with an adult as opposed to the submissive conduct taught in the culture. In addition, inadequate sampling of specific behaviours when operationalizing may result in construct bias (Van de Vijver & Tanzer, 2004, in Reynolds & Suzuki, 2012).

Secondly, is the concern of method bias, which refers to the inadequately matched sample on which the test is based. The instrument itself containing items which the administrators themselves are not familiar with and lastly, the test not being properly administered by the administrator (Van de Vijver & Tanzer, 2004, in Reynolds & Suzuki, 2012). Given that the present research was undertaken by a first time/ novice ADOS administrator, the issue of method bias with regard to the instrument and the administration is highly probable. Although the scores generated were agreed upon by a panel consensus and the administration process was supervised by a trained clinician, this does not deem the notion of method bias improbable.

Lastly, is the issue of item bias, this refers to the inadequate and inaccurate translation of items in the test, which impacts directly on the manner in which clients respond to the item. Due to poor translation, back translation and substitution of words, there is a danger of what the item is meant to be measuring getting lost, as well as the client being unsure as to what is required of them as they are being presented with something that they cannot relate to (Van de Vijver & Tanzer, 2004, in Reynolds & Suzuki, 2012). In the context of the present research where a Western construct is being administered in a South African cultural context, accurate translation is key in attaining valid and reliable results. Given that the proper translation procedures were not followed according to ADOS manual guidelines, it is probable that due to low familiarity of constructs within the test and the administrator, meanings may have been lost through translation. This directly impacts on the correlation between what the task intended to test for, what was actually tested and what the scores generated actually represent.

2.4 Summary

There is relatively little research pertaining to African children's behaviour during psychological assessments and to their response to the ADOS. This research aims to provide a clearer understanding and offer insight into the importance of understanding cultural backgrounds and acknowledging the impact they have on ASD detection and subsequent courses of treatment. This research also aims to argue for the need for such research and to highlight key areas of concern which require further investigation, as well as to point out possible problematic areas to be aware of and account for in future research.

Chapter 3

Methodology

The present is considered a preliminary attempt at laying the groundwork for further studies on assessing how Zulu ancestry children respond to the ADOS. The study systematically observed and describes how a sample of Black South African children behaved in terms of ADOS defined criteria relating to Communication; Reciprocal Social Interaction; Play; and Restricted Behaviours and Stereotyped Interests.

The cultural adaptation of tests to meet the needs of specific contexts and population groups has been a focus of much empirical work. For example, Foxcroft and Roodt (2009) have written extensively about issues related to cultural sensitivity and cultural fairness, in order to ensure that there is an element of cultural sensitivity throughout the testing process, so as to ensure the testing is ethically carried out (Foxcroft & Roodt, 2009).

According to the San Diego Prevention Research Area, when testing and adapting measures the “shared norms” (*Guidelines for culturally appropriate measures*, 2012) or most socially desired behaviour expected and the collectively shared beliefs and values of the community or target population must be taken into consideration. It is also considered important to take into account the linguistic manner and appropriateness of the test and if this correlates additionally with the reading and comprehension level of the community (*Guidelines for culturally appropriate measures*, 2012).

Furthermore, cultural adaptations of tests require a rigorous process of translation and adaptation, the main goal is reaching equivalence in the adaptation process. Conceptual equivalence is of great importance as the researcher must ascertain if the terms and concepts used in the test have the same meaning in the community in which the test will be carried out on (*Guidelines for culturally appropriate measures*, 2012). It must be noted that this process was not accurately followed; it must be acknowledged that the translations used may have inadvertently changed the meanings of the constructs used and could possibly result in inaccurate score representation.

Linguistic equivalence is essential for validity as the words used are required to have the same meanings to the community, therefore when translating and adapting tests, researchers must make sure that the items in the test have the same meanings to the community (*Guidelines for*

culturally appropriate measures, 2012). In addition to linguistic equivalence, which refers to words, metric equivalence pertaining to numbers is also important (*Guidelines for culturally appropriate measures*, 2012).

The concern that motivated the present study has a very specific focus: Are Black African children more likely to receive elevated (in which the higher the score, the more pathology is noted) scores on the Communication and Reciprocal Social Interaction categories of the ADOS, based on cultural values and the processes through which they are socialised? Should cultural factors elevate these scores, placing them at risk of receiving false positive diagnoses of ASD? The present study is thus proposing to set the groundwork for future studies of its kind by showcasing key areas of concerns in such research in an effort to inform future studies premised on the question of whether or not Black African children behave socially and communicate according to different normative patterns when compared with their Indian and White counterparts and if they do, whether this makes a difference to the diagnosis provided by the ADOS test.

The present study is based on careful observations of children on whom the ADOS was administered. Video recordings of the ADOS testing as the process took place were then coded according to specific behaviour patterns listed in the ADOS. The sample consisted of children from Black African, Indian and White race groups matched primarily on age from a sample of children from special needs schools in KwaZulu-Natal.

3.1 Aim and Rationale

The main aim and purpose of the present research was to provide a preliminary attempt in creating a framework for future studies which aim to attempt to test the assumption that Autism Spectrum Disorders have universally occurring behavioural indices, irrespective of cultural background.

Since ASD are considered to be a form of neurodevelopmental disorders occurring across all cultures, there is an assumption that it is possible to translate the ADOS to make systematic observations to assist in diagnosing ASD in all population groups. The main aim of this research

was to provide a foundation for better equipped methodologically designed studies to explore this area.

The ADOS provides operational definitions for each dimension of the coding schedule; with some of these being summated on the algorithm to arrive at the ASD or autism cut-offs. Despite this attempt at objectivity and the elimination of observer bias, clinical judgement is required in many instances, based on the clinician's judgement about the child's abilities in relation to the normative population. There is frequently a clause in the coding process that allows for a normative judgement to be made; for example, in the coding system for Module 2, on the Language and Communication scale, item B1 describes conversation. This item refers to the ability of the child to hold a verbal back-and-forth basic level conversation with the caregiver or examiner; but the elements in this item differ with regard to various children. Some may have vocalizations with a severely limited range of facial expression, gaze and gesture throughout the assessment, however they do respond, whereas other children may have vocalizations with limited eye contact, gaze and facial expression. This may occur only in the early stages of the assessment due to shyness or apprehensiveness toward the foreign environment. However, these are not the conventional conversational gestures which were portrayed in the training videos of the ADOS, this is possibly contradicted later in the scoring schedule when it states, for example, that four elements are required for a child to score on the normal/typically developing code: i.e. "examiner opens, child comments, examiner responds and child responds to response" (Lord et al., 2008, p.7 of Module 2 coding schedule).

While the ADOS includes interesting tasks that evoke ASD-related behaviours, based on past literature, it is suspected that the underlying constructs may not be relevant to South African children in the same way as they apply to Western children. The present research aimed to provide insight into the problems with and areas in need of further revisions when attempting to test these assumptions in the South African context. In particular, this study focused on the patterns of Communication; Reciprocal Social Interaction; Play; and Stereotyped Behaviours and Restricted Interests, as described in the ADOS.

The objective of the present study was to serve as an initial investigation into the presence of culturally derived behaviours and mannerisms, as to inform future studies aimed at assessing the applicability of the ADOS in South Africa, with particular regard to Zulu ancestry children

currently residing in KwaZulu-Natal. The present study expected to find data which contributes to the collaboration of ideas and experience in an attempt to design a robust study aimed at determining the applicability of the ADOS in South Africa. Given that the main aim was to provide feedback for future studies in terms of cultural applicability and the comparisons drawn were between the races of Black African, Indian and White children, reference to typical and atypical development was not considered as a category of comparison. Thus, the aim of this research is to provide introductory information on the behaviour of Black African children compared to Indian and White children during assessment. The reasoning behind this was with the rationale of using this particular study as a pilot test in order to highlight key areas of concern, problematic areas in conducting such a project and possible recommendations to combat these. The reason for doing this was done with the broader aim of informing future studies aimed at assessing the applicability of the ADOS within the South African context. It must be emphasised that the current study, with the particular flaws identified, in no way aims to draw conclusions regarding the standardization and applicability of the ADOS in the South African context.

In summary, the main aim of this research was to:

- Investigate the possible issues that may arise when future studies attempt to validate the ADOS; and
- Outline the problematic areas, in terms of sampling, language, administration and logistics that arise when conducting such research and providing possible recommendations to address these.

The rationale behind this was for providing a source of groundwork information to inform future studies aimed at assessing or investigating the applicability of the ADOS within the South African context.

It is suggested that the present study will address these aims through critically analysing the sampling frame and providing a critical account of how the sample was reached. Secondly, by addressing the manner of administration and subsequent results - these will be critically discussed as opposed to drawing absolute conclusions. Lastly, the overall shortfalls of this design will be presented with suggested recommendations. The present study is aimed at providing

insight into the downfalls of the particular research in an effort to help strengthen future studies in this area as the topic of concern is of importance in the South African context.

The categories of behaviour used to compare differences between Black African, Indian and White children are:

- a) Language and Communication
- b) Reciprocal Social Interaction
- c) Play
- d) Stereotyped Behaviours and Restricted Interests

3.2 Sampling

The sample used in this study was already collected and made available to the researcher. It is known that during collection, purposive sampling was used due to logistical, time, and monetary constraints and was deemed to be successful in accommodating such limitations without hindering the integrity and quality of data collected (Durrheim & Painter, 2006). Typically and atypically developing children were included in the sample as a by-product of using children in special needs schools, however, the status of their typical and atypical development was not used as a factor in the comparisons made. The race groups used were Black African, Indian and White. Children included in this study fulfilled the following sampling criteria:

- Either of African ancestry: most children were from the isiZulu ethnic group, although some had one Xhosa or Sotho parent.
- Or of Indian or White ancestry
- The total number of subjects used in this study was 68, which comprised of 39 Black African ancestry children, 16 Indian ancestry children and 13 White children. Due to the lack of control in accessing the data used it is clear that the Black African children category is free of doubt with regards to violations of assumptions due to the large sample size, however the other race groups are in danger. This further highlights the fact that results should be interpreted with caution.
- Aged between 6 and 11 years, and of both genders although the majority were male. The mean age was 9 years old across the sample.

- Parent or primary caregiver gave informed written consent for the child to participate and to be video recorded. Collecting photographic data can be more daunting than written data and so this was made explicit in the consent forms as well as to the children before the video camera was switched on. Child assent was obtained verbally by the administrator.

Table 1: Summary of Sample Subgroups and Sizes

Race Group	Sample Size
Black African	39
Indian	16
White	13

Before outlining where the samples which were used were accessed from, it must be noted that since this research is a basic preliminary attempt at piloting an exploration study, the screening methods used were of utmost simplicity and can be regarded as basic screening methods. Samples were merely distinguished by race and recruited based on the fact that they were in special schooling institutions. This research will go on to mention the subgroups used and then provide a critical account of the implications of using such groups.

3.2.1 African Ancestry Children

This sub-sample was identified from the current database of the Asenze Research Site in the Valley of a Thousand Hills, a rural area of KwaZulu-Natal. This database was developed during a longitudinal study that has tracked children since their birth. The Principal Investigators for the Asenze study gave permission to use the database (see Appendix 1), to identify children who were considered to be developing without difficulty. A variety of assessment procedures had been used on this sample and their parents. Importantly, the children were identified as following a typical developmental pathway after having been physically examined and screened by a medical doctor. The nature of difficulties that could have been identified in this medical screening included various physiological problems at birth or during early development, (including visual or hearing impairments and the presence of various neurological problems, malnutrition and deaths of close relatives).

The African ancestry children who participated in the present study were not previously assessed for psychological disorders. All of these children lived in a rural area which was more traditional in their ways and customs and was still overseen by traditional leaders: an *inkosi* and *induna*. It was thus considered that these children were more likely to be being raised in accordance with Zulu traditions and cultural values. The children identified for the sub-sample, including their mothers or primary caregivers, were provided free transport to and from the research site, and were given tea and sandwiches while at the research site.

3.2.2 Indian Ancestry and White Ancestry Children

These children were accessed from a special needs school in a peri-urban area in KwaZulu-Natal. Whilst children are only supposed to be admitted to a special needs school based on the results of a formal assessment, in this resource-scarce environment, many of the children had been admitted on the basis of their apparent difficulties and the humaneness of the educators who could blatantly agree that the child had special needs, therefore in many instances, no formal assessment of the child had been done.

Before any child was assessed, full written informed consent was obtained from the parent or primary caregiver and child assent was obtained verbally. It was necessary to include in the informed consent forms details about the study and specific consent to video record the assessment process (see Appendix 2). In addition, when the child came into the testing room, they were introduced to the examiner and photographer, an outline of the study was provided when required and appropriate, and every child was shown the camera and asked specifically if they could be recorded. In some situations, the child's attention could not be focussed for long enough to obtain assent, so parental consent was used on its own. It could be argued that by drawing the child's attention to the camera, the researcher could have set up a situation where the child felt more inhibited; however, this was preferable to the child suddenly becoming aware that s/he was being filmed, and this had not been discussed with them. It would have been both a breach of the child's right to informed consent as well as a breach of trust.

3.3 Critical Account of Sampling Frame and Associated Procedures

3.3.1 Inadequate Combination of Comparison Groups Used

The researcher acknowledges that in order to facilitate an adequate comparison on racial or cultural differences, the samples used need to be matched on all contributing areas. In the case of

this thesis, several of these categories were not matched. These include, unequal subgroups, unmatched sample size, wide age range and the subsequent modules chosen, gender matching within the sample, impact of different SES and the inadequate and unwarranted translation. These issues will be dealt with in detail further on, but at this stage should be noted when viewing the results.

The present thesis in no way aims to appear robustly sound and in a position to draw inferences on the applicability of the ADOS. Within the sample size there are unmatched race groups which were administered the ADOS by an untrained ADOS administrator and scoring was done by uncertified ADOS individuals. Furthermore, proper etiquette and following of copyright laws in the translation into isiZulu and adaptation of ADOS instruments was done at the discretion of the administrator and not in accordance with ADOS manual requirements, which implies that the version of the ADOS used in this study was provisional. In practice this would render results invalid, however it must be stressed that this study is preliminary in nature and does not seek to draw inferences, comparisons or conclusions on data that was collected in violation of ADOS guidelines. Results presented must be interpreted with caution and this thesis should be viewed as a preliminary study outlining the key problems that can arise in undertaking a study of this nature. The overall aim, as mentioned above, is to inform future research strategies in this area.

3.4 Instruments

There were two main instruments used in this study, namely the Behaviour during Assessment Form (Appendix 3) and an outline of the Autism Diagnostic Observation Schedule (ADOS) (Appendix 4).

The Behaviour during Assessment Form (Appendix 3) served as a checklist and summary for notes about a child that a clinician would normally make when assessing a child. It simply served as a short-hand method of creating notes on each child. This form also highlighted key areas that could be of concern during the assessment process. The format of the form is based on the standard mental state examination process, with adaptations applicable to the ADOS context: for example, appearance, mood and affect, eye contact, energy levels, attitude toward examiner, behaviour in relation to context, concentration and attention, motor coordination, attitude to toys and the assessment context as a whole. Whenever a child is assessed it is necessary to consider

more broadly the child's reactions and behaviour. The behaviour during assessment form is not standardised as this was not the intention behind the use of the form. The intention was simply to provide a way in which qualitative notes could easily be recorded and then added as the context required, in relation to each individual child.

3.4.1 The ADOS

Before going on to present the ADOS, it must be acknowledged at the outset that the version of the ADOS used in the current context was provisional to say the least. The basic translation and adaptations used in the administration of the ADOS was done at the administrator's discretion and not via the required procedures of ADOS translation. There is currently no approved isiZulu translation of the ADOS. In addition, in some cases there was the presence of a third person in the testing room; this is not in accordance with ADOS manual requirements and must be noted and taken into consideration while reviewing the results of this thesis.

The ADOS has a semi-structured and standardized form of assessment of communication, social interaction and play for individuals who have been referred for assessment with a specific concern about ASD (Lord et al., 2008). The ADOS is considered as the gold standard (Sikora et al., 2006) and has been held in high regard. It consists of carefully created activities which are structured in a specific way so as to allow the examiner to identify any types of behaviours which are characteristic of ASD. The ADOS comprises four Modules, each suited to children of different levels of verbal ability, as well as the various developmental stages and chronological age expectancies (Lord et al., 2008). In the present study, children were assessed using Modules 1, 2 and 3, with the Module being selected in accordance with the manual instructions. It is unfortunate that most of the typically developing children were assessed using Module 3, while the atypically developing children were assessed using either Module 1 or 2. However, understanding the link between culture and the ADOS tasks was the aim of this study and not the standardisation of the ADOS, or any specific modules.

Modules 2 and 3 comprise 14 tasks respectively, while Module 1 has 10 tasks. Each child was assessed using only one Module, which takes approximately 45 minutes to complete. The specific tasks are presented in Table 2 below. Since the tasks are not the focus of coding of behaviour, these are not explained in detail. However, a few of the tasks shall be briefly described to provide the reader with an idea of how the child is assessed.

Table 2: Outline of tasks included in each of the three ADOS modules used in the study

Module 1	Module 2	Module 3
<p>Free play: This task serves as an ice breaker to help the child become at ease and comfortable with the environment. In addition, this task also serves as an opportunity for the examiner to assess the child's independent use of the toy and notice if any repetitive behaviours, social interaction or communication takes place.</p>	<p>Construction task: this task serves as a warm up activity to make the child more at ease with the testing environment, as well as to observe the child's interactive behaviour during a structured task. This task investigates whether the child asks for assistance during a structured task.</p>	<p>Construction task: As described in the Module 2 column.</p>
<p>Response to name: This task assesses the child's response to his/her name being called when it is called with the deliberate intent of getting their attention.</p>	<p>Response to name: As described in the Module 1 column.</p>	<p>Make-believe play: The purpose is for the examiner to observe the participant's creative and imaginative use of the toys provided and the degree to which they can use them beyond their most obvious function. It also assesses if the child chooses items appropriate to their interest level and cognitive demands.</p>

<p>Response to joint attention: is to examine the child's response to the examiner's use of eye contact coordinated with facial orientation, verbalisation and pointing in an effort to draw their attention to a far-away object.</p>	<p>Make-believe play: is for the examiner to observe participant's behaviour, creative and imaginative use of the toys provided and the degree to which they can use them beyond their most obvious function. It also assesses if the child chooses items appropriate for their interest level and cognitive demands.</p>	<p>Joint interactive play: this task aims to assess the degree and quality of the participant's coordination of behaviour and affect with the examiner. In this task the examiner must assess whether the participant helps to pack away toys.</p>
<p>Bubble play: this task aims to elicit eye contact and vocalisation from the child with coordinated pointing/reaching in an effort to direct the attention of the examiner/caregiver to a distant object. Any unusual sensory mannerisms can also be observed here.</p>	<p>Joint interactive play: this task aims to assess the degree and quality of the participant's coordination of behaviour and affect with the examiner. In this task the examiner must assess whether the participant helps to pack away toys.</p>	<p>Demonstration task: this task assesses the participant's ability to communicate a familiar series of actions, using body gesture or mime, with language, as well as to report on a familiar event.</p>
<p>Anticipation of routine with objects: this task is aimed at assessing the child's anticipation and initiation of the repetition of an action routine with objects.</p>	<p>Conversation: the purpose of this activity is to assess the child's ability to carry out a basic level back-and-forth conversation, and as well as for the examiner to generate a language sample.</p>	<p>Description of a picture: the purpose of this activity is to generate a sample of language and other communicative behaviours. This is also an opportunity to assess for spontaneous disclosures.</p>

<p>Responsive social smile: this activity can be coded throughout the assessment and is aimed at the child's ability to smile at a social overture from an adult.</p>	<p>Response to joint attention: is to examine the child's response to the examiner's use of eye contact coordinated with facial orientation, verbalisation and pointing in an effort to draw their attention to a faraway object.</p>	<p>Telling a story from a book: the aim of this activity is to assess the participant's ability to recall a sequential story from a book of pictures.</p>
<p>Anticipation of social routine: this task is aimed at assessing the child's anticipation of, request for and participation in social routine.</p>	<p>Demonstration task: this task assesses the participant's ability to communicate a familiar series of actions, using body gesture or mime, with language, as well as to report on a familiar event.</p>	<p>Cartoons: the purpose of this activity is to observe the manner in which the participant narrates the story, uses gesture to enact events and integrates gesture with gaze and language.</p>
<p>Functional and symbolic imitation: this task is aimed at observing the child's imitation of simple actions with real objects and meaningless placeholders for those objects.</p>	<p>Description of a picture: the purpose of this activity is to generate a sample of language and other communicative behaviours. This is also an opportunity to assess for spontaneous disclosures.</p>	<p>Conversation and reporting: the purpose of this activity is to assess the participant's ability to engage in a back-and-forth conversation and describe an event or situation without any visual cues. This also provides an opportunity to gain a language sample, and gauge spontaneity.</p>

<p>Birthday party: this activity is used to create an opportunity for the child to engage in symbolic and functional play.</p>	<p>Telling a story from a book: is to assess the participant's ability to recall a sequential story from a book of pictures, and to provide an opportunity for the examiner to assess participant's spontaneous comments about social relations and affect.</p>	<p>Emotions: in this task, the examiner is required to probe at least 2 emotions and explore the contexts they occur in and the participant's individual experiences of these emotions.</p>
<p>Snack: this activity is to give the child an opportunity to make requests in a familiar context.</p>	<p>Free play: the purpose of the free play exercise is to create a relaxed environment with no demands or intrusions for the child to have a break. In addition, this creates an opportunity for the examiner to assess the child's independent use of the toys and their engagement with the examiner or caregiver.</p>	<p>Social difficulties and annoyance: the aim of this activity is to assess the participant's insight into personal difficulties and sense of responsibility for their own actions. In addition, this task is to assess the participant's understanding of the appropriateness and implications of their feelings.</p>
	<p>Birthday party: this activity is used to create an opportunity for the child to engage in symbolic and functional play.</p>	<p>Break: the purpose of this task is (a) to give the participant a break from the social demands of the assessment and (b) to provide an opportunity for the examiner to observe the participant in a less structured environment. The break may be given at any stage and more than one break may be taken.</p>

	<p>Snack: this activity is to give the child an opportunity to make requests in a familiar context.</p>	<p>Friends and marriage: the purpose of this task is to obtain a detailed description of one or more relationships the participant wishes to describe as friendships. This is also an opportunity for the examiner to assess spontaneity and gain a language sample.</p>
	<p>Anticipation of routine with objects: this task is aimed at assessing the child's anticipation and initiation of the repetition of an action routine with objects.</p>	<p>Loneliness: the aim of this activity is and the purpose for these specific questions is to assess the participant's insight into their social situation and ability to describe their emotional reaction to it.</p>
	<p>Bubble play: this task aims to elicit eye contact and vocalisation from the child with coordinated pointing/reaching in an effort to direct the attention of the examiner/caregiver to a distant object. Any unusual sensory mannerisms can also be observed here.</p>	<p>Creating a story: The purpose of this task is to observe the creativity in a play-like situation that is appropriate for older children, adolescents and adults.</p>

Note: Adapted from *Autism Diagnostic Observation Schedule*, pp.62-65, by C. Lord, M. Rutter, P.C. DiLavore and S. Risi.2008. United States of America: Western Psychological Services.

The first task in module 3 is called the 'construction task.' This task serves as a warm up activity for the child, as well as providing an opportunity for the examiner to observe and note the behaviour of the child during a structured task. In the constructions task, the child is presented

with a shape puzzle and puzzle pieces, s/he is given a few pieces and is then assessed as to whether they request more pieces to complete the puzzle or if they wait for the examiner to offer them more (Lord et al., 2008).

Following the construction task is a 'make-believe play,' this task aims to examine the extent to which the participant uses the materials provided to produce a sequence of events and uses the items provided beyond the most obvious function, in this task, the materials are placed on the table in front of the child and then introduced to the toys and action figures. The examiner then observes how the child plays both functionally and imaginatively with the toys. The main aim is for the examiner to observe any type of interaction and non-goal directed play (Lord et al., 2008).

'Joint interactive play' is the third task, the main aim of which is to evaluate the reciprocity shown by the participant during play time. In joint interactive play, the examiner then introduces himself/herself to the situation and attempts to play with the child by positively imitating actions in play made by the child or asking leading questions which allow the child to include him/her into the play (Lord et al., 2008).

The fourth task is called the 'demonstration task' which is used as a means to find out how the participant represents and showcases familiar actions and gestures through the use of their body to illustrate an object. In the demonstration task, the child is required to act out and verbalise with gesture and co-ordinated gaze a routine event such as washing their face or brushing their teeth. If it appears that the child is having difficulty with the task, the examiner may present them with props such as a towel, and bar of soap (Lord et al., 2008).

'Description of a picture' is the fifth task which aims to assess the participant's spontaneous language and communication skills, In this task, the child is presented with a picture and they are probed to describe what objects they see; which also permits the examiner to obtain a language sample (Lord et al., 2008).

The sixth task is referred to as 'telling a story from a book,' which is used as a means of ascertaining what captures the participant's interests and illicit spontaneous language and communication. In this task, the examiner presents the child with a story book and tells the child

the story for a few pages but then includes the child by prompting or encouraging the child to then turn the pages and describe or report what is happening in the book (Lord et al., 2008).

‘Cartoons’ is the seventh task, which aims to evaluate the participant’s use of spontaneous and conventional gestures, their response to humour, and the degree of insight and flexibility when adapting a story to an audience. In this task the examiner shows the child a short story in cartoon format on different cards and the child is then required to act out the story in the order it happens, with gesture and verbalisation (Lord et al., 2008).

‘Conversation and reporting’ is the eighth task which aims to focus on the extent to which the participant elaborates on the comments made by the examiner and their ability to hold a back-and-forth conversation. The examiner is required to present enough leads, guides and prompts to the child in order to facilitate a conversation on a specific topic. It is important for the examiner to use topics of interest to the child so they have the knowledge to carry on with the interchange (Lord et al., 2008).

Task nine, ‘emotions,’ is also a conversational task aimed at eliciting information about the various emotions which the participant can identify themselves feeling. In this task there are set questions which are set by the ADOS to ask, although the questions may be asked in any order. The examiner is required to probe until the child offers their own definition of a minimum of two emotions and their experience of these emotions (Lord et al., 2008).

‘Social difficulties and annoyance’ is the tenth task and this task aims to focus on the participant’s perception of what the various social difficulties are and any insights they may have about the various social difficulties that they are faced with. As in the previous task, there are also a set of questions for this task that the examiner has to ask the child and the examiner is required to probe and get a sense of whether the child has a sense of responsibility for their actions, as well as getting a sense of the child’s insight into personal issues and social difficulties (Lord et al., 2008).

The ‘break’ is the eleventh task which aims to assess how participants occupy themselves during free time, in this task; the child is presented with various toys and stationery to play with during the task. The examiner is required to leave the child to play independently while he/she catches

up on their notes. After several minutes, the examiner should join in for a while before moving on to the next task (Lord et al., 2008).

‘Friends and marriage’ is the twelfth task which aims to assess how the participant conceptualizes the concepts of friends and marriage. In this task, the examiner asks the child a set of questions provided by the ADOS and aims to get a sense of the conceptualisation the child has about these topics (Lord et al., 2008).

The thirteenth task is ‘loneliness’ which assesses the participants’ understanding on the concept of loneliness and how they view loneliness in relation to themselves. This task also involves a set of questions, and is aimed to provide a sample of the child’s insight into social situations and their ability to describe their emotions (Lord et al., 2008).

The last task is called ‘creating a story’, the focus of which is to assess the participant’s creative use of various objects in creating a narrative story. In this task, the child is presented with a packet of random toys, they are required to pick out three toys without choosing them specifically and narrate a sequential story from the toys which they have chosen. The examiner may do this task as an example for the child, before the child does so (Lord et al., 2008).

The ADOS is a complicated test to administer. The clinical psychologist and the child psychiatrist involved in the data collection phase in the present study had each received training in the administration procedure. The researchers and the counselling psychologist were provided with training by both of above-mentioned professionals and also viewed the training videos that are distributed by the publishers of the ADOS, in preparation for the study.

3.4.2 Coding of the ADOS

The assessment of the child using the ADOS is not based on successful completion of specific tasks, but the behaviour during the entire assessment procedure is coded for ASD-related behaviours. Normal behaviour is coded 0, while the presence of abnormal behaviour is coded as 1, 2, or 3, with clear descriptions about how to decide between these codes for the presence of abnormal or atypical behaviour. A code of 8 or 7 is also permissible in instances where there is insufficient evidence of specific behaviour to accurately allocate a code. The coding dimensions are set out in Table 3. In order to ensure reliability in this study, each participant was coded by more than one person. There were different groupings involved in the coding, but there were

never fewer than three practitioners involved. The main practitioners who conducted the coding included a registered clinical psychologist, a child psychiatrist and a counselling psychologist who carried out the assessments with the isiZulu speaking participants. All scores were reviewed and consensus reached for each score.

Table 3: Table showing the coding dimensions used in the ADOS

	<u>Behaviour type</u>	<u>Coding dimensions</u>
A	Language and communication	8 criteria are defined, of which five are included in the algorithm.
B	Reciprocal social interaction	11 criteria are defined, of which 7 are included in the algorithm.
C	Play	2 criteria are defined and one is coded in the algorithm under the category Imagination and Creativity
D	Stereotyped behaviours and restricted interests	4 criteria are defined, of which 3 are included in the algorithm.
E	Other abnormal behaviour	Coding for over activity, tantrums, aggression, negative or disruptive behaviour and anxiety are described and these are not included in the algorithm but enable the examiner to take into account these dimensions of child behaviour that could profoundly impact on the validity and reliability of the assessment.

Note: Adapted from *Autism Diagnostic Observation Schedule*, p.77, by C. Lord, M. Rutter, P.C. DiLavore and S. Risi.2008. United States of America: Western Psychological Services.

3.5 Data Collection

After obtaining informed consent from the legal guardian, and assent from the child, the child was brought to the testing room. At the schools, the Occupational Therapy Room was used and in the other instance a small hall was used.

When testing African ancestry children it was necessary to enlist the assistance of an isiZulu mother tongue speaker. A counselling psychologist was employed at the rural assessment site

and she administered the ADOS. As a mother-tongue isiZulu speaker, she was able to ensure effective communication. Furthermore, having worked in the area for some time, she was familiar with the nuances and colloquial terminology used, which helped to ensure that the interpretation of data collected was accurate.

Indian and White ancestry children in this sample were all being schooled in English medium schools and thus were relatively familiar with English, so they were administered the ADOS in English. It is believed that sufficient allowance was made for any language barrier and that communication was comfortable for all participants in this study. However, it is acknowledged that in addressing the language barrier with the children, it in turn negatively affected the reliability of the results as translation was not in accordance with the translation procedures of the ADOS manual and its developer.

Each administration of the ADOS was video recorded so that they could be viewed later by three researchers who arrived at consensus coding for each dimension required in the ADOS coding schedules. It must be noted that although a consensus was reached, it does not ensure reliability of findings as the researchers involved in this process are not reliability accredited by the developers of the ADOS, causing results to be viewed with the utmost caution. In this case, consensus scoring was considered to be the most appropriate procedure to adopt as none of the researchers were certified by the authors of the ADOS as research reliable. Therefore it was decided not to investigate inter-reliabilities but rather to assess in the best interest of the child and in line with the purpose of the study. Whenever there was debate about which code to award, the issue was fully discussed and if no consensus could be reached, then the opinion of the person who was working with the child was entered into the coding sheet.

A qualified and experienced clinical psychologist, who had been trained in the administration of the ADOS, participated in the coding of all children. The training video material provided by the authors of the ADOS had been viewed, as well as some training sessions having been conducted with the researchers involved. In addition to completing the scoring sheets of the ADOS, the Behaviour during Testing form was completed and contemporaneous notes were made while the ADOS was being administered and again while viewing the video material.

The researcher took down written notes based on the observations of the behaviour exhibited by the child so as to ensure that all administrations were documented efficiently. Although these steps were taken, the researcher acknowledges that it makes results invalid to an extent because of the fact that the administrator used, translation undertaken and method of scoring were not in accordance with ADOS requirements.

3.6 Reflexivity

The aspect of reflexivity, which refers to a critical account of how the researcher has impacted on the research study, was taken into careful consideration during this study. In particular, personal reflexivity points to an understanding of how the researcher's values, experiences and identity shaped the research. In the case of the present study, the researcher's identity as a young, South African Indian female student of a higher socio-economic status did have an impact on the perception of the behaviour being exhibited by the participants. The researcher's socio-economic background was anticipated to have a likely influence on the conceptualisation of the child's behaviour. In addition, the socio-cultural background also unconsciously provided a lens through which the researcher viewed the participants' behaviour. While viewing the videos together, the three researchers would frequently discuss the observed patterns of behaviour and reflect on their own cultural values and child rearing expectations. When these discussions arose, they were documented and then carefully considered alongside the operational definitions provided in the ADOS manual and scoring sheets, before arriving at the consensus code to be used for the child's profile. The most frequently debated issues revolved around the issue of Black African children being likely to maintain sustained eye contact, despite the preconceived assumption that Zulu ancestry children would avoid eye contact as an indicator of respect, whether they had ASD or not; as well as their ability to sit and wait to be given direction. Time and again the researchers observed how Zulu ancestry children had the ability to sit quietly and wait, often without having anything that caught their attention, and without being able to request verbally, although frequent requests were made at a non-verbal level, through the use of eye contact.

3.7 Ethical considerations

Confidentiality throughout the data collection and throughout this research study was ensured by being careful not to use the participants' real names and providing pseudonyms when having to refer to specific participants when needed, for example "Child Tag 2244". The supervisor overseeing this particular research and the main research project was asked to assist when the evaluation procedure require a competent and registered professional to provide clarification on the matter at hand.

Ethical approval for this study was applied for and granted by the Research Ethics Committee of UKZN (see Appendix 5). In line with the Singapore Statement of Research Integrity (2010), Belmont Report of Ethical Guidelines for Research and the APA research code, five principles of ethics have been considered (Rosenthal & Rosnow, 2008). Firstly, in response to respecting the 'autonomy' of participants, a detailed informed consent form was constructed for participants to complete prior to the commencement of the assessment. This form provided an overview of the study and a description of the procedures that were going to take place. It also contained a section detailing the fact that the groups were to be video recorded. Participants were also notified that they were free to leave the study at any point without any consequence.

Secondly, with regards to the principle of 'trust', participants were assured that everything that was said by them in the evaluation and intake would remain confidential. In an effort to further protect participants' privacy, pseudonyms were recorded on the interview transcripts, thus ensuring that participants cannot be linked to any given response. In an effort to further ensure trust, participants were periodically asked if they were comfortable with the process and wanted to proceed or if they required any assistance. 'Honesty' was maintained throughout the research during interactions with participants and writing up of results. 'Accountability' was upheld in terms of the conduct of the research, as well as unfavourable outcomes.

Thirdly, in terms of 'nonmaleficence', this study did not present any grave direct or indirect harm to participants. Participants may at times have been psychologically stressed as they were in the unnatural setting of the consultation room. The structured and unnatural environment of the assessment room may have provided temporary stress to participants, however the participants were carefully monitored and were made as comfortable as possible. Participants were verbally

informed that should they have any concerns, they were welcome to contact the researcher who would refer them for further support and they would be able to assess support from the clinic in which they were being assessed. 'Professional courtesy and fairness' was maintained throughout data collection and dissemination of findings.

Fourthly, with regard to 'beneficence', this study offered benefits to participants in terms of receiving free basic screening. They were also given direct access to facilities in the clinic, should these have been required, during the duration of the larger K-ASD Study. On a broader level, the present study aims to benefit future research in this under researched area by providing a database of lessons learnt from this study.

Finally, as stated above, this study maintained 'justice' and 'good stewardship' through making the data available for future studies pertaining to this area of interest and in addition this data will contribute to the larger international study mentioned above. In addition, justice was maintained by ensuring that participants received adequate and appropriate support should they have become distressed by the process in any way. With regards to research integrity, justice was maintained by stating the flaws in research design and execution and notifying Principal Investigators of these flaws (see Appendix 6).

All video recordings and written notes of data were destroyed upon the completion of the study, and during the duration of the study all data was kept on the supervisor's hard drive with a secure password.

In addition, principles of responsibilities according to the Singapore statement on research integrity (2012) were adhered to. 'Honesty' was maintained throughout the research process including when interacting with participants and parents/caregivers, as well as in the analysis of the data collected and when this dissertation was written up.

'Accountability' was maintained during this research by giving out contact details and permission to contact the researcher in the consent form, as well as reiterating accountability throughout research and the researcher was available to take responsibility for the work that was done by her. Throughout the conduct of this research accountability was maintained by the researcher, including in the writing up of results.

‘Professional courtesy and fairness’ were maintained throughout the research process and during any contact with the assessment site and participants and parents/caregivers, this was especially adhered to in terms of the cultural sensitivity showed to the sample group in this study.

‘Good stewardship’ was shown with regard to researching on behalf of others; as mentioned earlier, this specific study was a part of a larger study and the data collected was also used in the larger study therefore, in working with the research team collecting data, good stewardship was maintained throughout.

‘Integrity’ was maintained throughout this research by maintaining trustworthiness and taking responsibility for the research requirements and various demands gathered from the research, as well as taking responsibility for the downfalls in this particular research.

‘Adherence to regulations’ were met in this research process, with regard to the requirements of time and regulations of the assessment site and as well as regulations of UKZN’s School of Psychology. This is in terms of their rules and requirements for submissions and conduct of research, although the regulations of the ADOS were not adhered to by unknowingly not respecting copyright requirements.

‘Research methods’ were chosen appropriately to the context of this research and what it aimed to explore. These were deemed to be ethically sound and did not pose any grave harm to participants. All conclusions formed in this research were explored and analysed critically in combination with data collected and literature sourced, and in addition, all results and findings presented in this dissertation were interpreted objectively and all information available was presented in this dissertation.

‘Research records’ of data collected were kept on separate computer hard drives for a length of time during this study, as well as all procedures undertaken in this research having been revealed. This ensured verification of data to be possible, and will enable replication of study in the future if required.

‘Research findings’ are produced in this study and will be openly made available to UKZN’s School of Psychology in the form of a master’s dissertation, as well as to the larger study on which this study is based.

The researcher was mindful of ‘societal considerations’ and respected these throughout this research process. The community’s cultural values, beliefs and what was deemed appropriate behaviour was followed by the researcher. The societal benefits were also weighed against any possible risk of this study.

3.8 Data Analysis

In the first stage of this research, the researcher simply tried to identify patterns of response in the child participants while the ADOS was being administered. The behaviours chosen were theoretically informed by the ADOS manual. These areas were then scored and coded in an algorithm designed for the ADOS. The specific areas of focus, according to the ADOS manual, for observation include:

1. The overall level of non-echoed language
2. Amount of social overtures/maintenance of attention
3. Speech abnormalities associated with Autism (intonation, volume, rhythm, rate)
4. Behaviour used in communication (descriptive, conventional, instrumental, or informational gestures)
5. Use of gestures (expressive gesture, information gestures)
6. Reciprocal social interaction (eye contact, facial expression, language production and linked non-verbal communication, shared enjoyment in interaction and empathy, quality of social overtures and responses)
7. Evidence of imagination and creativity
8. Stereotypic behaviours and restricted range of interests
9. Overall level of rapport

Once these behaviours were scored, they were entered into the algorithm of the ADOS and calculated into theoretically informed categories of Communication; Reciprocal Interaction; Play; and Stereotyped Behaviour and Restricted Interests.

Once specific patterns of behaviour were established, ANOVA was chosen as an appropriate method of analysis due to the dependent variables being analysed separately in this study, as well as the need for a comparison between more than two groups. Given the unequal cell sizes, in

order to ensure that the statistical assumptions were not violated, a Kruskal-Wallis test was used in the case of an insignificant Levene's test. Given the unequal cell sizes, heteroskedasticity (lack of homogeneity of variance) would have most likely interacted with the unequal sample sizes, thereby producing unreliable conclusions, this motivated the use of a Kruskal-Wallis test in an attempt to account for heteroskedasticity (Howell, 2010).

Chapter 4

Results

The outputs presented below illustrate the results from the ANOVA tests run on the data generated from the ADOS assessment coding sheet. Results are presented in the categories of Communication, Reciprocal Social Interaction, Play and Stereotyped Behaviours and Restricted Interests. In this chapter, results are presented and explained as they appear in the output. These have been presented in this manner as to inform the reader plainly of the results.

As previously mentioned, the aim of this study was to produce a preliminary attempt in investigating the possible areas of concern which may arise when attempting to assess the applicability of the ADOS in the South African context. This study was geared around highlighting the challenging areas, in terms of sampling, language, administration, SES and logistics that arise when conducting such research and possible recommendations to address these in an overall attempt to inform future studies aimed at assessing or investigating the applicability of the ADOS within the South African context.

As such, results will be presented and then further discussed in light of the main aims of this study, as well as in relation to theory, the implications and associated limitations.

It should be noted that, as mentioned throughout, this study was a preliminary attempt to understand the applicability of the ADOS in the South African context and in no way attempts to draw conclusions and assertions on the applicability of the ADOS. Given the many confounding variables addressed in the previous chapter, as well as the shortfalls in administration, the results presented below should be interpreted with caution.

4.1 Communication

4.1.1 Output of Levene's Test for Communication

The homogeneity of the variance is an assumption of the ANOVA method and thus a Levene's test is presented below:

Table 4: Test of Homogeneity of Variances for Communication

Levene Statistic	df1	df2	Sig.
.179	2	65	.836

The Levene's test for homogeneity was used in testing homogeneity of variance in order to establish whether or not the variance of scores in each of the groups being compared is the same. In this instance, Levene's test showed an alpha of 0.83. Since alpha is greater than 0.05, it can be concluded that the assumption of homogeneity has not been violated in this study.

4.1.2 Output of ANOVA run for Communication

In the output below, an ANOVA is used to compare the difference race groups of Black African, Indian and White children:

Table 5: ANOVA for Communication

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	118.922	2	59.461	5.500	.006
Within Groups	702.769	65	10.812		
Total	821.691	67			

The ANOVA output generated for communication showed a significance value of 0.006. Since alpha is less than 0.05, there is a significant difference between the mean scores of the four groups. However, it does not indicate in which group the difference lies.

4.1.3 Output of Games-Howell Multiple Comparisons test for Communication

In the table below, a Games-Howell Multiple Comparisons test was run comparing African, Indian and white children in the behavioural category of communication. Typically developing, atypically developing and undiagnosed children were mixed in all race groups being compared:

Table 6: Games-Howell Multiple Comparisons test output for Communication

	(I) Race	(J) Race	Mean	Std. Error	Sig.	95% Confidence Interval	
			Difference (I-J)			Lower Bound	Upper Bound
Games- Howell	Black	Indian	2.346*	.800	.014	.41	4.28
		White	3.000*	.989	.014	.55	5.45
	Indian	Black	-2.346*	.800	.014	-4.28	-.41
		White	.654	.943	.770	-1.72	3.02
	White	Black	-3.000*	.989	.014	-5.45	-.55
		Indian	-.654	.943	.770	-3.02	1.72

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

As shown in the output above, a significant difference was found in communication between the groups tested. Black African children, when compared to Indian children had a *p* value of .014 and when compared to White children, a *p* value of .014 was shown. The output above shows that there is a significant difference among Black African children when compared to Indian and White children, with regard to communication. This is evident in the mean difference scores of Indian children (2.34) and White children (3.0) when compared to Zulu ancestry children, showing that Zulu Ancestry children fall within the race group that differed most from the mean with regard to communication.

Indian children, when compared to Black African children, generated a *p* value of .014 and when compared to White children, generated a *p* value of .770. The most significant difference in communication when comparing Indian children to both Black African and White race groups, was found between Indian and Black African children as the multiple comparisons showed a mean difference of -2.43, as compared to a mean difference of .654 when compared to White children.

The third comparison was made by comparing White children to children in both the Indian and Black African race groups. When the communication scores of White children were compared to Black African children, a p value of .014 was generated, with a p value of .770 generated when compared to Indian children. The significant difference in scores was found between White and Black African children, with a mean difference of -3.00, as compared to a mean difference of -.654 when compared to Indian children.

With regard to communication, the Black African race group of children was shown to have the biggest difference when compared to Indian and White children, who were not found to be significantly different with regard to their communication scores.

4.2 Reciprocal Social Interaction

4.2.1 Output of Levene's Test for Reciprocal Social Interaction

The homogeneity of the variance is an assumption of the ANOVA method and therefore a Levene's test is presented below:

Table 7: Test of Homogeneity of Variances for Reciprocal Social Interaction

Levene Statistic	df1	df2	Sig.
1.248	2	65	.294

Levene's test for homogeneity of variances was used to establish if the variances of each score in each group being compared are the same. In this case, the Levene's test showed reciprocal social interaction to have a significance value of 0.29. Since this is greater than alpha 0.05, it can be stated that the assumption of homogeneity of variance has not been violated and variances of each of the groups are the same.

4.2.2 Output of ANOVA run for Reciprocal Social Interaction

In the ANOVA output presented below, the difference in reciprocal social interaction scores between Black African, Indian and White children is compared:

Table 8: ANOVA for Reciprocal Social Interaction

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	284.036	2	142.018	7.636	.001
Within Groups	1208.846	65	18.598		
Total	1492.882	67			

As can be seen above, the ANOVA output shows a *p* value of 0.001. Since 0.001 is less than alpha of 0.05, it can be stated that there is a significant different in reciprocal social interaction in one or more of the groups being compared.

4.2.3 Output of Games-Howell Multiple Comparisons test for Reciprocal Social Interaction

In the table below, a Games-Howell Multiple Comparisons test was run comparing Black African, Indian and White children in the behavioural category of reciprocal social interaction. Typically developing, atypically developing and undiagnosed children were mixed in all race groups being compared:

Table 9: Games-Howell Multiple Comparisons test output for Reciprocal Social Interaction

	(I) Race	(J) Race	Mean Difference	Std. Error	Sig.	95% Confidence Interval	
			(I-J)			Lower Bound	Upper Bound
Games- Howell	Black	Indian	3.827*	1.178	.008	.93	6.73
		White	4.462*	1.536	.024	.55	8.38
	Indian	Black	-3.827*	1.178	.008	-6.73	-.93
		White	.635	1.677	.924	-3.57	4.84
	White	Black	-4.462*	1.536	.024	-8.38	-.55
		Indian	-.635	1.677	.924	-4.84	3.57

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

As can be seen in the output above, when Black African children were compared to Indian children they received a *p* value of 0.008; since this is lower than alpha of 0.05 it indicates that

there is a significant difference in reciprocal social interaction. In addition, a mean difference of 3.82 is generated, showing that there is a significant difference between Black African and Indian children. When compared to White children a significant difference was noted as well, indicated by a *p* value of 0.02 and further indicated by a mean difference score of 4.46. These scores show that Black African children differ significantly from Indian and White children in reciprocal social interaction.

When Indian children were compared to Black African children, they generated a *p* value of 0.008 and a mean difference score of -3.82. When compared to White children, Indian children generated a *p* value of 4.84 and a mean difference score of 0.63. The most significant difference was found between Indian and African children with a mean difference score of -3.82, as compared to 0.63.

The third comparison showed that White children when compared to Black African children received a *p* value of 0.024 and a mean difference score of -4.462, while when compared to Indian children, received a *p* value of 0.924 and a mean difference score of -0.635. The most significant difference in reciprocal social interaction was found between Black African and White children, as indicated by the asterisk above the mean difference score of -4.462.

4.3 Play

4.3.1 Output of Levene's Test for Play

The homogeneity of the variance is an assumption of the ANOVA method and therefore a Levene's test is presented below:

Table 10: Test of Homogeneity of Variances for Play

Levene Statistic	df1	df2	Sig.
1.225	2	65	.300

A Levene's test for homogeneity of variances was run to find out if the variances of each score in each group being compared is the same. The output from the Levene's test run on play, generated a significance value of 0.3. Since 0.3 is greater than alpha (0.05) it can be stated that

the assumption of homogeneity of variance has not been violated and the variances in each of the groups being compared are the same.

4.3.2 Output of ANOVA run for Play

In the ANOVA output presented below, the difference between the scores in the category of play between Black African, Indian and White children are being compared:

Table 11: ANOVA for Play

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	20.952	2	10.476	2.667	.077
Within Groups	255.284	65	3.927		
Total	276.235	67			

As indicated above, the ANOVA output for play generated a significance value of 0.077. Since this is greater than alpha of 0.05, it is assumed that there is no significant difference between the groups being compared in terms of play. However, in order to be certain that heteroskedasticity was accounted for, a Kruskal-Wallis test was run. David Howell (2010) reports that heteroskedasticity can interact with unequal sample size groups (in the present study the sample groups are unequal in size) to produce misleading results, so it is important to guard against this error.

4.3.3 Output of Kruskal-Wallis test for Play

Due to p being greater than alpha, a Kruskal-Wallis test was run to ensure that there are no significant differences between the race groups being compared. The tables below show the results:

Table 12: Kruskal-Wallis test for Play - Ranks

	Race	N	Mean Rank
Play	African	39	39.81
	Indian	16	32.19
	White	13	21.42
	Total	68	

Table 13: Statistics for Kruskal-Wallis test for Play

Test Statistics ^{a,b}	
	Play
Chi-Square	9.299
Df	2
Asymp. Sig.	.010

a. Kruskal-Wallis Test

b. Grouping Variable: Race

As can be seen above, the significant value generated from the Kruskal-Wallis test was 0.01. Since p is less than alpha of 0.05, we can assert that there is in fact a significant difference between the groups being compared in play and further analysis can proceed.

4.3.4 Output of Games-Howell Multiple Comparisons test for Play

In the table below, a Games-Howell Multiple Comparisons was run comparing Black African, Indian and White children in the behavioural category of play:

Table 14: Games-Howell Multiple Comparisons test output for Play

	(I) Race	(J) Race	Mean Difference	Std. Error	Sig.	95% Confidence Interval	
			(I-J)			Lower Bound	Upper Bound
Games- Howell	Black	Indian	.466	.648	.754	-1.15	2.08
		White	1.462*	.502	.018	.23	2.70
	Indian	Black	-.466	.648	.754	-2.08	1.15
		White	.995	.678	.323	-.69	2.68
	White	Black	-1.462*	.502	.018	-2.70	-.23
		Indian	-.995	.678	.323	-2.68	.69

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

From the multiple comparisons table above, it can be seen that Black African children, when compared to Indian children received a p value of 0.754 and a mean difference score of 0.466. When compared to White children, a sig value of 0.018 was calculated with a mean difference score of 1.462. From this it can be seen that the most significant difference in play was between Black African and White children.

On the other hand, when Indian children were compared to Black African children, a p value of 0.754 was noted, with a mean difference score of -0.466. When compared to White children, a p value of 0.323 was generated and a mean difference score of 0.995 was noted in this instance. Indian children were found to have a significant difference when compared to Black African children with regard to the category of play.

White children were shown to have a p value of 0.018 when compared to Black African children, with a mean difference score of -1.462. In contrast, when compared to Indian children, a p value of 0.323 was generated and a mean difference score of -0.995 was shown. The significant difference between the groups being compared was between White and Black African children, as indicated by the asterisks above the mean difference scores.

4.4 Stereotyped Behaviours and Restricted Interests

4.4.1 Output of Levene's Test for Stereotyped Behaviours and Restricted Interests

The homogeneity of the variance is an assumption of the ANOVA method and when heteroskedasticity is present at the same time as unequal sample size groups misleading results can be generated (Howell, 2010). Therefore as a result, a Levene's test is presented below:

Table 15: Test of Homogeneity of Variances for Stereotyped Behaviours and Restricted Interests

Levene Statistic	df1	df2	Sig.
2.156	2	65	.124

A Levene's test was run in order to ascertain whether the groups being compared have equal variances or not. In this instance, the Levene's test for homogeneity of variance showed the significance value to be 0.124. Since 0.124 is greater than alpha of 0.05, it can be stated that the assumption of homogeneity of variance has not been violated and all variances of the groups being compared are the same.

4.4.2 Output of Kruskal-Wallis test for Stereotyped Behaviours and Restricted Interests

Due to p being greater than alpha, a Kruskal-Wallis test was run to ensure that there are no significant differences between the race groups being compared. The tables below show the results:

Table 16: Kruskal-Wallis test for Stereotyped Behaviours and Restricted Interests - Ranks

	Race	N	Mean Rank
SBRI	African	39	35.72
	Indian	16	32.50
	White	13	33.31
	Total	68	

Table 17: Statistics for Kruskal-Wallis Test for Stereotyped Behaviours and Restricted Interests

Test Statistics ^{a,b}	
	SBRI
Chi-Square	.432
Df	2
Asymp. Sig.	.806

a. Kruskal-Wallis Test

b. Grouping Variable: Race

As can be seen from the output above, sig 0.806 is greater than alpha 0.05. This confirms that there are no significant differences between the groups being compared in stereotyped behaviours and restricted interests.

Chapter 5

Discussion of Results

5.1 Deviations from standard ADOS procedure

The administration of the ADOS used in this study was in contrast with the ADOS requirements set by the authors of the test. Firstly, translations used in this study were done at the administrator's discretion and not in accordance with Western Psychological Services guidelines. No permission was obtained for translation, and no approved isiZulu translation of the ADOS exists, meaning that the version used in this study was strictly provisional.

Secondly, the rules set by the ADOS instruct that the testing environment consist of only the administrator and child. The presence of an interpreter, as was used in this study, is not permissible and alters the interactional and social dynamics for the child, thus rendering the scores obtained to be inaccurate representations of ability. In addition to administration limitations, the person who was administering the ADOS in this study was not a certified trainer, thus invalidating findings and preventing inferences being drawn. Furthermore, given that the researchers involved in scoring and other aspects of the test were not trained to become research reliable by the ADOS trainers, the scores generated are found to be an invalid representation of the children's actual ability. As a result, all results presented below must be interpreted with caution. Although the clinician overseeing this project has worked with ASD children and has experience in the administration of the ADOS, she was not accredited as research reliable nor was she experienced to the extent required by the ADOS to conduct such assessments. This must be taken into account when interpreting results.

5.2 Limitations of the Design

Firstly, the size of the subgroups used are not equal and in addition vary greatly from each other. This poses obvious difficulty in drawing general comparisons but was found to be of more concern when running statistical tests on the data. The issue was noticed by the researcher, although lack of access to the required resources meant that this aspect could not be corrected. Given the unequal subgroup size, inferences drawn must be interpreted with caution.

Secondly, the ages of children used were between 6 and 11 years old, as mentioned. The importance of age in determining which behaviours are deemed appropriate and inappropriate in ASD detection is acknowledged by the researcher. It is a known fact that age plays an important role in deciding which module is used. In this study, the mean age across all sample groups was shown to be 9 years. Module 3 was used based on the appropriate age and on verbally fluent children, whereas Modules 1 and 2 was used on children who appeared to have no or limited verbal ability. Modules were chosen at the discretion of the administrator, this in itself provides an inadequate account of module justification, given that the administrator herself was not ADOS certified. The higher demands of Module 3 in comparison to Modules 1 and 2 are viewed to add to the inaccuracy that is present in the comparison groups and further emphasise that the comparisons drawn should be viewed with caution. It is possible to go as far as to say that verbal ability appeared limited due to the intimidation of the testing environment itself, and not necessarily due to limited ability.

Thirdly, with regards to gender in the subgroups used, as statistically shown, ASD is prevalent in males. This was the same with regards to the sample used in this study. Predominantly males were used across all race groups, with only two females present in the Black African race group. It is an important factor to take into consideration when drawing comparisons and the fact that there were no females matched in the Indian and White race groups further emphasises the need to view comparisons with caution.

Fourthly, socio-economic status (SES) between race groups is being compared. Given that the Black African subgroup was from a rural area in KwaZulu-Natal and the Indian and White subgroups were accessed from a peri-urban, but urban nonetheless, area in KwaZulu-Natal, it causes SES to impact on comparisons as a confounding variable. The SES element itself undermines the comparisons made in this study. Although it is acknowledged that this is poor practice in research, as from the outset it creates a disadvantage in performance, it must be reiterated that this research is not intended to draw comparisons and conclusions but to highlight areas in need of further investigation and integral factors, such as SES, which must be taken into consideration when conducting research of this nature in future.

Lastly, the variability of ASD presentation is not accounted for in this study. The impact of using typically and atypically developing children in the same comparison group undoubtedly presents

a confounding variable in results produced. The fact that possible ASD across the comparison group are not accounted for and subsequently matched, in effect invalidates findings and does not allow any plausible inferences to be drawn from them.

While the researcher acknowledged that autism does not differentiate among different cultural and racial groups, the manner in which behaviours are expressed during the administration of the ADOS and how this related to the culture of the groups is of interest.

This study therefore aimed to produce a preliminary attempt in investigating the possible areas of concern which may arise when attempting to assess the applicability of the ADOS in the South African context. The rationale behind this was to illustrate the problematic areas, in terms of sampling, language, administration, SES and logistics that could arise when conducting such research and making possible recommendations to address these, in an overall attempt to inform future studies aimed at assessing or investigating the applicability of the ADOS within the South African context.

It should be noted that, as mentioned throughout, this study was a preliminary attempt to understate the applicability of the ADOS in the South African context and in no way attempts to draw conclusions and assertions on the applicability of the ADOS. As a result, conclusions should be interpreted with caution.

This discussion consists of four parts referring to the categories of behaviours; Communication, Reciprocal Social Interaction, Play and Stereotyped Behaviours and Restricted Interests. The findings included in the previous chapter will be presented in a discussion format with information from the behaviour during assessment form referred to where appropriate. Secondly, results will be theoretically contextualised in the light of relevant literature and critically discussed.

5.3 Communication

In the behavioural aspect of communication, as can be seen in the results above, African children were found to differ most significantly from White and Indian children, whereas Indian and White children communicated in a similar manner. This aspect is twofold, as in one regard, the

language medium maybe have hindered communicative effectiveness, and on the other hand there is the influence of cultural normative behaviour. The issue of language can be ruled out to an extent as allowances were made in instances where the language barrier was an issue, by means of using an isiZulu administrator and teacher aid. However there is the danger that given the unwarranted translations used, the meanings may have differed from what the ADOS intended. Cultural normative behaviour, however, was viewed to have played a role in the level of communication. Black African students were found to have limited verbal and non-verbal communication when compared to Indian and White children. A confounding variable, however, is the fact that the children were separated into race groups and not socio-economic groups, this variable alone is argued to account for the variability in scores between the race groups being compared. The fact that Black African children were accessed from rural areas and compared to urban children placed them at a disadvantage from the onset, rendering this outcome as an unclear representation of variance. Knowingly inferring conclusions based on the fact would be unethical on the part of the researcher. It is therefore proposed that the comparisons presented be interpreted with caution and not viewed as conclusions reached.

Based on this study, Black African children were found to have lower levels of eye contact and appeared to have deliberately avoided direct eye contact with the ADOS administrator during the testing process. Black African children were found to have a lower degree of spontaneous vocalization toward the administrator, however, when probed and given 'permission' responded in a subdued manner toward the administrator. This was different to the behaviour exhibited by Indian and White children, who showed regularity in their vocalization toward the administrator. In the instance of Indian and White children being assessed, frequent spontaneous and probed verbal communication was observed. This difference is hypothesised to be due to cultural practices which in terms of communication, especially with regard to eye contact and verbalization, is found to be different between Black African cultures and Indian and White cultures. The vast difference in SES background is hypothesised to have been another confounding variable in this comparison.

Black African children were found to have more non-verbal than verbal communication, however, when compared to Indian and White children, but were still found to exhibit less communication overall. The act of pointing and using gestures was found to be common in

African children, although there were seldom instances of spontaneity. Indian and White children, on the other hand, exhibited both spontaneous and probed pointing and gestural behaviour during the assessment process. Many of the Black African children included in this study are from rural areas, as compared to urban Indian and White children, and are therefore socialized according to cultural norms of behaviour in the presence of an adult. In addition, the context of assessment was either at a clinic or at a school, which are more formal environments as compared to the home environment, thereby possibly deeming any playful or carefree behaviour to be inappropriate. The combined elements of both culture, testing environment and rural versus urban background are argued to be the contributing factors in the lower levels of communication found in Black African children in this study.

The argument that culture defines the way that a child behaves and as a result communicates, is also investigated by Shiraeeve and Levy (2010) who mention in their article that Black African children are culturally moulded to be compliant and quiet, especially in the presence of an adult, as compared to Western families who encourage outspoken and assertive behaviour. Although submissiveness and reluctance to be assertive in communicating with an adult is viewed as a weakness in Western society, this behaviour is encouraged in many African societies as it links directly with the notion of respect, which is of prime importance in Black African culture (Shiraeeve & Levy, 2010).

The difference in communication style is further explored by Chandler et al. (2008), by illustrating how Western cultures are more concerned with linear communication which is well articulated, has corresponding non-verbal communication and a direct focus on response. In contrast, non-Western cultures tend to communicate in circular patterns which have diverse areas of focus and in some cases are made up on minor non-verbal cues over full verbal communication, which may cause a Western mind to view this behaviour as a lapse in communication skills (Chandler et al., 2008). This highlights an important aspect of non-Western communication which every individual outside of non-Western culture should be mindful of, especially in instances where a Western construct is used to evaluate the communication ability of a non-Western culture.

Overall, although results from this study correlate with findings from previous studies, it would be careless not to view them in context of this particular research. Given the unmatched samples

being compared, with the important confounding variable of SES and the language medium, one cannot confidently say that these results are a clear representation of the population group. The results do, however, highlight that communication styles differ between each comparison group and may prove worthwhile to research in future, ensuring that all confounding variables are properly accounted for.

5.4 Reciprocal Social Interaction

In this study and in accordance with the ADOS manual, reciprocal social interaction refers to eye contact, facial expression directed to others, shared enjoyment in interaction, spontaneous initiation and response to joint attention and overall quality of social overtures (Lord et al., 2008). Children in this study were therefore evaluated in these aspects and the notion of reciprocity and spontaneity were of key interest. Given the nature of data collection and assimilation in this study, results presented below are to be viewed critically and with caution.

As can be seen in the previous chapter, reciprocal social interaction showed the same behaviour pattern as that of communication where Black African children were found to differ significantly from Indian and White children. This is possibly due to the fact that communication and reciprocal social interaction are linked in terms of overall communication and interaction.

Due to the interconnectedness of communication and reciprocal social interaction, it is understood in terms of the similarity in responses. As mentioned above, and in accordance with the behaviour during assessment, Black African children were found to have less eye contact with the administrator and limit facial expressions directed toward the administrator. This was in contrast with Indian and White children who used eye contact as a means of reassurance to continue with the activity, and varied facial expression. Shared enjoyment in the interaction was less often expressed in Black African children who disclosed enjoyment only after being asked, whereas Indian and White children spontaneously displayed enjoyment, all of which suggests that the black children were attending to negative face and the other race children to positive face (Terkourafi, 2004).

It is argued that the reasoning behind this behaviour is culturally based as well, given the interrelationship with communication and the fact that interactional behaviour arises from

upbringing, which is culturally derived (Nsamenang, 2007). The issue of a lack of spontaneous or reciprocal interaction in Black African children when compared to Indian and White children, reiterates the concept of respect being upheld in their interaction with adults, as it is deemed disrespectful to initiate contact with an adult, one is rather taught to speak only when spoken to (Nsamenang, 2007). This, however, should be viewed in context, given the unequal SES backgrounds of each child, and the fact that they are being compared to each other, one cannot conclude that this difference is true beyond reasonable doubt. Given the several confounding variable interactions within this comparison, it would be unethical to deem this as absolute.

The very notion of reciprocal social interaction is based on reciprocity between the parties involved in the interaction, this assumes equal grounding for the interaction, however this is contradictory to the one-sided “vertical” (Lassiter, 1999, p.1) distribution of power which Zulu ancestry children are taught when interacting with an adult or authority figure. Black African children were found to follow instructions during the administration of the ADOS, as opposed to initiating an activity, whereas Indian and White children were found to be more willing to initiate joint interaction with the administrator. Although coding lower scores (in Black African children) for this behaviour in the ADOS will contribute to a diagnosis of autism or other ASD, it is important to note that this behaviour may not be due to behavioural abnormalities but may in fact be due to cultural socialization which encourages submissive and culturally defined, respectful behaviour. This may have been further impacted on by the fact that there were more than two people in the testing room and the presence of an additional adult may have further intimidated children, and caused inhibited responses. The presence of an extra person may have disadvantaged the performance of Zulu ancestry children in particular.

Nyasani (1997, in Lassiter, 1999) argues for this point as well, stating that children from traditional African homes are deep-seated in their socialization with a cultural value, belief and action system that is vastly different to that of a Western or urban child. He argues that all behaviour is centred on keeping in line with cultural behaviour references, especially in formal settings, with people of authority (Nyasani, 1997, in Lassiter, 1999).

In relation to previous literature, this dynamic is further emphasized in the argument put forward by Tek and Landa (2012) who argue that with regard to external instruments, a discrepancy

results between the culture of the instrument and the culture of the child being tested. This inherently results in incongruent results between the outcome of the test and actual status of the child. Berry et al. (2005) further emphasize this point and hold that only in the case of different groups being in contact with each other, can the notion of acculturation take place and allow for an integration of behavior styles. In this case, rural children were compared to urban children, therefore not allowing such to take place. Although South African Indian and White children are also of a different culture to those that the ADOS is intended to be used on, their behavior can be explained by the fact that they have had exposure to Western behavior traits through access to media and other outlets, as well as living in an urban area, as opposed to the rural Black African children who have been socialized under different cultural practices and ideologies (Lassiter, 1999). It is argued that if the sample were matched according to SES, the difference in behavior would not have been significantly different.

As mentioned previously, given the different cultural and SES backgrounds of the test and the children being compared, it is of prime importance to acknowledge this interpretation of results as preliminary and inconclusive in nature. A study conducted by Beeger et al. (2009, in Tek & Landa, 2012) emphasised this point by arguing that results from their study show that when the administration of vignettes from a European ADOS test was applied to a sample of non-European people, administrators were more likely to gain a false positive and incorrectly diagnose a patient with autism (Beeger et al., 2009, in Tek & Landa, 2012). Although this was based on European and non-European countries, the basic trend of this study is applicable to the South African context and this study. Although the mechanics in sample selection and matching in the current study are flawed, results from this study and the previous study show this to be an area in need of further investigation. It is argued that in attempting this, future researchers should ensure that the sample groups are finely matched in terms of group size, age, SES and gender in order to gain credible and reliable results.

5.5 Play

With regard to play in this study, results show a different pattern in response when compared to that of communication and reciprocal social interaction. In this instance, Black African children were found to have the most significant difference when compared to White children, whereas

Indian children were found to generate similar scores when compared to Black African and White children. In this case, the difference was observed to be between Black African and White children.

Play refers to the functional play with objects and showcasing of instances of imagination and creativity according to the ADOS (Lord et al., 2008). In the present study, Zulu ancestry children were found to play more functionally with objects instead of creatively, while White children displayed both creative and functional uses of objects. This highlights the importance of the cultural background of the child in testing situations, as well as the SES status and subsequent socialization of Black African children in the present study. Although this may be true however, given the fact that the comparisons were drawn between children from rural backgrounds and children from urban backgrounds, it immediately creates a disadvantage for rural children as they are being tested on first time exposure to objects that are unfamiliar to them, yet are familiar and may even appear basic to urban children. The comparison illustrated goes beyond race and illustrates the impact of SES on behaviour, given the context and samples used in this study, differences may be attributed more to SES than cultural/racial background.

Gosso et al. (2007, in Shiraeve & Levy, 2010) support this standpoint by the argument put forward from a study conducted which yielded results indicating how culture and SES were found to be synchronised with both the external environment and the social dimensions within it. Results from Gosso et al. (2007) show that children from well developed, urban areas and higher socio-economic statuses, have a more developed ability to be able to play imaginatively and creatively when compared to children from rural and under developed areas (Gosso et al., 2007, in Shiraeve & Levy, 2010).

The reasoning behind this is that urban children were found to be encouraged to play with both recreational items as well as pretend play with functional items; play was encouraged and continued over time. In contrast, children from rural and under developed communities were more concerned with the necessities and functional aspects of an object and the practice of recreational play was untapped. This highlights the difference in play between Black African and White children to be both culturally, socially and economically based. In addition, the difference presented in this study may be exaggerated due to the unequal size of the groups being compared, in addition to the rural subgroup being compared to the urban subgroup.

It is argued that although play is based on the physical ability of the child, it is moulded by the influences around the child, such as culture and environment. Play is evident in all cultures, however, the compositions and end results differ in accordance to cultural practices (Hyun, 1998). Functional play of rural Black African children should therefore be understood in terms of what they are exposed to in their daily lives and taught through cultural practices, as opposed to merely scoring them lower than that of an urban child who is often exposed to and encouraged to play in the abstract. Thereby highlighting the importance of comparing matched samples, had the study matched SES and compared the groups, results would have been more representative of the actual difference (or not) between Black African and White children.

5.6 Stereotyped Behaviours and Restricted Interests

Stereotyped behaviours and restricted interests is a category in the ADOS which refers particularly to atypically developing children who are either autistic or on the ASD spectrum. As can be viewed in the discussion of results thus far, a significant difference was found between the Black African children and the other race groups, however, in this instance, there are no significant differences between Black African and White children, Black African and Indian children, and Indian and White children. All race groups responded similarly to “presses” eliciting stereotyped behaviours in autistic or ASD in this study. This very fact confirms the results of this study with regard to stereotyped behaviours and restricted interests, and the validity of the ADOS in highlighting typically developing children.

This illustrates the accuracy of the ADOS, as well as the argument that autism and other ASD are not race or ethnicity specific, but are found to be present among all race and ethnic groups.

Although results from the present study indicate that stereotyped behaviours and restricted interests were successfully highlighted in all race groups being compared, studies have shown that detection of these are usually different among racial and ethnic groups (Mendell, Wiggins, Carpenter, Daniels, DiGuseppi, Durkin, Giarelli, Morrier, Nicholas, Pinto-Martin, Shattuck, Thomas, Yeargin-Allsopp, & Kirby, 2009). Mendell et al. (2009) argue in their article that misdiagnosis and late detection are common amongst racial minority groups due to the manner in which they interpret the symptoms. They attribute these late diagnoses and, at times, misdiagnoses to the fact that there may be inadequate screening processes, as well as the

influence of the parent. The issue of inadequate screening processes is directly related to the current study. Given that this was a preliminary attempt in setting the foundation to further research, basic screening procedures were done and in effect left out many other procedures. This inadvertently caused confounding variables as the basic screening adopted could easily have missed underlying psychological conditions which could have unknowingly impacted on the results of this study.

In addition, the overlap in symptoms between ASD can cause a misdiagnosis, Mendell et al. (2009) use the presence of repetitive interests and stereotyped behaviours (which is part of stereotyped behaviours and restricted interests) to highlight this by mentioning how these compulsions can be just as easily diagnosed as an Obsessive Compulsive Disorder at such a young age (Mendell, et. al. 2009).

As argued for, construct bias and method bias must be addressed by the instrument in order to preserve the integrity of the psychological test. This study is not able to evaluate these constructs in terms of the ADOS, given the flawed design and unmatched sample.

Having mentioned all the behavioural categories, there remains an overall concern affecting the validity of the results presented. In an effort to avoid repetition, these will be discussed in relation to the overall results presented.

The very basis of the ADOS is to detect ASD, and in order to draw inferences, through rigorous screening procedures, children are categorized as developing either typically or atypically. Given that basis, and the use of this instrument within an ASD population, the fact that children were not matched in terms of typical and atypical development further nullifies the results of this study.

The variance of symptom presentation and disorder manifestation is a common theme in this disorder. Children are viewed to range from non-verbal on the spectrum to Asperger's syndrome and from low IQ to significantly advanced IQ levels. By not matching typically and atypically developing children, this research has prevented an acceptable comparison to be drawn on any level. Matching of ASD typically and atypically developing children is imperative to drawing comparisons in scoring patterns and not accounting for this factor not only provides a confounding variable in results but deems the comparisons themselves as invalid. This error

means that varying developmental disorders are randomly spread across the sample and prove to confound results and provide an unclear representation of scoring patterns between groups. This further emphasises the point that the results presented are in no way equipped to draw inferences from and should be viewed with utmost caution.

Chapter 6

Critical Conclusions and Implications

As mentioned at the onset of this study, the main aim was to test the assumption that Autism Spectrum Disorders have universally occurring behavioural indicators, regardless of the cultural background and influences that the child may have been exposed to.

Firstly, with regard to communication, the main difference was found between Black African children and other race groups. Indian and White children were found to score similarly to each other in terms of communication. The researcher attributed these differences to language and culture, however given that the testing environment was not as per ADOS manual requirements, the conclusions reached cannot be attributed to limitations in the ADOS but more so to shortfalls in the sampling frame and unmatched samples used in this study. In other words, the difference in responses of Black African children when compared to Indian and White children during the administration of the ADOS, with particular regard to communication, is hypothesised to be due to the cultural socialization and subsequent normative behaviour, in addition to the unequal SES backgrounds which were inadvertently being compared. It is viewed that the SES factor impacted more on results than the cultural factor.

Black African children were found to display more non-verbal than verbal behaviour indicating that they do have adequate ability to communicate, however, due to the cultural influences, the style of communication, especially with an adult, is found to be different.

Reciprocal social interaction was found to yield results similar to that of communication, this may be due to the similarity and interconnectedness of the two categories. As mentioned in the discussion, the main premise of reciprocal social interaction is based on the interaction of adopting a reciprocal dynamic between the administrator (adult) and the child. This reciprocity is the main factor in ensuring that the child scores well in this category. The differences between Zulu ancestry children and Indian and White children in this category are found to be both culturally based and based on the fact that rural children were being compared to urban children, creating an unequal comparison group at the onset. In addition, reciprocity advocated for in this interaction is the polar opposite to the cultural teachings of most African cultures which sternly instruct one-way interaction and create a “vertical” (Lassiter, 1999, p.1) power and subsequent

interactional dynamic between child and adult when interacting. This is viewed to have been perpetuated by the presence of extra adults in the testing environment.

Play, which refers to the third behaviour category showed results to differ from the pattern of communication and reciprocal social interaction. Indian and Black African children were found to score similarly with regard to play and African children were found to differ mostly when compared to White children. It is argued that the reason behind the difference in play is based on the differences in the cultural and economic backgrounds of the children.

Based on the Apartheid doctrine of past South Africa, Black African and Indian children were exposed to a different lifestyle than that of White children. Survival was of prime importance to non-Whites and their behaviour was subsequently based on what would ensure survival and create ease in living. This highlights the importance of acknowledging the cultural background of the child in the testing environment. Given this very point, the fact that rural Black African children were being compared to urban White children further illustrates the inaccuracy inherent in the results derived from this study.

The fourth behavioural category, stereotyped behaviours and restricted interests, yielded similar results for all race groups. This particular category refers to the typically developing ASD children and the presence of atypically developing behaviour, such as uncontrolled, repetitive or compulsive behaviour traits throughout the testing process. This category illustrates that stereotypical behaviour can be highlighted and exposed with the ADOS, regardless of race, thereby accepting the assumption that autism and ASD have universally occurring behaviour traits.

6.1 Undeniable Limitations and Recommendations

Although this is a critical area in need of research, as mentioned throughout, limitations are embedded throughout the planning and execution of this study. Firstly, with regards to the size of the sample subgroups; groups were not of the same size, nor were they in similar ballpark figures or ranges. The uneven size renders a problem for the statistical analysis method used as well as the representativeness and accuracy of findings. Scoring patterns noticed could be purely based

on the uneven sample size and are not an accurate representation of the groups being compared, rendering comparisons flawed. In addition, although an age range was used, ages were not matched throughout the sample, causing yet another confounding variable in results. It is recommended for future research that all subgroups used in comparative studies have matched samples, be of equal sizes and be large enough to allow for robust statistical testing.

Secondly, the issue of gender is not appropriately addressed and matched within the sampling frame used. This causes increased limitations to the results presented given that a higher incidence rate of autism, ADHD and other ASD are found to be prevalent in males. This factor is important to control for in a study such as this and not having done so highlights the carelessness of the research team. In future, researchers should make a concerted effort to diligently match the sample groups which they intend drawing comparisons from. Male and female participants should be matched throughout the study design.

Thirdly, one needs to bear in mind that children from rural areas were being compared to children from urban areas throughout this research. This is highly problematic in drawing conclusions on the comparisons made as the rural versus urban dynamic creates a confounding variable in the results reached, thereby rendering the results insignificant and an inaccurate representation of the comparisons drawn. This variable on its own is viewed to contribute significantly to the variability in social, educational and psychological testing performance. Drawing inferences on such a basis yields results to be invalid and in poor practice. Future studies are urged to learn from this lesson and to ensure that the study design accounts for urban versus rural backgrounds. It is also stressed that comparisons should not be made across the two groups in terms of race, ability, culture or any other factor.

Similarly, SES is not accounted for in the design of this study. Given the above mentioned rural versus urban confound, SES is equally confounding. The known disproportion of SES between these groups is not accounted for in this study and therefore creates a further confounding variable undermining the results, which needs to be meticulously accounted for in future research designs by ensuring that proper matching is carried out in order to ensure accuracy of results. These factors have proved to be a major downfall in this study and should serve as a learning point for future research.

Fourthly, the lack of accounting for the matching of variation and placement of typically and atypically developing children solidifies the inaccurate and invalid research findings of this study. The fact that unidentified and ad hoc sets of varying developmental disorders are unevenly spread out across the sample groups being compared is unacceptable in modern research practices. The researcher humbly acknowledges the severity and importance of matching the number of typically and atypically developing children, in addition to their severity and placement on the ASD spectrum. In future research, more attention should be paid to distinguishing typically developing from atypically developing children and furthermore to acknowledge that atypical development cannot be treated as an umbrella term; there are complex degrees of development, presentation of disorders and pervasive disorders that need to be taken into account.

In addition, rigorous screening methods should be employed in order to uncover underlying medical conditions which may impact on a child's performance in the ADOS administration. Intensive developmental, clinical and neuropsychological assessments are advised for participants in future research, in an attempt to rule out the possibility of external disorders confounding the results of the study. This is especially relevant to research in the South African context given the high levels of HIV infection, parasitic infestations, poverty, and a host of CNS affecting pervasive disorders which may impact on the functioning of a child during assessment. Having not taken these elements into account leaves the results vulnerable to multiple confounds, thereby invalidating findings.

A further limitation to this study lies in the administration and unjustified translation. Although this study was meant for educational purposes, it does not justify that translations were done at the discretion of the administrator; the proper translation procedure was not followed. Future researchers are urged to conduct translations via the Western Psychological Services before attempting to make adjustments to the ADOS as the ADOS is copyrighted and legally one must get permission from copyright holders to translate the test. In addition to this, the current study deviated further from the norm by allowing an additional individual in the testing room, which created an adverse environment and could have contributed to hindering the children's performance. It must be noted that this is not in accordance with ADOS administration guidelines and should not be repeated in the future.

The ADOS holds that only certified ADOS trainers are allowed to administer the ADOS and this was not the case in this study, this point should be considered throughout the interpretation of results from this study. Furthermore, the panel used to achieve score consensus was not deemed research reliable by the creators of the ADOS, meaning that reliability is not ensured in the scores which were agreed upon. Even though this research was a pilot study and did not aim to draw conclusions about the tests validity from its findings, this fact is important to consider and it is imperative that should future research be conducted in this area, all members are certified research reliable in the ADOS. In this thesis, intensive experience with ASD children was limited to the clinician overseeing the project and did not extend to the research team. It is suggested that this should be addressed in future research and it should be ensured that all members of the research team are adequately equipped in dealing with ASD children.

An additional limitation with regards to the logistics of this study is that although this study is intended as an exploratory study which laid the foundation for further exploration, given that this dissertation needed to be completed within a period of one year, it was not possible to use an experimental or even a quasi-experimental design, with matched samples and to properly define the research design of this study. This made it difficult to justify the decisions made during the study with regard to data analysis and data collection. As a result, the quantitative analysis has been limited to describing the differences in variations of certain behaviours; it is suggested that the K-ASD Study then consider this information in greater detail and use it to inform or serve as a comparison for future studies.

6.2 Critical Evaluation of Researcher's Impact on Findings

The researcher's position as an Indian South African was found to directly impact on the testing environment. The cultural difference also made the researcher more lenient and prone to excusing Indian children's behaviour as culturally acceptable; a phenomenon which was also noted with the Black African administrator and African children. It was deemed to be to the advantage of this study that the administrators were of different races so that when leniencies were noticed, they were brought to the attention of the administrator and the administrator then became more conscious and aware of these tendencies. The differences in socio-economic status were obvious to the researcher, although oblivious to the child.

Guilt was felt with regards to the inexperience of the researcher, it was thought that the children were not receiving quality administrations and that this added to their lack of access to proper resources, however, the fact that this process was overseen by trained, professional clinicians made this process ethical. This experience has proved to be a humbling, insightful, and growing experience for the researcher, both personally and professionally.

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Appendix 1
Request for Permission to Conduct Research

5 March 2012

To Whom It May Concern

Request for permission to conduct research

I am a current Masters student in Psychology at the University of KwaZulu-Natal (Pietermaritzburg). My research project is with regards to assessing the behaviour during psychological assessment in African children.

I am writing to you asking for permission to access the identified database list of typically and atypically developing ASD children in my study and in addition to use the research site and the ADOS purchased for the K-ASD Study. The focus of my study is mainly on patterns of social interaction and reciprocal social interactions, as described in the ADOS, as well as other behaviours that are observed during the administration of the ADOS to both typically and atypically developing children in the age range of 6 – 11 years. In this study I aim to explore how typically and atypically African children respond during the administration of the ADOS and more generally in the psychological testing situation.

The names of participants will not be used in any form in the final research project and all equipment used belonging to the research site will remain at the site and will only be utilized during the duration of the assessment.

I believe that this study could benefit the greater K-ASD Study as it will contribute to the existing body of knowledge and contribute information pertaining to an area where there is limited knowledge.

I would feel privileged to work on your site and would greatly appreciate your approval.

Thanking You,

Kershia Sunjeevan

Masters student

Cell: 083 678 7885

Dr. Beverley Killian (PhD)

Supervisor

Tel: 033-2605371

Appendix 2
Informed Consent

1 March 2012

Dear parent/s or caregiver,

Consent for your child to participate in a research study

You and your child are invited to participate in a large research project. This part of the study will be run by two psychology Masters Students from the University of KwaZulu-Natal, under the direction of Dr. Beverley Killian. I am wanting to assess children who have an autism spectrum disorder and those who do not, so that I can assess the behaviour of African children during psychological assessment.

Autism Spectrum Disorders (ASD) tends to be very difficult to identify, and research literature suggests that the ADOS (Autism Diagnostic Observation Schedule) is the current “gold standard” for the diagnosis of ASD. There is very limited information available about the behaviour of African children during assessment and this research aims to provide more information on the topic, and in addition will aim to assess if the ADOS is in fact valid and applicable within the African context. The Principal Investigators in this study are Dr Shuaib Kauchalis (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).

A key staff member will who is employed by the Assessment Centre and who is isiZulu speaking will assist in the running of this study. We are asking for your consent for 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.

The assessment process will be conducted at the Assessment Centre at the Valley Trust. The assessment will take approximately 45 minutes to conduct and with your permission will be video

recorded as well and made available to the researchers involved in the study and used for research purposes only.

There will be no remuneration in cash or kind for participation in the project, however transport to and from the site will be provided. 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 neither you nor your child will experience any adverse effects from such withdrawal or refusal.

Should you have any questions please feel free to contact me, my supervisor or the ethics committee of UKZN .

Sincerely,

Kershia Sunjeevan

Dr. Beverley Killian

Ms. Phume Ximba

Masters student

Supervisor

Ethics Committee

Cell: 083 678 7885

Tel: 033-2605371

Tel: 031-260 3587

Section A: CONSENT OF PARENT OR CAREGIVER

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

Signature of parent

Date

Should you be concerned in any way, please do provide us with contact numbers so that we can be in contact with you:

Phone Numbers:

Section B: ADDITIONAL CONSENT/ASSENT TO VIDEO AND PHOTOGRAPH 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	Date

Appendix 3

Behaviour During Assessment Form

K-ASD study: behaviour during assessment

Child Tag: Study nuc:

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

Descriptions	NAD	Code
1. Body Size		X
1.1 Underweight	x	
1.2 Overweight	x	
2. Grooming & Hygiene		X
2.1 Poor	x	
2.2 Excessively neat	x	
2.3 Unusual appearance	x	
3. Facial expression	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	x	
4. Eye Contact		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	
4.5 No eye contact	x	
4.6 Fleeting eye contact	x	
4.7 Peripheral eye contact	x	
4.8 Looks past examiner	x	
5. Energy Levels		X
5.1 Fatigue evident from beginning	x	
5.2 Fatigue evident towards end of session	x	
5.3 High energy level but not too disruptive	x	

5.4 High and highly disruptive (unable to sit still)	x	
5.5 Other (Specify)	x	
6. Attitude to examiner		X
6.1 Talkative	x	
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	x	
7. Behaviour (Appropriate behaviour to context)		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	x	
8. Speech		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	x	
8.5 sing song tone	x	
8.6 No speech	x	

K-ASD study: behaviour during assessment

Child Tag: Stud nuc:

Name: Date of birth: Gender: Home Language:

8.7. Flat-robot like		
8.8. Pronunciation difficulties	X	
8.9. Stutter or stammer	X	
8.10. Immediate echolalia	X	
8.11. Delayed echolalia	X	
8.12. Uses sounds to communicate	X	
8.13. Frequently reverts to one topic	X	
8.14. Other		
9. Concentration and attention		X
9.1 Unable to focus on a task	X	
9.2 Highly distractible	X	
9.3 Distracted by peripheral objects	X	
9.5 Hyperactive	X	
9.6 Day dreams	X	
9.7 Remains focussed on a special interest area	X	
10. Motor-coordination (Fine and Gross)		X
10.1 Difficulties with fine motor coordination	X	
10.2 Repetitive fine motor movements	X	
10.3 Gross motor difficulty: specify	X	
10.4 Stereotypical behaviour impacts on other movements (e.g. flapping)	X	
10.5. Low muscle tone (slumps over the desk, or can't sit up straight)		
10.6. Clumsy		
10.7. Rocking (whole body)		
11. Attitude to toys and assessment (plays appropriately with toys)		X

11.1. Seems nervous to touch toys	X	
11.2 Rough with toys	X	
11.3 Frequently checks verbally or nonverbally if permitted to touch toys	X	
11.4 Toys evoke potential contextual concerns (bullying, interpersonal aggression, etc) Specify	X	
11.5 Frequently asks to take toys home	X	
11.6 Unable to focus on available toys as distracted by box of toys	X	
11.6 Unable to focus on available toys as distracted by others things in room	X	
11.7. Lines up toys	X	
11.8. Takes toys without asking	X	
11.9 Plays imaginatively with toys		
11.9. Other	X	
12. Cognitive process		X
12.1 Seems below average in cognitive functioning	X	
12.2 Seems above average in cognitive functioning/and or general knowledge	X	
12.3 Curious and ask questions	X	
12.4 Above average fund of knowledge (not related to special interest)	X	
12.5. Slow to process or understand instructions	X	
12.6 Other: specify	X	
13. Mood and affect		X
13.1. Anxious	X	
13.2. Seems sad/depressed	X	
	X	
	X	
14. Behaviours after assessment		X

K-ASD study: behaviour during assessment

Child Tag: Stud num:

Name: Date of birth: Gender: Home Language:

14.1. Extremely happy to reunite		
14.2. Shows no evidence of reuniting happily		
14.3. Behaviour changes upon reuniting: Specify		
14.4. Other: Specify		
15. Areas of strength identified	X	X
Specify:		
16. Contextual issues of concern		
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		
17. Vision		
18. Hearing		
19. General health status		

Examiners:.....

General comments:

Any action required in the best interest of the child?

Appendix 4

Outline of the Autism Diagnostic Schedule (Module 3)

Activities	Items Needed	Purpose
1. Construction Task	Block puzzle	This aims to serve as an ice-breaker and warm-up activity to introduce the child to the testing process, as well as serve as an opportunity to observe the child's interactive behaviour during a structured task. This task investigates if the child asks for assistance during a structured task.
2. Make-believe Play	<p><i>Bag 3:</i> 2 male action figures, 1 female action figure, 3 "props" (one for each action figure), miniature hairbrush, 2 small tools, toy dinosaur.</p> <p><i>Bag 2:</i> 2 small spoons, 2 plates, a tea pot, measuring cup, toy car, hologram spin disk, and 2 pieces of "junk" (small piece of cloth and small "jewellery" box)</p>	The purpose of this activity is for the examiner to observe participant's behaviour, creative and imaginative use of the toys provided and the degree to which they can use them beyond their most obvious function. It also assesses if the child chooses items appropriate for their interest level and cognitive demands.

3. Joint interactive play	Materials from “Make-believe play”	This task aims to assess the degree and quality of the participant’s coordination of behaviour and affect with the examiner. It is important for the examiner to make it clear that the task is a collaborative one. In this task the examiner must assess whether the participant helps to pack away toys.
4. Demonstration task	Hand towel and soap	The purpose of this task is to assess the participant’s ability to communicate a familiar series of actions, using body gesture or mime, with language, as well as to report on a familiar event.
5. Description of a picture	Picture cards of typical subsistence African rural living	The purpose of this activity is to generate a sample of language and other communicative behaviours. This is also an opportunity to assess for spontaneous disclosures.

6. Telling a story from a book	2 picture books	The aim of this activity is to assess the participant's ability to recall a sequential story from a book of pictures, and to provide an opportunity for the examiner to assess the participant's spontaneous comments about social relations and affect.
7. Cartoons	<i>Series A:</i> Fisherman/pelican series <i>Series B:</i> Monkey/coconut series	The purpose of this activity is to observe the manner in which the participant narrates the story, uses gesture to enact events and integrates gesture with gaze and language.
8. Conversation & reporting	-	The purpose of this activity is to assess the participant's ability to engage in a back-and-forth conversation and describe an even or situation without any visual cues. This also provides an opportunity to gain a language sample, and gauge spontaneity. In addition, it provides an opportunity to assess the participant's evaluation and recount of non-routine events.

9. Emotions	-	In this task, the examiner is required to probe at least 2 emotions and explore the contexts they occur in and the participant's individual experiences of these emotions.
10. Social difficulties & annoyance	-	The aim of this activity is to assess the participant's insight into personal difficulties and sense of responsibility for their own actions. In addition, this task is to assess the participants understanding of the appropriateness and implications of their feelings.
11. Break	Shape puzzle, drawing paper, set of 8 markers, pin art, spin pen, small radio, current newspaper, magazine & materials from "Make-believe play."	The purpose of this task is (a) to give the participant a break from the social demands of the assessment and (b) to provide an opportunity for the examiner to observe the participant in a less structured environment. The break may be given at any stage and more than one break may be taken.

12. Friends & Marriage	-	The purpose of this task is to obtain a detailed description of one or more relationships the participant wishes to describe as friendships. This task also aims to gain a description of the participant's understanding of the concept of friendship and the idea of establishing family unit and building long term relationships. This is also an opportunity for the examiner to assess spontaneity and gain a language sample.
13. Loneliness	<ul style="list-style-type: none"> • Do you ever feel lonely? • Do you think other (young) people in your circumstance ever feel lonely? • Are there things that you do to help yourself feel better? 	The aim of this activity and the purpose for these specific questions is to assess the participant's insight into their social situation and ability to describe their emotional reaction to it.
14. Creating a story	6 items with a purpose, 6 items with no clear purpose	The purpose of this task is to observe the creativity in a play-like situation that is appropriate for older children, adolescents and adults.

Note: Adapted from *Autism Diagnostic Observation Schedule*, pp.62-65, by C. Lord, M. Rutter, P.C. DiLavore and S. Risi.2008. United States of America: Western Psychological Services.

Appendix 5 Ethical Approval



7 September 2012

Ms Kershia Sunjeevan 208505267
School of Applied Human Sciences – Psychology
Pietermaritzburg Campus

Dear Ms Sunjeevan

Protocol reference number: HSS/0349/012M
Project title: Exploring how typically and atypically developing African children respond during the administration of the ADO5 and more generally in the psychological testing situation.

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 6

Letter to Principal Investigator



UNIVERSITY OF KWAZULU-NATAL

INYUVESI YAKWAZULU-NATALI

15 April 2014

Dear Dr. Kuchali and Prof. Chagghan,

I would like to thank you for affording me the opportunity to use the data from your larger K-ASD Study for my master's thesis. I have since used and analysed the data using ANOVA. I have submitted my thesis for examination and received feedback. I thought it would be necessary to inform you of the comments received.

There has been much criticism surrounding the validity of findings generated, given the improper use of the ADOS. These are explained below.

Administration: the manner in which the ADOS was administered during this study is found to be conducted contrary to regulations set by the creators of the ADOS. The clinician administering the test must be ADOS trained and certified in order for his/her assessment of the child to be found as credible. In this case, the administrator was not certified by the ADOS, regardless of the fact that she was a trained clinical psychologist. The reason that a certified and experienced administrator is needed is due to the fact they need to be able to assess the quality of symptoms presented by the child. Given that the variability of symptom presentation in ASD is argued to be its defining feature, an experienced administrator is needed to differentiate between performance anxiety (for example) and indicators of ASD.

An additional error in the administration of the ADOS was found with regards to having an extra individual in the testing room. The ADOS instructs that only the child and administrator be in the room. The presence of an extra individual changes the interactional dynamic and presents a confounding variable in results or scores generated. Furthermore, comparing rural to urban children undoubtedly changes the comparison dynamic and goes as far as to sabotage group performance from the onset. This was the case in my study and therefore made it difficult to draw sound and valid conclusions from the results.

Translation: the administrator informed translation used in this study is viewed to be against ADOS requirements. Should any population require translations to the ADOS manual and test, one is required to contact Western Psychological Services and proceed with translation requests through this channel. The independent translations render the version of the ADOS used invalid and thus invalidates any results generated from those administrations. It is suggested that for the purposes of the K-ASD Study, the research team initiate this process via Western Psychological Services in order to obtain accurate translations of the ADOS and prevent further invalid assessments.

Research Reliability: the “panel” used to reach a consensus of scores in an attempt to ensure reliability has in effect violated any form of reliability. The reason for this is that any individual or group engaging in this process must be accredited as research reliable by the authors of the ADOS, and in this case none of us were, thereby rendering results to be unreliable and incapable of being generalizable to the study population.

Screening methods: the basic screening methods employed to categorize typical from atypical development are insufficient. The reason for this is that the basic screening employed does not account for any underlying disorders which may impact on and, in effect, confound the results generated. There are many complex underlying symptoms and other illnesses which impact on performance and are simply missed by basic screening methods. To then knowingly draw inferences from this, deems results severely confounded and incapable of having conclusions drawn from them. It is suggested that rigorous rescreening be done on participants in order to rule out any confounding illnesses or disorders.

As I have the opportunity to identify these methodological constraints, I hope that by sharing these insights, your study team will be able to account for them in future studies and that this may help in the K-ASD Study.

Once again I thank you for allowing me access to your data and I hope that this feedback is beneficial to you and your research team.

Kind Regards,

Kershia Sunjeevan