

# **Assessing an isiZulu questionnaire with educators in primary schools in Pietermaritzburg to establish a baseline of knowledge of Autism Spectrum Disorder.**

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**Declaration:**

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



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

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

Signed:



Ms. Carol Mitchell

Date: 2014/11/24

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## ABSTRACT

Autism Spectrum Disorder (ASD) is a significant childhood disorder and has a growing prevalence rate across the world. It has been identified in children from a wide range of racial groups, ethnicities and socio-economic groups, making it a globally relevant disorder. However, poorly developed research on ASD in Africa makes it difficult to determine the prevalence rate, presentation and level of knowledge regarding the disorder locally. Therefore, assessing knowledge of ASD amongst professionals is a useful starting point for research in countries where research on ASD is limited. Educators in particular are a vital resource due to the likelihood of their early identification of developmental delays in children of school going age. Awareness studies reveal that professionals have poor awareness of ASD and therefore what educators in South Africa know about ASD needs to be established. In order to do so, a culturally relevant measure is required. This study aimed to translate an established measure into *isiZulu* and then assessed its reliability as a measure of knowledge in the local context. This was done in a pilot study with postgraduate students at the University of KwaZulu-Natal, and then again in a larger sample of students and educators. The study then investigated the level of knowledge of ASD amongst educators in Edendale, Pietermaritzburg by using the *isiZulu* measure. The results suggested that the questionnaire was a reliable measure of knowledge amongst educators in Pietermaritzburg. Educators were found to have a good baseline knowledge of ASD but their knowledge was found to be lacking in specific detail. This indicated that there is an opportunity for further research and interventions to develop knowledge of ASD within the local context.

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### **Frequently used acronyms**

ASD	Autism Spectrum Disorder
DSM-IV-TR	Diagnostic and Statistical Manual Fourth Edition (Text Revision)
DSM 5	Diagnostic and Statistical Manual Fifth Edition
PDDs	Pervasive Developmental Disorders
KCAHW	Knowledge about Childhood Autism amongst Health Workers
APA	American Psychological Association
CDC	Centre for Disease Control and Prevention
UKZN	University of KwaZulu-Natal

## CHAPTER ONE

### INTRODUCTION

#### **1.1. Introduction**

Research shows that Autism Spectrum Disorder (ASD) is the fastest growing childhood disorder across the globe and has been identified in children from a variety of racial groups, ethnicities and socio-economic groups (Imran et al., 2011; Centre for Disease Prevention and Control [CDC], 2013). This makes ASD a globally significant developmental disorder. However, studies indicate that very little is known about this disorder in Africa (Bakare, Ebigbo, Agomoh, & Menkiti, 2008) and South Africa more specifically (Springer, van Toorn, Laughton, & Kidd, 2013).

Poorly developed research on ASD in South Africa makes it difficult to know what the situation is locally. Furthermore, ASD is a complex disorder and falls on a spectrum, which makes it difficult to identify. It is further complicated by the recent change in the diagnostic system. Bakare and Munir (2011a) state that low levels of knowledge about ASD in Sub-Saharan Africa are a call to researchers to improve the knowledge and awareness of ASD amongst the general public (Bakare & Munir, 2011a). It is therefore important to investigate the levels of awareness of ASD in the general population, amongst professionals and amongst educators in particular. Educators are a vital resource as they are often the first to identify developmental difficulties amongst children of school going age.

Awareness studies amongst professionals across the globe have revealed that professionals have poor awareness of ASD. However, what South African educators know about ASD has

yet to be established. In order to investigate awareness in the South African context, a culturally appropriate measure needs to be developed. This requires translation into a local language, *isiZulu* for use in KwaZulu-Natal, in order to ensure that the results of the study are not confounded by language issues.

The Knowledge of Childhood Autism amongst Health Care Workers (KCAHW) questionnaire devised by Bakare et al. (2008) was identified as a potentially useful measure within the local context. It was developed for use in Nigeria to assess knowledge of ASD amongst health care workers. It was recommended for use in Sub-Saharan Africa in developing countries where knowledge of ASD is unknown.

## **1.2. Aims and objectives of the study**

This study had the following aims and objectives. Two aims and two objectives were identified for this research.

### **1.2.1. Aims of the study**

1. The first aim of this study was to translate the original KCAHW questionnaire from English into *isiZulu* for use in the South African context, and to assess its reliability as an *isiZulu* measure of knowledge of ASD.
2. The second aim of the current research was to use the translated KCAHW questionnaire in order to assess knowledge of ASD amongst educators in Edendale, Pietermaritzburg.

### **1.2.2. Objectives of the study**

1. The first objective of the study was to determine whether or not the translated KCAHW questionnaire was a reliable measure of knowledge of ASD.
2. The second objective of this study was to determine the baseline knowledge of ASD amongst educators in Edendale, Pietermaritzburg.

### **1.3. Research questions**

The research investigated the following questions:

1. Is the *isiZulu* KCAHW questionnaire a reliable measure of knowledge of ASD?
2. What do educators in Edendale know about identifying the core symptoms of Autism Spectrum Disorder?

### **1.4. Methodological approach**

This research had a multiphase methodological approach. Phase one included the translation of the KCAHW questionnaire which included a forward translation, blind back translation and expert consultation. Following this was phase two which first involved testing the translated questionnaire in a pilot study with 30 postgraduate students from UKZN. When the pilot produced inconclusive results, the student sample was increased to 50 students in order to compare the performance of the questionnaire across two different samples. The questionnaire was then administered to 50 educators and 20 students in order to have two equally sized sample groups. The reliability of the questionnaire was then assessed using

statistical analyses. Cronbach's alpha was calculated and a factor analysis was run. Phase 3 involved analysing the data from the educator sample using statistical methods in order to identify the baseline knowledge of ASD amongst educators specifically.

## **1.5. Terminology**

Recent changes to the DSM 5 have complicated this already complex childhood disorder. Studies concluded prior to 2013 are discussed within this dissertation with reference to the terms they used, namely autism and Asperger syndrome, whilst Autism Spectrum Disorder will be used throughout to refer to the diagnostic spectrum.

Various terms used throughout the dissertation are defined as follows:

### **1. Asperger Syndrome**

Asperger syndrome is a childhood developmental disorder as defined by the DSM-IV-TR (American Psychological Association [APA], 2000). It is classified as a Pervasive Developmental Disorder (PDD) and is identified by marked impairments in social communication and behaviour (APA, 2000).

### **2. Autism**

Autism is a childhood developmental disorder as defined by the DSM-IV-TR (APA, 2000). It is classified as a Pervasive Developmental Disorder (PDD) and is identified by marked impairments in social communication, social interaction and behaviour (APA, 2000).

### 3. Autism Spectrum Disorder (ASD)

ASD is the new term referring to what was previously known as autism and Asperger syndrome. ASD was introduced in the DSM 5, which was published in 2013. ASD is defined as a childhood developmental disorder marked by impairments in social interaction and communication, with the presence of restricted and repetitive behaviour (APA, 2013).

### 4. KCAHW questionnaire

The KCAHW questionnaire is a measure of knowledge of ASD developed by Bakare et al. (2008). It was first used to assess knowledge amongst health care workers in Nigeria. It has 19 items divided into four domains and is in a multiple-choice format.

### 5. Sizabantwana network

The Sizabantwana network refers to a group of under-resourced schools in Edendale and Imbali townships in Pietermaritzburg. Through partnership with UKZN, educator capacity is developed to address psychosocial needs within the communities serviced by the schools. These schools were chosen as a result of an already established partnership with UKZN through one of the thesis supervisors.

## **1.6. Outline of the study**

In chapter one, the background and motivation for the study was introduced. The aims and objective of the study were outlined and the terms used within the study were defined.

Chapter two provides an overview of the history of ASD as well as literature that is relevant to the current study. In chapter three, the methodology of this study is outlined according to the various phases. Research design, sampling, data collection, data analysis and ethical

considerations are addressed. Additionally, the translation process is discussed in detail and relevant changes to the questionnaire are highlighted. In chapter four, the findings of this study are presented and they are discussed in chapter five. In chapter six, opportunities for future research and the implications of the study are explored.



## CHAPTER TWO

### LITERATURE REVIEW

Research shows that Autism Spectrum Disorder (ASD) is the fastest growing childhood disorder in the world (Imran et al., 2011). As a result, knowledge about this disorder is progressing as researchers develop a greater understanding of how ASD is viewed, diagnosed and treated across cultures.

In this chapter, the history of ASD and its evolution with regards to diagnostic criteria will be explored. The changes in the DSM 5 will be a particular focus. The epidemiology of the disorder will then be outlined as well as the impact of ethnicity and culture on the perceptions and diagnosis of ASD. ASD in the African context will then be examined. There will be a specific focus on South Africa and the challenges faced in identifying ASD amongst South African children. The importance of early intervention will be highlighted. Awareness studies as a means of measuring knowledge of ASD amongst professionals and the public will then be discussed and studies from around the world and amongst educators, more specifically, will then be examined. The Knowledge of Childhood Autism amongst Healthcare Workers (KCAHW) questionnaire will be introduced as a useful awareness measure. The challenges with regards to adapting such measures for the South African context are identified.

#### **2.1. Autism Spectrum Disorder: A brief introduction**

Autism Spectrum Disorder (ASD) is a neurologically based developmental disorder that is defined by deficits in social interaction and communication, as well as by the presence of restrictive behaviours (APA, 2013). Deficits can be noted across multiple contexts. It is this

particular combination of symptoms that define ASD from other developmental disorders such as Intellectual Developmental Disorder or Social Communication Disorder (APA, 2013; Bregman, 2005). ASD can usually be identified before the age of three (Frank-Briggs, 2012) and is almost five times more common in boys than girls (Centre for Disease Control and Prevention [CDC], 2014).

The first major criterion for a diagnosis of ASD is marked deficits in social interaction and communication. This refers to the inability to reciprocate with others on a relational level (APA, 2013). Impaired social interaction skills range from a lack of eye contact to an inability to take interest in others (APA, 2013). Impaired communication may present in various ways, depending on the child. For example, a child may not respond to name-calling, or fail to initiate conversations with others (APA, 2013; Childress, Conroy, & Hill, 2012).

The second major criterion for a diagnosis of ASD is the presence of restrictive behaviours. This refers specifically to repetitive patterns of behaviour, activities and interests (APA, 2013). A child may present with the inability to be flexible with routines, or with repetitive hand gestures known as flapping (APA, 2013; Childress et al., 2012). Children with ASD are commonly fixated on particular interests and develop ritualistic behavioural patterns around said interests (Childress et al., 2012). A child may, for example, line up his or her toys in a straight line every day on multiple occasions.

Although there are no known biological markers, children with ASD may present with physical markers. Ear malformations and atypical dermatoglyphics are amongst recorded symptoms (Sadock & Sadock, 2007). Autistic children also occasionally present with ambidexterity for longer than the average neuro-typical child (Sadock & Sadock, 2007).

ASD occurs along a spectrum whereby specific developmental symptoms range from severe to mild. This severity component marks one of the more significant changes to the diagnostic criteria of ASD in the fifth edition of the Diagnostic and Statistical Manual (DSM 5). This will be discussed in further detail in this chapter.

### **2.1.1. The etiology of ASD**

Global research around this increasingly common childhood disorder is developing but pinpointing an exact cause has proven elusive. Different cultures perceive the diagnostic criteria in different ways, perhaps not as atypical development at all, thus adding to the complexity of diagnosis, identification and understanding of its onset.

Researchers believe that a combination of genetic and environmental risk factors interact to cause ASD (Autism Speaks, 2010). Specific genes responsible for this disorder have been identified and so it is possible that some people are more prone to develop it than others. About 10% of cases may be as a result of Fragile X syndrome, Tuberous Sclerosis or Angelman's syndrome (Autism Speaks, 2010).

Recent studies suggest that ASD may be the result of complex immune system irregularities such as pregnancy influenza or a diet low in folic acid (Autism Speaks, 2010). Some researchers believe that complications during pregnancy, such as a lack of oxygen, can be the cause and it is also debated whether or not parental age has any effect on the development of ASD (Autism Speaks, 2010). In Africa, researchers once believed that ASD was the result of malaria infections but this theory has subsequently been debunked (Mankoski et al., 2006).

## **2.2. The evolution of Autism Spectrum Disorder**

Leo Kanner first coined autism as Infantile Autism in 1943 in a study on childhood developmental disorders (Daily, 2005). He observed and described eleven children who presented with unusual behaviours, namely the inability to form bonds with caregivers and intolerance for changes in routine (Bregman, 2005). Kanner also noticed unusual sensitivities, delayed language skills and uneven cognitive development amongst his sample (Bregman, 2005). According to Kanner, these symptoms represented a childhood disorder that was easily confused with childhood schizophrenia, or mental retardation (Sadock & Sadock, 2007).

In 1944, Hans Asperger published a paper on what he called Asperger syndrome (Frith, 1991). His cases revealed similar developmental patterns to those in Kanner's case studies and he specifically noted impaired social skills and restricted patterns of interest in his clients (Bregman, 2005). However, the children Asperger worked with had strikingly good linguistic and problem solving skills (Bregman, 2005).

In time, Kanner and Asperger concluded that their disorders shared major symptoms relating to behaviour and social communication skills (Frith, 1991). They came to agree that their disorders were in fact the same, but presented in different ways (Frith, 1991). They noticed that there were differences in the severity of certain symptoms (Frith, 1991). Asperger, for example, noticed that his clients had good language skills whereas Kanner's clients did not. This principle applied to mutually recognised symptoms such as repetitive behaviours and non-verbal communication skills (Frith, 1991). Thus, autism and Asperger syndrome came to be considered similar disorders on a severity continuum.

In 1980, autism was included in the third edition of the DSM (DSM-III) as a childhood disorder called Infantile Autism (Bregman, 2005). The DSM-III diagnostic criteria for Infantile Autism were restrictive and narrow, which resulted in a revised edition called the DSM-III-R (Bregman, 2005). The DSM-III-R was criticised for being too inclusive, so after field-testing the diagnostic criteria again, the DSM-IV was released in 1994. In the DSM-IV, autism was classified under an umbrella term known as Pervasive Developmental Disorders (PDDs). Autism, Asperger syndrome, Rett's syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) were all categorised as PDDs. In 2000, a revised version of the DSM-IV (DSM-IV-TR) was released and the umbrella term was maintained (Kaufmann, 2012).

The diagnostic criteria for autism in the DSM-IV-TR called for six symptoms to be met across three domains (Autism Speaks, 2013a). The three domains included social communication, social interaction and repetitive behaviours. Bregman (2005) outlines the major criteria for a diagnosis as follows. Firstly, a child had to exhibit a qualitative impairment in social interaction skills. This may present as an inability to respond to familiar faces or as a lack of relational reciprocity. Secondly, a child had to show impaired social communication skills. For example, an autistic toddler might not coo and an autistic teenager might not be able to reciprocate verbally in a conversation. Thirdly, a child had to display repetitive and restricted behaviours. A child may present with repetitive hand gestures or obsessive routines, for example. Furthermore, the onset of symptoms had to be prior to the age of three and had to cause significant impairment in daily functioning (APA, 2000). Related PDDs had to be ruled out before a diagnosis of autism could be made.

Similarly, the DSM-IV-TR outlined Asperger syndrome as a qualitative impairment in social

interaction marked by restricted and repetitive behaviours (APA, 2000). These two specific domains were defined similarly to autism. The delays in development had to cause significant impairment and could not otherwise be accounted for by related PDD diagnoses (APA, 2000). In contrast to autism, however, a diagnosis of Asperger syndrome specified that the child have no cognitive delay and no language development delays.

The DSM 5 was released in 2013 with significant changes in multiple domains. The change most pertinent to this study involves the diagnostic criteria for autism. The umbrella term, PDD, has been collapsed and a new diagnosis called Autism Spectrum Disorder (ASD) has been implemented (Kaufmann, 2012). Autism Spectrum Disorder now encompasses Kanner's or classic autism, Asperger syndrome, high-functioning autism, infantile or childhood autism and atypical autism (APA, 2013). There are no clear diagnostic criteria for the differences between autism and Asperger syndrome in the DSM 5 because it is argued that they are the same condition, separated only by degrees of severity (APA, 2013). ASD, according to the DSM 5, therefore, refers to a childhood developmental disorder that exists on a spectrum whereby specific developmental symptoms range from severe to mild (APA, 2013).

### **2.2.1. The new diagnostic criteria for ASD in the DSM 5**

Autism Spectrum Disorder in the DSM 5 is defined by impairments in only two specific domains: namely social communication and interaction, and restricted repetitive behaviours (APA, 2013). See Table 1 for diagnostic criteria. A diagnosis can be made on evidence of at least three communication deficits and two repetitive behavioural symptoms “in the early

Table 1

*Diagnostic criteria for Autism Spectrum Disorder (APA, 2013)*

---

**A.** Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify current severity:* Severity is based on social communication impairments and restricted repetitive patterns of behaviour (See Table 2)

**B.** Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify current severity:* Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

**C.** Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

**D.** Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

**E.** These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

*Note.* Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

*Specify if:* With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

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developmental period” (APA, 2013, p. 50). Symptoms must cause significant impairment. Additionally, a diagnosis of ASD according to the DSM 5 must include a description in terms of the following: any known genetic cause such as Fragile X syndrome or Rett's syndrome; the child's level of language and intellectual disability; the presence of co-morbid medical conditions such as seizures, anxiety, depression and gastrointestinal problems (Autism Speaks, 2013a).

One of the major diagnostic changes in the DSM 5 is the implementation of a severity scale. Impairments must be rated on a three-point severity scale. See Table 2 for the severity criteria. Level one, for example, refers to symptoms that cause interference in daily functioning but can be reduced with support (Autism Speaks, 2013a). Level three, on the other hand, refers to symptoms that cause severe disturbance and require substantial support (Autism Speaks, 2013a). Additionally, severity is determined by the pattern of onset of symptoms and associated conditions such as cognitive skills and environmental factors (Kaufmann, 2012). The DSM 5 relies on the clinician to determine the severity level of the diagnosis.

Thus, the terms autism and Asperger syndrome are obsolete and Autism Spectrum Disorder is now the only term in use.

### **2.2.2. Reasons for the changes**

The Autism Research Institute (2014) states that there are two main reasons for the DSM 5 changes. Firstly, they argue that the diagnostic criteria for PDDs in the past were not precise enough. Research done by the Institute found that there were cases whereby one child was diagnosed with various PDDs by different clinicians because the differences between the PDDs were unclear. The DSM 5 therefore attempts to bring a new degree of clarity to the



Table 2  
*Severity Scale (APA, 2013)*

Severity	Social communication	Restricted, repetitive behaviours
Level 3	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	<ul style="list-style-type: none"> <li>• Inflexibility of behaviour</li> <li>• Extreme difficulty coping with change</li> <li>• Restricted/repetitive behaviours markedly interfere with functioning in all spheres</li> <li>• Great distress/difficulty changing focus or action</li> </ul>
Level 2	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	<ul style="list-style-type: none"> <li>• Inflexibility of behaviour</li> <li>• Difficulty coping with change</li> <li>• Restricted/repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts</li> <li>• Distress and/or difficulty changing focus or action</li> </ul>
Level 1	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	<ul style="list-style-type: none"> <li>• Inflexibility of behaviour causes significant interference with functioning in one or more contexts</li> <li>• Difficulty switching between activities</li> <li>• Problems of organization and planning hamper independence</li> </ul>

symptom combinations that define Autism Spectrum Disorder. This degree of definition and clarity aims to reduce diagnostic confusion, thus purifying the ASD diagnostic process.

The second reason for the collapsing of the PDD umbrella is related to the diagnostic criteria that define autism and Asperger syndrome. The Autism Research Institute (2014) states that autism and Asperger syndrome are defined by a common set of symptoms and should be one common diagnosis on a continuum. However, they suggest that this may reduce the number

of people who receive a diagnosis of ASD in the future due to more stringent diagnostic criteria.

The changes may affect global prevalence as suggested above. Global prevalence of ASD has increased dramatically in the past 40 years, from a rare disease to having a prevalence rate as high as 2.64% in some countries (South Korea in this case) (Autism Speaks, 2013b). Fifty percent of this increase in prevalence can be attributed to changes in diagnostic criteria in the DSM-IV and DSM-IV-TR, according to Autism Speaks (2013b). However, they go on to say that prevalence increases are also influenced by environmental factors, genetics and advanced research. The Centres for Disease Control and Prevention (CDC) (2013) state that the new diagnostic criteria of the DSM 5 may result in a decrease in global prevalence of ASD, over time. The prevalence of ASD is discussed below as it relates to assessing what people know about ASD.

### **2.3. Epidemiology of Autism Spectrum Disorder**

Prevailing increases in prevalence may be due to changes in diagnostic criteria, but are equally due to external factors. Thus, prevalence rates must be viewed within context. Studies conducted around the world have discovered that ASD can be identified in children from all racial groups, ethnicities and socio-economic groups (CDC, 2013) – making it a globally relevant developmental disorder.

Research suggests that it is on the rise worldwide (Bakare et al., 2008) and it is believed to be the fastest growing childhood disorder in the world (Imran et al., 2012). As a result, knowledge of this specific developmental disorder has grown incrementally in developed

countries (Mandell, Novak, & Zubritsky, 2005). Most prevalence rates pertain to the DSM-IV-TR terms, namely, autism and PDDs.

The national census in the United Kingdom (UK) in 2011 revealed that 695,000 people had autism and Asperger syndrome (The National Autistic Society, 2013). That equates to a prevalence rate of 1.1% across the UK (The National Autistic Society, 2013). In 2000, 1 in 150 American children were believed to have ASD and current estimates are that 1 in 88 American children are autistic (CDC, 2013). Less is known about the prevalence of ASD across South America.

A study done in South Korea delivered a more concerning result with a prevalence rate of 2.6% (CDC, 2013). Kim et al. (2011, as cited in Elsabbagh et al., 2012) researched PDD prevalence in South Korea and found the alarming rate of 189/10000 cases amongst the general population, followed by Japan where the rate was 181/10000 cases. China, by contrast, only revealed a rate of 16/10000 cases (Wong & Hui, 2008, as cited in Elsabbagh et al., 2012). Prevalence across the Middle East has been researched, and rates remain quite low by comparison to other regions. Oman, for example, reports a 1.4/10000 prevalence rate (Al-Farsi et al., 2010, as cited in Elsabbagh et al., 2012).

In Africa, a preliminary observation done in the 1970s suggested that the rate of ASD was lower than the UK (Elsabbagh et al., 2012). However, the data was inconclusive but did provide crucial information that highlighted the presence of ASD in varied geographical regions (Elsabbagh et al., 2012). No published data on the prevalence rates in Africa exists to date (Elsabbagh et al., 2012).

The average prevalence rate according to the CDC (2013) is 1% in Asia, Europe and North America, which indicates an increase in ASD cases. However, Rhoades, Scarpa, & Salley (2007) state that healthcare professionals lack critical information about this developmental disorder and that that results in opportunities missed for successful intervention. Furthermore, in spite of ASD being identified across all racial groups and ethnicities, ethnicity and culture influence perceptions of ASD. Research suggests that culture and ethnicity impact the rate of referral, age of diagnosis and interpretation of symptoms. The impact that ethnicity and culture have on knowledge and diagnosis of ASD is discussed below. This is significant to this study as it highlights cultural and ethnic issues, which might have bearing on how professionals in South Africans interact with ASD.

### **2.3.1. Ethnicity and ASD**

Ethnicity connotes “groups of individuals sharing a sense of common identity, a common ancestry, and shared beliefs and history” (Sadock & Sadock, 2007, p. 168). Research originating mainly in the USA suggests that disparities exist with regards to service availability for different ethnicities and that ethnicity impacts known prevalence rates, diagnosis and treatment of ASD.

What is known about the global prevalence of ASD is influenced by ethnicity such that individuals of particular ethnicities appear to report ASD more frequently (CDC, 2009, as cited in Elsabbagh et al., 2012). Studies in North America reveal that the prevalence of ASD amongst Caucasian children is greater than that of African American or Hispanic children (Elsabbagh et al., 2012). However, since an increase in prevalence across all ethnicities, genders and racial groups has been noted in North America it is unlikely that children of

particular ethnicities are differentially affected by ASD (Elsabbagh et al., 2012). There could be multiple factors influencing the lower prevalence amongst minorities in the United States. Firstly, Elsabbagh et al. (2012) argue that poor service availability amongst minorities in the United States results in disorders like ASD being unreported. Secondly, they suggest that variable income levels affect service availability such that lower income earning individuals are less likely to report ASD at medical institutions (Elsabbagh et al., 2012). The ability to afford professional assistance, and the availability of said services, is influenced by ethnicity in the United States (Keen, Reid, & Arnone, 2010).

Ethnicity, furthermore, appears to influence the age of diagnosis and the impact of that diagnosis on the child. Studies done by Mandell et al. (2009) across the United States suggest that African American children are diagnosed at later stages in childhood than Caucasian children. They also found that black and Hispanic children do not have their diagnoses documented in their health and education records, which significantly impacts the quality of education and health care they receive. This was especially true of black children with low IQ scores (Mandell et al., 2009).

Mandell et al. (2009) did another study in the United States on medical records and found that black children were more likely to be diagnosed with childhood disorders other than ASD before they received a diagnosis of ASD – conduct disorder and adjustment disorders were the common choices to name a few. They found that Caucasian children were more likely to receive an ASD diagnosis before the alternatives. However, they go on to say that it is not possible to determine whether or not ethnicity is the result of these disparities, or if the disparity lies within the diagnostic process across cultures. However, what remains is a sense of disparity amongst different ethnicities with regards to ASD diagnoses.

Whilst the research predominantly originates in the United States, the evidence suggests that ethnicity influences the services available to children with ASD symptoms. Thus, when assessing what people know about ASD, one has to consider the population's ethnicity in order to allow for differences in how the disorder is perceived or reported.

### **2.3.2. Culture and ASD**

Culture is defined as “a group of people's way of life, consisting of predictable patterns of values, beliefs, attitudes and behaviours” (Mandell & Novak, 2005, p. 110). One would expect that culture, therefore, influences not only how one reacts to behaviour, but also how one perceives behaviour. Pachter and Harwood (1996) state that culture also affects the way in which people address deviations in behaviour (Mandell & Novak, 2005).

One's culture, beliefs and perceptions may impact one's interpretation of mental health symptoms. Daley (2004, as cited in Mandell & Novak, 2005) compared families in two countries in order to study the impact of culture on the perception and identification of symptoms of ASD. They found that Indian families based in India were more likely to notice a social interaction deficit in a child first, whereas American families based in the United States typically notice a delay in communication first (Mandell & Novak, 2005). This highlights the importance of social behaviour and interaction in India and suggests that in America, being able to communicate is of greater significance than how one behaves. This is significant as it suggests that development must be viewed within the cultural context. Bernier et al. (2010) and Daley (2002) raise an important issue with regards to ASD and culture (as cited in Kang-Yi, Grinker, & Mandell, 2013). They state that although the diagnostic criteria for ASD have been standardised across cultures, specific symptoms may

carry specific meaning in different cultures. Farver and Lee Shun (2000, as cited in Kang-Yi et al., 2013) found this to be true in South Korea. They discovered that Korean children spend more time playing alone and disengaging from social communication than the average Western child. In fact, 75% of Korean children's playtime is solitary. ASD is, however, defined by an inability to engage in social interaction. Thus, if not viewed within the context of Korean norms, the majority of Korean children would be diagnosed with a social interaction deficit. Freeth, Sheppard, Ramachandran, & Milne (2013, p. 2570) say that "it is likely that Western and Eastern cultures may differ in the expression of, and also perhaps the perception of, autistic symptomatology." This highlights the importance of viewing a child and his or her symptoms within the cultural context that they present.

Context is significant when viewing features of ASD in African cultures as well. The inability to make eye contact is considered a significant symptom of ASD (Autism Speaks, 2013a). However, when looking closely at other cultures, one might find that a lack of eye contact has a particular meaning. In the Zulu culture in South Africa, for example, children do not make eye contact with elders out of respect for them (Rudwick, 2008). This is also the case in many Asian countries (Matson et al., 2011). Symptoms must be viewed within the cultural context in which they present in order to be understood.

Moreover, culture can influence the treatment and acceptance of ASD (Bernier et al., 2010). Children presenting with symptoms consistent with ASD in Africa are often believed to be possessed by evil spirits (Ori, 2010). In Ethiopia, there have been cases of children presenting with core symptoms who were tied up and locked away in order to be hidden from the world for their unusual behavioural patterns (Haileselassie, 2011). Furthermore, traditional healers and spiritualists are often sought in Africa when intervention is required to understand illness

(Naidoo, Shabalala, & Bawa, 2003). This help-seeking behaviour impacts what is known about the prevalence of ASD on the African continent, as this data is not always available in public records (Bakare & Munir, 2011a).

When assessing what is generally known about ASD, one has to keep in mind that culture informs what people understand and perceive to be deviant development. An assessment tool that gauges understanding of ASD must take cultural factors into consideration. One way that this can be addressed is to include experts with the same culture as the target population to collaborate in the process of producing assessment measures.

ASD has globally recognised symptoms but these symptoms may be interpreted differently across different cultures. This was discussed generally above, but in light of this study, it is important to understand how ASD is viewed, diagnosed and treated in Africa and South Africa more specifically. This is discussed below.

#### **2.4. Autism Spectrum Disorder in Africa**

Some cases have been reported where autistic African children were viewed as possessed, however, limited knowledge of ASD in Africa paints an incomplete picture (Bakare et al., 2008). There is now no doubt that ASD exists in Africa amongst African children (Ametepee & Chitiyo, 2009). A brief historical perspective of ASD in Africa is discussed below.

Thereafter, recent studies will be highlighted.



#### **2.4.1. An historical perspective**

As early as the 1970s, reports of ASD in Africa were recorded by Victor Lotter (Elsabbagh et al., 2012). Lotter studied a sample of children with mental retardation, across nine major cities in six African countries (Ametepée & Chitiyo, 2009). He worked in Ghana, Kenya, Nigeria, Zimbabwe, Zambia and South Africa and diagnosed nine out of 1312 children with autism (Bakare & Munir, 2011b).

Firstly, Lotter's findings suggested that boys present with ASD more frequently than girls (Ametepée & Chitiyo, 2009). This result was consistent with cases documented in North America at the time (Ametepée & Chitiyo, 2009). Secondly, Lotter observed core ASD symptoms in his sample group: namely, impairments in communicative ability and social interaction, stereotypical behaviours and limited interests. However, some of the more common ritualistic behaviours – such as rocking, flapping and self-aggression - were not identified in his sample (Ametepée & Chitiyo, 2009). Mankoski et al. (2006) confirmed this disparity and found that African children manifest unique ritualistic behaviours such as twisting. Thirdly, Lotter concluded that ASD is co-morbid with low intellectual functioning. However, his sample consisted of children with mental retardation and thus the validity of his findings was questioned (Ametepée & Chitiyo, 2009).

Thus, Lotter's research concluded that ASD in Africa occurs more frequently in boys, is associated with low intellectual functioning, and that it presents similarly to Western cases despite unique attributes. His findings form the basis from which all ASD research in Africa has developed, however, he has been criticised for representing an uneven sample group (Ametepée & Chitiyo, 2009).

#### **2.4.2. Recent studies across Africa**

More recently, Belhadj et al. (2006, cited in Bakare & Munir, 2011b) studied the link between intellectual functioning and autism. They confirmed Lotter's findings and stated that low intellectual functioning was a co-morbid disability in 60% of the African autistic children they studied in Tunisia. Furthermore, Lotter's observation regarding the gender ratio persists today. The CDC (2014) recently published findings that state that boys present with ASD almost five times more frequently than girls.

However, ASD research in Africa is limited. According to a study conducted by Bakare and Munir (2011a), only nine articles on ASD in Africa were published between January 2000 and December 2009 (Bakare & Munir, 2011a; Ametepee & Chitiyo, 2009). Furthermore, a statistical study on 764 globally published journal articles on ASD confirmed that 78% and 16% were from North America and Europe respectively (Springer et al., 2013). Only 4% of the articles represented the rest of the world, which includes Africa (Springer et al., 2013). Thus, very little is known about the prevalence of ASD in Africa (Bakare & Munir, 2011a). Substantial conclusions cannot be made regarding specific prevalence rates of ASD on the continent, or how it may present in this context.

Although few studies have been done on ASD in Africa, those that have documented specific cases, have noted that there are more non-verbal cases than verbal cases (Bakare & Munir, 2011c). This could suggest that autistic children in Africa present as mute and that many are unable to develop language skills whatsoever (Bakare & Munir, 2011c). A study done in Tunisia reported a similar observation: fifty one percent of the cases were non-verbal in nature (Belhadj et al., 2006, as cited in Bakare & Munir, 2011c). The same trend was noticed

in Tanzania where Mankoski et al. (2006) observed that seventy one percent of the cases were non-verbal. This is significant as it may highlight a specific combination of symptoms associated with African autistic children (Belhadj et al., 2006, cited in Bakare & Munir, 2011c; Mankoski et al., 2006). However, this could also be explained by the possibility of a higher reporting rate amongst non-verbal children due to more easily identifiable atypical development. Thus, broad conclusions regarding this issue cannot be made.

One of the reasons for the limited data in Africa relates to the availability of resources. Ametepee and Chitiyo (2009) state that what is known about ASD in Africa appears to be isolated to elite families who have access to extensive medical care in major cities. Medical care is usually provided in major cities where wealthier families reside (Ametepee & Chitiyo, 2009). Thus, records of ASD pertain to families with access to said medical care. This could explain the overrepresentation of elite African families in the literature on ASD in Africa. Moreover, research is usually done via an institution, such as a hospital, which the average African family cannot afford to attend (Ametepee & Chitiyo, 2009). Thus, very little is known about the status of ASD in rural Africa.

Finally, mental health issues appear to be diagnosed late in Africa and amongst individuals of African descent. There are cases in Nigeria where the first time that patients with mental health needs received traditional medical care was in adolescence (Bakare et al., 2008). Furthermore, Mandell et al. (2005) observed that African American children were diagnosed a year and a half later than the average Caucasian child in the United States. This is not an issue isolated to Africa but to Africans abroad.

The historical and recent studies in Africa mentioned demonstrate the little that is known about ASD on the continent to date. They also highlight the challenges facing professionals when it comes to diagnosing this disorder. ASD in South Africa is discussed specifically below.

## **2.5. Autism Spectrum Disorder in South Africa**

As is the case with Africa as a whole, the prevalence rate of ASD in South Africa is not known (Springer et al., 2013). No epidemiological studies have been conducted to date in South Africa and the impact of ASD on the South African population is unknown (Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013). In South Africa, the terms ASD and PDD continue to be used interchangeably despite the updated diagnostic criteria in the DSM 5 (Springer et al., 2013). There is a great need for research on ASD and related issues in South Africa.

As already highlighted, global prevalence rates are increasing. Research shows that Autism Spectrum Disorder (ASD) is the fastest growing childhood disorder in the world (Imran et al., 2011). Based on prevalence rates in the United States from 2007, it is implied that 270 000 people in South Africa could have ASD, and this number may be increasing by 5000 cases per year (Springer et al., 2013). Springer et al. (2013) state that there was an 8.2% increase in the number of cases presenting with ASD symptoms in Johannesburg between 1996 and 2005. This echoes global trends of increase in prevalence and highlights the need for autism awareness and research in South Africa.

As previously noted, Bakare and Munir (2011a) found that African autistic children are frequently non-verbal. In South Africa, Springer et al. (2013) conducted a study in the Western Cape to determine how South African children present verbally. If a child used more than 10 independent words (not echoed), they were considered to be verbal. If they used less than 10 words, they were classified as non-verbal. 72% of their cases were non-verbal, reflecting a trend commonly found in previous studies.

### **2.5.1. Difficulties relating to ASD in South Africa**

According to Malcolm-Smith et al. (2013) intervention for ASD is scarce and it is likely that ASD cases are undiagnosed in South Africa. One reason for this is the lack of service availability in disadvantaged communities (Malcolm-Smith et al., 2013). They state that one of the challenges facing South Africa with regards to ASD is that even when the disorder is identified, there is no intervention network to support the child (Malcolm-Smith et al., 2013). Doctors are reluctant to refer cases from rural areas due to the limited resources available. This hinders the long-term prognosis of the autistic child (Malcolm-Smith et al., 2013).

The second challenge pertaining to ASD in South Africa relates to assessment. Standardised measures have not yet been devised in all the national languages, making it difficult to screen for ASD in South Africa (Malcolm-Smith et al., 2013). However, screening tools are being translated and adapted for use in South Africa through the University of Cape Town (UCT) (Malcolm-Smith et al., 2013). There is a growing need for culturally sensitive resources in South Africa, which aim to inform practices surrounding disorders like ASD. Research is also being conducted at UCT regarding the Early Start Denver Model that may prove to be a cost-

effective and relevant intervention method that can be delivered by parents in the South African context (Malcolm-Smith et al., 2013).

A third issue relating to the diagnosis of ASD in South Africa pertains to education levels. Keen et al. (2010) state that less educated parents are less likely to approach health care services in order to assess their child. According to UNICEF (2012), South African schools have a lower performance rate than many countries in Africa. This suggests that the education level of the average South African is below average. Uneducated parents are less likely to seek professional care for a child with deviant development (Keen et al., 2010). This directly impacts knowledge of the prevalence and baseline knowledge of ASD in South Africa, particularly in under-resourced communities.

A clear prevalence rate in South Africa may be unknown due to the vast number of people living in rural areas. Bakare and Munir (2011b) state that very little is known about ASD amongst the rural communities of Africa. This is echoed in trends across other African countries where the bulk of research is amongst elite families in cities, as previously discussed (Ametepee & Chitiyo, 2009). Whilst one cannot assume that this applies to South Africa, Mandell et al. (2005) state that research may result in data that is not a reflection of all communities.

Finally, due to the development in research on ASD globally, ASD can be diagnosed from as early as two years old (Mandell et al., 2005). However, studies described by Mandell et al. (2005) have shown that the global average regarding age of diagnosis is at school going age. Despite increased awareness and ability to identify core symptoms of ASD, children are not receiving the early intervention that optimizes their long-term prognosis (Mandell et al.,

2005). This highlights the need for increased ASD awareness in order to assist in the reduction of late diagnoses. Moreover, these findings highlight the significant role that educators play in identifying ASD. Children are typically diagnosed in their school going years. Due to the amount of time children spend at education facilities annually, educators are a primary target for ASD awareness research in South Africa.

Thus, what is known about ASD in South Africa remains inconclusive and there is a need for further research within this field in the South African context. There is a need for greater awareness of this childhood disorder amongst the general public and professionals, with a particular focus on educators. One way to gauge the level of awareness amongst educators is to conduct research that aims to measure what they know. Awareness studies appear to be pivotal starting points for ASD research as awareness precedes intervention.

## **2.6. Autism Spectrum Disorder awareness studies**

Despite developments in science and a greater understanding of ASD, there is wide variation amongst professionals when it comes to the diagnosis and treatment of ASD (Imran et al., 2012). This suggests that professionals have an unclear understanding of ASD. One way to gauge the level of awareness amongst professionals is to conduct research that aims to measure what professionals know. Awareness studies appear to be pivotal starting points for ASD research as awareness precedes intervention.

### **2.6.1. The importance of awareness studies**

Awareness studies are significant as they establish an area of need, which drives research.

They also highlight samples that require intervention and at times, highlight specific areas of need. ASD awareness studies specifically pinpoint the need for early intervention and education programmes amongst professionals. Furthermore, awareness studies on ASD set a platform from which further research can develop.

Frank-Briggs (2012) discusses the impact that knowledge and awareness of ASD has on long-term prognosis by referring to research done in Nigeria. ASD is relatively unknown in Nigeria and so, children are diagnosed at school-going age (Bakare et al., 2008). Other medical conditions, such as malaria and poor nutrition, often mask ASD, which can delay the diagnosis. This results in delayed intervention. Frank-Briggs (2012) states that delayed intervention negatively impacts the long-term prognosis for autistic children. She states that caretakers must be educated about ASD in order to assist in early identification of warning signs so as to inform an early intervention plan. The same can be said for educators who need to know how to identify ASD in children of school-going age.

Rhoades et al. (2007) further emphasise the importance of early diagnosis. They state that early intervention enables families to make appropriate education plans and to set up family support systems which drastically impact the success of the autistic child, and their family. Early identification of ASD is crucial for improving functioning of children with ASD (Mandell et al., 2005). Therefore, awareness studies on ASD that are used to inform education about ASD are vital as they enable early identification.

As highlighted, awareness precedes intervention. Thus, studies that aim to assess awareness levels also pave the way for further research. Very little is known about ASD in South Africa and an awareness study may be an effective starting point. Bakare and Munir (2011a) add



that low-level knowledge of ASD in Sub-Saharan Africa is a call to researchers to improve the knowledge and awareness of ASD amongst the general public.

Increasing public awareness of ASD in South Africa will improve identification of this developmental disorder (Springer et al., 2013). Bakare and Munir (2011a) suggest a school-based awareness study to improve knowledge of ASD. As a result, this research aims to improve knowledge of ASD by conducting school-based awareness studies. There is, therefore, a particular focus on what educators know about ASD.

### **2.6.2. ASD awareness studies around the world**

One of the first awareness studies on autism was conducted in Canada by Stone et al. (1987, as cited in Imran et al., 2012). They did a survey in the 1980s that showed that across various disciplines, professionals had an inaccurate idea of what autism was. The study revealed that professionals considered autism to be a temporary emotional disability (Imran et al., 2012). Their study has formed the basis from which other research has been built and their findings have recently been confirmed in more up-to-date studies done in the United States, Nigeria, India and Pakistan (Imran et al., 2012; Rhoades et al., 2007). Many of the awareness studies that follow Stone et al.'s (1987) research have also been conducted to assess knowledge of ASD amongst professionals across disciplines, in order to develop a greater understanding of the baseline knowledge of ASD in specific populations.

An awareness study done in France by Planch et al. (2004, as cited in Rhoades et al., 2007) showed that paediatricians minimised parents' concerns about ASD because they were unfamiliar with the details of the disorder (Rhoades et al., 2007). Fourth year medical

students were unable to discuss cause, onset, prognosis and treatment of Autism Disorder, and 33% of families found that paediatricians discussed unconventional and empirically unsupported therapy methods (Rhoades et al., 2007). Rhoades et al. (2007) state that this is significant as it suggests that healthcare professionals lack critical information about this developmental disorder and that that results in opportunities missed for successful intervention. This results in late or incorrect diagnoses, which impacts intervention.

Imran et al. (2012) conducted an awareness study in Pakistan. They used a questionnaire called "The Autism Survey Questionnaire" to assess awareness amongst health workers in Lahore. Doctors, speech therapists, psychologist, psychiatrists, paediatricians and neurologists were asked to join the study. Their survey consisted of a rating scale based on the DSM-IV-TR criteria for autism and had four sections. The first section asked about the volunteer's experience of autism. The second detailed symptoms and the volunteer was asked to list how significant the symptom was in diagnosing the disorder. The third section dealt with perceptions of autism and finally section four asked about treatment methods. The results of their study concluded that there is an unbalanced view of autism in Pakistan. The majority of professionals agreed on the basic diagnostic criteria, but not on the age of onset and how autism relates to speech delays. Most of the respondents believed that autism is a temporary childhood disorder. Furthermore, the respondents felt that autism is a form of Schizophrenia. One of the implications of these findings is that relevant professionals have a responsibility to disseminate accurate information to the public about autism in Pakistan (Imran et al., 2012).

Khanna and Jariwala (2012) researched pharmacists' knowledge of autism on the premise that autism is increasingly being managed with medication. They provided an online questionnaire that was available for one month. They emailed 2543 pharmacists in the state

of Mississippi in the United States and invited them to answer the questionnaire. One hundred and fifty two participants responded and answered the online questionnaire. The questionnaire consisted of Likert scale, true/false and open-ended questions. The study revealed that 23% of the respondents did not know that autism is a developmental disorder and 32% did not know that it has genetic origins.

Rhoades et al. (2007) also did an online survey in the United States of America. Their sample consisted of 146 people from Virginia who were either parents or caretakers of individuals with autism. Their survey assessed demographics, the diagnostic process, sources of support and the need for local services relating to children with autism. Their specific awareness focus was based on the age of diagnosis, however, the survey revealed that paediatricians and health care workers in Virginia were unable to provide families with the correct information about autism. They discovered that only 20% of the participants found out what they know about autism from professionals; the majority educated themselves about autism via the Internet. This study also identifies a need to educate professionals and the general public about autism.

### **2.6.3. Awareness amongst educators**

Williams, Schroeder, Carvalhc and Cervantes (2011) conducted a pilot study of educators using a perceptions and knowledge survey. Their survey was given to a randomized sample of 54 educational graduate programme students in the South Western United States. They argued that school-based intervention for children with autism is on the increase and thus, educators must know how to identify autism. The perception section consisted of 12 Likert scale questions. The knowledge section had 15 open-ended questions about definitions,

diagnosis and treatment of autism. Williams et al. (2011) found that their participants' perceptions of autism were within the average range, whilst their factual knowledge of autism was within the low to average range. They concluded that professionals must be cautious about assuming that education staff understand autism. Their study established a need for education about autism amongst educators.

A study conducted in Great Britain investigated what educators in both the mainstream and special needs sectors knew about disorders like ASD (York, van Fraunhofer, Turk, & Sedgwick, 1999). One hundred and two questionnaires were completed by special needs staff and 40 questionnaires were completed by mainstream educators (York et al., 1999). Their study found that 99% of the special needs educators and 100% of the mainstream educators knew what ASD was (York et al., 1999). Sixty seven percent of special needs educators and 27% of mainstream educators had experience teaching a child with ASD (York et al., 1999). The most frequently observed features of ASD were social and communication difficulties, obsessive behaviour traits, lack of eye contact and the lack of defining physical features (York et al., 1999). The study concluded that their sample had a reasonably good level of knowledge and awareness of ASD (York et al., 1999).

Another study conducted in Karachi, Pakistan, amongst 170 primary school educators revealed that 55% of the educators knew about ASD as a result of media exposure (Arif, Niazy, Hassan, & Ahmed, 2013). Nine percent of educators reported that they had had formal training on ASD (Arif et al., 2013). Fifty seven percent of the educators indicated that proper training would be useful for educators (Arif et al., 2013).

A study conducted by Lian et al. (2007) in Singapore amongst 503 educators revealed that 68% of educators in their study had sufficient knowledge of ASD to pass a knowledge assessment test. Four percent scored 100% on the measure (Lian et al., 2007). Their study concluded that there were significant deficits in educator knowledge of childhood developmental disorders generally and that the majority of educators possessed a minimum level of knowledge of ASD (Lian et al., 2007). Their study also revealed a general lack of knowledge regarding the impact of early intervention for children with ASD (Lian et al., 2007).

These awareness studies highlight the varying range of ASD awareness amongst educators awareness. Some populations have a good knowledge base and others do not. Furthermore, what South African educators know about ASD has not been established. As a result, this study aims to assess educator knowledge through an awareness study. In order to do this, an awareness measure is required. The KCAHW questionnaire is discussed below.

#### **2.6.4. The KCAHW awareness study**

In May 2007, the African Network for the Prevention and Protection Against Child Abuse and Neglect (ANPPCAN) collaborated with the World Bank in order to carry out an ASD awareness survey in Nigeria (Bakare et al., 2008). This research was initiated on the presumption that under-resourced communities have limited knowledge of ASD (Bakare et al., 2008). The survey revealed that the public had a low level of knowledge of ASD and that health care workers had a low to average level of knowledge and awareness. The results were contrary to global trends of growing ASD awareness (Bakare et al., 2008). Furthermore, the survey questionnaire used by ANPPCAN and the World Bank appeared to be problematic in that it was not easily understandable or accessible (Bakare et al., 2008). As a result, Bakare et

al. (2008) modified the questionnaire and devised the “Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire” (refer to Appendix 1).

Bakare et al. (2008) state that in order to improve an autistic child’s prognosis, early intervention is critical. Thus, the KCAHW questionnaire was devised to achieve two goals: firstly to establish a baseline of knowledge of ASD; secondly to create a tool that could inform education campaigns in Nigeria amongst health care professionals (Bakare et al., 2008).

Bakare et al. (2008) administered the KCAHW questionnaire twice and their study involved a test re-test methodology. The health care workers, on average, obtained very low scores on the KCAHW Questionnaire. The total mean scores for the two tests were 9.6 and 9.8 respectively. This indicates that the health care workers knew very little about ASD and that intervention was required in order to increase awareness of ASD in Nigeria (Bakare et al., 2008).

Bakare et al. (2008) analysed the questionnaire according to Cronbach's alpha and the result indicated that the English KCAHW questionnaire has a good internal consistency. They also evaluated mean scores to determine the questionnaire’s reliability over time. The KCAHW questionnaire is therefore a reliable questionnaire as documented by Bakare et al. (2008). In addition, it was concluded that it could be applied to other developing countries within Sub-Saharan Africa where knowledge of ASD is limited (Bakare et al., 2008). It is particularly useful in developing countries where little is known about ASD as it can inform policy formulation regarding professional education (Bakare et al., 2008).

Bakare et al. (2008) discuss several reasons for low levels of knowledge and awareness of ASD amongst Nigerian health care workers. The first relates to exposure. Most of the ASD research originates in the US and there is limited exposure in Africa. Secondly, there is a lack of working experience with ASD. They suggest that ASD is undiagnosed due to an inability to recognise the disorder as a result of low levels of knowledge and awareness. The third reason may be culturally oriented. According to Bakare et al. (2008), ASD may not be diagnosed due to discrimination and stigmatization associated with developmental disorders of this nature in Nigeria.

## **2.7. The KCAHW questionnaire in the South African context**

ASD awareness studies are significant for a number of reasons. Firstly, awareness studies highlight areas of need and can inform interventions that impact the long-term prognosis of children with ASD. Secondly, awareness studies can inform psycho-education that aims to assist and support families. Thirdly, awareness studies in schools aim to inform educators about ASD in order to enable them to identify the disorder early. This positively impacts prognosis as well.

Bakare et al. (2008) concluded that the KCAHW questionnaire is useful in Sub-Saharan Africa because the baseline knowledge of ASD is not established. The KCAHW is a tool that assesses the baseline knowledge of ASD. It is particularly useful in developing countries because there is low knowledge and awareness of ASD in developed countries as a result of limited ASD research production (Bakare et al., 2008). Moreover, it is useful in communities with limited resources because under-resourced regions are usually the most uninformed about ASD (Bakare et al., 2008). The KCAHW questionnaire thus aims to assess the levels of

knowledge and awareness of ASD in order to inform education programmes. The KCAHW questionnaire could therefore be an appropriate awareness measure for use in the South African context to assess the baseline knowledge of ASD amongst educators.

A questionnaire devised in Nigeria is not necessarily relevant to the South African context. Researchers have found that developing culturally relevant resources is complex, as cultural aspects have to be considered carefully. Wilford (2012) assessed the *isiZulu* version of the Autism Diagnostic Observation Schedule [ADOS]. ADOS picture cards, for example, had to be altered to reflect South African cultural practices: Americanised scenes were replaced with South African village scenes and white-skinned dolls were replaced with dark-skinned dolls. In terms of using the KCAHW questionnaire in South African context, steps need to be taken to ensure that it is culturally relevant. One way in which the KCAHW questionnaire can be made more culturally relevant is to translate it into a South African language. Sperber (2004) states that the translation and adaptation of a measure must be implemented with attention to critical issues. Two such issues are reliability and validity, which will be outlined below.

### **2.7.1. Measure adaptation: reliability and validity**

Critical issues when adapting a measure are reliability and validity. Reliability of a measure is defined as “the consistency with which it measures whatever it measures” (Roodt, 2013a, p. 48). Validity, on the other hand, concerns “what the test measures and how well it does so” (Roodt, 2013b, p.58). However, establishing reliability and validity can be a challenging and intricate process.



Reliability is established by means of statistical analysis. When calculating the reliability of a measure, a degree of error may still exist because subjects are not fixed in their subjective presence when exposed to a test or measure (Roodt, 2013a). This implies that scores when assessing reliability are not necessarily a true reflection of the measure but rather an estimation. Respondent error refers to an error made by the participant (Roodt, 2013a). Common errors include incomplete answering, systematically answered sets or when knowledge is falsified (Roodt, 2013a). Administrative error refers to errors due to non-standardised assessment practices across settings (Roodt, 2013a). Errors could include variations in instructions, assessment conditions, interpretation or scoring procedures (Roodt, 2013a).

“The validity of a measure is directly proportional to its reliability” (Roodt, 2013b, p.65). Thus, various types of validity are also important in developing a measure. The first type that is pertinent to this research is content validity and more specifically face validity. Face validity refers to what the measure appears to measure (Roodt, 2013b). For this process, a trusted expert assesses the look and feel of a measure in order to determine its desirability (Roodt, 2013b). The second is construct validity and more specifically factorial validity. This type of validity is used when constructing a new measure and involves running a factor analysis in order to reveal the underlying dimensions of a measure (Roodt, 2013b). This type of validity is also useful in determining the structure of a measure (Roodt, 2013b).

When adapting a measure into another language, reliability and validity become central in determining the usefulness of the measure. However, before these two criteria can be assessed, the measure has to be translated.

### **2.7.2. Measure adaptation: translation issues**

Translation is defined as the process whereby “the meaning and expression in one language (source) is tuned with the meaning of another (target) whether the medium is spoken, written or signed” (Crystal, 1991, p. 346 as cited in Regmi, Naidoo, & Pilkington, 2010). The majority of South Africans have inadequate access to psychological services due to the lack of translated resources (Modell, Balchin, & Ameen, 2010). The need to produce a translated questionnaire has been established but translation is a multifaceted task and can be fraught with challenges.

Firstly, South Africa has 11 official languages and despite the need for translated tools and measures, it is a complex task to develop measures that carry test equivalence (Bornman, Sevcik, Ronski, & Pae, 2010). Thus, Bornman et al. (2010) state that a linguistic focus when translating may yield results that are unfavourable. Conceptual equivalence, as opposed to linguistic equivalence, involves applying cultural knowledge to the language used in translation (Bornman et al., 2010). Close examination of the translations at various stages within the translation process aims to ensure that equivalence is gained (Regmi et al., 2010). Emmel (1998, as cited in Regmi et al., 2010) states that it is important for the researcher to discuss meaning discrepancies with the translators in order to ensure that the closest meaning is obtained.

In order to devise a reliable translation, equivalence is an important criterion. Flaherty et al. (1998, as cited in Regmi et al., 2010) further confirm the need for semantic, criterion and conceptual equivalence when translating. Semantic equivalence refers to similarity of

meaning and ensures that the translation carries the same meaning as the original. Criterion equivalence ensures that the translation is in line with the target culture.

There is a debate as to whether or not a concept keeps its meaning through the translation process (Chang et al., 1999; Flaherty et al., 1988, as cited in Regmi et al., 2010). In the case of the KCAHW questionnaire, this refers to whether or not the translated measure actually measures knowledge of ASD, and further, whether the concept of autism is captured in the translation process. It is not enough to simply translate a measure from English to *isiZulu*. The challenge is to devise a measure that is “culturally relevant and comprehensible while maintaining the meaning and intent of the original” (Sperber, 2004, p. 124). Due to the fact that the original KCAHW was constructed in English, there is the risk that the questionnaire is culturally hegemonic (Sperber, 2004). However, since it was made by Africans in Africa, this risk is reduced.

The significance of securing a valid translation lies in the fact that the failure to do so results in erroneous data (Sperber, 2004). There are various types of problems relating to translation that Sperber (2004) outlines. The first is related to the failure to include cultural nuances. This is particularly significant with regards to technical terms, jargon and slang words. The second issue relates to words that may carry multiple meanings in the target language. Here, the translators may need to make use of examples to clarify meaning (e.g. explaining the nuance of a *social smile*). Thirdly, excellent translations do not necessarily equate to cultural relevance. Sperber (2004) relates a case whereby an excellently translated health insurance questionnaire was administered in Israel. Despite the faultless translation, the participants failed to understand the questions, as they had no personal understanding of health insurance, as it is a service provided by the state in Israel.

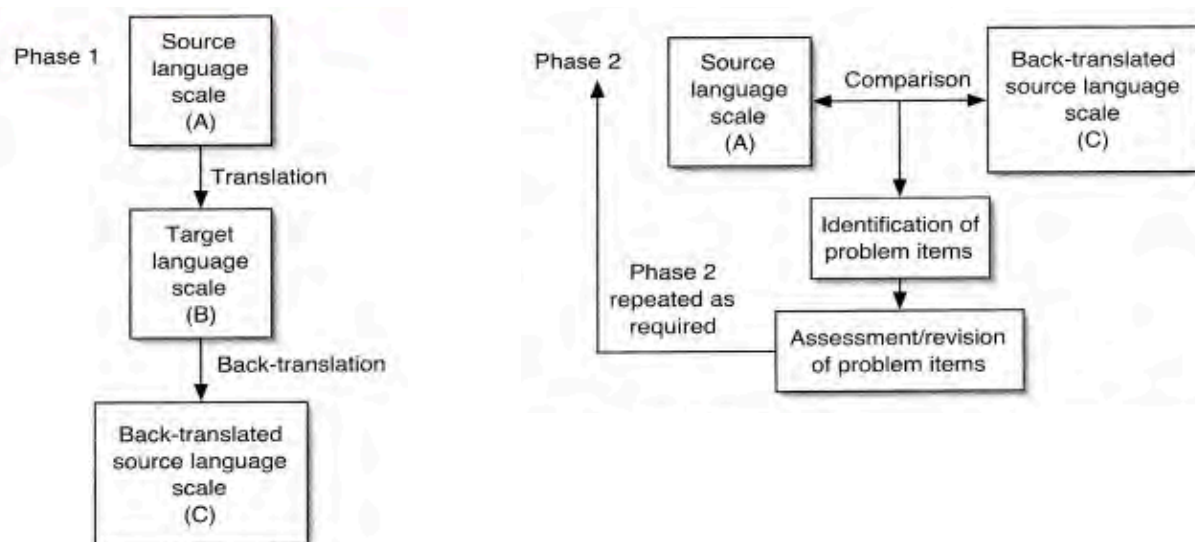
Furthermore, studies suggest that there is substantial psychological and behavioural variation amongst the human population (Henrich, Heine, & Norenzayan, 2010). As a result, it is impossible to predict whether or not two *isiZulu* samples will perform similarly when faced with the same psychological or behavioural process such as answering a questionnaire.

Research in the USA amongst university students shows that student samples perform in highly unusual ways and are often unrepresentative of the greater population in spite of their frequent use in studies that aim to produce generalisable results (Henrich et al., 2010).

However, similarities do also exist across populations and variation in performance may be due to environmental or demographic differences (Henrich et al., 2010). Thus, when assessing the usefulness of a translated measure in two different samples, one has to bear these challenges in mind.

Thus in conclusion, there are great challenges involved in translating the KCAHW questionnaire into *isiZulu*. According to Brislin's cross-cultural model of translation, a text must be translated into the target language by at least two translators and then one of the translators should back-translate the text back into the original language in order to assess the translation's accuracy (Regmi et al., 2010). Bornman et al. (2010) reinforce the proposal to use Brislin's model as it allows for linguistic and conceptual equivalence. According to Sperber (2004) however, Brislin's method can create problems when there is no communication between the researcher and the translators. She states that in order to secure a valid translation, the original translation has to be adjusted as discrepancies are found and that the inclusion of an expert is imperative. Therefore, a combination of the two models will be employed. Refer to Figure 1 for a flow chart of the recommended procedures regarding the translation process.

**Figure 1.** A flow chart depicting a valid translation process (Sperber, 2004)



## 2.8. Conclusion

In this chapter, the history of ASD and its evolution with regards to diagnostic criteria were explored. The changes in the DSM 5 were a particular focus. The epidemiology of the disorder was then outlined as well as the impact of ethnicity and culture on the perceptions and diagnosis of ASD. ASD in the African context was then examined. There was a specific focus on South Africa and the challenges faced in identifying ASD amongst South African children. The importance of early intervention was highlighted and awareness studies as a means of measuring knowledge of ASD amongst professionals and the public were discussed. Awareness studies from around the world and amongst educators, more specifically, were examined. The need for a tool to measure what educators know about ASD was established and the KCAHW questionnaire was introduced. However, in order to prioritise cultural relevance, the KCAHW questionnaire requires adaptation and translation into appropriate languages for the South African context. The challenges with regards to measure adaptation were discussed, with a specific focus on reliability, validity and translation.

## 2.9. Aim and rationale

ASD is complex and falls on a spectrum. It is further complicated by the recent change in the diagnostic system. The prevalence of ASD around the world indicates that it is a syndrome of concern but the lack of research in Africa and South Africa makes it hard to know what the situation is locally. Children are likely not to be diagnosed which results in a missed opportunity for early intervention. The research on ASD in Africa is limited. Part of the problem lies in identifying children with symptoms, which are not going to be recognised in a context of poor awareness and alternative meaning systems. In this context, educators form an important resource as they are often the first to pick up difficulties with children when they enter the schooling system. It is therefore important to know about awareness of ASD in the general population, amongst professionals and amongst educators in particular. Awareness studies have revealed that professionals have poor awareness of ASD. However, what educators in South Africa know about ASD has yet to be established. In order to establish awareness an appropriate tool needs to be utilised. In order to try to ensure that this tool is most useful it needs to be translated into a local language so that the results are not confounded by language issues.

This study therefore had two aims:

The first aim was to translate the KCAHW questionnaire from the original English into *isiZulu* and then to assess its reliability as an *isiZulu* measure. A possible outcome would be the development of a reliable *isiZulu* measure of ASD awareness. The second aim of this research was to assess knowledge of ASD amongst educators in Pietermaritzburg using the translated KCAHW questionnaire.

Therefore, this study had two questions that it aimed to answer. Firstly, regarding the translated KCAHW questionnaire: is the *isiZulu* KCAHW questionnaire a reliable measure of knowledge of ASD? Secondly, with regards to the baseline knowledge of ASD amongst educators, this study aimed to answer the following question: what do educators in Edendale know about identifying the core symptoms of Autism Spectrum Disorder?

The methods involved in developing a reliable measure of knowledge, as well as the steps required to assess knowledge of ASD are outlined in chapter three below.

## CHAPTER THREE

### METHODOLOGY

This chapter outlines the methods used to conduct this research. It firstly discusses the measure used and the adaptations to it for the South African context. The research design is described with the specific phases in detail. Phase one describes the translation process of the KCAHW questionnaire. In phase two the questionnaire was tested in a pilot study. This also involved the reliability testing of the questionnaire. Phase three aimed to identify what educators know about ASD. Sampling, data collection and data analysis are discussed. Finally, the ethical considerations of this study are highlighted.

#### **3.1 The KCAHW questionnaire**

The Knowledge about Childhood Autism among Health Workers (KCAHW) questionnaire was devised by Bakare et al. (2008) in 2007. The questionnaire was chosen for this study due to its origination in Africa, its reliability and its usefulness in developing countries with low-level knowledge of ASD, specifically in communities where resources are limited (Bakare et al., 2008).

The KCAHW questionnaire is a paper and pencil test with 19 questions divided into four domains. Refer to Table 3 for a list of the items in the questionnaire devised by Bakare et. al. (2008). Each domain addresses a different aspect of ASD according to the DSM-IV-TR diagnostic criteria. Domain one addresses difficulties associated with social interaction; domain two deals with communication; domain three addresses obsessive patterns of behaviour; and finally, domain four is based on the diagnostic criteria for ASD and the



Table 3

*Items on the KCAHW questionnaire by Bakare et al. (2008)*

<b>Domain 1: social interaction symptoms</b>		<b>Answers</b>
1	Marked impairment in use of multiple non-verbal behaviours such as eye-to-eye contact, facial expression, body postures and gestures during social interaction?	(A) Don't Know (B) Yes (C) No
2	Failure to develop peer relationship appropriate for developmental age?	(A) Don't Know (B) Yes (C) No
3	Lack of spontaneous will to share enjoyment, interest or activities with other people?	(A) Don't Know (B) Yes (C) No
4	Lack of social or emotional reciprocity?	(A) Don't Know (B) Yes (C) No
5	Staring into open space and not focusing on any thing specific?	(A) Don't Know (B) Yes (C) No
6	The child can appear as if deaf or dumb?	(A) Don't Know (B) Yes (C) No
7	Loss of interest in the environment and surroundings?	(A) Don't Know (B) Yes (C) No
8	Social smile is usually absent in a child with autism?	(A) Don't Know (B) Yes (C) No
<b>Domain 2: communication symptoms</b>		
1	Delay or total lack of development of spoken language?	(A) Don't Know (B) Yes (C) No
<b>Domain 3: behaviour symptoms</b>		
1	Stereotyped and repetitive movement (e.g. hand or finger flapping or twisting)?	(A) Don't Know (B) Yes (C) No
2	May be associated with abnormal eating habit?	(A) Don't Know (B) Yes (C) No
3	Persistent preoccupation with parts of objects?	(A) Don't Know (B) Yes (C) No
4	Love for regimented routine activities?	(A) Don't Know (B) Yes (C) No
<b>Domain 4: etiology of ASD</b>		
1	Autism is Childhood Schizophrenia?	(A) Don't Know (B) Yes (C) No
2	Autism is an auto-immune condition?	(A) Don't Know (B) Yes (C) No
3	Autism is a neuro-developmental disorder?	(A) Don't Know (B) Yes (C) No
4	Autism could be associated with Mental Retardation?	(A) Don't Know (B) Yes (C) No
5	Autism could be associated with Epilepsy?	(A) Don't Know (B) Yes (C) No
6	Onset of autism is usually in, (A) neonatal age, (B) infancy, (C) childhood.	(A), (B) or (C)

etiology of the disorder. There are a total of 19 questions in the survey, all in multiple-choice format with three possible answers: yes, no or unsure. Question 19 also has three possible answers but the options relate to specific age groups. A score of one point is allocated to a correct answer, and zero to an incorrect answer. Therefore, a maximum score of 19 points is possible; a minimum score of 0 is possible.

### **3.1.1. The KCAHW questionnaire and the DSM 5**

The KCAHW questionnaire was formulated using the DSM-IV-TR criteria for autism. The DSM 5 diagnosis for autism has changed and it is now referred to as Autism Spectrum Disorder as discussed. Autism in the DSM-IV-TR was defined by three major diagnostic criteria, namely: impaired social interaction skills, impaired social communication skills and a display of repetitive and restrictive behaviours. These three criteria are reflected as domain one, two and three respectively in the KCAHW questionnaire. In the DSM 5, ASD is diagnosed on the basis of two criteria, namely: impaired social communication and interaction, and restricted repetitive behaviours (APA, 2013). Symptoms associated with impaired social communication and interaction are reflected in domains one and two respectively. Repetitive behavioural symptoms are reflected in domain three. Thus, the KCAHW questionnaire remains an adequate representation of the new criteria for ASD. It seems likely that the changes in the DSM 5 will not directly impact the usefulness of the KCAHW questionnaire

## **3.2 Research design**

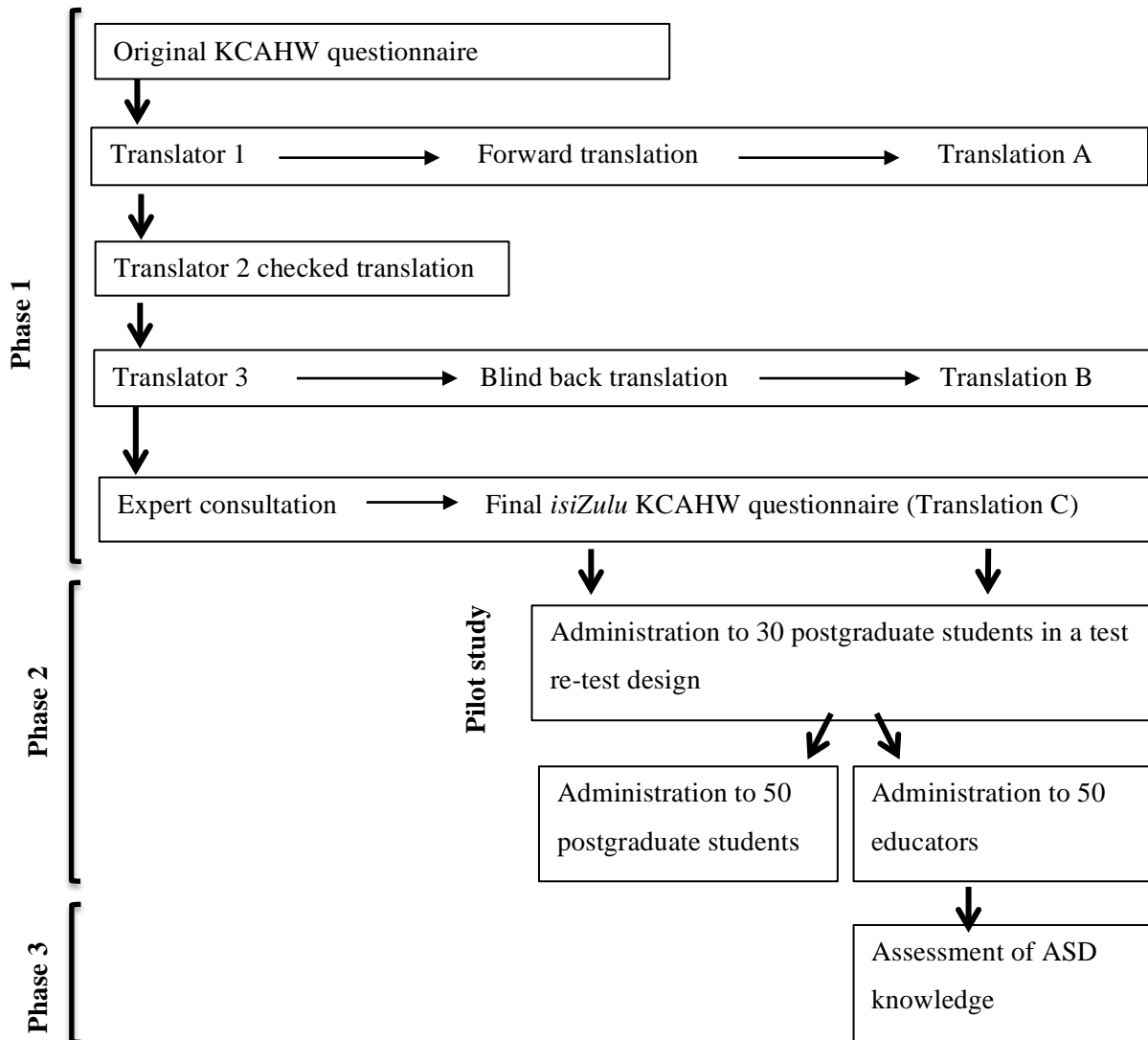
This research followed a quantitative design. Quantitative research is based on data that is

numeric and that can be analysed statistically (Durrheim, 1999b). This study aimed to produce an *isiZulu* KCAHW questionnaire that is reliable in the South African context. This process involved several steps in three distinct phases. Phase one involved the translation of the instrument. Phase two was focussed on assessing the reliability of the *isiZulu* questionnaire. This was done by administering the questionnaire to a group of post graduate psychology students and thereafter to the sample of educators. Phase three involved assessing what educators know about ASD by administering the *isiZulu* questionnaire. These phases are outlined in more detail below. Refer to Diagram 1 for a visual depiction of the process involved in this study.

### **3.2.1. Phase one**

In phase one of this study, the English KCAHW questionnaire devised by Bakare et al. (2008) was translated into *isiZulu*. The questionnaire was translated according to Brislin's model of blind back-translation in cross-cultural contexts (Regmi et al., 2010). However, according to Sperber (2004), Brislin's methodology can create problems when there is no communication between the researcher and the translators during the translation and checking phases. She states that in order to secure a valid translation, the original translation has to be adjusted as discrepancies are found and that the inclusion of an expert is imperative. Therefore a combination of both models was employed which is outlined below in Diagram 1 (Regmi et al., 2010; Sperber, 2004).

**Diagram 1.** A diagram depicting the three-phase process involved in this research



- a) Translator one translated the English questionnaire into *isiZulu* (Translation A).  
 Translator two checked the translation and made changes. The first and final copy of the forward translation can be found in Appendix 2.
- b) Translator three did a blind back-translation of the *isiZulu* questionnaire back into English (Translation B, see Appendix 3).
- c) The researcher compared translation A and B. Discrepancies were negotiated with Translator 3 and changes were implemented. This process highlighted the problem

items that required revision. At this point, criterion, conceptual and semantic equivalence were assessed. The problem items were revised by the translator and this process was repeated as required until equivalence was gained. The final back-translation and all changes made can be found in Appendix 3.

- d) The *isiZulu* questionnaire was reviewed by an experienced bilingual psychologist for linguistic and cultural discrepancies. Suggested changes were implemented accordingly (Translation C, see Appendix 4).

#### ***3.2.1.1. The isiZulu translation and back-translation***

Difficulties were encountered in the translation process due to the fact that some of the concepts cannot be directly translated into *isiZulu*. One such example was the word ‘Schizophrenia,’ which is predominantly referred to as ‘schizophrenia’ in spoken *isiZulu*. In such instances, a decision was made to include the technical *isiZulu* medical term as well as the term used in spoken *isiZulu*. Therefore, the *isiZulu* word *onezimilozimbili* was used, and the English term was placed in brackets to ensure conceptual understanding. Another example was the word ‘mental retardation’ used in domain four. One of the translators explained that in *isiZulu*, it is difficult to differentiate between mental retardation and mental disturbance and therefore, one term was used that reflects both.

Attempts were therefore made to maintain semantic accuracy, not necessarily linguistic accuracy (Regmi et al., 2010). A direct translation does not necessarily directly translate the same meaning when doing cross-cultural translation (Regmi et al., 2010).

### 3.2.1.2. *Translation adjustments*

All translators expressed that Domain 4 was the most challenging to translate. They stated that the medical jargon was complicated to express accurately in *isiZulu*. Words such as ‘schizophrenia,’ ‘epilepsy’ and ‘neonatal’ were challenging to translate as they are either expressed in English or by way of a description in spoken *isiZulu*. One of the drawbacks of the translation process of this study was the fact that the translators were not necessarily familiar with some of the technical jargon due to their inexperience in the medical and psychological fields. Translator A and B opted for code-switching and descriptive examples as a way of reducing the complexity of the jargon in order to add value to the translation. For example, in Domain 4 question 5: ‘epilepsy’ was translated and the term *isifo sokuwa* was also included. This term literally means “the disease where you fall down,” which is how epilepsy is referred to in spoken *isiZulu*.

Another way in which the translators reduced the complexity of the jargon was by making use of concrete examples where necessary. This was done in order to ensure conceptual translation, rather than a purely linguistic one. For example, in Domain 3 question 3 had to be clarified by means of an example. The *isiZulu* translation did not specify the difference between whole-object focus and part-object focus. Therefore, an example was included to ensure that the correct concept was being addressed.

Below is a summary reflecting a range of the conceptual discrepancies that were encountered and how the changes were implemented.

### *Domain one*

There was a conceptual discrepancy with regards to question four and the use of the term ‘emotional reciprocity.’ At first, the translators interpreted the concept to mean emotional intelligence. The translations were then adjusted to include the ‘give and take’ nature of reciprocity as opposed to emotional intelligence. *Ukuswela isenaniselo semizwa nangokuhlalisana nabanye* encapsulates the reciprocity intended in the question.

There was a conceptual discrepancy in question seven with regards to the concept of a social smile. A social smile is a developmental milestone and it occurs in response to something someone does (Iannelli, 2007). The issue of social smile was very difficult to convey at first, as the concept was not fully understood by all the parties involved. Once conceptual understanding was gained by means of extensive communication between the researcher and translators, the translations were adjusted to express the concept of a social smile accurately. A meaningful example was also included in brackets to ensure that the correct meaning was being conveyed to the participants.

### *Domain two*

There was a conceptual discrepancy in question one that was identified when comparing the back-translation with the original English KCAHW. The question addresses the language symptoms associated with ASD, namely the delay in speech development and/or the total lack of speech development. The *isiZulu* questionnaire did not clearly convey the latter. This is however critical in the African context where children with ASD are usually non-verbal (Bakare & Munir, 2011c). The translations were appropriately changed.

### *Domain three*

Question three required a conceptual adjustment to the *isiZulu* translation, as well as the back-translation. This question was concerned with the preoccupation with specific parts of a whole object. For example, children with ASD typically become fixated on the wheels of the car and not necessarily the car itself. The first back-translation referred to the inability to complete tasks. This was conceptually inaccurate and was therefore adjusted to refer to the tendency to be fixated on details, rather than whole objects. Additionally, an example was included in order to assist in the transference of the meaning.

Similarly, question four required a conceptual adjustment to both the *isiZulu* translation and back-translation. Question four is concerned with regimented routines amongst children with ASD. The first back-translation referred to the enjoyment of regimented routines but failed to encapsulate the insistence on routine. Adjustments were made appropriately.

### *Domain four*

Question six reflected a conceptual discrepancy. The terms used to refer to relevant developmental periods were subjective. As a result, specific age markers were included to refine the concepts. For example, infancy was defined as between zero and 24 months old. Both the *isiZulu* translation and back-translation were adjusted accordingly.

#### **3.2.1.3. Expert consultation**

Following the translation of the questionnaire it was submitted to two experts for scrutiny.



One of the experts assessed the *isiZulu* questionnaire for face validity. Face validity determines the extent to which the questionnaire appears to measure knowledge of ASD (Roodt, 2013b). The expert psychologist specifically analysed language and cultural discrepancies in the translated questionnaire. The questionnaire was also reviewed by a second expert psychologist for additional consultation.

Upon the advice of the two experts the *isiZulu* KCAHW questionnaire retained the use of the English word for autism, as “autism” is not a word commonly used in *isiZulu* and as a result there is no direct translation of the word. It was also suggested that a question be added to the instructions page, namely “Uyazi yoni ukuthi yini i-Autism?” which translates as, “Do you know what autism is?” This question was included as it allowed the researcher more clarity as to the departure point for each participant.

Other changes to specific items were made on the recommendations of the expert psychologist. It should be noted however that she highlighted the difficulties that exist in translating *isiZulu* as a result of dialects. She noted that one must be mindful of dialects when translating as it can result in confusion or misinterpretation.

#### ***3.2.1.4. Aesthetic changes to the questionnaire***

Once the questionnaire was translated, a few changes were made to the format of the questionnaire. The researcher changed the structure of the questionnaire in order to improve the aesthetics and user-friendliness of the questionnaire. This included inserting the original instructional remark at the beginning of each domain. A demographic section, an example question and an introduction question were also added.

Upon completion of the translation phase of the study, the questionnaire was ready for administration to the two sample populations in order to assess its reliability. Refer to Appendix 4 for the translated and complete *isiZulu* KCAHW questionnaire.

### **3.2.2. Phase two**

Phase 2 first involved testing the questionnaire in a pilot test with 30 psychology honours students at UKZN. Thereafter, the questionnaire was administered to 20 additional students and 50 educators.

#### ***3.2.2.1. The pilot study***

A pilot study was conducted to assess the reliability of the translated questionnaire prior to using it to assess educators' knowledge of ASD. Bakare et al. (2008) used a test re-test methodology to assess the reliability of the original measure. They administered the KCAHW questionnaire twice, to one sample, and compared the mean scores in order to identify whether or not the test measured knowledge of ASD consistently over time. Additionally, they calculated Cronbach's alpha to determine the internal consistency of the questionnaire.

The *isiZulu* questionnaire was piloted with 30 psychology honours students at UKZN, two weeks apart. These students were selected due to their accessibility to the researcher which made this a purposive sample. Students were informed that participation involved two test administrations and that the second administration would take place two weeks later. This first recruitment yielded five participants. Prior to the administration of the questionnaire to

the five participants, an information letter and consent form were provided (refer to Appendix 5). The *isiZulu* questionnaire was then administered to the participants. The test administration took approximately 15 minutes.

This process was repeated the following week in order to recruit more participants and an additional three participants volunteered to complete the questionnaire. The researcher concluded that the Pietermaritzburg honours class would not yield a sample big enough for the purpose of this study and so postgraduate students within the same school on the Howard College campus were recruited. Thirty five students who were fluent in *isiZulu* on the UKZN Howard campus were recruited.

Two weeks after each administration, the questionnaire was administered to the participants again. Thirty correctly completed questionnaires with time one and time two data resulted. The data was analysed statistically for reliability. Cronbach's alpha was calculated and the mean scores of the sample were compared. According to Schmitt (1996), alpha scores and correlations must be analysed to draw any conclusions about reliability. Thus, a correlation analysis was generated in order to identify Pearson's correlation coefficient. This was done in order to identify the relationship between the total scores from the test and re-test (Pallant, 2005).

#### ***3.2.2.2. The student and educator samples***

The next step was to administer the questionnaire to two parallel sample populations: postgraduate students and educators respectively. Firstly, the *isiZulu* KCAHW questionnaire was administered to an additional twenty *isiZulu* speaking postgraduate psychology students

in the School of Applied Human Sciences at the University of KwaZulu-Natal (UKZN) to increase the original sample size to 50. Of the original pilot test questionnaires, time one questionnaires were included in the final data set. Secondly, the *isiZulu* KCAHW questionnaire was administered to fifty *isiZulu* speaking educators in Edendale, Pietermaritzburg.

The aim of administering the questionnaire to two samples was to allow for two sets of data that could be compared in order to determine the factors that influence reliability. Firstly, this design allowed for two sets of data that could be analysed descriptively. The demographic information provided descriptions of the two samples, which were analysed to determine whether or not these factors influenced the reliability of the questionnaire. Demographic information included age, language and ethnicity. Secondly, two populations provided two data sets that could be analysed again for the reliability of the questionnaire: namely by an internal consistency determination.

### **3.2.3. Phase three**

In phase three of this study, the data collected from the educator sample was analysed statistically in order to assess the extent of knowledge of Autism Spectrum Disorders amongst the educators in Edendale, Pietermaritzburg. Answered questionnaires were scored in order to determine the individual scores as well as the scores for each domain. Individual scores indicated the baseline knowledge of educators. The mean score of the sample population was calculated in order to determine the average baseline across the sample population. The scores for each domain were calculated and analysed in order to determine whether or not specific domains were more familiar to educators. The data was also analysed

according to the demographic information provided in order to determine whether or not the results were correlated in any way.

### **3.3.Sampling**

This study made use of purposive and convenience sampling. Purposive sampling involves a selected sample group based on theoretical reasons; convenience sampling is based on the accessibility of a sample (Durrheim, 1999a). Participation was voluntary and there were no perceived risks to the participants.

Phase two of this study involved two sample groups: students and educators. Fifty participants were sufficient in each sample population in order to yield enough data to run parallel statistical analyses (van Voorhuis & Morgan, 2007). Participants had to be fluent in *isiZulu*. The samples were both purposive and convenient: they were purposive as participants were specifically selected on the basis of their first language; they were convenient due to the geographical availability and accessibility of the sample to the researcher.

#### **3.3.1. Student sample population**

Postgraduate students within the discipline of psychology were recruited due to their geographical location to the researcher, which also enabled an easy access to the large number of students in the school. Additionally this population was selected due to their demographic constellation which increased the likelihood of recruiting *isiZulu* speakers.

### **3.3.2. Educator sample population**

The second sample population was educators in Edendale. Schools were selected based on their inclusion in the Sizabantwana network. The Sizabantwana network refers to a group of under-resourced schools in Pietermaritzburg. These schools were chosen as a result of an already established partnership with UKZN through one of the thesis supervisors. Refer to Appendix 6 for a list of the Sizabantwana schools and specific target schools in Edendale.

The schools in the Sizabantwana network were analysed according to their geographical location. The specific target schools in Edendale were selected for this research for multiple reasons. Firstly, the schools are all in the same community, thus yielding results for a specific population. The schools are also within close proximity to one another, increasing the generalisability of the results for the Edendale community and similar communities. Thirdly, the schools are classified as Quintile one, two and three schools and are therefore under-resourced. Bakare et al. (2008) state that the KCAHW questionnaire is useful in under-resourced communities. Finally, the schools were the most geographically accessible to the researcher, which reduced the cost of the study.

### **3.4. Data Collection**

Data collection was done using the translated KCAHW questionnaire (refer to Appendix 4).

After the questionnaire was translated into *isiZulu* it was administered to two sample populations as described above. The questionnaire was a pencil and paper test and took a maximum of 30 minutes to complete. An explanation of instructions was listed on the questionnaire. Respondents were not asked to supply any identifying details. Participation

was voluntary and confidential. In phase two of this study, participants were given the *isiZulu* questionnaire to complete. The sample population consisted of 50 students and 50 educators respectively.

### **3.4.1. The student sample**

In addition to the original 30 participants recruited in the pilot study, the UKZN Pietermaritzburg psychology masters students were recruited in the same manner as the original sample. The group was approached and invited to participate in the study and the study was explained to them. Benefits, risks and confidentiality were explained. The students were advised that they could withdraw at any stage. The target sample population size was reached after one recruitment attempt.

#### ***3.4.1.1. Data collection considerations amongst the student population***

The researcher initially tried to recruit first language *isiZulu* speakers. It soon became apparent that a large portion of the Honours students are in fact not native speakers but are nevertheless fluent in *isiZulu*. Furthermore, a few first language *isiZulu* students related that they could not take part as they do not speak or read *isiZulu* fluently.

### **3.4.2. The educator sample**

Secondly, educators were recruited to join the study by telephonic contact with principals of the target schools. A time was arranged for a school visit in order to explain the study. Five schools provided access and staff meetings were arranged on respective days. A request was

made that if educators were willing to participate, that the questionnaire be administered on the day of the visit. The principals were accommodating to this request. Principals were provided with an information letter in *isiZulu* prior to the administration to educators. Refer to Appendix 7a and 7b for the information letter and translated letter.

The study was verbally explained to the educators and the participants were given an information sheet about the study (refer to Appendix 8a). These documents were translated into *isiZulu*, as their English proficiency was unknown (refer to Appendix 8b). Any questions that the participants had were answered. Prior to the administration of the questionnaire, the participants were asked to sign a consent form agreeing to their participation in the study (refer to Appendix 8b). The *isiZulu* questionnaire was then administered to the participants. The test administration took approximately 15 minutes and participants were asked to answer the questionnaire independently. Once complete, the questionnaires were collected and the participants were free to leave. This process was repeated at each school respectively. Refreshments were provided. The target sample population size was reached after five school visits.

#### ***3.4.2.1. Qualitative observations of educator responses to the questionnaire***

When addressing the educators at one particular primary school, the researcher explained the study and proceeded to hand out the questionnaires. However, she was stopped and asked, “What is autism?” This brought about a brief discussion around the concept of ASD with great caution as to not explain the symptoms, which would have affected the reliability of the results. However, the researcher was surprised to find that none of the educators knew what autism was. They began to ask about specific symptoms and appeared to confuse the disorder



with other learning barriers such as hyperactivity and stammering. As a result, most of the educators at this school marked “No” for the qualifying question. However, when calculating their scores on the questionnaire the researcher realised that the educators in fact had a basic understanding of ASD. One educator scored 17 out of 19 for the questionnaire, suggesting a thorough understanding.

At more than one school the educators suggested that the best way to present a questionnaire in *isiZulu* is in fact to present a bilingual questionnaire. They would have preferred to have the English translation included below the *isiZulu* translations in order to confirm their understanding of the *isiZulu*.

### **3.5. Data Analysis**

This study aimed at producing an *isiZulu* KCAHW questionnaire that is reliable in the South African context. To establish reliability, statistical methods had to be applied to the data. Finally, the third phase involved statistical analysis to determine the extent to which educators can identify ASD in children.

#### **3.5.1. Phase two**

In the pilot test, Cronbach’s alpha was calculated and the mean scores of the student sample were compared. According to Schmitt (1996), alpha scores and correlations must be analysed to draw any conclusions about reliability. Thus, a correlation analysis was generated in order to identify Pearson’s correlation coefficient. This was done in order to identify the

relationship between the total scores from the test and re-test with the student sample (Pallant, 2005).

Two sets of data were provided by the two sample populations, namely the students and educators. The data was analysed statistically to determine reliability. Firstly, the statistical programme SPSS was used to identify the following sample descriptions: mean ages, mean years of experience (educators only), ethnicity breakdown as well as the frequency of total scores amongst the populations. These scores determined the differences between the sample groups. SPSS was then used to calculate Cronbach's alpha again. The alpha scores of the two samples were then compared to identify whether or not there was a difference in the reliability of the translation across two different sample populations. The sample description data was then analysed to identify its impact on the reliability of the measure. SPSS was then used to run a factor analysis. This showed the number of underlying factors represented by the *isiZulu* questionnaire, which is useful in identifying the structure of the measure (Tredoux, Pretorius & Steele, 1999).

### **3.5.2. Phase three**

In phase three of this study, the data was analysed statistically in order to assess the extent of knowledge of Autism Spectrum Disorders amongst the educators in Edendale, Pietermaritzburg. Educators' total scores were calculated and individual domain scores were tabulated in SPSS. The mean score of the sample population was then calculated in order to determine the average baseline of knowledge across the sample population. The scores for each domain were calculated and analysed in order to determine whether or not specific

domains were more familiar to educators. Educators' perceptions of ASD with regards to verbal skills were addressed by statistically analysing the responses to domain two.

The data was also analysed according to descriptive information provided in order to determine whether or not the results are correlated in any way. For example, the age of the educator was correlated with individual scores to determine whether or not age influenced knowledge of ASD. Age, experience, total scores and answers to the introductory question were correlated with one another.

### **3.6. Ethical considerations**

#### **3.6.1. Community participation**

The schools chosen for this study belong to the Sizabantwana network that one of the supervisors has collaborated with before. In her capacity as supervisor, she provided access to these schools and a relationship with the schools was already established prior to the study.

#### **3.6.2. Social value**

This study does not aim to educate educators or students about ASD and therefore provides no direct benefit to the participants. However looking to the future, there is the prospect of benefit as this research aims to provide an *isiZulu* questionnaire that can be used to identify educators that have limited knowledge of ASD. This is beneficial as the questionnaire can be used to inform education about knowledge of ASD amongst educators.

### **3.6.3. Scientific validity and integrity**

The researcher received a scholarship from the National Research Foundation (NRF) for this research. No imposition was stipulated other than acknowledgment of the NRF funding for the research. Thus, the scholarship had no bearing on the outcome of the research. The design and results were not influenced by any stakeholders.

An established measure with recommended use for Sub-Saharan Africa was used. However, the measure was made more applicable to the South African context by way of translation. The questionnaire was translated using a well researched method and expert advice was sought to assess the accuracy of the translation. This is important as it impacts the generalisability of the findings. The design of the study included a pilot study in order to assess the reliability of the measure before use. Finally, the participants were recruited from a number of different schools in Pietermaritzburg and participation was voluntary. These factors contribute to a valid study that aims to be generalisable to the greater KwaZulu-Natal context where *isiZulu* is widely spoken.

### **3.6.4. Fair selection of participants**

This study made use of purposive and convenience sampling. Purposive sampling involves a selected sample group based on theoretical reasons, and convenience sampling is based on the accessibility of a sample (Durrheim, 1999a). The samples were purposive as participants were specifically chosen on the basis of their first language; they were convenient due to the geographical availability and accessibility of the sample to the researcher. Participation was voluntary and participants were free to withdraw from the study at any stage of the process.

There was no direct benefit to any participants. Refreshments were provided in order to thank participants for their participation.

### **3.6.5. Risk-benefit ratio**

There were no perceived risks to the participants in this study. Consultations were offered in the event of participants requiring support after the questionnaire was administered. *isiZulu* and English documents were offered to all participants. The documents were provided by the Autism Society of South Africa and explain ASD in detail.

This study does not aim to educate educators about ASD and therefore provides no direct benefit to the participants. However this research aims to develop an *isiZulu* questionnaire that can be used to identify opportunities for education programmes about ASD for educators. Furthermore, the students were able to engage with research, which was of some benefit to them academically. This was particularly true for the Howard College students as the professor used the experience to illustrate the statistical concepts he was lecturing on (i.e. validity and reliability).

### **3.6.6. Independent and competent ethical review**

Approval was obtained from the UKZN Humanities and Social Sciences Research Ethics Committee. The protocol reference number for the pilot study is HSS/0006/014CA (see Appendix 9a). All amendments to the protocol were approved as well (protocol HSS/0268/014M, see Appendix 9b). The study was approved in April 2014 (see Appendix 9c). All amendments were approved (see Appendix 9d).

### **3.6.7. Adequate informed consent**

Prior to the administration of the questionnaire, the participants were asked to sign a consent form agreeing to their participation in the study. Information letters explaining all aspects of the study had been provided and questions had been answered prior to this. Questionnaires were only included in the data sample if the consent forms were signed by participants.

*isiZulu* consent forms were provided for educators as their English proficiency was unknown (see Appendix 8).

### **3.6.8. On-going respect for dignity**

Complete anonymity was maintained for this study as participants did not provide any identifying information on their questionnaires. A summary of the findings was offered to the participants, as well as a copy of the aforementioned Autism Society document in order to assist the participants in their understanding of ASD. Two schools requested the documents and they were promptly provided. None of the schools or students requested a copy of the findings of the study.

Electronic data was password protected. The data will be kept for five years in a locked filing cabinet with the researcher's supervisor in the School of Psychology at UKZN. Thereafter, data will be shredded and/or destroyed. The final study will be stored in the University library once complete but this will not compromise confidentiality. Should the researcher present the findings at a conference, or if the research is published, the confidentiality of the participants and schools will remain intact.

### **3.6.9. Permissions sought**

Gatekeeper permission was granted by all required stakeholders. Firstly, permission to conduct research with the schools that were part of the Sizabantwana network was obtained from the Department of Education. Permission was granted on the condition that the researcher provides feedback of the results to the Department's research office. Refer to Appendix 10 for the approval letter. Gatekeeper permission was then obtained telephonically from each principal respectively prior to school visits.

Approval to conduct research within the School of Applied Human Sciences with postgraduate students was obtained from the Dean of the School of Applied Human Sciences (Head) (refer to Appendix 11a). Firstly, the approval was granted for recruitment amongst the Honours students. However, when it became apparent that the sample population was too small, an amendment was requested (see Appendix 11b).

Finally, permission to use the questionnaire was granted by Dr. Bakare in 2014 (see Appendix 12).

### **3.7. Conclusion**

This chapter outlined the methods used to conduct this research. Firstly the measure used and the adaptation to it for the South African context was discussed. The research design was then outlined with specific detail about all three phases of this research. Phase one included the translation process of the KCAHW questionnaire. The errors, discrepancies and changes made to the back-translation were discussed. Phase two involved the reliability testing of the

questionnaire and phase three aimed to identify what educators know about ASD. Sampling, data collection and data analysis were discussed. Finally, the ethical consideration of this study was highlighted. The next chapter will discuss the results of the study.



## CHAPTER FOUR

### RESULTS

In this chapter, the results of the study are outlined. Firstly, the statistical findings with regards to the pilot test are outlined. Then the descriptive statistics for the two samples are presented. Relative ages, mean experience (educator sample only), ethnicity and total score frequencies are identified. Cronbach's alpha scores for both sample populations are provided and the results of a factor analysis are shown. The results of phase three are then presented. This includes the mean scores of the educators, a description of domain performance as well as a look at the correlation matrix. Here, the baseline knowledge of educators is demonstrated.

#### **4.1. Phase two: testing the reliability of the questionnaire**

This study aimed to produce an *isiZulu* KCAHW questionnaire that is reliable in the South African context. To establish reliability, statistical methods were applied to the data in various steps.

##### **4.1.1. The pilot test**

The Cronbach's alpha for the first test administration to the pilot student sample was .13 and the second administration resulted in an alpha score of .10. These scores are low and indicated that the questionnaire lacked internal consistency. A paired t-test analysis found an insignificant difference in the sample means. Time one ( $M = 11.40$ ) and time two ( $M = 11.47$ ) did not differ significantly (Sig. 2-tailed = 0.847). Pearson's correlation coefficient between the total scores of time one and time two was .55, which suggests a strong positive

correlation (Pallant, 2005).

This data was inconclusive. The Cronbach's alpha analysis suggested that the questionnaire lacked reliability but the analysis revealed that there were no particular items that were problematic. However, the low alpha value may have also been due to the small sample size and the homogenous nature of the student sample. Additionally, when a sample is not representative of the target population that the test is intended for, the value of the alpha is limited as it becomes an attribute of the test and sample rather than the test alone (Gwet, 2012). Furthermore, the paired t-test showed no significant difference in the mean scores between time one and time two administrations which suggested a degree of consistency. Thus, instead of re-writing the *isiZulu* scale, the decision was made to proceed in the hope that the educator sample would be better suited to the translated measure due to their dialect of *isiZulu* and age. The translated KCAHW questionnaire was therefore used to initiate the next part of phase two of the study.

#### **4.1.2. The student and educator sample**

The two data sets from the two samples were compared in order to identify any differences in the reliability of the questionnaire as well as to identify any possible reasons for the differences. The results are discussed below.

##### ***4.1.2.1. Description of sample and scores on the questionnaire***

The *isiZulu* KCAHW questionnaire was administered to an additional twenty *isiZulu* speaking postgraduate psychology students in the School of Applied Human Sciences at the

University of KwaZulu-Natal (UKZN) to increase the original sample size. Of the original pilot test questionnaires, time 1 questionnaires were included in the final data set. A total of 51 postgraduate students were recruited in the UKZN School of Applied Human Sciences department from both the Pietermaritzburg and Durban campuses. All questionnaires were completed fully, making them valid for analysis. The youngest respondent stated an age of 19 and the oldest student was 46. The mean age was 24.3 years. All participants could speak *isiZulu* and 48 (94.1%) were first language *isiZulu* speakers. The remaining 3 students (5.9%) stated that *isiXhosa* was their first language. All participants were black, with the exception of one student who was Indian. Refer to Table 4 for a detailed summary of the results and Appendix 13a for a detailed case summary of all participants.

A total of 51 educators were recruited from five primary schools in Edendale, Pietermaritzburg. All questionnaires were completed fully, making them valid for analysis. The youngest respondent was 25 years old and the maximum age was 60 years. The mean age was 46.3 years. All participants were first language *isiZulu* speakers (100%). All participants were black South African (100%). The average number of years of teaching experience amongst the educator sample was 19.29 years. The minimum number of years of experience reported was one year and the maximum number of years of experience was 35 years. Refer to Table 4 as well as Appendix 13b for a detailed case summary of all participants.

This data shows that the samples were similar with regards to language and ethnicity. The populations were different with regards to age and work experience. The student population showed an average age approximately 20 years younger than the educators. Additionally, the educators possessed an average of 19 years of working experience with children.

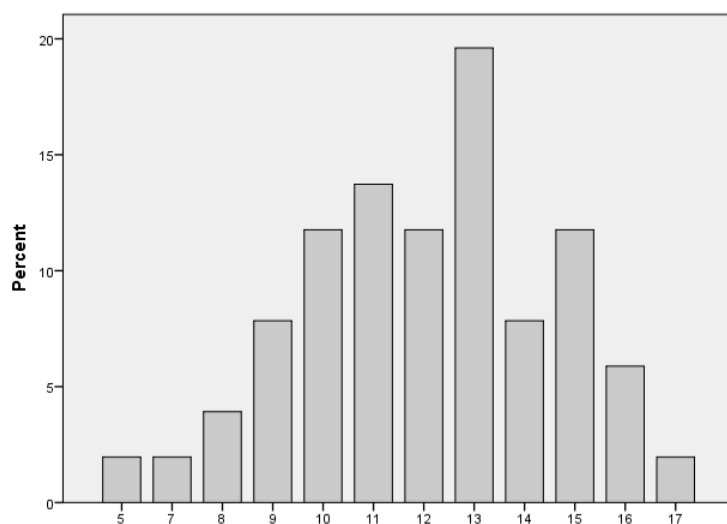
Table 4  
*Description of the sample*

	Variables	Student population	Educator population
Age	Minimum	19	25
	Maximum	46	60
	Mean	24.29	46.27
Language	<i>isiZulu</i>	48 (94.1%)	51 (100%)
	<i>isiXhosa</i>	3 (5.9%)	0
Ethnicity	black	50 (98%)	51 (100%)
	Indian	1 (2%)	0
Teaching experience	Minimum	N/A	1
	Maximum	N/A	35
	Mean	N/A	19.3

*Note.* Teaching experience was not applicable to the student population

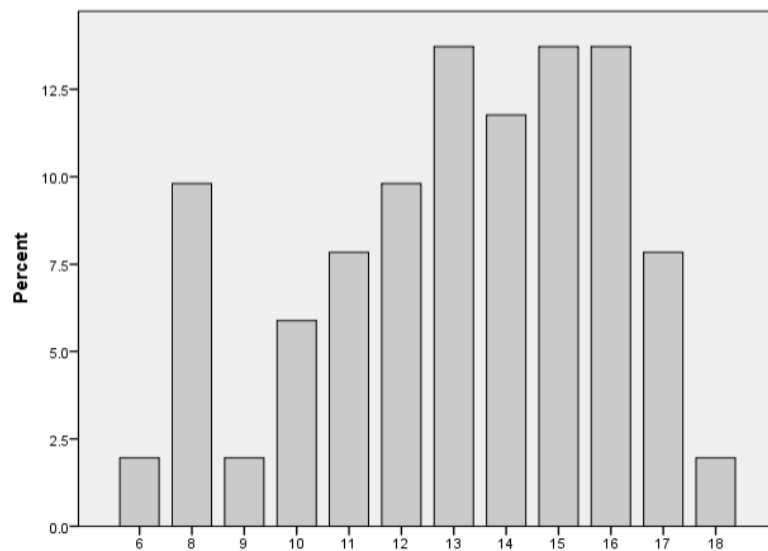
The total scores for each population were also analysed using SPSS. This analysis was run in order to gain an understanding of the distribution of scores across the two samples. In graph 1 there is evidence that 27.5% of the student population scored a total score of 10 or below. This suggests that 72.5% of the student population knew enough about ASD to score 50% or more on the questionnaire. Approximately 28% the population scored 13 points or more on the measure and 19.6% scored 15 or more. One student scored 17 points (2% of the population). These results suggest that approximately two thirds of the student population could identify half the symptoms of ASD.

**Graph 1.** Distribution of student total scores



Graph 2 shows that 19.6% of educators scored less than ten points on the questionnaire. This suggests that 80.4 % of educators knew enough features of ASD to score more than 50% on the questionnaire. Just less than half the population scored 13 points or more on the measure (49%). Nineteen educators (23.5%) scored 15 or more and two percent scored above seventeen (five educators). This data suggests that most of the educators knew enough about ASD to identify half of the symptoms presented.

**Graph 2.** Distribution of educator total scores



These graphs highlight the even distribution of scores amongst the two populations. The total scores in the student sample ranged from five to 17 and the total scores in the educator sample ranged from six to 18. The data also shows that overall, the educators performed better on the questionnaire. Comparatively, the educators had fewer participants scoring ten or below, more educators scoring at least 50% on the questionnaire and more educators scoring above 15.

#### ***4.1.2.2. Cronbach's alpha***

Firstly, no errors were detected in the data files, suggesting that the data was encoded correctly. Cronbach's alpha for the student population was .46 and .60 for the educator population respectively.

The student sample data (presented in Table 5) suggests that the removal of questions 14, 15 and/or 19 would increase the reliability of the measure. However, the difference is not significant and the alpha score would remain at or below .50 even with the deletion of said questions. The possible reasons for the low alpha scores have been discussed above. When compared to the pilot study where only 30 participants were recruited, the alpha value for this student sample was more favourable but it remained below .70. According to Pallant (2005), an alpha score of .70 and above suggests a reliable measure. Based on this information, the questionnaire is not reliable for this sample. Pike and Hudson (1998) caution this conclusion, however, as they suggest that low alpha scores may be the result of homogeneity in the response style of the sample. Refer to Table 5 for the distribution of alpha scores for the student population.

The educator sample data (presented in Table 6) suggests that the removal of questions 15, 14 and/or 19 would increase the reliability of the measure. Removing questions 14 and/or 19 would increase the alpha score but not significantly enough to result in a reliable alpha score. Removing question 15 (i.e. domain 4 question 2: "Autism is an auto-immune condition") would significantly impact the reliability of the questionnaire such that Cronbach's alpha would then be .68, which is considered reliable according to Pallant (2005). Refer to Table 6 for the alpha distribution of the educator population.

Table 5

*Cronbach's alpha if item deleted for the student population*

<b>Item</b>	<b><math>\alpha</math> if item deleted</b>	<b>Item</b>	<b><math>\alpha</math> if item deleted</b>	<b>Item</b>	<b><math>\alpha</math> if item deleted</b>
<b>1</b>	0.399	<b>8</b>	0.439	<b>15</b>	0.496
<b>2</b>	0.445	<b>9</b>	0.438	<b>16</b>	0.455
<b>3</b>	0.388	<b>10</b>	0.416	<b>17</b>	0.434
<b>4</b>	0.406	<b>11</b>	0.466	<b>18</b>	0.439
<b>5</b>	0.427	<b>12</b>	0.447	<b>19</b>	0.492
<b>6</b>	0.412	<b>13</b>	0.469		
<b>7</b>	0.436	<b>14</b>	0.484		

Table 6

*Cronbach's alpha if item deleted for the educator population*

<b>Item</b>	<b><math>\alpha</math> if item deleted</b>	<b>Item</b>	<b><math>\alpha</math> if item deleted</b>	<b>Item</b>	<b><math>\alpha</math> if item deleted</b>
<b>1</b>	0.536	<b>8</b>	0.551	<b>15</b>	0.686 **
<b>2</b>	0.601	<b>9</b>	0.592	<b>16</b>	0.548
<b>3</b>	0.549	<b>10</b>	0.572	<b>17</b>	0.550
<b>4</b>	0.598	<b>11</b>	0.563	<b>18</b>	0.600
<b>5</b>	0.610	<b>12</b>	0.550	<b>19</b>	0.646
<b>6</b>	0.596	<b>13</b>	0.595		
<b>7</b>	0.591	<b>14</b>	0.641		

*Note.* \*\* Indicates the item that would positively influence the alpha score.

The reliability analysis suggests that the removal of question 15 (“Autism is an auto-immune condition”) would increase the reliability to within an acceptable level. Twenty one educators (41.2%) answered ‘yes.’ Eighteen educators (35.3%) were unsure and twelve educators (23.5%) answered ‘no.’ The correct answer was ‘no.’ Thus, a total of 76.5% of the educators failed to answer this question correctly and this perhaps explains the reliability result.

Additionally, this question was in domain four, which was the most poorly answered of all domains. This suggests that educators have a poor understanding on the causes and origins of

ASD. However, considering the literature, which states that specific causes are unknown, this is not entirely unexpected.

#### ***4.1.2.3. Factor analysis***

A factor can be defined as a “group or clump of related variables” (Pallant, 2005, p173). This protocol was run in order to determine the number of factors in the *isiZulu* questionnaire (Tredoux et al., 1999). The data set included for this protocol combined the student and educator data. Ideally these results should be compared to the original data set done by Bakare et al. (2008) however this information was not available.

An examination of the Kaiser-Meyer Olkin (KMO) measure of sampling adequacy suggested that the sample was factorable as the KMO value is  $>0.6$  (refer to Table 7) (Pallant, 2005). Loadings less than .30 were excluded from the data set and so the analysis yielded a seven-factor solution with a simple structure. This was determined by looking at the eigen values above one as well as the scree plot, as outlined by Pallant (2005). The data in Appendix 14 shows that there are 7 factors and they account for 62% of the variance in the results.

However, according to Pallant (2005), one can narrow these factors down by analysing the scree plot further. By identifying the number of factors before major elbows in the scree plot, one can eliminate factors (Pallant, 2005). Refer to Figure 2 below for the scree plot.

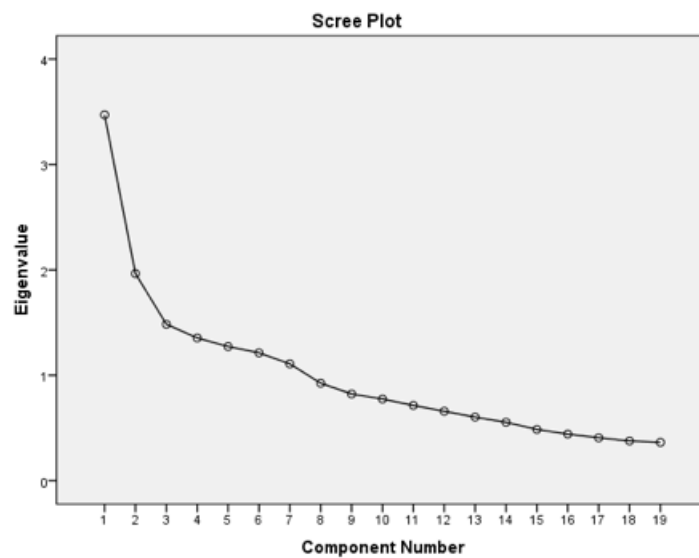
Accordingly, this data set has one primary factor represented in all the questions except question two, 13 and 19. Eighteen percent of the variance is explained by this one factor. This may suggest that the questionnaire measures one construct, namely ASD according to the diagnostic criteria.



Table 7  
Factor analysis results

KMO and Bartlett's Test		
Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		0.683
<hr/>		
Approx. Chi-Square		341.824
Bartlett's Test of Sphericity	df	171
	Sig.	.000

Figure 2. Factor analysis scree plot results



#### 4.2. Phase three: Educators' knowledge of ASD

The second aim of this study was to identify what educators know about Autism Spectrum Disorder. SPSS was used to analyse the mean scores of the educator sample as well as the domain scores. The mean scores of the sample populations were calculated in order to determine the average baseline of knowledge of ASD across the sample populations. The scores for each domain were also calculated and analysed in order to determine whether or not specific domains were more familiar to educators.

#### **4.2.1. Mean scores of the educator population**

The mean total score for the educator sample was 13.08 out of a possible total of 19. This suggests that the educators scored an average total score of 68% out of a possible 100% and that educators knew approximately 68% of the symptoms covered in the questionnaire. The lowest total score earned was six and the highest was eighteen.

##### ***4.2.1.1. Domain one***

In domain one, the mean score was 6.47 out of a possible eight which suggests that the educators had a high performance rate on the domain. The lowest score earned in that domain was three and the highest was eight. Nine educators (17.6%) scored a minimum of 50% in domain one. However, when analysing the domains it is evident that the majority of educators scored 75% or more on domain one (58.8%). This suggests a good rate of knowledge with regards to ASD symptoms associated with social interaction.

##### ***4.2.1.2. Domain two***

In domain two, the mean score was 0.78 out of a possible score of one which also suggests a high performance rate. The lowest score was zero and the highest one. Seventy eight percent of the educators scored 100%. This suggests that educators recognise that ASD affects communication and can be associated with a total lack of verbal skills.

#### ***4.2.1.3. Domain three***

In domain three, the mean score was 3.06 out of a possible four. The highest score earned was four and the lowest was zero. Twenty five and a half percent of the educators scored at least 50% for the domain. A high proportion of educators scored three or more for the domain (38 educators, 74.5%). Approximately 45% scored four out of four (100%). This suggests that educators recognise that ASD impacts behaviour in specific ways.

#### ***4.2.1.4. Domain four***

Domain four assessed knowledge about the etiology of ASD. The mean score for domain four was 2.73 out of a possible six. The lowest score was zero and the highest was five with 9.8% of the educators scoring one or below (five educators). Thirty four educators (66.6%) scored in the below average range of either two or three points and 76.5% scored 50% or less. Eleven educators (21.5%) scored four or above and 5.9% scored above 75%.

Refer to Appendix 15 for graphic representations of each domain and score distribution.

Refer to Table 8 and Table 9 below for a tabulated version of the data matrices.

These results suggest that the educators' performance was above average in domains one, two and three. As stated earlier, 80.4% of educators knew enough features of ASD to score more ten or more on the questionnaire. Approximately half the population scored 13 points or more on the measure and approximately 2% scored 17 or higher.

Table 8  
*Mean scores for the educator population*

	Minimum score	Maximum score	Mean score	Domain total score
Domain 1	3	8	6.47	8
Domain 2	0	1	0.78	1
Domain 3	0	4	3.06	4
Domain 4	0	5	2.73	6
Total score	6	18	13.08	19

Table 9  
*Percentage of correct scores*

	Percentage of correct scores		
	50% or less	75% or more	100%
Domain 1	17.6%	58.8%	33.3%
Domain 2	N/A	N/A	78.4%
Domain 3	25.5%	74.5%	45.1%
Domain 4	76.5%	5.9%	N/A
Total scores	19.6%	76.5%	N/A

These scores also suggest that domain four was the most challenging for the educators.

Domain two had the highest success rate but this is perhaps due to the fact that it is only one question. Domain three was the next most successful domain, followed by domain one. This may be in part due to the large number of questions in domain one (eight questions).

#### **4.2.2. Correlation matrix of the educator sample**

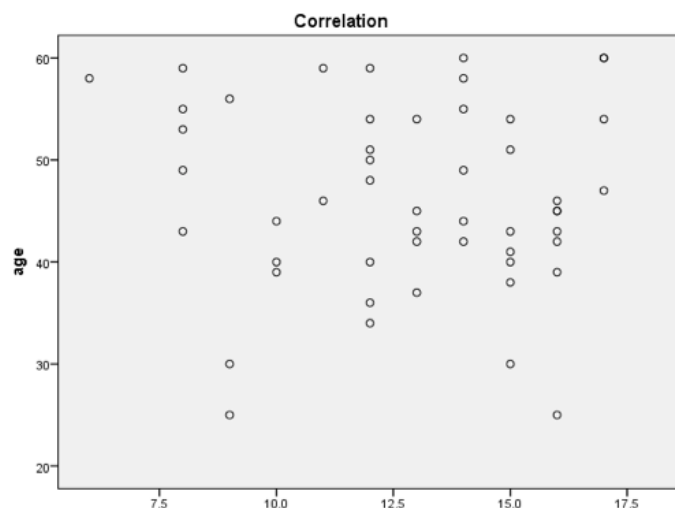
Correlations highlight the relationship between variables (Durrheim, 1999b). Variables such

as age, experience, total scores and answers to the introduction question were analysed in order to identify any relationship between the variables. Ethnicity and language were not included in this analysis due to the lack of variation across the sample.

Firstly, the scatter plot produced by SPSS suggest that there is no specific relationship between age and the total score achieved on the questionnaire. The variables are scattered and show no clear relationship with one another. Refer to Figure 3 for the scatter plot.

**Figure 3.** Correlation scatter plot for the educator population

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When looking at the variables more closely, one can see that there was a strong positive correlation between age and the number of years of teaching experience,  $r = .819$ ,  $p < .001$  (refer to Table 10). This result was anticipated as most educators gain experience as they grow older. This relationship is positively correlated.

There was a small negative correlation between total score and the score for the introductory question,  $r = -0.208$ ,  $p > .001$ . However, the significance level is greater than .05 and therefore

Table 10

*Pearson's correlation and significance level (2-tailed) for the educator sample*

		Age	Years of experience	Introduction score	Total score
Age	Pearson's Correlation	1	0.819 **	0.118	-0.064
	Sig. (2-tailed)		0.000	0.410	0.656
Years of experience	Pearson's Correlation		1	0.061	-0.078
	Sig. (2-tailed)			0.671	0.588
Introduction score	Pearson's Correlation			1	-0.208
	Sig. (2-tailed)				0.143
Total score	Pearson's Correlation				1
	Sig. (2-tailed)				

*Note.* \*\*. Correlation is significant at the 0.01 level (2-tailed).

this relationship is likely unstable. All other correlation relationships were not significant or strong. This suggests that the variables did not impact upon one another in significant ways. Furthermore, the data suggests that the inclusion of the introductory question was not particularly useful.

#### 4.2.3. Specific domain considerations

Given the issues raised in the literature review regarding the presentation of ASD in an African context, specific questions of interest were examined in detail. More than 60 % of the educators answered 'yes' for question 1 in domain 1 ("Marked impairment in use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction?"). Less than 20% answered 'no' and a small percentage were unsure. With regards to domain 2, ("Delay or total lack of development of spoken language?"), 40 educators (80%) answered 'yes' and therefore stated that ASD is associated with delayed or total lack of speech. Since the question did not separate the two (i.e. a delay or a total lack of skills), it is impossible to make broad conclusions regarding this issue.

However, there is evidence to suggest that educators associate ASD with communication difficulties.

#### **4.3. Conclusion**

In this chapter, the results of the study were outlined. Firstly, the statistical findings with regards to the pilot study were discussed. The data from the second phase was then detailed. This included an analysis of the sample populations' descriptive data such as relative ages, mean experience (educator sample only) and ethnicity. Additionally, total score frequencies were identified in order to identify the distribution of scores in the sample. Cronbach's alpha scores for both sample populations were identified in order to determine the reliability of the questionnaire across two different settings. The results of a factor analysis were also shown in order to examine the structure of the questionnaire. The results of correlation analyses were then provided to identify any relationships between the variables. Finally, the results of statistical analysis with regards to the educator sample were highlighted in order to identify the baseline knowledge of ASD amongst educators.

## CHAPTER FIVE

### DISCUSSION

In this chapter, the findings of the study are discussed in light of the literature presented in chapter two. The *isiZulu* version of the KCAHW questionnaire is discussed below with regards to its reliability and its usefulness as a measure of knowledge in the South African context. The baseline knowledge of ASD amongst educators is then explored in order to gain insight into what educators know about ASD in the South African context.

#### **5.1. The aim of the study**

ASD as a childhood disorder was outlined in chapter two and its growing prevalence across the globe was mentioned. The need to identify what professionals know about the disorder was explored in order to assist early intervention programmes for children diagnosed with ASD.

Bakare and Munir (2011a) state that school-based awareness studies improve knowledge about ASD. Springer et al. (2013) add that increasing public awareness of ASD improves identification of this developmental disorder. Thus, this research highlighted the need for awareness studies in South Africa, with a particular focus on educators. This research identified educators as the professionals most likely to encounter autistic children in South Africa because of their daily contact with children. Thus, this research aimed to assess the baseline knowledge of ASD amongst educators.



The KCAHW questionnaire was proposed as a potential tool to assess awareness. However, this measure had to be adapted for use in the South African context. The KCAHW questionnaire was translated into *isiZulu* for use in KwaZulu-Natal. This study therefore had two broad aims. The first was to establish a reliable *isiZulu* measure to assess knowledge of ASD. The second aim was to establish what educators in Pietermaritzburg know about ASD. These are discussed below.

## **5.2. KCAHW questionnaire adaption**

The KCAHW questionnaire was translated from the original English into *isiZulu* and then its reliability as an *isiZulu* measure was assessed. The process was lengthy and fraught with challenges which are outlined below.

### **5.2.1. Translation of the KCAHW questionnaire**

According to Crystal (1991, as cited in Regmi et al., 2010), translation refers to the process of transferring meaning in one language to another. In order to do this with the KCAHW questionnaire, a conceptual approach was adopted to translate items into culturally relevant language. The first challenge in translating in this way was related to the language used in the original questionnaire. Some research suggests that translators need not know anything about the subject matter in order to translate a document effectively (Sinaiko & Brislin, 1973). However, all three translators found the medical jargon challenging to translate. One of the reasons for this was due to the lack of equivalent terms in *isiZulu*. In these cases, code-switching was employed or words were translated by means of a description rather than a single word. This ensured the semantic, criterion and conceptual equivalence that Flaherty et

al. (1998, as cited in Regmi et al., 2010) suggest. Additionally, examples were included in order to specify nuances in words with multiple meanings. Another reason for these challenges was however related to the translators' lack of experience with technical medical and psychological jargon. In retrospect, their lack of experience served as a strength as they were then able to apply their language skills to suit the layperson who would most likely also be unfamiliar with the technical terms. Green and Thorogood (2004, as cited in Regmi et al., 2010) state that ensuring that one uses the correct words adds value to the translation process and this was attempted in every translation phase of this study.

Bornman et al. (2010) state that the application of cultural knowledge assists in maintaining conceptual equivalence when translating. Expert consultation was relied upon to provide insight into the way in which the questionnaire would be perceived by the sample.

Discrepancies in the translations were analysed and corrected through a lengthy process of communication between translators. However, the questionnaire could not simply be translated directly into *isiZulu*. Regmi et al. (2010) state that semantic equivalence is critical when translating from one language to another. This refers to similarity of meaning and ensuring that the translation carries the same meaning as the original, not necessarily the same words. In an attempt to achieve this, the questionnaire underwent multiple exchanges between translators and through expert consultation. Words were changed, phrases altered and examples provided in order to ensure that semantic equivalence was obtained. Although every effort was made to ensure this, during the administrations it was observed that multiple meanings continued to be conveyed through the language used in the questionnaire. This may have been due to geographical, familial and age differences amongst the participants, but may also be due to the complexities involved in a language like *isiZulu* because of multiple dialects.

Criterion equivalence was also prioritised in the translation process and refers to a translation that is in line with the target culture (Flaherty et al., 1998, as cited in Regmi et al., 2010). The aim was to devise a measure that was “culturally relevant and comprehensible while maintaining the meaning and intent of the original” (Sperber, 2004, p. 124). This meant that the questionnaire had to reflect what is known about ASD in the Zulu culture. One of the items of concern regarding criterion equivalence was question 1 in domain 1. Poor eye contact is often associated with ASD but there was speculation as to whether or not it would be considered symptomatic within the Zulu culture. Rudwick (2008) states that Zulu children do not make eye contact with their elders and thus perhaps this symptom is not recognised within the culture. However, the data suggests that most educators recognised non-verbal symptoms like poor eye contact to be consistent with ASD.

Despite the challenges faced, the translation phase produced a questionnaire that was consistent with the dialect of *isiZulu* used in Pietermaritzburg and that is considered to have face validity. It reflects one primary factor according to the factor analysis, which suggests that it has one construct: namely ASD diagnostic criteria. Additionally, when analysed statistically, the student participants scored similarly in the test and re-test phases of the pilot test. This suggests that individuals were able to obtain the same meaning for the items on two separate occasions, which suggests a degree of consistency in the language used.

The educators’ response to the questionnaire was unexpected. They requested a bilingual questionnaire, or an English one. Their preference was not the translated version that this study produced. They stated that their confidence in reading academic English is more advanced than their ability to do the same in *isiZulu*. This was an unexpected result of this

study and suggests that research conducted in a sample's mother tongue should be carefully considered.

### **5.2.2. Reliability of the questionnaire**

The first question this research aimed to answer was: is the *isiZulu* KCAHW questionnaire a reliable measure of knowledge of ASD? The study conducted by Bakare et al. (2008) with the KCAHW questionnaire showed a good reliability with an alpha score of .97. Additionally, they stated that the test re-test reliability of the questionnaire was good due to comparable results across two administrations. The mean total scores for time one and time two were 9.6 and 9.8 respectively. The pilot study in the current study using the *isiZulu* KCAHW revealed poor reliability if reliability is measured according to Cronbach's alpha alone. However, the paired t-test and correlations suggested that there were no significant differences between the test and re-test data. Thus, the reliability assessment was inconclusive. This may have been caused by a small sample size and the possibility that their response style was consistent due to homogenous information regarding ASD. The Durban students had completed an elective course on ASD the week before and therefore all had a relatively homogenous knowledge set. Pike and Hudson (1998) state that this can negatively influence the alpha score.

Reliability was then re-assessed amongst a larger student sample and a sample of educators. The analysis revealed that the *isiZulu* KCAHW lacked reliability amongst the student sample with an alpha score of .46. The data suggested that the removal of questions would not increase the reliability in any way. The alpha score of the educator sample was .60 but reached reliability with the exclusion of question 15. These results suggest that the degree of reliability is unstable due to variations in reliability across the two samples.

Removal of question 15 (i.e. domain 4 question 2: “Autism is an auto-immune condition”) would increase the reliability to within acceptable range (Pallant, 2005). The question was translated by making use of code-switching. It is possible that this caused confusion amongst the sample, or was misunderstood by the educators. However, this question may have resulted in poor performance as a reflection of the greater body of research that at times seems inconclusive around the specific cause of ASD.

One possible reason for the difference in reliability between the original study by Bakare et al. (2008) and this study may be due to the nature of the sample populations. Health care workers in Nigeria may have less exposure to a specific childhood disorder like ASD. As a result, their knowledge of ASD may be variable – some may have a high level of knowledge and some might have low levels of knowledge. As mentioned, Pike and Hudson (1998) state that alpha scores are influenced by the response style of the sample. A homogenous response style may result in a low alpha score whilst a heterogeneous one reveals a high alpha score. Since Cronbach’s alpha is a measure of consistency, their high alpha score may be the result of a variable response pattern.

When evaluating the difference in reliability between the samples used in this study one possible reason may be due to language. The educator sample may relate more to the dialect used in the questionnaire due to their geographical homogeneity. The student sample is likely to cover a greater cross-section of dialects due to the nature of universities gathering students from multiple regions. However, conclusions regarding this cannot be made as this information was not sourced from the participants and is only speculative.

Another reason may be related to the student sample itself. Authors have highlighted the

difficulties with using student samples to calculate alpha scores (Henrich et al., 2010, Gwet, 2012). Although university students are frequently recruited for studies that aim to generalise their results, students perform in unusual ways making them unrepresentative of the general population (Henrich et al., 2010). The poor reliability scores amongst the student sample may have been due to their qualitative difference when compared to the target educator sample. They were younger, westernised, geographically heterogeneous and had limited to no working experience with children. Furthermore, 30 of the 51 students had attended an elective on ASD as part of their honours course two weeks prior to the administration of the questionnaire. In light of what Pike and Hudson (1998) say about variability of knowledge and its influence on the alpha, this may account for the poor reliability in the student sample.

Roodt (2013a) states that a degree of administrative error can occur when administering a test or measure. A degree of this occurred amongst the educator sample. Although educators were instructed to work independently, they consulted one another in understanding what the question asked of them. This may have inflated the results. The students worked independently.

Despite the difficulties outlined above, if question fifteen is excluded, the questionnaire appeared to have a degree of reliability when administered to the educators. This suggests that the questionnaire has some utility amongst the target population. With some revision, it may prove useful in the KwaZulu-Natal context as a measure of knowledge.

#### ***5.2.2.1. Improvements to the questionnaire***

Poor performance in the reliability test in the student population suggests that changes could

be made to the questionnaire in order to improve its reliability in a wider population. The first suggestion is with regards to translation. The language could be simplified. Multiple participants remarked that although correct, the language was academic in nature and not 'everyday' *isiZulu*. Secondly, the domains could be collapsed and items rephrased so that there is more variation in the response pattern. Most of the answers on the questionnaire were 'yes' which may have enabled a set response style. For example, instead of, "Lack of social or emotional reciprocity?" the item could state, "Well developed social or emotional reciprocity?" where the answer is 'no' instead of 'yes.' Thirdly, the statement could be rephrased into questions, making them more readily accessible. A few participants requested assistance in understanding the phrasing of the questions. For example, instead of statements such as "Lack of social or emotional reciprocity?" the item could be presented as a question such as "Do children with ASD lack social or emotional reciprocity?" These suggestions may improve or impact the reliability of the questionnaire as they would possibly increase the likelihood of participants understanding the material and positively identifying more symptoms of ASD.

### **5.3. Baseline knowledge of ASD**

The second aim of this research was to assess knowledge of ASD amongst educators in Edendale using the translated KCAHW questionnaire. The question asked was: what do educators know about ASD and what is their baseline knowledge?

Bakare et al. (2008) found that health care workers had a low level of knowledge of ASD. Their total scores were 9.6 and 9.8 respectively. This indicates that on average, the educators knew less than 50% of the symptoms presented in the questionnaire. By contrast, the

educator sample in this study had an average score of 13.08. The data showed that 68% of the educators knew at least 50% of the symptoms of ASD. This suggests a reasonable level of knowledge on ASD. This result was unexpected when compared to the results of the Bakare et al. (2008) study as well as the other studies detailed in the literature review.

The differences in the results may be due to the type of professional involved. Educators have daily contact with children and this may influence their understanding of childhood disorders, unlike health care workers who may specialise in treating adults. Furthermore, the results may suggest that knowledge of ASD is higher in South African than in Nigeria.

Lian et al. (2007) concluded that their sample lacked general knowledge of ASD despite having enough knowledge to pass. The current study showed similar results as only 5.9% of the educators scored more than 68% suggesting that whilst the majority of the educators had a general knowledge of ASD, they lacked a specific knowledge of the facts. Thus both studies suggest that professionals may lack detailed knowledge of ASD even if they have general knowledge.

Much like the study conducted by York et al. (1999), the educators appear to know the basic features of ASD as reflected in domains one, two and three. However as with study conducted by Imran et al. (2012), the educators appeared to have an unbalanced knowledge of ASD. They could identify the core features but lacked specific knowledge about etiology and co-morbidities in domain four. This is not surprising, however, given that academic and medical fields do not yet know the exact cause of ASD either. Domain four was also related to knowledge about the age of onset and diagnostic features of ASD. Psycho-educational workshops could prove a useful way in which to assist in the development of knowledge



regarding ASD. This is a positive outcome of this research as it identifies an area of need in the community and serves to inform an intervention.

The studies mentioned in the literature review revealed that on average, professionals have low levels of knowledge of ASD. This study showed average levels knowledge of ASD and one reason may be due to the specific profession. Educators are exposed to childhood disorders and are perhaps expected to have a working knowledge of the disorders.

Furthermore, the educators were sampled from schools that belong to the Sizabantwana network. This means that at least one educator in each school has regular training on education-related topics. This educator often disseminates that information to the staff at his/her school, which suggests that the educators have secondary access to training on childhood disorders on a frequent basis. York et al. (1999) sampled special needs educators as well as mainstream educators and found that their knowledge was reasonable. The sample of educators in this study performed similarly and was also comprised of mainstream educators as well as those with access to informal special needs training.

The results suggest that the educator population has a reasonable baseline knowledge of ASD. This is despite the fact that many educators stated that they did not know what autism is in the introductory question on the questionnaire. One hypothesis regarding the frequent use of 'no' for the introductory question in spite of average or above average performance in total scores is related to the sociological concept of 'face.' Granger, Mills and Sibanda (2010) discuss the issue of 'face' in the Zulu culture and state that the need to maintain group face is important in social settings. Face is defined as group face or individual face in the African context (Granger et al., 2010). Group face refers to one's awareness of belonging to a group; individual face refers to one's desire to be liked by others (Granger et al., 2010). Individuals

tend not to function based on their own needs and goals first, but rather towards the goals of the group (Granger et al., 2010). Group belonging is of vital importance and any actions that threaten this are approached cautiously (Granger et al., 2010). As mentioned above, the educators discussed the questionnaire when answering it, suggesting that social dynamics may have impacted the way in which they answered. Despite the anonymity of the questionnaire, educators might have felt social pressure to understate their knowledge of ASD so as not to stand out as knowledgeable amongst their peers, thus preserving group unity. This could be one way of explaining the high percentage of participants who answered ‘no’ on the introductory question and yet answered 68% and more of the questions accurately.

The educators appeared to perform with an even distribution across variables such as age and work experience. No strong correlations were identified except one which was anticipated. Age and work experience were positively correlated suggesting that older teachers possessed more work experience. This did not appear to impact on their knowledge of ASD in any way. Perhaps the inclusion of questions such as, “Have you had any training in ASD?” or “Have you ever worked with a child with ASD?” would provide useful information regarding their sources of knowledge. This may also assist in identifying new correlations.

### **5.3.1. Knowledge of specific items**

The issue of verbal skills in children with ASD was also raised in the literature review, with particular reference to findings in the African context. The literature states that African children typically present with non-verbal ASD (Bakare & Munir, 2011a). However, this may be due to more identifiable atypical development in non-verbal children that results in a higher reporting rate. Whilst this critique cannot be validated, it raises an interesting question

with regards to how educators might perceive ASD in Africa. The current study tried to identify whether or not educators in Pietermaritzburg view ASD as primarily verbal or non-verbal. Forty educators (80%) stated that ASD is associated with delayed or total lack of speech. This suggests that the educators recognise that ASD is associated with a speech deficit of variable degree, not only a total lack of speech. This indicates that the educators have a holistic view of ASD as according to the DSM 5. This is beneficial but also indicates that they might benefit from information regarding typical onset in the African context. However, since the item in question did not separate the two (i.e. a delay or a total lack of skills), it is difficult to make broad conclusions regarding this issue.

In chapter two, the cultural practice of not making eye contact with an elder was highlighted. Rudwick (2008) states that Zulu children do not make eye contact with their elders and thus perhaps this symptom of ASD is not recognised within the culture. Question one (“Marked impairment in use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction?”) assessed knowledge of this symptom. The data suggests that more than 60% of the educators recognise that non-verbal behaviours are impaired in ASD. Given that the questionnaire item included many non-verbal behaviours, what the educators consider symptomatic regarding eye contact specifically cannot be determined further.

#### **5.4. Conclusion**

In this chapter, the findings of the study were discussed in light of the literature presented in chapter two. The findings related to the adaption of the original KCAHW questionnaire by Bakare et al. (2008) into an *isiZulu* version was discussed. The translation difficulties were

explored and then the reliability of the questionnaire was examined. Its usefulness as a measure of knowledge in the South African context was discussed and improvements to the measure were considered. The baseline knowledge of ASD amongst educators was then discussed in order to gain insight into what educators know about ASD in this region of South Africa. These findings were explored in comparison to studies done within the educational realm as well as other studies amongst other professionals. The educators' specific knowledge of particular aspects of ASD was then explored in light of the Zulu culture in KwaZulu-Natal.

## CHAPTER SIX

### CONCLUSION

#### 6.1. Conclusion

ASD is a complex disorder and is complicated further by recent diagnostic changes in the DSM 5. Research shows that it is the fastest growing childhood disorder in the world (Imran, et al., 2011) and is therefore a syndrome of concern. However, the lack of research in Africa and South Africa makes it difficult to gauge the situation locally. As a result, it is likely that children are undiagnosed which results in missed opportunities for early intervention.

Research on ASD in Africa is limited. Limited awareness leads to delayed identification of symptoms which negatively impacts prognosis. Educators are therefore a critical resource as they are often the first to identify difficulties with children when they enter the school system. In chapter two, the importance of awareness of ASD in the general population, amongst professionals and amongst educators in particular, was established. The awareness studies explored in chapter two showed that professionals have poor awareness of ASD and that intervention is required. This study aimed to identify what educators in South Africa know about ASD.

Bakare et al. (2008) devised an awareness tool called the KCAHW questionnaire. It proved to be reliable in the original study and it was recommended for use in Sub-Saharan Africa, particularly where knowledge of ASD is unknown. It emerged as a likely choice for use in the South African context. However, in order to use it locally, it required translation. It was translated into *isiZulu* using a backwards and forwards translation method. The translation

process showed that *isiZulu* is complex in that it has many dialects with linguistic nuances. This research also highlighted that for the participants, formalised *isiZulu* is relatively difficult to read, which suggests that bilingual measures of knowledge are not necessarily the most effective in the local context. The technical jargon used in the original measure also provided challenges. In order to gain conceptual equivalence, concrete examples for items were included and expert consultation was sought to evaluate the cultural relevance of the translated measure. As a result of thorough examination, the measure was considered to have face validity.

After this rigorous translation process, an *isiZulu* KCAHW questionnaire emerged. The first aim of this study was to translate the KCAHW questionnaire from the original English into *isiZulu* and then to assess its reliability as an *isiZulu* measure. The pilot study revealed inconclusive results. When the questionnaire was tested with a bigger sample and across two different populations, the results showed that the questionnaire is a reliable measure of knowledge in the context for which it was designed, provided question 15 is removed. Factors that could have influenced reliability across contexts were identified. Some included the nature of the participants in the sample group, the existing knowledge base of the participants and how that affects response variability, the degree of error and the technicality of the language used.

The second aim was to assess knowledge of ASD amongst educators in Pietermaritzburg using the *isiZulu* KCAHW questionnaire. The results showed that the mean score for the educator sample was 13.08, suggesting a good level of knowledge of ASD. This was reasonably higher than the original study where the mean scores were 9.6 and 9.8 respectively. However, the analyses also showed that whilst the educators had a good general

knowledge of ASD, they lacked specific insight into the disorder, particularly with regards to etiology and age of onset. This suggests that there is an opportunity to provide educational resources to educators about ASD.

## **6.2. Limitations**

The original study by Bakare et al. (2008) produced a high Cronbach's alpha score. The current study generated a much lower Cronbach's alpha value and as a result, the reliability of the translated measure appears to be lower than the original questionnaire. This is compounded by the fact that the language of choice for this study was *isiZulu*, a complex language due to its predominantly oral history. This is particularly true for written and technical medical terms such as "auto-immune" which are either unknown or discussed by way of code-switching in everyday language.

Another limitation of this study relates to the sample population. Students were recruited due to the convenience of their accessibility. However, as Henrich et al. (2010) and Gwet (2012) state, university students are often unrepresentative of the general population and therefore can negatively influence findings. One factor that may have influenced the reliability amongst the student sample in this study was the homogeneity of their knowledge of ASD due to a course on ASD conducted in Durban prior to the recruitment. Another factor relates to the heterogenic nature of their geographical demographic. The students at UKZN come from various locations across KwaZulu-Natal, unlike the educators who are generally locals in Pietermaritzburg. This appears to have influenced the reliability of the questionnaire as was discussed in chapter five.

Additionally, the sample size was small. Whilst it allowed for valuable data to be produced, a larger sample size may have provided more insight into the reliability of the translated measure and possibly added to the generalisability of the results. Furthermore, the educators were recruited through the Sizabantwana network which may have skewed the results to a degree.

Finally, relying solely on the KCAHW questionnaire to assess educators' knowledge of ASD may have limited the results. Another instrument could have yielded different results or may have provided additional information to further develop the current understanding of knowledge of ASD amongst educators. However, no other instruments have been recommended for use in Sub-Saharan Africa and as a result, this instrument was the most applicable to the context.

### **6.3. Future research**

An interesting contribution made by the educators was with regards to the use of *isiZulu*. As indicated, the educators read their questionnaires aloud and assisted one another with the formalised *isiZulu*. As a result, one educator recommended that it would be easier for them to have a bilingual questionnaire. Subsequent school visits confirmed this unexpected finding. In spite of *isiZulu* being their first language, the educators would have preferred an English questionnaire and/or a bilingual one. Further studies could include the administration of a bilingual questionnaire in order to assess the difference in reliability that that change brings.

Secondly, the structure of the questionnaire could be adapted in various ways for easier use. First, the demographic information could be placed at the end of the questionnaire, rather



than at the onset. This could be done in order to prevent the participant from feeling primed by demographic information. Second, a Likert scale could be used as the answering format as opposed to the current multiple-choice format. This may provide a broader range of answers and also show more distinct levels of knowledge. Third, the domains could be collapsed for two reasons. Domain 2 only has one question which may statistically reduce the validity of the domains and whilst the domains reflect separate symptoms of ASD, they do not necessarily have to be demarcated in order to appear in the questionnaire. However, domain two could also benefit from more questions in order to assess a range of diagnostic features with regards to communication deficits in the DSM 5.

This leads to the third change, which relates to the DSM 5. The questionnaire could be updated to reflect the new criteria and include various symptoms across the spectrum. For example, not all children with ASD have delayed speech. Children previously diagnosed with Asperger syndrome are usually high functioning with regards to speech. Items could be included or adjusted to reflect these spectrum changes. Furthermore, the DSM 5 criteria for ASD are categorised differently to the DSM-IV-TR that the KCAHW questionnaire is modelled on. Thus collapsing the domains would be more consistent with the DSM 5.

Fourthly, the opening statement used by Bakare et al. (2008), namely “The following behaviours best describe a child with Childhood Autism” could be adapted to be more user friendly. A question, such as, “Do you think the following behaviours describe a child with autism?” may be more useful.

Fifthly, the nature of the questions could be adapted but this would impact the length of the questionnaire. Including questions about normal childhood development could broaden the

range of knowledge covered by the questionnaire, thus increasing the construct validity. For example, a question such as, “At 2 years of age, is a child able to say sentences of 2 to 4 words?” This would allow the researcher to compare what participants know about atypical development in comparison to typical development. Related to this, rewording the items so as not to construct the behaviours as negative might impact validity. For example, domain 1 question 8 states, “Social smile is usually absent in a child with autism.” Instead, the question could be worded as follows, “A social smile is present in a child with autism.” This would increase the variability in the responses and thereby reduce the possibility of set response styles.

Sixthly, one of the experts consulted suggested providing a few lines for qualitative comments, as it would add value to the questionnaire. She suggested including a question that asked the participants what they thought ASD was, in order to gain a descriptive response from participants. Other qualitative questions could include whether or not participants have had any experience with working with a child with ASD or if they have had any training in ASD. These could broaden the scope of the study and so add new dimensions to the data. Related to this is the expansion of the study itself, into more schools or a greater variety of schools. This would provide rich data and may also add to the reliability testing of the questionnaire.

Knowledge of ASD amongst educators can be assessed using other questionnaires, such as those mentioned in chapter two. However, there are other avenues worth considering for future research as well. For example, a qualitative approach using focus groups could be arranged during which educators’ knowledge of ASD could be assessed qualitatively by means of thematic analyses of discussion data. One-on-one interviews with specific educators

could be organised in order to explore what educators in specific fields know about ASD. For example, this would be particularly useful to assess what special needs educators know about this childhood disorder. Workshops about ASD could be held and knowledge of ASD before and after the workshop could be assessed in order to identify whether or not workshops are an effective method of knowledge dissemination. Finally, assessing the curriculum of institutions could yield interesting data as to whether or not ASD is included in educator training programmes.

#### **6.4. Implications**

In conclusion, the *isiZulu* KCAHW questionnaire appears to be a useful measure for use in the South African context. It provided significant information regarding educator knowledge of ASD in Edendale, Pietermaritzburg. However, as has been stated, adjustments to the questionnaire may improve its effectiveness, which will add to the limited body of knowledge of ASD in the South African context. Question 15 could be deleted, items could be added, statements reworded and the format reconsidered, for example. Furthermore, this research shows that intervention at the school level with regards to ASD awareness would be beneficial to develop educators' knowledge of ASD further. A specific focus on etiology, age of onset and typical features in the African context are recommended.

The questionnaire assesses educators' knowledge of ASD but does not provide detailed information about what ASD is thereafter. As a result, educators' knowledge is assessed but not necessarily contributed to or developed. The current research attempted to address this by disseminating brochures on ASD to schools after the data was collected. However, due to limited resources, schools may not be able to distribute the material to all the educators. Thus,

this research identified an area of need within the education system. Educators would benefit from workshops about ASD in order to provide them with practical training on how to identify the disorder, what to do once they identify a child with features of ASD and how to accommodate a learner with ASD in their classrooms.

Furthermore, what has not been addressed is the referral process once a child with ASD has been identified. One school requested information regarding this process and they were informed of the various avenues to consider for an assessment. However, what became evident is that educators are unaware of the resources at their disposal for referral.

Furthermore, they do not have information regarding the referral process or procedures. As a result, children remain undiagnosed and with little intervention. Thus, this research has highlighted an area for development regarding educators' access to and knowledge of referral sources. This would empower educators to intervene at the early stages of development which further improves prognosis.

ASD has a growing prevalence rate and thus, the future educators of South Africa ought to be trained on how to identify it, how to educate learners with ASD within the inclusive classroom and how to go about the referral process in order to impact learners' lives positively.

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## APPENDICES

### **Appendix 1: Original KCAHW questionnaire by Bakare et al. (2008)**

Please do not consult formal text books to answer these questions.  
Thank you for your time.

The following behaviours best describe a child with Childhood Autism:

#### Domain 1

i. Marked impairment in use of multiple non-verbal behaviours such as eye to eye contact, facial expression, body postures and gestures during social interaction?

(A) Don't Know, (B) Yes, (C) No

ii. Failure to develop peer relationship appropriate for developmental age?

(A) Don't Know, (B) Yes, (C) No

iii. Lack of spontaneous will to share enjoyment, interest or activities with other people?

(A) Don't Know, (B) Yes, (C) No

iv. Lack of social or emotional reciprocity?

(A) Don't Know, (B) Yes, (C) No

v. Staring into open space and not focusing on any thing specific?

(A) Don't Know, (B) Yes, (C) No

vi. The child can appear as if deaf or dumb?

(A) Don't Know, (B) Yes, (C) No

vii. Loss of interest in the environment and surroundings?

(A) Don't Know, (B) Yes, (C) No

viii. Social smile is usually absent in a child with Autism?

(A) Don't Know, (B) Yes (C) No

#### Domain 2

i. Delay or total lack of development of spoken language?

(A) Don't Know (B) Yes (C) No

#### Domain 3

i. Stereotyped and repetitive movement (e.g. Hand or finger flapping or twisting)?

(A) Don't Know (B) Yes, (C) No

ii. May be associated with abnormal eating habit?

(A) Don't Know, (B) Yes, (C) No

iii. Persistent preoccupation with parts of objects?

(A) Don't Know, (B) Yes, (C) No

iv. Love for regimented routine activities?

(A) Don't Know, (B) Yes, (C) No

#### Domain 4

i. Autism is Childhood Schizophrenia?

(A) Don't Know, (B) Yes, (C) No

ii. Autism is an auto-immune condition?

(A) Don't Know, (B) Yes, (C) No

iii. Autism is a neuro-developmental disorder?

(A) Don't Know, (B) Yes, (C) No

iv. Autism could be associated with Mental Retardation?

(A) Don't Know, (B) Yes, (C) No

v. Autism could be associated with Epilepsy?

(A) Don't Know, (B) Yes, (C) No

vi. Onset of Autism is usually in,

(A) Neonatal age, (B) Infancy, (C) Childhood

## **Appendix 2: Translation A (forward translation of the KCAHW questionnaire)**

*Changes made to the final forward translation can be seen in **bold**.*

Imibuzo ngoLwazi lwaBasebenza ngeZempilo mayelana ne"Autism" Yabantwana.

Ngicela ningacwaningi ezincwadini ngaphambi kokuphendula le mibuzo. Ngibonga isikhathi sakho. Lezi zindlela zokuziphatha zichaza ingane ene "Autism".

### Isiqephu 1

<b>First forward-translation A</b>	<b>Final forward-translation A</b>
i. Ukungakwazi ukusebenzisa izindlela eziningi ngaphandle kokukhuluma njengokubhekana emehlweni, umumo wobuso, ukumiswa komzimba nokunqathuzisa izandla uma kuthintanwa.	i. Ukungakwazi ukusebenzisa izindlela eziningi ngaphandle kokukhuluma njengokubhekana emehlweni, umumo wobuso, ukumiswa komzimba nokunqathuzisa izandla uma kuthintanwa.
ii. Ukuhluleka nokuba nobudlelwane bontanga obufanele lobo budala?	ii. Ukuhluleka nokuba nobudlelwane bontanga obufanele lobo budala?
iii. Ukukhombisa ukuthi akafuni ukujabula nabanye, ukuba nomnako noma ukwenza izinto nabanye?	iii. Ukukhombisa ukuthi akafuni ukujabula nabanye, ukuba nomnako noma ukwenza izinto nabanye?
iv. Ukuswela isenaniselo semizwa nangokuhlalisana nabanye?	iv. Ukuswela isenaniselo semizwa nangokuhlalisana nabanye?
v. Ukugqolozela obaleni engabukisisi lutho?	v. Ukugqolozela obaleni engabukisisi lutho?
vi. Kungathi ingane iyisithulu noma isimungulu?	vi. Kungathi ingane iyisithulu noma isimungulu?
vii. Ukungabi nomnako ngenhlalo yendawo yakhe?	<b>vii. Ukungabi nogqozu ngenhlalo yendawo yakhe?</b>
viii. Kujwayelekile ukuthi akukho ukumamatheka enganeni uma kukhona abanye?	viii. Kujwayelekile ukuthi akukho ukumamatheka enganeni uma kukhona abanye? (Isibonela: ingane iyamamatheka uma kumamatheka abanye noma iculelwa?)

### Isiqephu 2

<b>First forward-translation A</b>	<b>Final forward-translation A</b>
i. Ukuphuza kokuqhubeka noma kungekho ukuqhubeka kokukhuluma?	i. Ukuphuza kokuqhubeka noma kungekho ukuqhubeka kokukhuluma?

### Isiqephu 3

First forward-translation A	Final forward-translation A
i. Izindlela zokunyakaza ziyaphindwa noma zihlala zifana (isib. Ukugwincigwinciza isandla noma iminwe)	i. Izindlela zokunyakaza ziyaphindwa noma zihlala zifana (isib. Ukugwincigwinciza isandla noma iminwe)
ii. Kungahlanganiswa nezindlela zokudla ezingajwayelekile	ii. Kungahlanganiswa nezindlela zokudla ezingajwayelekile
iii. Uhlala elibaziseke ngezingxenye zezinto	iii. Uhlala elibaziseke ngezingxenye zezinto. <b>Isibonelo: Unako amasondo emoto hhayi imoto yonkhe.</b>
iv. Ukuthanda impikelelwana yezenzo, zihlala zenziwa ngendlela efanayo?	iv. Ukuthanda impikelelwana yezenzo, zihlala zenziwa ngendlela efanayo, <b>engejabuli umazishintja?</b>

### Isiqephu 4

First forward-translation A	Final forward-translation A
i. I-Autism ingukuba nezimilozimbili zomntwana (Schizophrenia)	i. I-Autism ingukuba <b>umntwana onezimilozimbili</b> (Schizophrenia)?
ii. I-Autism kusho ukuba nesifo esi (auto-immune)	ii. <b>I-Autism kusho ukuba nesifo lapho umzimba uzilwelayo esibizwa nge-auto-immune?</b>
iii. I-Autism isifo sokukhula kwemizwa?	iii. I-Autism <b>yisimo senkinga nokukhula kwemizwa?</b>
iv. I-Autism ingaba ihlangene nokukhubazeka kwengqondo	iv. I-Autism ingaba ihlangene nokukhubazeka kwengqondo
v. I-Autism ingaba ihlangene nesithuthwane	v. I-Autism ingaba ihlangene nesithuthwane
vi. Ukuqala kwe-Autism kujwayele ukuba esikhathini (A) esingaphambi kokuzalwa , (B) sobungane (izinyanga months 0 – ?), (C) sobuntwana (iminyaka years ? - ?)	vi. Ukuqala kwe-Autism kujwayele ukuba esikhathini (A) esingaphambi kokuzalwa, <b>(B) sobuntwana (izinyanga months 0 – 24),</b> <b>(C) sobungane (iminyaka years 2-18)</b>

### **Appendix 3: Translation B (back-translation of the isiZulu KCAHW Questionnaire)**

*Changes made to the final back translation can be seen in **bold**.*

Questions regarding the level of knowledge of people who work with Autistic children

Please do not check your books or notes before answering these questions. Thank you for your time. These are behavioural signs of a child with Autism.

#### Section 1

<b>First back-translation B</b>	<b>Final back-translation B</b>
i. Failing to use a variety of ways of communicating such as eye contact, facial expression, body language and shaking hands.	i. Failure to use a variety of ways of communicating such as eye contact, facial expression, body language and <b>hand gestures</b> .
ii. Does the child display an inability to build a relationship with his/her peers?	ii. Does the child display an inability to build a relationship with his/her peers?
iii. Does the child display a lack of interest in having fun with others, have a close friend or do activities with others?	iii. Does the child display a lack of interest in having fun with others, have a close friend or do activities with others?
iv. Does the child show a lack of emotional intelligence when relating to others?	iv. Does the child show an <b>inability to exchange emotions when relating to others?</b>
v. Does the child daydream? Or does the child stare aimlessly?	v. Does the child daydream? Or does the child stare aimlessly?
vi. Is the child mute?	vi. Is the child <b>deaf or dumb?</b>
vii. Is there a lack of care shown for the place he/she lives in or surroundings?	vii. Is there a lack of <b>interest</b> shown for his/her surroundings?
viii. Is it normal for a child with Autism to seem unhappy?	viii. Is it normal for a child with Autism to smile when others are around? ( <b>e.g. when someone sings to the child, does h/she smile?</b> )

#### Section 2

<b>First back-translation B</b>	<b>Final back-translation B</b>
i. Does a child with Autism take a long time to learn how to speak even if he/she does not know how to speak?	i. <b>Does a child with Autism take a long time to learn how to speak or perhaps never speaks at all?</b>



### Section 3

First back-translation B	Final back-translation B
i. Body movements are repeated or always the same. (E.g. playing with or flapping the hand or fingers).	i. The child displays the same body movements <b>repetitively</b> . (e.g. playing with or flapping the hand or fingers).
ii. Not being able to eat in what would be considered a normal way of eating or eating in ways that are unusual.	ii. Not being able to eat in what would be considered a normal way of eating or eating in ways that are unusual.
iii.. He/she is always busy with activities which are never completed or finished.	iii. <b>He/she is always focuses on the details of objects rather than the whole object (e.g. focussing on the wheels of a car rather than the whole car).</b>
iv. Continually enjoying the same actions over and over again.	iv. Continually enjoying the same actions over and over again and <b>insists that routines do not change.</b>

### Section 4

First back-translation B	Final back-translation B
i. Is Autism the same as schizophrenia?	i. Is Autism the same as schizophrenia?
ii. Is Autism a disease that just appears of its own accord?	ii. Autism is related to <b>auto-immune disease?</b>
iii. Is Autism a disease which prevents mental development?	iii. Is Autism a disease which is related to brain development?
iv. Is Autism related to mental disturbance?	iv. Is Autism related to mental retardation?
v. Is Autism related to epilepsy?	v. Is Autism related to epilepsy?
vi. When does Autism start? Does it start.. (A) Before birth , (B)Baby stage (0-2 months, (C) Childhood (2-18 years)	vi. When does Autism start? Does it start.. (A) Before birth, (B)Baby stage (0 months – 24 months), (C) Childhood (2years - 18 years of age)

## **isiZulu Knowledge about childhood Autism amongst health workers questionnaire**

**Ngiyacela ugcwalise okulandelayo ukuze usize kulolucwaningo:**

- Ngineminyaka ewu \_\_\_\_\_ yobudala
- Sengifundise iminyaka ewu \_\_\_\_\_
- Ngi- ☐ Mnyama ☐ Indiya ☐ Ikhaladi ☐ Mhlophe
- Ngiyakhuluma ☐ isiZulu ☐ isiXhosa ☐ isiNgisi ☐ isiBhunu

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**Imiyalelo:**

Imibuzo ngoLwazi lwaBasebenza ngeZempilo mayelana ne “Autism” kubantwana

**Zungeleza impendulo efaneleyo**

- **Isibonela**  
**Inyanga yokuqala onyakeni uMasingana**  
☐ Angazi ☒ Yebo ☐ Cha

Ngiyabonga ngesikhathi sakho.

---

**Uyazi yoni ukuthi yini I-Autism?**

☐ Yebo ☐ Cha

## Isiqephu 1

**Zungeleza impendulo efaneleyo. Lezi zindlela zokuziphatha zichaza ingane ene “Autism”:**

- 1) Ukungakwazi ukusebenzisa izindlela eziningi ngaphandle kokukhuluma njengokubhekana emehlweni, umumo wobuso (*facial expression*), ukumiswa komzimba nokunqathuzisa izandla uma kuthintanwa.  
☐ Angazi ☐ Yebo ☐ Cha
- 2) Ukuhluleka nokuba nobudlelwane bontanga obufanele lobo budala?  
☐ Angazi ☐ Yebo ☐ Cha
- 3) Ukukhombisa ukuthi akafuni ukujabula nabanye, ukuba nomnako noma ukwenza izinto nabanye?  
☐ Angazi ☐ Yebo ☐ Cha
- 4) Ukuswela isenaniselo semizwa nangokuzwelana nabanye?  
☐ Angazi ☐ Yebo ☐ Cha
- 5) Ukugqolozela obaleni engabukisisi lutho?  
☐ Angazi ☐ Yebo ☐ Cha
- 6) Kungathi ingane iyisithulu noma isimungulu?  
☐ Angazi ☐ Yebo ☐ Cha
- 7) Ukungabi nogqozu ngenhlalo yendawo yakhe?  
☐ Angazi ☐ Yebo ☐ Cha

8) Kujwayelekele ukuthi akukho ukumamatheka enganeni uma kukhona abanye?

(Isibonela: ingane iyamamatheka uma kumamatheka abanye noma iculelwa?)

☐ Angazi ☐ Yebo ☐ Cha

## Isiqephu 2

**Zungeleza impendulo efaneleyo. Lezi zindlela zokuziphatha zichaza ingane ene “Autism”:**

1) Ukuphuza kokuqhubeka ukukhuluma noma kungekho ukuqhubeka kokukhuluma?

☐ Angazi ☐ Yebo ☐ Cha

## Isiqephu 3

**Zungeleza impendulo efaneleyo. Lezi zindlela zokuziphatha zichaza ingane ene “Autism”:**

1) Izindlela zokunyakaza ziyaphindwa noma zihlala zifana ( isib. Ukugwincigwinciza isandla noma iminwe)

☐ Angazi ☐ Yebo ☐ Cha

2) Kungahlanganiswa nezindlela zokudla ezingajwayelekile

☐ Angazi ☐ Yebo ☐ Cha

3) Uhlala elibaziseke ngezingxenye zezinto. Isibonelo: Unaka amasondo emoto hhayi imoto yonke.

☐ Angazi ☐ Yebo ☐ Cha

4) Ukuthanda impikelelwana yezenzo, zihlala zenziwa ngendlela efanayo, engejabuli umazishintja?

☐ Angazi ☐ Yebo ☐ Cha

## Isiqephu 4

### Zungeleza impendulo efaneleyo

#### Lezi zindlela zokuziphatha zichaza ingane ene “Autism”:

- 1) I-Autism ingukuba umntwana onezimilozimbili (Schizophrenia)?  
☐ Angazi ☐ Yebo ☐ Cha
  
- 2) I-Autism kusho ukuba nesifo lapho umzimba uzilwelayo esibizwa nge-auto-immune?  
☐ Angazi ☐ Yebo ☐ Cha
  
- 3) I-Autism yisimo senkinga nokukhula kwemizwa?  
☐ Angazi ☐ Yebo ☐ Cha
  
- 4) I-Autism ingaba ihlangene nokukhubazeka kwengqondo  
☐ Angazi ☐ Yebo ☐ Cha
  
- 5) I-Autism ingaba ihlangene nesithuthwane (isifo sokuwa)  
☐ Angazi ☐ Yebo ☐ Cha
  
- 6) Ukuqala kwe-Autism kujwayele ukuba esikhathini  
☐ esingaphambi kokuzalwa ☐ sobuntwana (izinyanga months 0-24)  
☐ sobungane (iminyaka years 2-18)

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**Ngiyabonga Kakhulu.**

*Natalie Hutton*

## **Appendix 5: Information sheet and consent form for Honours students**

Dear Student

My name is Natalie Hutton, and I am an Educational Psychology Masters student at the University of KwaZulu-Natal, Pietermaritzburg campus. I wish to conduct an Autism awareness study using an instrument called the “Knowledge about Childhood Autism among Health Workers (KCAHW)” Questionnaire.

The KCAHW questionnaire has been translated into *isiZulu* for use in the South African context. I have translated the questionnaire into *isiZulu* so that it is more applicable to the South African context. However I need to check the reliability of the translated instrument. I am therefore looking for volunteers in the 2014 Psychology Honours class to assist me with this process. In order to participate you need to be fluent in *isiZulu*.

The study will take no longer than 30 minutes and requires no prior knowledge or experience in Autism Spectrum Disorders. You will be asked to complete a pencil and paper questionnaire. Please note that the design of this study involves a test-retest methodology and thus participation involves answering the questionnaire twice, with a two-week interval. Participation requires attendance at both test administrations. You will not be asked to provide any identifying details. The results of the questionnaire will be analysed statistically for reliability, ensuring complete anonymity. Your participation will remain confidential and private.

Please note that your participation is on a volunteer basis only and you are free to withdraw at any stage. Should you wish to withdraw there will not be any negative consequences for you. Participating in this study is unlikely to benefit you directly in any way, but additionally there are no perceived risks involved. This study aims to develop a questionnaire that can be used to assess knowledge about Autism Spectrum Disorder (ASD) in the South African context, which adds value to the field of psychology and that you may have use for in the future.

A brief summary of the results of this study will be made available for your interest and this project will be available in the UKZN library once complete. Should you wish to receive a copy of the results, please email me to inform me of your interest. Your contact details will

remain confidential and will be destroyed after information has been sent to you. Additionally, should you wish to know more about ASD as a result of this study, I will provide an English or *isiZulu* information booklet that explains more about this developmental disorder. Furthermore, I will be available for a consultation should you wish to discuss the questionnaire and any questions that may arise regarding it.

Your identity will be kept confidential throughout this research process. The data from the research will be kept for five years in a locked filing cabinet with the researcher's supervisor in the Psychology department at the University of KwaZulu-Natal. Electronic data will be password protected. Thereafter it will be shredded and/or destroyed. The results of this study will be statistical in nature and participants' names will not be on the collected data. The study will therefore not compromise confidentiality in any way. No volunteers will be identified by name and you will not be asked to provide identifying information on the questionnaire they complete. The final study will be stored in the University library once complete but this will not compromise confidentiality. Should the researcher present the findings at a conference, or if the research is published, the confidentiality of the participants will remain intact.

If you have any questions about this study or if you would like to be made aware of the findings of this study, feel free to contact me by email at [nataliekhutton@gmail.com](mailto:nataliekhutton@gmail.com). You may also contact my supervisor, Dr Mary van der Riet (033-2606163). If you have any concerns about the nature of the study at any point, you may also contact Ms P. Ximba at the UKZN Human Social Sciences Ethics Committee (Tel: 031 260 3587).

Thank you for considering this request.

Kind regards,  
Natalie Hutton

## CONSENT FORM

**Please sign and return the following if you choose to take part in this study:**

- I \_\_\_\_\_ (print name) voluntarily consent to participate in the research project entitled, “Assessing an *isiZulu* Autism Spectrum Disorder questionnaire with educators in primary schools in Pietermaritzburg.”
- I understand that I will not be forced to participate in this study.
- I understand that I can change my mind about participation, at any time, by notifying the researcher of my decision to end participation in this project.
- I understand that I will attend **two** test administration sessions with the researcher.
- I have read the above description of this study and I understand what the study involves.

---

Participant's signature

---

Date



## **Appendix 6: Sizabantwana School List**

All of the schools listed below are in the greater Pietermaritzburg area.

Alston Primary School	Izwilesizwe Primary School	Philani Primary School
Ashdown Primary School	Khethindlelenhle Primary	Qhamukile Primary School
Dlokwakhe Primary School	School	Sanzwili Primary School
Ekhukanyeni Special School	Khobongwane Primary	Sibongamandla Primary School
Fezokuhle Primary School	Kwa-Mpungose Primary School	Silwanetshe Primary School
Funulwazi Primary School	Lungisile Primary School	Sinathing Primary School
Henryville Primary School	Mthethomusha Primary School	Slangspruit Primary School
Hlelingomuso Primary School	Muzi Thuzi Primary School	Sombongangani Primary
Hopewell School	Ndabenhle Primary School	School
Isisbongo Primary School	Ndlelayabasha Primary School	Zamazulu Primary School
Iwahlanga Junior Primary	Ndeleshane Primary School	Zamuxolo Primary
School	New Hanover Primary School	

### **Specifically chosen schools from the Sizabantwana school list for this study:**

The average distance of these schools from UKZN is 27km, making it a convenient sample.

1. Ashdown Primary School  
20km from UKZN Psychology Department
2. Henryville Primary School  
31km from UKZN Psychology Department
3. Sibongamandla Primary School  
18km from UKZN Psychology Department
4. Funulwazi Primary School  
25km from UKZN Psychology Department
5. Hlelingomuso Primary School  
36 km from UKZN Psychology Department
6. Philani Primary School  
36km from UKZN Psychology Department

## **Appendix 7a: English information sheet for principals**

Dear Sir/Madam

My name is Natalie Hutton, and I am an Educational Psychology Masters student at the University of KwaZulu-Natal, Pietermaritzburg campus. I wish to conduct an Autism awareness study using an instrument called the “Knowledge about Childhood Autism among Health Workers (KCAHW)” Questionnaire. The KCAHW has been translated into *isiZulu* for use in the South African context.

I am looking for primary school teachers in the Pietermaritzburg area who are willing to volunteer for this study. In order to participate, the teachers need to be first language *isiZulu* speakers. I would like to request permission to invite teachers at your school to participate in this study.

The study will take no longer than 30 minutes and requires no prior knowledge or experience in Autism Spectrum Disorders. The participants will be asked to complete a pencil and paper questionnaire. They will not be asked to provide any identifying details. The results of the questionnaire will be analysed statistically for reliability, ensuring complete anonymity. Their participation will remain confidential and private.

Please note that your participation is on a volunteer basis only and you are free to withdraw at any stage. Should you wish to withdraw there will be no negative consequences. Participating in this study is unlikely to benefit you directly, but additionally there are no perceived risks involved. This study aims to develop a questionnaire that can be used to assess knowledge about Autism Spectrum Disorder (ASD) in the South African context, which you may find useful in the future. A summary of the findings of this research will be provided upon completion.

A brief summary of results of this study will be made available for your interest and this project will be available in the UKZN library once complete. Should you wish to receive a copy of the results, please email me to inform me of your interest. Your contact details will remain confidential and will be destroyed after information has been sent to you.

Additionally, should you wish to know more about ASD as a result of this study, I can provide an English or *isiZulu* information booklet that explains more about this

developmental disorder. Furthermore, I will be available for a consultation should you wish to discuss the questionnaire and any questions that may arise regarding it.

Your identity will be kept confidential throughout this research process. The data from the research will be kept for five years in a locked filing cabinet with the researcher's supervisor in the Psychology department at the University of KwaZulu-Natal. Electronic data will be password protected. Thereafter it will be shredded and/or destroyed. The results of this study will be statistical in nature and participants' names will not be on the collected data. The study will therefore not compromise confidentiality in any way. No volunteers will be identified by name and they will not be asked to provide identifying information on the questionnaire they complete. The final study will be stored in the University library once complete but this will not compromise confidentiality. Should the researcher present the findings at a conference, or if the research is published, the confidentiality of the participants and schools will remain intact.

If you have any questions about this study, please contact me by email at [nataliekhutton@gmail.com](mailto:nataliekhutton@gmail.com). You may also contact my supervisor, Dr Mary van der Riet (033-2606163). If you have any concerns about the nature of the study at any point, you may also contact Ms P. Ximba at UKZN's Human Social Sciences Ethics Committee (Tel: 031 260 3587). Thank you for considering this request.

Kind regards,  
Natalie Hutton

## **Appendix 7b: isiZulu information sheet for principals**

Sawubona Mnumzane noma Nkosazana

Igama lami nguNatalie Hutton. Ngingumfundi enyuvesi yase KwaZulu Natali, emGungundlovu lapho engenza iMasters kwiEducational Psychology. Ngifuna ukwazi kabanzi ngezingane ezikhubazekile, ezine eAutism. Ngizosebenzisa imibuzo emayelana nolwazi lweAutism kubantu bezempilo. Lemibuzo ibhalwe ngesiZulu khona izosebenza emphakathini yaseNinguzimu Africa.

Ngifuna abothisha abangathanda ukuphendula lemibuzo. Ngizocela imvumo yekuthi abothisha esikoleni sakho baphendule lemibuzo. Kufanele babebhatha abakhuluma *isiZulu*.

Ukuphendula lemibuzo kuzothatha imizuzu engamashumi amathathu. Akunankinga uma bothisha bengazi lutho ngengane ekhubazekile, bangayiphendula lemibuzo. Labothisha angeke babuzwe izinto eziyimfihlo yabo. Imiphumela yalemibuzo izohlolwa ngendlela ethembekile. Ukuzibandakanya kwabo nalendatshana kuyoba yimfihlo.

Uyaziswa ukuthi ukubamba iqhaza kwakho kulolucwaningo ukwenza ungeke ukhokhelwe. Uvumelekile ukuthi uhoxe nanoma isiphi isikhathi. Uyaziswa futhi ukuthi ukuhoxa kwakho ngeke kube nomthelela omubi kuwena.

Ukubamba iqhaza kucwaningo olunjena kungenzeka kungakukomelisa wena gqo khepha akukho ubungozi noma umthelela omubi ongakwehlela.

Inhlalo yalolucwaningo ukuthi yakhe imibuzo ehlanganisiwe yocwaningo(questionnaire) ezonginikwa ulwazi lokuthi abantu bazini ngesihloko esicwaningwayo okuyisifo se AUTISM Spectrum Disorder(ASD mafishane) lapha eNingizimu Afrika. Lolucwaningo luzokhulisa ulwazi kwisifundo se Psychology esiqonda ukucabanga komuntu futhi ulwazi locwaningo lungenzeka lusetshenziswe ngenkathi ezayo.

Isichazelo esifingqiwe semiphumela yocwaningo siyotholakala kumtapo wolwazi eNyuvesi yase KwaZulu-Natal uma seluqediwe. Uma ufisa ukuthola ikhophi yemiphumela ngicela ungithumele I –email ungazise. Izinamba zakho ziyogcinwa ziyimfihlo futhi zilahlwe

ngendlela ephephile emva kokuba imiphumela isithunyelwe. Ngaphezu kwalokhu uma ufisa ukwazikabanzi nge Autism Spectrum Disorder ngenxa yalolucwaningo ngizokhipha isiqephu esinemininingwane ngesiZulu nangesiNgisi esizochaza ngalisisifo esihlasela ukukhula. Ngaphezu kwalokhu ngiyatholakala uma ufisa ukuxoxisana nami mayelana nalembuzo ehlanganisiwe yocwaningo futhi nanoma imiphi imibuzo ongabanayo ngalesisihloko.

Igama lakho sizoligcina libe imfihlo kulolucwaningo. Imininingwane esizoyiqoqa kulolucwaningo izogcinwa iminyaka emihlanu(5) endaweni ekhiyiwe KuMphathi wocwaningo we Psychology eNyuvesi yase KwaZulu Natal. Imininingwane ezofakwa kumakhomputha yona uzovikelwa nge *Password* ezokwenza ukuthi ibonwe abantu abafanele kuphela. Emuva kweminyaka emihlanu lemininingwane izolahlwa ngendlela ephephile. Imiphumela yalolucwaningo izophuma ifingqe ngezinamba, ngeke avele amagama abantu. Ayikho imininingwane eyimfihlo ezovela ukuthi iphuma kubani, futhi akekho ozocelwa imininingwane ezoveza kalula ukuthi ivela kubani. Imiphumela izohlala kumtapo wolwazi weNyuvesi futhi kuyaqinisekiswa ukuthi angeke ikhiphe imininingwane eyimfihlo, nomalungakhishwa kuConference ulwazi olutholakele lulolucwaningo noma iphume ibe ibhuku abantu abanike ulwazi lwabo ngeke badalulwe.

Uma unemibuzo mayelana nalomsebenzi noma ufuna ukwazi imiphumela yalesisifundo ungangithinta kwi-email ethi: [nataliehutton@gmail.com](mailto:nataliehutton@gmail.com). Ungathintana noMphathi wami u Dokotela Mary van der Riet kulenombolo: 033 2606163. Uma kukhona into ngalolucwaningo ekukhathazayo ngendlela olubekekengayo lolucwaningo ungakwazi ukuthula isikhalo sakho ku Nkosazana u Ms. P. Ximba ose UKZN Human Social Sciences ethics committee kunombolo ethi: 031 260 3587. Ngiyabonga ngokusicabanga lesisicelo sami.

Ngiyasibonga isikhathi sakho.

Natalie Hutton

## **Appendix 8a: Information sheet and consent form for participants**

Dear Participant

My name is Natalie Hutton, and I am an Educational Psychology Masters student at the University of KwaZulu-Natal, Pietermaritzburg campus. I wish to conduct an Autism awareness study using an instrument called the “Knowledge about Childhood Autism among Health Workers (KCAHW)” Questionnaire. The KCAHW has been translated into *isiZulu* for use in the South African context.

I am looking for primary school educators in the Pietermaritzburg region who are willing to volunteer for this study. In order to participate you need to be an *isiZulu* first language speaker.

The study will take no longer than 30 minutes and requires no prior knowledge or experience in Autism Spectrum Disorders. You will be asked to complete a pencil and paper questionnaire. You will not be asked to provide any identifying details. The results of the questionnaire will be analysed statistically for reliability, ensuring complete anonymity. Your participation will remain confidential and private.

Please note that your participation is on a volunteer basis only and you are free to withdraw at any stage. Should you wish to withdraw there will not be any negative consequences for you. Participating in this study is unlikely to benefit you directly in any way, but additionally there are no perceived risks involved. This study aims to develop a questionnaire that can be used assess knowledge about Autism Spectrum Disorder (ASD) in the South African context, which adds value to the field of psychology and that you may have use for in the future.

A brief summary of results of this study will be made available for your interest and this project will be available in the UKZN library once complete. Should you wish to receive a copy of the results, please email me to inform me of your interest. Your contact details will remain confidential and will be destroyed after information has been sent to you.

Additionally, should you wish to know more about ASD as a result of this study, I can provide an English or *isiZulu* information booklet that explains more about this

developmental disorder. Furthermore, I will be available for a consultation should you wish to discuss the questionnaire and any questions that may arise regarding it.

Your identity will be kept confidential throughout this research process. The data from the research will be kept for five years in a locked filing cabinet with the researcher's supervisor in the Psychology department at the University of KwaZulu-Natal. Electronic data will be password protected. Thereafter it will be shredded and/or destroyed. The results of this study will be statistical in nature and participants' names will not be on the collected data. The study will therefore not compromise confidentiality in any way. No volunteers will be identified by name and they will not be asked to provide identifying information on the questionnaire they complete. The final study will be stored in the University library once complete but this will not compromise confidentiality. Should the researcher present the findings at a conference, or if the research is published, the confidentiality of the participants and schools will remain intact.

If you have any questions about this study or if you would like to be made aware of the findings of this study, feel free to contact me by email at [nataliekhutton@gmail.com](mailto:nataliekhutton@gmail.com). You may also contact my supervisor, Dr Mary van der Riet (033-2606163). If you have any concerns about the nature of the study at any point, you may also contact Ms P. Ximba at the UKZN Human Social Sciences Ethics Committee (Tel: 031 260 3587). Thank you for considering this request.

Kind regards,  
Natalie Hutton

## CONSENT FORM

**Please sign and return the following if you choose to take part in this study:**

- I \_\_\_\_\_ (print name) voluntarily consent to participate in the research project entitled, “Assessing an *isiZulu* Autism Spectrum Disorder questionnaire with educators in primary schools in Pietermaritzburg.”
- I understand that I will not be forced to participate in this study.
- I understand that I can change my mind about participation, at any time, by notifying the researcher of my decision to end participation in this project.
- I have read the above description of this study and I understand what the study involves.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date



## **Appendix 8b: isiZulu information sheet and consent form for participants**

Sawubona Mnumzane noma Nkosazana

Igama lami nguNatalie Hutton. Ngingumfundi enyuvesi yase KwaZulu Natali, emGungundlovu lapho engenza iMasters kwiEducational Psychology. Ngifuna ukwazi kabanzi ngezingane ezikhubazekile, ezine eAutism. Ngizosebenzisa imibuzo emayelana nolwazi lweAutism kubantu bezempilo. Lemibuzo ibhalwe ngesiZulu khona izosebenza emphakathini yaseNinguzimu Africa.

Ngifuna abothisha abangathanda ukuphendula lemibuzo. Kufanele babebbothisha abafundisa emabangeni aphantsi (Gr 1-7) futhi babebbothisha abahlala emGungundlovu.

Ukuphendula lemibuzo kuzothatha imizuzu engamashumi amathathu. Akunankinga uma ophendula lemibuzo engazi lutho ngengane ekhubazekile, angayiphendula lemibuzo. Loyo muntu angeke abuzwe izinto eziyimfihlo yakhe. Imiphumela yalemibuzo izohlolwa ngendlela ethembekile. Ukuzibandakanya kwakho nalendatshana kuyoba yimfihlo.

Uyaziswa ukuthi ukubamba iqhaza kwakho kulolucwaningo ukwenza ungeke ukhokhelwe. Uvumelekile ukuthi uhoxe nanoma isiphi isikhathi. Uyaziswa futhi ukuthi ukuhoxa kwakho ngeke kube nomthelela omubi kuwena.

Ukubamba iqhaza kucwaningo olunjena kungenzeka kungakukomelisa wena gqo khepha akukho ubungozi noma umthelela omubi ongakwehlela.

Inhloso yalolucwaningo ukuthi yakhe imibuzo ehlanganisiwe yocwaningo(questionnaire) ezonginikwa ulwazi lokuthi abantu bazini ngesihloko esicwaningwayo okuyisifo se AUTISM Spectrum Disorder(ASD mafishane) lapha eNingizimu Afrika. Lolucwaningo luzokhulisa ulwazi kwisifundo se Psychology esiqonda ukucabanga komuntu futhi ulwazi locwaningo lungenzeka lusetshenziswe ngenkathi ezayo.

Isichazelo esifingqiwe semiphumela yocwaningo siyotholakala kumtapo wolwazi eNyuvesi yase KwaZulu-Natal uma seluqediwe. Uma ufisa ukuthola ikhophi yemiphumela ngicela ungithumele I –email ungazise. Izinamba zakho ziyogcinwa ziyimfihlo futhi zilahlwe

ngendlela ephephile emva kokuba imiphumela isithunyelwe. Ngaphezu kwalokhu uma ufisa ukwazikabanzi nge Autism Spectrum Disorder ngenxa yalolucwaningo ngizokhipha isiqephu esinemininingwane ngesiZulu nangesiNgisi esizochaza ngalisisifo esihlasela ukukhula. Ngaphezu kwalokhu ngiyatholakala uma ufisa ukuxoxisana nami mayelana nalembuzo ehlanganisiwe yocwaningo futhi nanoma imiphi imibuzo ongabanayo ngalesisihloko.

Igama lakho sizoligcina libe imfihlo kulolucwaningo. Imininingwane esizoyiqoqa kulolucwaningo izogcinwa iminyaka emihlanu(5) endaweni ekhiyiwe KuMphathi wocwaningo we Psychology eNyuvesi yase KwaZulu Natal. Imininingwane ezofakwa kumakhomputha yona uzovikelwa nge *Password* ezokwenza ukuthi ibonwe abantu abafanele kuphela. Emuva kweminyaka emihlanu lemininingwane izolahlwa ngendlela ephephile. Imiphumela yalolucwaningo izophuma ifingqe ngezinamba, ngeke avele amagama abantu. Ayikho imininingwane eyimfihlo ezovela ukuthi iphuma kubani, futhi akekho ozocelwa imininingwane ezoveza kalula ukuthi ivela kubani. Imiphumela izohlala kumtapo wolwazi weNyuvesi futhi kuyaqinisekiswa ukuthi angeke ikhiphe imininingwane eyimfihlo, nomalungakhishwa kuConference ulwazi olutholakele lulolucwaningo noma iphume ibe ibhuku abantu abanike ulwazi lwabo ngeke badalulwe.

Uma unemibuzo mayelana nalomsebenzi noma ufuna ukwazi imiphumela yalesisifundo ungangithinta kwi-email ethi: [nataliehutton@gmail.com](mailto:nataliehutton@gmail.com). Ungathintana noMphathi wami u Dokotela Mary van der Riet kulenombolo: 033 2606163. Uma kukhona into ngalolucwaningo ekukhathazayo ngendlela olubekekengayo lolucwaningo ungakwazi ukuthula isikhalo sakho ku Nkosazana u Ms. P. Ximba ose UKZN Human Social Sciences ethics committee kunombolo ethi: 031 260 3587. Ngiyabonga ngokusicabanga lesisicelo sami.

Ngiyasibonga isikhathi sakho.

Natalie Hutton

## ISIVUMELWANO

**Sayina leliphepha uliphindise kimi uma ufuna ukuphendula lemibuzo.**

- Mina \_\_\_\_\_ (bhala igama) ngivuma ukuthi ngizophendula lemibuzo yomsebenzi ekuthiwa “iAssessing an *isiZulu* Autism Spectrum Disorder questionnaire with educators in primary schools in Pietermaritzburg.”
- Ngiyaqonda ukuthi ngiyazikhethela ukuphendula lemibuzo, akekho ongiphoqile futhi ngingasho mesengingafuni ukuqhubeka ngalomsebenzi.
- Ngiyifundile incwadi eyiphezulu ngaqonda ukuthi lomsebenzi umayelana nani.

\_\_\_\_\_  
Sayina

\_\_\_\_\_  
Usuku

## **Appendix 9a: Humanities & Social Sciences Ethics Research Committee Approval (REC) for pilot study**



15 January 2014

Ms Carol Mitchell (215359)  
School of Applied Human Sciences - Psychology  
Pietermaritzburg Campus

Protocol reference number: HSS/0006/014CA  
Project title: A pilot study to investigate the reliability of an isiZulu version of the "Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire"

Dear Ms Mitchell,

### **Pilot Study Full Approval – Expedited**

In response to your application dated 20 December 2013, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol have been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

Please note: Research data should be securely stored in the discipline/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr Shenika Singh (Chair)

/ms

cc Academic Leader Research: Professor Doug Wassenaar  
cc School Administrator: Mr Sbonelo Duma

### **Humanities & Social Sciences Research Ethics Committee**

Dr Shenika Singh (Chair)

Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban 4000

Telephone: +27 (0) 31 260 3587/8350/4557 Facsimile: +27 (0) 31 260 4808 Email: [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za) / [soymann@ukzn.ac.za](mailto:soymann@ukzn.ac.za) / [mohun@ukzn.ac.za](mailto:mohun@ukzn.ac.za)

Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)



100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

## Appendix 9b: Amendment to ethical clearance for pilot study



19 March 2014

Ms Carol Mitchell (215359)  
School of Applied Human Sciences - Psychology  
Pietermaritzburg Campus

Protocol reference number: HSS/0006/014CA  
Project title: A pilot study to investigate the reliability of an isiZulu version of the "Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire"

Dear Ms Mitchell,

### **Amendment Approval**

This letter serves to notify you that your application for an amendment dated 04 March 2014 has now been approved.

- Change(s) to the research methodology.

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form; Title of the Project, Location of the Study must be reviewed and approved through an 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 discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol.

Yours faithfully

Dr Shenuka Singh (Chair)

cc Academic Leader Research: Professor Doug Wassenaar  
cc School Administrator: Mr Sbonelo Duma

Humanities & Social Sciences Research Ethics Committee  
Dr Shenuka Singh (Chair)

Westville Campus, Govan Mbeki Building

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Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)



1910 - 2010  
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Founding Colleges: Edgewood Howard College Medical School Pietermaritzburg Westville

## Appendix 9c: Humanities & Social Sciences REC Approval for study



14 April 2014

Mrs N Hutton (214546890)  
School of Applied Human Sciences – Psychology  
Pietermaritzburg Campus

Protocol reference number: HSS/0268/014M

Project title: Assessing an isiZulu Autism Spectrum Disorder questionnaire with educators in primary schools in Pietermaritzburg

Dear Mrs Hutton,

### Full Approval – Expedited

In response to your application dated 02 April 2014, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol have been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

**PLEASE NOTE:** Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr Shenuka Singh (Chair)

/ms

Cc Supervisors: Ms Carol Mitchell and Dr Mary van der Riet  
cc Academic Leader Research: Professor D Wassenaar  
cc School Administrator: Mr Sbonelo Duma

### Humanities & Social Sciences Research Ethics Committee

Dr Shenuka Singh (Chair)

Westville Campus, Govan Mbeki Building

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Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)



100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville



## Appendix 9d: Humanities & Social Sciences REC amendment approval for study



15 May 2014

Mrs N Hutton (214546890)  
School of Applied Human Sciences – Psychology  
Pietermaritzburg Campus

Protocol reference number: HSS/0268/014M  
Project title: Assessing an *isiZulu* Autism Spectrum Disorder questionnaire with educators in primary schools in Pietermaritzburg

Dear Mrs Hutton,

### Provisional Approval / Amendment

I wish to confirm that your application dated 11 May 2014 in connection with the above mentioned project has been provisionally approved as follows:

- Change of sample size
- Additional site (School of Education & Development)
- Gatekeeper permission letter required (School of Education & Development)

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/Methods must be reviewed and approved through an 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 discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol.

Yours faithfully

Dr Shenuka Singh (Chair)

/ms

Cc Supervisors: Ms Carol Mitchell and Dr Mary van der Riet  
cc Academic Leader Research: Professor D Wassenaar  
cc School Administrator: Mr Sbonelo Duma

Humanities & Social Sciences Research Ethics Committee

Dr Shenuka Singh (Chair)

Westville Campus, Govan Mbeki Building

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Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)



Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville



09 July 2014

Mrs N Hutton (214546890)  
School of Applied Human Sciences – Psychology  
Pietermaritzburg Campus

Protocol reference number: HSS/0268/014M  
Project title: Assessing an *isiZulu* Autism Spectrum Disorder questionnaire with educators in primary schools in Pietermaritzburg

Dear Mrs Hutton,

**Amendment – Expedited Application**

I wish to confirm that your application dated 11 May 2014 in connection with the above mentioned project has been provisionally approved as follows:

- Change of sample size
- Additional site

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/Methods must be reviewed and approved through an 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 discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol.

Yours faithfully

Dr Shenuka Singh (Chair)

/ms

Cc Supervisors: Ms Carol Mitchell and Dr Mary van der Riet  
cc Academic Leader Research: Professor D Wassenaar  
cc School Administrator: Mr Sbonelo Duma

**Humanities & Social Sciences Research Ethics Committee**

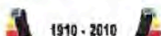
Dr Shenuka Singh (Chair)

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Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)



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Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville



18 November 2014

Mrs N Hutton (214546890)  
School of Applied Human Sciences – Psychology  
Pietermaritzburg Campus

Dear Mrs Hutton

Protocol reference number: HSS/0268/014M

New project title: Assessing an isiZulu questionnaire with educators in primary schools in Pietermaritzburg to establish a baseline of knowledge of Autism Spectrum Disorder

**Approval Notification – Amendment**

This letter serves to notify you that your request for an amendment received on 03 November 2014 has now been approved as follows:

- Change in Title

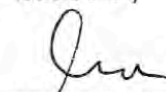
Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form; Title of the Project, Location of the Study must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

**PLEASE NOTE:** Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol.

Yours faithfully



Dr Shenuka Singh (Chair)

/ms

Cc Supervisors: Ms Carol Mitchell and Dr Mary van der Riet  
cc Academic Leader Research: Professor D Wassenaar  
cc School Administrator: Mr Sbonelo Duma

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**Humanities & Social Sciences Research Ethics Committee**

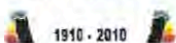
Dr Shenuka Singh (Chair)

Westville Campus, Govan Mbeki Building






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Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)



100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg  Westville

## Appendix 10: Approval from the Department of Education



education

Department:  
Education  
**PROVINCE OF KWAZULU-NATAL**

Enquiries: Sibusiso Alwar

Tel: 033 341 8610

Ref.:2/4/8/1/31

Mrs N Hutton  
P O Box 813  
Hilton  
3245

Dear Mrs Hutton

### **PERMISSION TO CONDUCT RESEARCH IN THE KZN DoE INSTITUTIONS**

Your application to conduct research entitled: **“An awareness study to assess the baseline knowledge of Autism Spectrum Disorder amongst educators in Pietermaritzburg”**, in the KwaZulu-Natal Department of Education Institutions has been approved. The conditions of the approval are as follows:

1. The researcher will make all the arrangements concerning the research and interviews.
2. The researcher must ensure that Educator and learning programmes are not interrupted.
3. Interviews are not conducted during the time of writing examinations in schools.
4. Learners, Educators, Schools and Institutions are not identifiable in any way from the results of the research.
5. A copy of this letter is submitted to District Managers, Principals and Heads of Institutions where the intended research and interviews are to be conducted.
6. The period of investigation is limited to the period from 01 February to 28 November 2014.
7. Your research and interviews will be limited to the schools you have proposed and approved by the Head of Department. Please note that Principals, Educators, Departmental Officials and Learners are under no obligation to participate or assist you in your investigation.
8. Should you wish to extend the period of your survey at the school(s), please contact Mr. Alwar at the contact numbers below.
9. Upon completion of the research, a brief summary of the findings, recommendations or a full report / dissertation / thesis must be submitted to the research office of the Department. Please address it to The Director-Resources Planning, Private Bag X9137, Pietermaritzburg, 3200.
10. Please note that your research and interviews will be limited to schools and institutions in KwaZulu-Natal Department of Education (Umgungundlovu District).

**Nkosinathi S.P. Sishi, PhD**  
**Head of Department: Education**  
**Date: 25 March 2014**

#### **KWAZULU-NATAL DEPARTMENT OF EDUCATION**

POSTAL: Private Bag X 9137, Pietermaritzburg, 3200, KwaZulu-Natal, Republic of South Africa  
PHYSICAL: 247 Burger Street, Anton Lembede House, Pietermaritzburg, 3201. Tel. 033 392 1004  
EMAIL ADDRESS: [keholegile.connie@kzndoe.gov.za](mailto:keholegile.connie@kzndoe.gov.za); CALL CENTRE: 0860 596 363;  
WEBSITE: [www.kzneducation.gov.za](http://www.kzneducation.gov.za)

...dedicated to service and performance  
Fax: 033 392 4203

## **Appendix 11a: UKZN Department of Psychology Gatekeeper permission**

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**From:** Nhlanhla Mkhize  
**Sent:** 20 December 2013 11:34 AM  
**To:** Carol Mitchell  
**Cc:** Pops Pillay  
**Subject:** RE: Gatekeeper permission to approach psychology honours students in 2014

Dear Ms Mitchell

Permission is hereby given to proceed with the piloting of the instrument.

Sincerely

N. Mkhize, PhD

Dean & Head: Applied Human Sciences

UKZN

**From:** Carol Mitchell  
**Sent:** Friday, December 20, 2013 11:31 AM  
**To:** Nhlanhla Mkhize  
**Cc:** Pops Pillay  
**Subject:** Gatekeeper permission to approach psychology honours students in 2014

Dear Professor Mkhize

### **Gatekeeper permission to approach psychology honours students:**

One of my masters students (for 2014) wishes to conduct a study using an instrument called the “Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire.” This questionnaire was developed by Bakare et al (2008) and is said to be suitable for use in Southern African countries. We would like to use the questionnaire to assess the knowledge of Autism Spectrum Disorders in primary school educators in the Pietermaritzburg region. We have translated the questionnaire into isiZulu so that it is more applicable to the South African context. However we need to check the reliability of the translated instrument. We are therefore looking for volunteers in the 2014 Psychology Honours class to assist us with this process. Students will be approached in an honours seminar and volunteers will be requested. The study will take no longer than 30 minutes and requires no prior knowledge or experience in Autism Spectrum Disorders. The students will be asked to complete a pencil and paper questionnaire. They will not be asked to provide any identifying details. The results of the test will be analysed statistically for reliability, ensuring complete anonymity. Their participation will remain confidential and private. Students will be free to withdraw at any stage. Participating in this study is unlikely to benefit the student in any way, but additionally there are no risks involved.

Please find a copy of the ethical clearance proposal form attached.

The HSSREC has indicated that email permission from the Dean/HOS is acceptable.

Thank you for considering this request.

Regards

Carol

## Appendix 11b: Amendment to gatekeeper permission

28 May 2014

Dear Professor Mkhize

### Gatekeeper permission to approach Postgraduate students:

My study, entitled "Assessing an isiZulu Autism Spectrum Disorder questionnaire with educators in primary schools in Pietermaritzburg" was granted Gatekeeper permission under the supervision of Ms. Carol Mitchell (please see below). The study has since been granted full ethical clearance for the design (protocol reference number is HSS/0268/014M). The study is co-supervised by Dr. Mary van der Riet.

Gatekeeper permission was granted on the basis that my sample population be Psychology Honours students at UKZN. However, the design has changed such that a greater sample is required.

#### Motivation:

In order to run a data analysis, the phase one sample must be compared with the sample of educators in Edendale. The current phase one sample is comprised of Psychology Honours students as per the approval. However, the sample has proven to be restricted and in order to obtain more participants, the sample constraints need to be widened. Thus, this amendment serves to request that Honours and Masters students within the School of Applied Human Sciences be included in the sample population.

Please could you grant me permission to widen my sample to both Honours and Masters students across disciplines within the School of Applied Human Sciences.

Yours sincerely,

Natalie Hutton (Student number: 214546890)

I, Professor N. Mkhize, Dean and Head of School (Applied Human Sciences), agree to the sampling of postgraduate students within the School of Applied Human Sciences.



Sign

28/5/2014

Date

## **Appendix 12: Permission letter from Dr. Bakare**

Bakare, Muideen <mobakare2000@yahoo.com>

19  
Jun

Dear Natalie,

Thank you for your interest in KCAHW Questionnaire. You are permitted to use the Questionnaire in your study in as much as the following conditions are fulfilled:

1. Original reference of the work should be properly cited.
2. You provide us with adequate information about your study in relation to KCAHW Questionnaire (Sending a short Proposal of the study on what will be the use of KCAHW Questionnaire will do).
3. You intimate us about the final publication(s) produced from the study carried out using the KCAHW questionnaire.

Thank you once again for your interest.

Sincerely,

Muideen

**Dr. Muideen Owolabi Bakare, M.B.B.S, FMCPsych, MNIM**  
**Consultant Psychiatrist & Head, Clinical Services and Training**  
**Child and Adolescent Unit, Federal Neuro-Psychiatric Hospital,**  
**Upper Chime, New Haven, Enugu, Enugu State, Nigeria**  
**Phones - +234-703-0970-079, +234-805-2210-933**  
**Skype: mobakare1**

**&**  
**Adjunct Lecturer**  
**Department of Internal Medicine**  
**College of Medicine, Enugu State University of Science and Technology (ESUT),**  
**Enugu, Enugu State, Nigeria**

<http://cndinitiatives.com/>

**We never know how much we are capable until we are challenged!!!**

### Appendix 13a: Case summary for the student population

Case Summaries							
	Age	Introduction	Total score				
1	21	yes	13	27	23	yes	10
2	23	yes	11	28	22	yes	13
3	23	yes	12	29	27	no	12
4	26	yes	10	30	23	yes	9
5	41	yes	11	31	23	no	12
6	21	yes	12	32	21	no	9
7	21	yes	11	33	22	no	14
8	28	yes	10	34	23	no	15
9	22	yes	13	35	21	no	13
10	21	yes	11	36	31	no	15
11	23	yes	15	37	28	no	13
12	24	yes	9	38	22	no	13
13	21	yes	10	39	21	no	17
14	21	yes	13	40	42	no	8
15	22	yes	10	41	25	yes	7
16	22	yes	16	42	24	no	5
17	24	yes	12	43	22	no	9
18	24	yes	15	44	24	yes	14
19	19	yes	11	45	25	yes	13
20	27	yes	11	46	22	yes	16
21	23	yes	14	47	24	yes	11
22	21	yes	10	48	23	yes	14
23	21	yes	12	49	24	yes	15
24	23	yes	8	50	24	yes	15
25	22	yes	13	51	46	yes	16
26	23	yes	13	Total	51	51	51

a. Limited to first 100 cases.

### Appendix 13b: Case summary for the educator population

Case Summaries				
	Age	Years of teaching experience	Introduction	Total score
1	44	20	yes	10
2	30	10	yes	9
3	40	15	yes	10
4	46	14	no	16
5	56	30	yes	9
6	58	27	yes	14
7	54	31	blank	12
8	41	15	no	15
9	37	10	yes	13
10	59	20	yes	11
11	51	32	yes	12
12	59	21	no	12
13	34	15	no	12
14	60	29	no	17
15	25	2	no	16
16	60	32	yes	17
17	43	22	yes	15
18	50	17	yes	12
19	43	8	yes	8
20	39	20	no	10
21	55	26	no	8
22	58	35	yes	6
23	55	30	yes	14
24	51	22	no	15
25	42	20	yes	16

26	59	35	yes	8
27	44	14	no	14
28	60	34	no	14
29	42	12	no	13
30	45	22	no	16
31	54	32	no	15
32	46	20	no	11
33	40	11	no	15
34	43	1	no	13
35	36	2	yes	12
36	47	19	no	17
37	38	12	no	15
38	54	30	no	13
39	49	26	no	14
40	45	15	yes	16
41	45	12	yes	13
42	40	10	yes	12
43	53	31	yes	8
44	25	9	yes	9
45	49	13	blank	8
46	42	20	no	14
47	54	34	yes	17
48	43	12	no	16
49	48	18	no	12
50	30	5	yes	15
51	39	12	no	16
Total	51	51	51	51

a. Limited to first 100 cases.

## Appendix 14. Factor analysis results for the total population

### Component Matrix

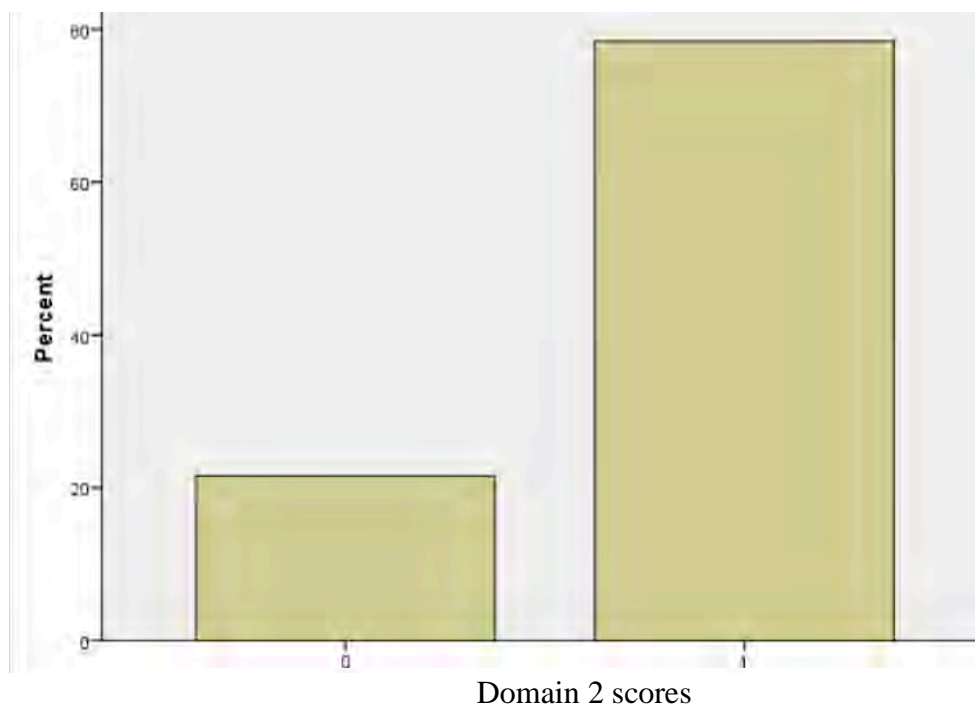
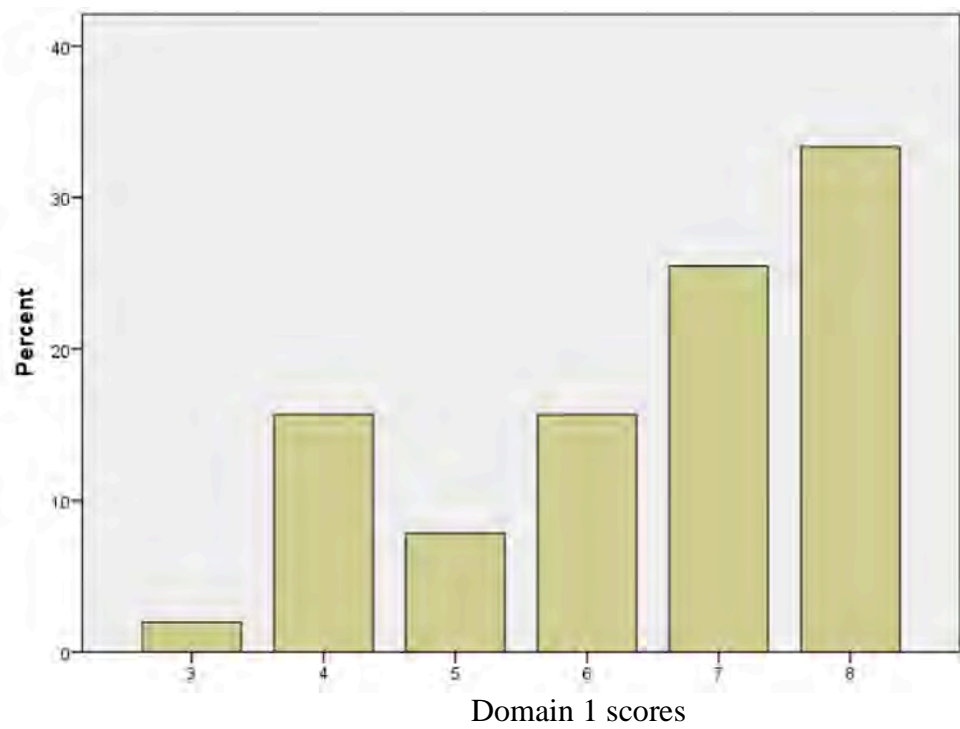
	Component						
	1	2	3	4	5	6	7
question 1	.405	.601					
question 2			-.424	.609			
question 3	.561	.325		.335			
question 4	.323	.418	-.549				
question 5	.364	-.505					
question 6	.478	-.367					
question 7	.419		-.438				-.355
question 8	.491						.573
question 9	.303			.653		-.336	
question 10	.381		.318			.351	
question 11	.450				-.471		
question 12	.449	.404				-.341	
question 13		.448			-.431		
question 14	-.467	.426			.491		
question 15	-.590	.372					
question 16	.646						
question 17	.510					-.346	-.353
question 18	.449	-.321					
question 19			.582			.440	

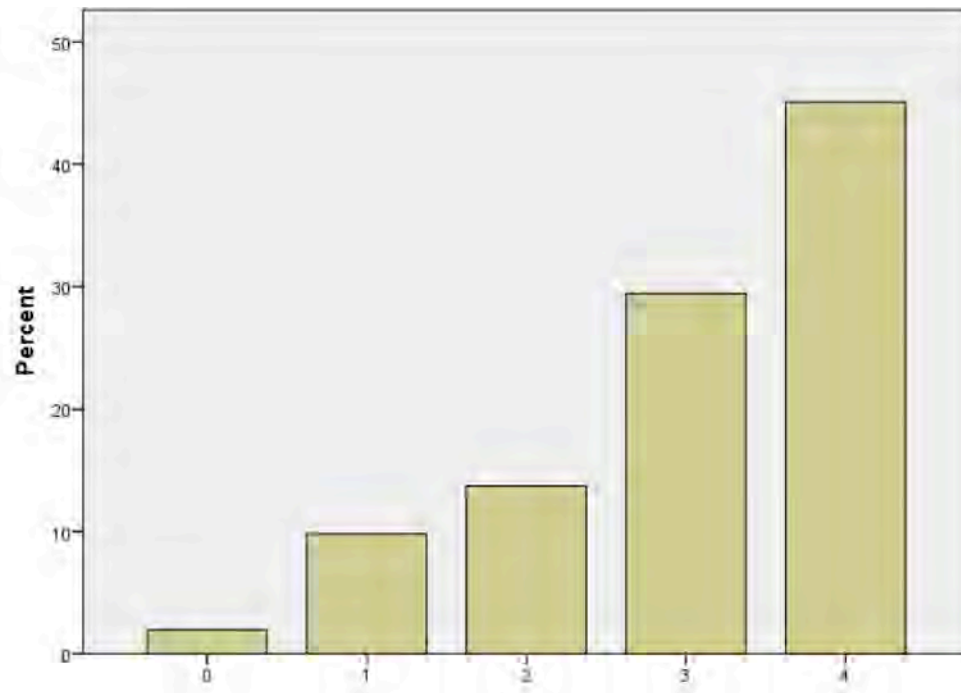
Extraction Method: Principal Component Analysis.  
a. 7 components extracted.

Component	Initial Eigenvalues		
	Total	% of Variance	Cumulative %
1	3.472	18.272	18.272
2	1.965	10.342	28.614
3	1.484	7.813	36.427
4	1.354	7.128	43.555
5	1.273	6.700	50.255
6	1.213	6.386	56.640
7	1.109	5.835	62.476
8	.925	4.868	67.343
9	.823	4.330	71.673
10	.775	4.078	75.751
11	.714	3.759	79.510
12	.658	3.465	82.976
13	.603	3.175	86.150
14	.555	2.919	89.069
15	.486	2.560	91.629
16	.442	2.329	93.958
17	.407	2.143	96.101
18	.377	1.985	98.086
19	.364	1.914	100.000

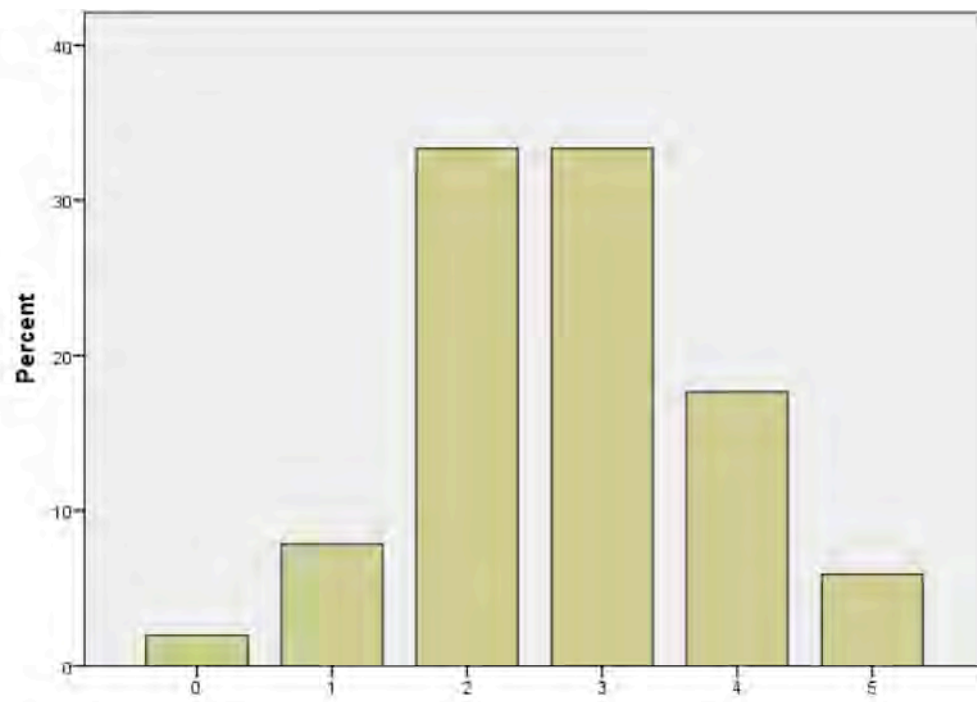


**Appendix 15: Graphic representations of educator performance in each domain**





Domain 3 scores



Domain 4 scores