

Autism Screening in Children:  
Using the Social Communication Questionnaire in a Western Cape Population

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**COMPULSORY DECLARATION**

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## Abstract

Autism spectrum disorder (ASD) has a global prevalence of approximately one percent of all new births. There is a lack of literature on autism in South Africa. South African children are waiting years for diagnoses, despite the fact that early diagnosis and subsequent intervention appear to have a positive effect on the outcomes of the intervention. A screening device to detect ASD could be used to speed up the diagnostic process. This study tested the viability of using the Social Communication Questionnaire (SCQ) in a Western Cape state-funded hospital. This thesis describes Phase 1 of a larger study. The 40 item SCQ was adapted and translated into Afrikaans and isiXhosa. The English, Afrikaans and isiXhosa versions of the SCQ were administered to parents of very young children attending the Red Cross Children's Hospital's developmental clinic (N = 228, age range of children = 3.00-5.97 years). Positive results were that no relationship was found between age and SCQ score, or between SCQ language version and SCQ score were found. However there was a relationship between SCQ score and socioeconomic status, indicating a possible bias in the SCQ. Internal reliability of the SCQ versions was analysed and was satisfactory. The factor structure of the English SCQ was examined. Two and four factor solutions were explored, with the two factor solution proving the best fit with good internal reliability. This two factor solution reflected the recent changes to the Diagnostic and Statistical Manual of Mental Disorders, as well as previous findings on the SCQ and the ADI-R, the diagnostic instrument on which the SCQ was based. Preliminary results of Phase 2 of the larger study were analysed. Eighteen children received an Autism Diagnostic Observation Schedule (ADOS) assessment; the current gold standard for diagnosing ASD. SCQ scores proved to be a good predictor of ASD diagnosis, predicting 17 out of 18 individuals correctly. Further research on isiXhosa and Afrikaans versions of the SCQ as well as the predictive power, sensitivity and specificity and cut-off scores for the SCQ is recommended.

## Introduction

Autism spectrum disorder (ASD) has a global prevalence of approximately one percent of all new births (Baird et al., 2006; Fombonne, 2009; Robins, 2008). Symptoms of the disorder, such as language difficulties, problems with communication and social interaction, and preoccupation with adherence to routines, become more evident as the child matures. These symptoms can generally be detected in children as young as 2 years old (Cox et al., 1999). Once detected, there are numerous interventions that can help autistic children develop skills and modify their symptom profile. A critical point, however, is that the earlier the interventions are introduced the better chance the child and his/her caregivers may have of managing the symptoms and reducing the impact they have on everyday functioning (Canal-Bedia et al., 2011; Robins, 2008; Robins, Fein, Barton, & Green, 2001).

Despite the fact that ASD is a global problem there is surprisingly little South African literature on the topic. No epidemiological studies have been conducted and there is a paucity of information on diagnosis and treatment. Furthermore, there is a lack of awareness of ASD in low socioeconomic status (SES) groups. Despite this lack of information, when caregivers become concerned about their child's development they do tend to seek help (Drs. K. Donald & W. Vogel, personal communication, March, 2012). Diagnosis occurs predominantly at specialised developmental clinics as, due to the lack of biological markers, diagnosing ASD requires highly trained individuals to conduct comprehensive observation and assessment of the child as well as extensive interviews with their caregiver. This is a time-consuming and costly process. There are very few developmental clinics in the Western Cape and those that exist are overburdened and have long waiting lists. South African children can wait for years for a diagnosis, which impacts negatively on them because early diagnosis and early intervention are said to be critical for improved developmental outcomes (Allen, Silove, Williams, & Hutchins, 2007).

This thesis focuses on the first phase of a larger study that aims to investigate how the above-mentioned problem of delayed diagnosis could be ameliorated by testing the viability of using an ASD screening questionnaire, the Social Communication Questionnaire (SCQ), in a Western Cape population. The SCQ is a screening instrument that has the potential to time- and cost-effectively pinpoint children with a high likelihood of having autism. It is possible that this instrument could be used at health care clinics in order to detect individuals who might have autism at as early a stage as possible, in this way bringing high priority individuals to developmental clinics more quickly. By improving diagnostic efficiency, children with autism can access services and interventions at an earlier age.

## **Changing Definitions of Autism**

Kanner (1943) first brought attention to the neurodevelopmental disorder which became known as autism. His paper presented descriptions of 11 children who were physically and cognitively healthy, but who had social-communicative symptoms that, at the time, did not fit the criteria for any specific disorder. Kanner described the main symptoms that were present across the 11 cases and in so doing, gave the first insight into one of the main features of autism: a focus on the inner world, rather than the environment.

Seventy years later, the syndrome Kanner described has been placed on a spectrum under the category of autism spectrum disorder (ASD). Until recently (May 2013), the disorder was classed by the text revision of the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association [APA], 2000). Symptoms that had to be present before the age of 3 years for a DSM-IV-TR diagnosis of autism were (1) impairments in social interaction, (2) impairments in communication, and (3) repetitive or stereotyped behaviours, restricted interests, and activities.

There were many criticisms of the DSM-IV-TR diagnostic criteria for ASDs (Lord & Bishop, 2010). The diagnostic criteria were therefore changed in the newly revised Diagnostic and Statistical Manual of Mental Disorders, the DSM-5 (APA, 2013). The triad of affected areas of behavior was reduced to two core areas. The previously distinct areas of social interaction and communication were combined to form social-communication, the first of the two core areas. The second area remained repetitive or stereotyped behaviours, restricted interests, and activities. In order to receive a diagnosis of ASD using the DSM-5, an individual must have deficits in all three specified areas of the social-communication domain: reciprocating social or emotional interaction, developing and maintaining relationships, and non-verbal communication. Additionally, the individual must also show at least two of the following indications of repetitive and restrictive behaviours: repetitive speech, movement or use of objects; unusually intense, fixated interests; severe hyper- or hypo-reactivity to sensory stimuli; and excessive adherence to routines and behaviour patterns and resistance to change in these routines. These symptoms must negatively impact everyday functioning and must be present in the early developmental period; though symptoms may only be noticed when greater demands are present later in life. This is a change from the DSM-IV in which diagnosis for autistic disorder required specified behaviours or deficits to emerge before the age of 3 years. This change in the DSM-5 encourages earlier diagnosis while allowing for individuals whose behavior is not noticed until a later stage to still qualify for a diagnosis.

Additional changes, to areas other than diagnostic criteria, have been made to the DSM. It is well established that cases of autism fall across a spectrum involve varying degrees of the traits of the disorder (Christ, Kanne, & Reiersen, 2010; Pandey et al., 2008). For this reason the newly revised DSM has collapsed what were previously four different diagnoses, namely autistic disorder, Asperger's syndrome (AS), childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (PDD-NOS), into a single diagnostic category of autism spectrum disorder (ASD).

The revisions to the DSM-5 have not been without controversy (Lord & Bishop, 2010). Although based on empirical data (Huerta, Bishop, Duncan, Hus, & Lord, 2012), the changes made to autism spectrum disorders in the DSM-5, viz., decreasing the symptom domains and describing individual variation in terms of severity along a spectrum rather than individual categories, are seen by some as backsliding (Lord & Bishop, 2010). The trend of the past few decades had been to attempt to better define and delineate the symptoms of autistic disorder relative to other forms of ASD and those of ASD relative to other developmental disorders (Matson, Nebel-Schwalm, & Matson, 2007). The multicategorical model of the DSM-IV-TR was an attempt to better understand the deficits related to the various subtypes (Lord & Bishop, 2010), in the hope of enabling therapists and families to understand more specific aspects of the individual's disorder and therefore better fulfill the individual's needs (Shattuck & Grosse, 2007).

However, the application of diagnosis using these bounded disorders was not feasible. Diagnosis using subtypes was found to be unreliable and several aspects of the DSM-IV-TR were problematic. Wing, Gould and Gillberg (2011) reported that practically many individuals did not clearly fit into one particular type of ASD and an individual who fitted into one of the ASD diagnostic categories could, with time, be found to fall under a different diagnostic category. They further criticised the DSM-IV-TR for its over general diagnostic criteria, which did not provide enough guidance to practitioners. Dickerson Mayes, Calhoun, and Crites (2001) found that the DSM-IV criteria for Asperger's syndrome were not practical and were rarely met. None of the participants in their study, who had previously been diagnosed with Asperger's syndrome, met the DSM-IV-TR criteria for the disorder. They postulated that many clinicians used literature and popular opinion instead of the DSM-IV-TR criteria when diagnosing individuals with Asperger's syndrome. The DSM-5 (2013) therefore attempted to rid ASD of what appeared to be artificial categories and to improve the diagnostic criteria. Although Huerta et al. (2012) found that the DSM-5 has higher specificity and sensitivity compared to the DSM-IV-TR, other results have been less positive.

Due to the very recent nature of the changes, few studies thus far have investigated the diagnostic validity between the DSM-IV-TR and the DSM-5. One such study, by Huerta et al. (2012), demonstrated good agreement between the DSM-IV-TR and the DSM-5. In a sample of 4 453 individuals, using only parent report, 91% of the individuals diagnosed with ASD using the DSM-IV-TR were identified using the DSM-5 criteria. On the other hand, McPartland, Reichow and Volkmar (2012) found that only 61% of the individuals diagnosed with an ASD using the DSM-IV were identified as having ASD using the DSM-5. Although specificity was high at 0.94, sensitivity varied by disorder and was very low for individuals with Asperger's disorder at 0.25 and individuals with PDD-NOS at 0.28. Furthermore, intellectual ability had a large effect on sensitivity. In individuals with IQ scores lower than 70, sensitivity was 0.70. In individuals with IQ scores of 70 and above sensitivity was very low at 0.46. However, this study by McPartland et al. (2012) was criticised due to its use of the draft criteria of the DSM-5, which were later changed.

Furthermore, due to the fact that the DSM requirements have only very recently changed, cognisance must be had of the effects of these changes to the DSM when reviewing the literature, evaluating screening tools and comparing this study to other similar studies. Due to the very recent changes and the subsequent shortage of findings on the final version of the DSM-5, it is unclear whether the changes in the diagnostic criteria will significantly change the population that is diagnosed, affecting diagnostic and screening measures. For example, currently the gold standard instruments for autism diagnosis are the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) and the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000). These diagnostic methods of observation and interview are necessary due to the lack of biological markers of ASD. These instruments have been reliably used for several years (Berument, Rutter, Lord, Pickles, & Bailey, 1999; Lee, David, Rusyniak, Landa, & Newschaffer, 2007; Witwer & Lecavalier, 2007). However, due to the very recent changes, diagnostic instruments and screening measures that are in use are based on diagnostic criteria from previous versions of the DSM. This may impact the ability of screening measures to successfully detect children who would be diagnosed with ASD using the DSM-5. It is therefore important to maintain awareness of the possible complications when making comparisons between this research project and previous studies which used DSM-IV-TR criteria and to examine whether the proposed screening measure can predict ASD that is diagnosed using the DSM-5 diagnostic criteria.

The changes in the DSM have altered the requirements on screening measures. Previous studies on screening measures focused on the ability of such measures to

discriminate children with Autistic Disorder from children with other autism spectrum disorders (e.g. Berument et al., 1999, Chandler et al., 2007, Lee et al., 2007). Because there is now only one diagnosis, screening needs only to differentiate children likely to be on the spectrum from those not exhibiting signs of ASD. Furthermore, the softening of the age of onset requirement may affect the performance of the screening measures. For example, the Lifetime version of the SCQ, suitable for children older than 5 years, contains many items that focus on the individual's behavior between their 4<sup>th</sup> and 5<sup>th</sup> years. If this behaviour does not manifest at this age, due to lack of demands great enough for everyday functioning to be affected, individuals with less severe ASD may be misidentified by the SCQ. It would therefore be important that the ability of the Lifetime SCQ to identify DSM-5 diagnosed individuals be assessed.

The changes in the DSM affect this study in a number of ways. Firstly, this study must determine the ability of the SCQ to screen children based on the new diagnostic criteria of the DSM-5. Secondly, comparisons between this research project and other validation studies must be made with caution, bearing in mind the possible differences in the ASD population. Lastly, demands on the screening measure will be lower, only the general disorder of ASD need be identified, rather than several subtypes.

### **Autism Spectrum Disorder Epidemiology**

There is increasing international focus on ASD, likely due to high prevalence rates. Due to the lack of ASD prevalence rates for South Africa and other African countries, this section will report on prevalence rates established in other countries. Using prevalence data from other countries may be regarded as problematic: Although ASD is a neurodevelopmental disorder (Christ et al., 2010) and studies in various countries have reported similar data (Baird et al., 2006; Robins et al., 2001), estimated prevalence rates vary somewhat within individual countries and between different studies.

Current reported rates are very high. Recently, two studies on prevalence rates in the United States of America have found very similar rates, reporting 110 per 10 000 and 113 per 10 000 respectively (1 in 88; Kogan et al., 2009, Centers for Disease Control and Prevention, 2012). The Centers for Disease Control and Prevention furthermore reported that ASDs are five times more common in males than females. A prevalence rate of 116 per 10 000 was found in England (Baird et al., 2006). Kim et al. (2011) reported a very high ASD prevalence rate, of 2.64%, in a community in South Korea. In contrast, other studies have reported a slightly lower rate than that given by the Centers for Disease Control: Parner et al. (2011)

reported a rate of 68.5 ASD individuals per 10 000 in Denmark and 51 per 10 000 in Western Australia.

There are clearly large differences in prevalence estimate of autism with rates of just one former subtype of ASD, autistic disorder, ranging from 0.08% to 0.4% of the population (Baird et al., 2006) and rates of all ASDs ranging from 0.5% of the population to 2.64%. The differences in rates and the generally increasing estimates over time have been attributed to a number of causes. These are firstly, differences in diagnostic measures used by different studies, such as using self-report of diagnosis versus the outcome on specific diagnostic instruments. Secondly, differences may be due to between-study differences in definitions of autism, such as including more broad criteria, which results in higher prevalence estimates. Thirdly, when rates are reported, the question of whether autistic disorder specifically, or ASD generally, is being measured is not always clearly defined.

Despite these differences in prevalence rates, the most commonly accepted rate for ASD prevalence is 1% of the population (Baird et al., 2006; Fombonne, 2009; Robins, 2008). In South Africa, there are just over a million individuals born each year (Statistics South Africa, 2013). If South Africa has a similar prevalence rate to other countries such as England, Australia, America, Denmark and South Korea, this would mean that at least 10 000 children with ASD are born every year. This suggests therefore that a large number of individuals need to be assessed and diagnosed.

### **Best Prognosis: Early Diagnosis**

Until very recently, ASD has been difficult to diagnose in children below the age of 3 years (Robins et al., 2001). This is due to the fact that symptoms present differently in young children and many of the symptoms have yet to develop (Allen et al., 2007). One example is that language problems cannot be identified until the stage that speech is normally expected to develop (Robins et al., 2001). Language develops between the ages of 1 and 2 years, with a great deal of inter-individual variability, making it difficult to detect delays in this domain in very young children (Chandler et al., 2007). Another example is that repetitive behaviours are only clearly noticeable around the age of 4 and 5 years of age (however, they do manifest increasingly between the ages of 2 and 4 years; Cox et al., 1999).

It has, however, been shown that clinicians can reliably diagnose autism in toddlers of 20 months (Cox et al., 1999). In a survey of 614 parents in the United Kingdom, Howlin and Asgharian (1999) found that the average age that children with autism received their diagnosis was 5 years. There was, however, a large discrepancy between the age of the child

when the parents first became worried and the age when the child was diagnosed. On average, the 614 parents of children with autism suspected that their child had developmental problems around the age of 1.5 years and sought help when their child was 2 years old (Howlin & Asgharian, 1999). This indicates that there are discernible signs and symptoms in toddlers and that diagnosis could occur well before the age of 5 years. Due to findings such as these, diagnostic tools aimed at assessing very young children have been developed. One example is the ADOS Toddler module, which was shown to be successful in a sample of children between 12 and 30 months old (Luyster et al., 2009).

The fact that most children are only diagnosed around the age of 5 is of great concern due to the fact that a number of empirical studies have demonstrated that the earlier interventions are implemented, the better the child's prognosis tends to be, and, conversely, that delayed diagnosis can result in a worse prognosis (Canal-Bedia et al., 2011). Early intervention is said to result in decreases in the symptoms of communication problems and social interaction problems, and greater cognitive abilities (Robins, 2008). Such intervention may lead to long-lasting improvements for those affected by ASD (Robins et al., 2001).

There are many different intervention strategies, such as parent-mediated intervention, interventions that focus on social skills (Cotugno, 2009), structured teaching (Panerai, Ferrante, & Zingale, 2002) and pharmacological interventions (Leskovec, Rowles, & Findling, 2008). These studies on the efficacy of the respective interventions all reported successful positive change in various skills or characteristics of the individuals who received the treatment.

Nevertheless, not all studies are as positive about ASD interventions. A number of studies, see for example Howlin, Magiati and Charman (2009), Rogers and Vismara (2008) and Warren et al. (2011), focus on reviewing efficacy studies. Although these studies acknowledge that differences were seen in individuals following interventions, they conclude that the methods used in efficacy studies were too flawed to draw any definite conclusions. However, as Warren et al. (2011) point out, although outcomes in studies may appear small, when applied outside of the laboratory they could result in profound improvements in quality of life for individuals with autism and their families. Early intervention thus is seen as having significant potential, but there is a need for further research to ensure that interventions have the full potential impact.

Early diagnosis may be necessary in order to improve the lives of those affected by ASD and to best use the resources of the government health system (Watson et al., 2007).

People with ASD incur large costs on the educational, medical, and social sectors (Baird et al., 2006). Better prognosis can reduce these costs (Robins, 2008).

A cost analysis study was conducted in America by Jacobson, Mulick, and Green (1998). This study compared costs associated with individuals with autism in an intensive early intervention versus in those in regular education with support, individuals in regular interventions at a later stage in life and individuals who required intensive intervention at a later stage in life. The costs for children who took part in the early intervention and obtained full, partial or minimal effects were much lower than the costs for children who did not receive the benefits of early interventions and needed intensive support throughout their lives. These savings in costs were between \$187,000 and \$203,000 per individual from ages 3 to 22 years and from \$656,000 and \$1,082,000 per individual from ages 3 to 55 years. It is therefore more cost-efficient to provide early intervention, assuming that early intervention significantly improves the functioning of many individuals with ASD.

Due to the lack of state-funded health care resources in South Africa, much of the burden of payment falls on parents and caregivers. These figures are therefore all the more troubling for a South African population. It is therefore of utmost importance that diagnostic assessments takes place at the earliest age at which reliable diagnosis is possible. Early diagnosis could be facilitated through employing a screening device which could be given to parents at regular check-up appointments at local clinics. If the screening device indicates a high risk of ASD, further diagnostic assessments could be urgently recommended. Alternatively an ASD screening device could be used in a developmental clinic in order to identify children likely to have ASD. Diagnostic assessments could then be conducted on these children. Screening devices can thus be very useful. However, careful attention must be paid to balancing the predictive power of the instrument with the costs of time, money and skills needed to administer it (Watson et al., 2007). These considerations are discussed in the next section.

### **ASD Screening Tools**

Due to the fact that there are currently no biological markers to detect ASD, diagnosis must be based on examination of behaviour (Canal-Bedia et al., 2011). Behavioural diagnostic tools, like the ADI-R and ADOS, should attempt to make the process as cost-effective, far-reaching, uncomplicated and quick as possible. However, full diagnostic assessments require history-taking and careful observation, which may take between several hours and several days. It is therefore not feasible to do these as part of a regular paediatric

check-up due to already over-burdened professional services. Screening measures can help in this regard because they can be done quickly and therefore routinely, in order to identify children who need the comprehensive diagnostic assessment (Chandler et al., 2007).

A screening process is ideal for ASD for the following reasons: firstly, the cost of not detecting ASD is high due to the loss of time in intervention and the resulting financial and developmental costs; secondly, screening can help identify behavioural symptoms and can therefore be used to determine whether a child is likely to have ASD; and thirdly, suitable screening measures are already available as are interventions to which children can be referred after a diagnosis has been made (Robins, 2008). In short, screening for ASD is a cost-effective method that enables clinicians to flag cases that require further attention.

A number of screening instruments have been developed for ASD. Some of these, such as the Pervasive Developmental Disorder Screening Test-II (Siegel, 2004, as cited in Watson et al., 2007), have not been validated within a general population. Others, such as the First-Year Inventory (Watson et al., 2007) and the Early Screening for Autistic Traits questionnaire (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006), have proved to be relatively ineffective as they have led to incorrectly classifying children with ASD as not being on the spectrum (Watson et al., 2007). This is a problem with sensitivity of the screening instrument.

Sensitivity, in the case of an ASD screening device, is the ability to correctly classify children who have ASD as positive for possibly being on spectrum. Specificity, on the other hand, is the ability to correctly classify typically developing children as negative for possibly being on the spectrum. If a test has a lower cut-off point, i.e. few points need to be scored in order to be classed as positive, sensitivity is likely to be high. This is due to the fact that many people would reach the cut-off point and be classed as at a high-risk of having ASD, therefore more individuals with ASD would be correctly classified. If a test has a high cut-off point, i.e. many points must be scored in order to be classed as positive, specificity is likely to be high. This is due to the fact that fewer people would reach the cut-off point and more would be classed as low-risk. Therefore more individuals without ASD would be correctly classified. Good levels of both sensitivity and specificity are essential in order for a screening measure to be useful. For screening devices, sensitivity and specificity rates between 70% and 80% have been recommended (Glascoe, 2005; Kamphaus, DiStefano, Dowdy, Eklund, & Dunn, 2010). However, this is complicated by the fact that when sensitivity is increased, specificity conversely decreases, and vice versa. The Social Communication Questionnaire is

a screening device for ASD which has both good sensitivity and specificity levels. This measure is discussed below.

### **The Social Communication Questionnaire**

The Social Communication Questionnaire (SCQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999), formerly known as the Autism Screening Questionnaire, is a 40-item self-report questionnaire developed for use as an ASD screening device. The SCQ requires that the child's primary caregiver fill out questions based on behaviour that the caregiver is likely to have observed, such as language abilities and social interactions. The SCQ takes less than 15 minutes to be completed by the caregiver and less than 5 minutes to be scored. Scores can range from 0 to 39 with higher scores indicating a higher chance of the individual having ASD. The SCQ is said to require no specific knowledge or skills relating to ASD in order for it to elicit reliable information (Berument et al., 1999). This is particularly important in countries with limited resources in the health sector, such as South Africa, as the SCQ can be administered by any personnel in primary or specialised health care settings.

The SCQ can be used as a level one or level two screening tool (Johnson & Myers, 2007; Oosterling et al., 2010; Schanding, Nowell, & Goin-Kochel, 2012). A level one screening device is used in the general population, whereas a level two screening device is used in specialist clinics, in which an at-risk subset of individuals has already been identified (Johnson & Myers, 2007).

The SCQ is based on the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994). The ADI-R is a modified version of the Autism Diagnostic Interview (ADI, Le Couteur et al., 1989). It is a semi-structured, investigator-based interview which is conducted by a trained individual with the parent/caregiver of the individual who possibly has ASD. The ADI-R can be used to diagnose individuals with mental ages from around 18 months through to adulthood and takes around two and a half hours to complete.

The validation study of the ADI-R by Lord et al. (1994) was separated into two studies, one conducted to determine reliability and the other to determine validity. The reliability study compared 10 individuals with autism and 10 handicapped or language impaired individuals without autism, using the ADI-R ( $N = 20$ ). Internal reliability was determined in the three diagnostic domains. Alphas of items in the social domain ranged from 0.54 to 0.77. Those in the communication domain ranged from 0.45 to 0.70. Those in the restricted and repetitive behaviours ranged from 0.30 to 0.53. Reliability of the six raters was tested. In the social domain, weighted kappas were above .70 for 12 of the 15 items.

Weighted kappas were above .69 for all of the 13 social items. All seven of the restricted and repetitive behavior items had weighted kappas above .63. Reliability over time was demonstrated with a small sample. Of the 25 items, exact agreement was higher than 83% for all but six, for which exact agreement was reached by four out of six raters.

For the validity study, 15 additional individuals with autism and 15 additional handicapped or language impaired individuals without autism were combined with the previous twenty participants ( $N = 50$ ). Significant differences between the groups were found in most of the items used for diagnosis in the social, communication and restrictive and repetitive behavior domains. All but one of the 25 autistic participants was classified correctly using the ADI-R. Two of 25 the non-autistic participants were incorrectly classified. They both had many co-morbid diagnoses and met requirements by only one point in two of the three domains.

The ADI-R is used globally and is seen, in combination with the ADOS, as the gold-standard of autism diagnostics (Cohen, 2003; Filipek et al., 2000). The reliability and standards of the instruments are maintained through intensive, in-person training given by certified trainers, which is compulsory for practitioners who administer the instruments (Lord et al. 2000). Clinical administration of the ADOS-2 and ADI-R can only be conducted by an individual once they have demonstrated interrater reliability with other trained administrators (Lord et al., 2000). For research purposes, the individual administering the tests must attend research training and achieve reliability on training tapes and send tapes of conducted assessments to their specialised trainer in which interrater reliability is confirmed (Lord et al., 2000; Lord et al., 1994).

The SCQ is thus based on a reliable, well-regarded and widely used diagnostic tool, which has shown very positive results upon validation. However, the ability of the SCQ cannot be based solely on the measure upon which it is based. For this reason, validation studies on the SCQ are discussed below.

### **SCQ Validation Studies**

As mentioned above, different cut-off points result in different levels of specificity and sensitivity. It is essential then that a balance between the two is found and this has been a focus of most SCQ validation studies.

Berument et al. (1999) conducted the first validation of the SCQ by screening a sample of 200 individuals between the ages of 4 and 40 years who had previously taken part in studies. Of these individuals there were 160 who were previously diagnosed with ASD and

40 who were not on the spectrum. The 40 that were not on the spectrum had been diagnosed with other disorders, ranging from Rett syndrome to conduct disorder. Within this sample, the optimum cut-off score for ASD was found to be 15, which yielded a sensitivity score of 85% and a specificity score of 75%. A cut-off of 22 was used to discriminate people with autistic disorder from those with other PDDs. In summary, the SCQ was found to discriminate very well between ASD and non-ASD cases.

However there were several weaknesses in the method and the generalisability of this validation and Berument et al.'s study has been criticised for their participant population characteristics (Chandler et al., 2007). Firstly, the population was drawn from a number of different research and clinical sources and was therefore not likely to represent the general population. Secondly, some of the sample were adults, despite the fact that the screening device is designed to pick up symptoms of autism early in life. Thirdly, the ADI-R had been completed by parents of the participants and, due to the fact that the SCQ is based on the ADI-R, this may have affected the answers given on the SCQ. Lastly, these individuals already had diagnoses, which is likely to have influenced their parents' or caregivers' knowledge of autism and the way they then answered the questions. Since this initial validation study many other validation studies, seeking to better investigate the usefulness of the SCQ in the general population, have been conducted.

Chandler et al. (2007) attempted to improve on the method used by Berument et al. (1999) and examined the SCQ in the United Kingdom in a sample of only 9 to 10 year olds. These children were sampled from an intervention program for children with and without ASD and from the general population. Diagnostic assessments using the ADOS and ADI-R were conducted on 255 of the participants. The conclusion of the study was that the SCQ is a valid screening device. They reported sensitivity and specificity scores of .88 and .72 respectively when distinguishing between children with ASD and those without ASD. Parental education and IQ were not found to affect SCQ scores.

Witwer and Lecavalier (2007) conducted a similar study in the United States of America and found a sensitivity of .92 and a specificity of .62 when using the initial cut-off of 15 in a sample of school-aged children with ASD and intellectual disability. They compared the SCQ to another screening measure, the Developmental Behaviour Checklist–Autism Screening Algorithm (DBC-ASA; Brereton, Tonge, Mackinnon, & Einfeld, 2002), and found the SCQ to be superior.

Very recently Schanding et al. (2012) conducted a study in America, examining the SCQ in a very large sample of 3 375 children. Of these children, 1 163 had been diagnosed

with ASD and were between the ages of 4 and 18 years, with a mean age of 8.53 years ( $SD = 3.50$ ). The remaining participants were siblings of the children with ASD and were 4 years and older, with a mean age of 9.34 years ( $SD = 3.63$ ). Schanding et al. found a very low optimum cut-off score of 7. This resulted in excellent sensitivity and specificity, 97.4% and 96.5% respectively.

As is clear from the studies described above, the SCQ successfully identifies children with ASD in the general population. However, children in the general population are likely to be typically developing and have few of the behaviours described in the SCQ. Children with other developmental difficulties or disorders, such as intellectual disability, Down syndrome or Attention Deficit/Hyperactivity Disorder, may be more likely to display certain behaviours described in the SCQ. Typically developing children are therefore likely to score lower on the SCQ and sensitivity and specificity estimates would be higher. The SCQ aims to identify children with ASD. It is therefore important to assess the ability of the SCQ in a more challenging sample, where children have developmental disorders other than ASD. Furthermore, optimum cut-off scores for these samples should be determined, to be used in developmental clinics for level two screening. Some such studies are reviewed below.

The ability of the SCQ to differentiate between autism and other specific disorders has been explored in a number of studies. Magyar, Pandolfi, and Dill (2012) examined the ability of the SCQ to distinguish children with ASD in a sample of 71 children with Down syndrome between the ages of 4 and 14 years. They found that using a cut-off score of 10.5 the sensitivity and specificity of the SCQ was good at 72.7% and 76.3%.

Ghaziuddin, Welch, Mohiuddin, Lagrou, and Ghaziuddin (2010) examined the ability of the SCQ to identify children with ASD, in a sample of 98 children with and without Attention Deficit/Hyperactivity Disorder (ADHD). The mean ages of the mixed ASD and ADHD group, the only ASD group and the only ADHD group were 9.2, 10 and 8.4 years respectively. Ghaziuddin et al. (2010) found significant differences in SCQ scores of the ASD only and the ADHD only groups, and not between the ASD only and the mixed ASD and ADHD groups. This showed that the SCQ distinguished between ADHD individuals with ASD and ADHD individuals without ASD.

Despite these seemingly positive results, these studies did not focus on the age group which is in most need of the screen – younger children. For example, Chandler et al. (2007) used a sample of 9-10 year olds and the mean age of Witwer and Lecavalier's sample was 8.3 years ( $SD = 2.3$ ) for the intellectual disability group and 10.2 ( $SD = 2.5$ ) for the ASD group. Due to the fact that most children are diagnosed at the age of 5 years (Howlin & Asgharian,

1999), many of these children are likely to already have diagnoses. Their parents are therefore more likely to have more knowledge of ASD and the symptoms thereof than the average parent. The answers given on the SCQ may thus be coloured by this knowledge and the knowledge that their child has ASD. The SCQ scores of children with ASD may therefore be inflated and those of children without ASD lowered by this knowledge. As a result of this the sensitivity and specificity scores would be inflated. The populations used in these studies therefore do not reflect the population in which the SCQ is likely to be used. Although most of the above studies found good sensitivity and specificity scores with a cut-off of 15, Berument et al. (1999) warned that optimum cut-off levels may vary with the population being screened. This is demonstrated in the optimum cut-off of seven, found by Schanding et al. (2012). These cut-off scores are therefore not necessarily suitable for the screening population at which the SCQ is aimed; that is, young children between the ages of 3 and 5 years. Studies that examine the SCQ in this population are therefore examined below.

**Sensitivity and specificity of the SCQ in very young population.** Numerous studies have attempted to validate the use of the SCQ in young children. Most have looked at samples between the ages of 3 and 5 years (e.g., Allen et al., 2007; Eaves, Wingert, Ho, & Mickleson, 2006; Snow & Lecavalier, 2008; Wiggins, Bakeman, Adamson, & Robins, 2007), though some have looked at younger populations. Although some studies took place in the UK, where the screening tool was developed, other studies tested the SCQ in other populations, in Australia, China, Canada, Holland, Germany and the United States of America (USA).

One of these validation studies assessed the ability of the SCQ to differentiate between children with ASD and children with other developmental difficulties. Snow and Lecavalier (2008) examined the SCQ in sample of pre-school children ( $N = 65$ ) aged 30-70 months who were suspected of having developmental difficulties. The study, which took place in the USA, illustrated the value of changing the cut-off score, as specificity and sensitivity were initially low when the cut-off was 15, but rose considerably when it was reduced. The optimal cut-off was 13, which had a sensitivity of 0.85 and a specificity of 0.40. This specificity is not very good and would result in many children without ASD being sent for assessments. Snow and Lecavalier also found that the SCQ most accurately predicted ASD in children with low intellectual and adaptive functioning.

There were, however, a number of weaknesses in the study by Snow and Lecavalier. The sample was made up of only 65 individuals. Furthermore, of the 54 children with ASDs, only 10 were female. Although this ratio of boys to girls is expected due to higher prevalence

of ASD in males, ten females is a very small sample statistically speaking. The non-ASD group was significantly older than the ASD group, which may have affected the scores. The ASD and non-ASD groups were not matched on intellectual or adaptive functioning. These differences in groups may therefore have affected the respective SCQ scores.

A second study assessing the SCQ in a younger age group took place in the USA. Wiggins et al. (2007) used a sample of 37 children who had attended a developmental clinic and had taken part in ADOS assessments. The age range was 17-45 months, with mean ages of 32 and 34 months for the non-ASD and ASD groups respectively. The optimal cut-off point was 11, lower than that recommended by Snow and Lecavalier (2008). The sensitivity and specificity were both 0.89, which was much better than that reported by Snow and Lecavalier. However, these sensitivity and specificity scores may be misleading, as in this sample assessment and diagnosis occurred before screening. In real world application of the SCQ, assessment and diagnosis would happen after screening, and the parents would therefore not know whether their child has ASD or not and would likely have less information about the disorder. The fact that parents had been through the assessment process and knew their child's diagnosis may well have had an effect on the answers they gave on the SCQ.

Lee et al. (2007) conducted a study with a larger sample. Two hundred and sixty eight children between the ages of 3 and 5 years, who were receiving special education services, took part in the study. SCQ score was compared against parent- or institution- reported ASD diagnoses. The optimal cut-off score was 12. Sensitivity and specificity scores were 79.6 and 82.2 respectively when using parent-reported diagnoses and 88.9 and 77.1 respectively when using diagnoses reported by educational institutions. As in many of the other studies, the problem remains that the parents filled in the SCQ subsequent to their child receiving a diagnosis. As discussed, this introduces a bias due to knowledge of ASD and the knowledge of their child's ASD status.

Studies have been conducted in which children who did not yet have a diagnosis were sampled. Allen et al. (2007) assessed the SCQ in an Australian population. This was a well-designed study with fewer flaws than the studies previously discussed. The sample size was nevertheless quite small, with only 81 parents completing the SCQ. The participants were children between the ages of 2 and 6 years who did not have definitive diagnoses prior to taking part in the study. SCQs were sent out to parents whose children had been referred to a state-wide specialist clinic. Parents filled out the SCQ before their children took part in diagnostic assessments. The optimal cut-off in this population was also found to be 11, as in

the study by Wiggins et al. Sensitivity and specificity was 0.93 and 0.58 for children between the ages of 2 and 6 years. Sensitivity and specificity were higher, 1.00 and 0.62 respectively, for children between the ages of 3 and 5 years, using the same cut-off of 11. Besides the small sample size, another limitation was that only one participant with ASD was female. The results can therefore not be generalised to females as well as males.

A similar study, in which the sample resembled the target population of the SCQ, was conducted in Canada by Eaves et al. (2006). This sample was larger than that of Allen et al. (2007) with 151 children between the ages of 3 and 6 years taking part. Parents of children who had been referred to a developmental clinic filled in the SCQ before their first visit to the clinic. The children were subsequently assessed and then diagnosed by paediatricians and/or psychologists. These diagnoses were compared to the SCQ scores. Interestingly, Eaves et al. chose a cut-off of 15, as although sensitivity increased to 0.92 when a cut-off of 11 was used, specificity dropped to an unacceptable level of 0.35. At a cut-off of 15 sensitivity and specificity were both good, at 0.71 and 0.79 respectively.

The finding by Allen et al. (2007) that the SCQ was less effective in children below the age of 3 years was replicated in a study by Oosterling et al. (2009). Oosterling et al. examined the SCQ in the Netherlands in a sample of very young children, between the ages of 8 and 44 months. They found that the SCQ did not perform well enough to be used as a level two screening device, in other words, in an already identified at-risk population. Using a cut-off of 11, sensitivity was good at 0.84, but specificity was inadequate at 0.28. When using a cut-off of 15, both sensitivity and specificity were low, at 0.66 and 0.64 respectively. They suggested that an adapted form of the SCQ, with fewer questions may be more successful. When only the 16 most predictive items were used, with a cut-off value of five, sensitivity was 0.82 and specificity was 0.49.

Later, Oosterling et al. (2010) examined the SCQ as a possible diagnostic tool for a sample of 208 toddlers. This sample, though slightly older than in their previous study, was younger than those used in other SCQ validation studies. In this study the children were between the ages of 20 and 40 months old. Oosterling et al. found that the SCQ was not accurate enough as a diagnostic tool. They did find that the specificity and sensitivity was higher in 36-40 month olds than in the younger toddlers. This suggests that the SCQ may need to be limited to use in children above the age of 3 years. Oosterling et al. suggest that this may be due to the fact that the SCQ is based on the ADI, a tool that was initially designed for children 4 years and older.

Comparisons between these validation studies are hindered due to methodological differences. These include differences in sample sizes, age of participants, proportion of ASD and control children, as well as differences in the control group samples and in diagnostic method, to name a few (Oosterling et al., 2010). Despite these differences, most of the studies reached the general conclusion that specificity and sensitivity were compromised in such a young population, and that the SCQ is therefore less effective in identifying autism in very young children. Despite lack of consensus on cut-off score in the various validation studies, findings from a number of these studies suggest that the SCQ generally has good sensitivity and specificity in children above the age of 3 years. However, due to the lower predictive power, it is only suited to perform as a screening device, rather than a diagnostic tool, as investigated by Oosterling et al. (2010).

There is, however, no agreed upon cut-off score, with suggestions ranging between 15 and 11 for younger populations. It is possible that the initial validation study's cut-off score of 15 may be too lenient when used with children under the age of 5 years. Ways to increase the sensitivity and specificity, and therefore the effectiveness of the tool, may be to lower the cut-off score. As seen above, the optimum cut-off score may also vary depending on the population screened. Hence, the optimum cut-off score and the SCQ's appropriateness for the South African population's needs must be tested before it can be disseminated to clinics and hospitals. Furthermore, cut-off scores or validity may change if the test is translated.

**Sensitivity of non-English versions of the SCQ.** Two studies have examined translated versions of the SCQ. Gau et al. (2011) tested a Chinese version of the SCQ in a sample of 922 children between the ages of 2 and 18 years. Children with ASD were recruited from hospitals and their non-ASD siblings were used as controls. Gau et al. found that the ASD group scored significantly higher than the non-ASD group on the SCQ, but did not specifically examine sensitivity and specificity of the measure.

Bölte, Holtmann, and Poustka (2008) examined a German version of the SCQ in a large sample of 364 children. One hundred and sixty eight of these participants had ASD, 130 had other disorders, 44 had mental disability or learning problems and 22 were typically developing. The optimum cut-off point was found to be 16, with a sensitivity of 0.92 and a specificity of 0.94. However this high cut-off score and excellent sensitivity and specificity rates may be because the sample consisted of older children, likely to already have diagnoses. The mean age of the ASD group was 14.1 (SD = 8.8). Although initial sensitivity and specificity results were good, it is unclear whether this translation of the SCQ would be successful in a sample of young children.

Both these studies test translations of the SCQ. Nevertheless, the current study is unique and innovative as it is the first in which an adaptation of the SCQ, and the original SCQ itself, is tested in a developing country. To my knowledge, the SCQ has only been tested in countries more developed than South Africa, such as the United States of America, the United Kingdom, Canada, Holland, Germany, Australia and China.

### **Potential for Use of the SCQ in South Africa**

Currently, the SCQ is widely used in clinical practice and in research studies in the global north. That use is not replicated in South Africa, a developing-economy country with relatively fewer resources, a struggling health care sector, great disparities in socioeconomic status (SES) and a population that is culturally and linguistically diverse. Due to these differences, adaptation of the SCQ for use in this country might present more challenges than in more developed countries such as Australia. Nevertheless, Robins (2008) points out that the costs in time and money involved in adapting, validating, and using a screening device are insignificant when one takes into account (a) the benefit that early intervention as a result of early detection is said to have on the development and well-being of those affected by ASD, and (b) the costs associated with late intervention and subsequent management.

There is a wide variety of spoken languages and of cultures in South Africa. Generalising findings that are influenced by language and culture from one region of South Africa to the whole country is therefore not always possible. This is particularly pertinent due to the fact that the SCQ cut-off scores are highly dependent on the population that is tested.

Difficulties and problems that could arise in adapting the SCQ for use in Western Cape are not easily preempted, due to the lack of literature on the application of the SCQ in other developing countries. It is therefore useful to consider the additional requirements and complexities that may result in the Western Cape context.

One of the complexities of adaptation concerns the optimum balance between sensitivity and specificity. This balance is dependent upon the situation in which the screening device is being used. For example, in settings where resources are abundant, much greater emphasis may be placed on sensitivity, in order to capture all possible positives, while sacrificing specificity and therefore assessing more false positives. In other settings where false positives would waste precious time and resources, one might place a higher emphasis on specificity. While low specificity could waste resources by assessing more children who do not have ASD, low sensitivity would result in children with ASD going undetected and not receiving the correct diagnosis. The optimal sensitivity and specificity rates must

therefore be determined in the context of limited clinician time and resources, as we have in the Western Cape. If the SCQ does not perform well and an optimal balance between the two rates is not found, using the SCQ may not be worthwhile in a Western Cape population.

The population being screened also has an effect on the cut-off point, as shown by the differing optimum cut-off points found in various studies. The SCQ would therefore need to be validated for a representative population, and the optimum cut-off point found. A large majority of South Africans live in poverty. It is therefore of utmost importance to test the SCQ in this environment, as all the validation studies conducted so far have examined more wealthy populations. Furthermore, the Western Cape is a multi-cultural area with in which many languages of South Africa are spoken. This study would therefore need to test more than one language version of the SCQ, in order for the screening measure to be accessible to a large portion of the population. Sampling would need to include individuals from the various dominant cultures, in order to assess whether the SCQ is successful despite the cultural differences. Although the SCQ has been examined in various countries with different cultures, such as in the United States of America, Germany, the Netherlands and China, the SCQ has yet to be examined in an African population.

South Africa has many health care concerns, notably the HIV/AIDS pandemic and other infectious diseases such as tuberculosis and malaria and there are limited funds for health care concerns. There is, however, no reason why researchers and policy-makers should neglect the areas of diagnosis and treatment of ASD. ASD most likely occurs at a relatively high rate (1/100). With current population estimates this would suggest we might have around 60 169 individuals with ASD in the Western Cape and just over half a million (529 820) individuals with ASD in South Africa (Statistics South Africa, 2013). ASD is present throughout the lifespan of those with the disorder. Without intervention and management it negatively affects not only the individuals diagnosed, but also their family and caregivers. ASD prevalence and incidence rates in this country are probably as high as those in other countries. The fact that the disorder is reportedly becoming more common should raise alarm bells for the health care sector in South Africa. The complete lack of studies on ASD prevalence and screening in South Africa shows that there is a real need for an early screening device in this country.

In 2011 we conducted a small pilot project examining the validity of the SCQ in a Western Cape population. We found that the SCQ successfully discriminated between typically developing children and those diagnosed with ASD (although these groups were small;  $N = 50$ , and not fully representative of the Western Cape population). There was a very

high correlation between the SCQ scores and scores obtained on an ASD diagnostic instrument. This data indicates that this line of investigation is worth pursuing.

### **Summary and Conclusion**

Screening is a relatively quick and cost-effective way of determining the likelihood of the presence of certain disorders or illnesses. The SCQ is an ideal screening tool for ASD, as it (a) requires few skills to fill it out or administer it, and (b) is cost-effective, in terms of both time and money. Creating a version of the SCQ that is valid and reliable for the Western Cape population would be of great value.

The introduction of the SCQ as a widely-used tool would more quickly bring attention to children who possibly have ASD. As noted above, early identification and treatment can result in a much better prognosis, thus reducing the costs associated with later interventions and management.

### **Rationale**

As is clear from the review above, motivation for this study arises from a practical need. In order to receive treatment and access to services, individuals with ASD need to be seen by a specialist. There are very long waiting lists for admission into schools dedicated toward educating children with ASD. Admission into these schools requires a formal diagnosis to be made. There are also long waiting lists for treatment and therapies at the Red Cross Children's Hospital and Tygerberg Hospital. Again, appropriate treatment at those clinics is contingent upon a comprehensive diagnostic process. In order for high risk children to receive treatment as early as possible, these children must be diagnosed as soon as possible.

Screening can be used regularly and easily at primary and specialised health care sites, identifying children who show a high risk of having ASD. A screening process will allow schools and clinics to prioritise those children, whose results show that they have a high likelihood of being diagnosed with ASD, and could lead to earlier diagnosis and hence earlier intervention and better functional outcomes. Such screening will save valuable time and will also serve to put many parents at ease. Autism is a disorder that continues through one's lifetime and not only negatively affects the individual diagnosed with it, but their family and caregivers too. By achieving early diagnosis and, subsequently, early intervention and management, these negative effects may be greatly diminished. A reliable and valid screening device that can be used in South Africa would greatly benefit our society.

## **Specific Aims**

### **Aims of the Larger Study**

The larger study within which this thesis is nested was still being conducted at the time of this write-up. The larger study aims to determine whether two screening measures, the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001) and the Social Communication Questionnaire, can be used in the Western Cape to reliably assess whether a child is or is not likely to have autism spectrum disorder. This is being done through translating, administering and evaluating the results of English as well as Afrikaans and isiXhosa translations of the M-CHAT and SCQ in Phase 1 of the study. Phase 2 of the larger study involves assessing a subset of the participants using ASD diagnostic tools. The results of the assessments will be compared against the SCQ scores. A full evaluation of reliability, predictive power, optimum cut-offs and sensitivity and specificity will be conducted for each version in Phase 2 of the study. Furthermore, the study aims to expose problems that arise in using the translated versions of the SCQ, in order to pre-empt these problems occurring when used by practitioners.

### **Specific Aims of the Current Study**

This thesis focused on the SCQ and primarily on Phase 1 of the larger study. I aimed to examine, in detail, the process of translation, adaptation and then administration of the SCQ in an ecologically valid clinical setting. This setting is a developmental clinic in a state-funded hospital, one such setting in which the SCQ may be useful. In order to achieve this, the process of translation and adaptation of the screen was conducted and explored. The demographics of patients in this clinical setting, the developmental clinic of the children's hospital, were examined. The SCQ responses were explored individually, as a whole, and between language groups. Reliability estimates and factor analyses were conducted, as in the initial validation of the questionnaire by Berument et al. (1999). Additionally this thesis aimed to examine preliminary results of Phase 2, which were gathered at the time of write-up of this thesis.

## Methods

### Design and Setting

The design of the larger study is correlational, results of screening measures are compared against results on diagnostic assessment scores. The focus of the part of the research reported here was the description and assessment of whether the adapted English-language version (see Appendix A) and the Afrikaans and isiXhosa translated versions of the SCQ (see Appendix B and Appendix C) are appropriate for use in the Western Cape, and a preliminary assessment of the SCQ's ability to distinguish the likely presence of ASD from other developmental disorders. The overall study is made up of two phases. Phase 1 (the primary focus of the current thesis) involved translation and adaptation of the SCQ, administering the SCQ to parents in a clinic and analyzing the results of this data. Phase 2, which is still ongoing, involves administering ASD diagnostic assessments and interviews to subsets of the sample from Phase 1. In this write-up, the process of translation is described. Results from the first phase of the study, i.e. data collection in a developmental clinic located at The Red Cross Children's Hospital, are explored using statistical analyses. Preliminary results from the second phase of the study, the diagnostic assessment phase, are used for preliminary examination of the reliability and validity of the screening instrument by establishing the agreement between the results of the SCQ and those from gold-standard diagnostic instruments, the ADOS and the ADI-R. Lastly, problems encountered using these SCQ versions are discussed.

The major strength in the method used lies in the fact that the SCQ was tested in the real-world environment in which it may potentially be used, in a clinic for children with developmental problems. As indicated previously, the SCQ can be used as a level one or level two screening device (Oosterling et al., 2010; Schanding et al., 2012). In this study, the SCQ was used as a level two screening device, as it is used in a developmental clinic, with individuals already identified as at-risk (Johnson & Myers, 2007). Although the SCQ could also be used as a level one screening device in primary clinics, on children with developmental disorders as well as typically developing children, we have chosen to test the SCQ in its capacity as a level two screening device. Pilot data suggested that the SCQ distinguishes well between typically developing children and children with ASD. The more stringent test for the SCQ is whether it can successfully distinguish between children with ASD and those with other developmental disorders.

The environment and manner of testing used in this project thus replicate one way in which the SCQ could be used in South African clinics. This “real-world” manner of testing should expose problems which may be encountered in subsequent use of the SCQ.

### **Ethical Considerations**

Ethical approval was obtained from the Red Cross Memorial Children’s Hospital (see Appendix D) and from the Faculty of Health Science’s Human Research Ethics Committee (see Appendix E). Prof. Petrus de Vries applied on behalf of this project for Western Psychological Services approval of the SCQ translations.

**Informed consent.** All participants were required to read and sign informed consent documents at each different stage in the research.

In Phase 1 the interviewer explained the study and then asked potential participants if they would like to take part. The interviewer assured participants that their choice to participate, decline or discontinue participation would have no effect on their status or the services they receive at their clinic, that the participants would not be removed from any waiting list and that their access to standard assessments and treatments would in no way be affected. Participants were encouraged to ask questions.

Participants were contacted to take part in Phase 2 only if they had given consent during Phase 1 to be contacted for further research. For Phase 2 parents provided written informed consent to participate in the diagnostic assessment and, where appropriate and possible, children provided assent. Participants were given light snacks and were reimbursed travelling costs.

All results from the diagnostic assessments were promptly made available to the participants’ doctors (Drs. Donald and Vogel are co-investigators on the project) to be used in case management.

**Confidentiality.** Data for analysis was entered into spreadsheets which use only codes to identify participants. All data was securely stored and is only available to members of the research team. All participants were assured that they would not be identified in this write-up and will not be identified in any further write-ups of this research.

**Voluntary participation.** Participation in this study was voluntary. Participants were assured at every stage of the research that declining to take part or withdrawing from the study would have no impact on their status at the Red Cross Children’s Hospital or the services they would receive from the hospital.

**Possible risks.** There were no possible additional risks for parents who (already suspecting that their child had developmental problems) participated. They were approached on days when they were already scheduled to come into the hospital.

**Benefits for the participants.** Participants' doctors (via Dr Donald, head of the developmental clinic) were given the results of the SCQ and detailed information from the diagnostic assessments. All participants found to be on the autism spectrum were provided with an information sheet on ASD. This sheet contained basic information on ASD symptoms and available schools and support groups as well as links to further information (see Appendix F).

Participants found to have ASD were referred by Dr Donald for speech and occupational therapies at the Red Cross Children's Hospital. Parents who provided consent to be contacted for further research and whose children were on the spectrum will be invited to participate in a study which provides a form of therapy aimed at improving developmental and social skills.

**Benefits for society.** In the larger study we aim to assess the reliability and validity of the English, Afrikaans and isiXhosa versions of the SCQ, determine optimum cut-off points and, if need be, further adapt the SCQ for use in the Western Cape until it is a usable instrument. This will help realise the important goal of identifying high-risk ASD cases in a quick and cost-effective manner. By regular use in primary health care sites, this screening device has the potential to be of great use in identifying the possibility of ASD early in the affected individual's life and thus speed up access to necessary treatments resulting in improved outcomes.

### **Phase 1 - Screening**

**Participants.** Participants were parents or guardians of children between the ages of 3 years and 5 years 11 months, who presented at the Red Cross developmental clinic from September 2012 to June 2013,  $N = 240$ . We used an unselected series of cases, approaching all adults at the clinic. Children younger than 3 years old were not included as Allen et al. (2007) and Oosterling et al. (2009) have investigated the SCQ in children younger than 3 years old and demonstrated that it is not as reliable in this group. The SCQ has been shown to reliably predict ASD in children 3 years and older by a number of studies (e.g. Allen et al., 2007; Lee et al., 2007; Snow & Lecavalier, 2008).

Children 6 years and older were not included in the study, firstly, due to the fact that the screening device is being investigated for the use of flagging children who may have

ASD, such children are more likely to first enter the health system before the age of 6 years. Secondly, focusing on younger children in the study decreases the possibility that the parents have been exposed to information on autism. Older children are more likely to have already received a diagnosis of ASD and their parents are therefore more likely to have sought to learn more about the disorder. Furthermore, validity of the Lifetime version of the SCQ, used for individuals over the age of 5 years, may have been affected by the softening of the age-of-onset criteria in the DSM-5. A number of items in the Lifetime version focus on the 4<sup>th</sup> year of the individual's life and for this reason, the validity of the Lifetime version of the SCQ should be established against DSM-5 diagnoses, before it is used.

The best possible sample would include only first time visitors to the clinic or visitors without diagnoses, as these children would be least likely to have received a diagnosis or to have acquired additional knowledge of ASD. Unfortunately we were not able to sample this group, due to the low number of these participants in the period of data collection. Only twenty percent of the sample, 47 out of 228 participants, were first time visitors. Using a sample of 47 would have severely limited the reliability of the statistical findings and statistical tests available to use.

Children with marked sensory deficits (in vision or hearing) were excluded. Many of the questions in the SCQ assume that the subject can see and hear. These questions would either not be relevant for a child with hearing or vision impairments, or the results would be confounded by the impact of this impairment in relevant domains. There were no other exclusionary criteria.

Because an unselected series of cases was used, no demographic variables, other than age, were controlled for. Nevertheless, participants were likely to be from low SES backgrounds, as they were attending a state-funded clinic, rather than a more expensive private clinic (details of SES and other participant demographics are presented in the Results section). This low SES population was sampled as these are the people who are most in need of the screening measure. South Africa is a poor country where 52.3% of the population were reported to live below the poverty line (Statistics South Africa, 2012). People of high SES can avoid the long waiting times associated with state-funded clinics and hospitals by using private health care. However, the majority of South Africans cannot afford private health care and therefore wait months for appointments at state-funded health care institutions. A screening measure could be used most effectively in state-funded clinics when children attend check-ups, and would allow children found to possibly have ASD to be prioritised. Ruling

out children unlikely to have ASD would bring down the numbers of children waiting for assessments.

**Procedure.** On two mornings a week, from September 2012 until June 2013 either one or two researchers, fluent in English and Afrikaans, were present in the clinic waiting-room. On one day per week the researchers were joined by an isiXhosa assistant who administered the interview to isiXhosa speakers.

The researchers approached the parents of visiting patients. They explained what was involved in Phase 1 of the study and assured them that taking part, or declining to take part, in the study would have no impact on their or their child's status at the hospital and the services they receive. If the parent/s agreed to take part, confirmed that their child was older than 3 years and younger than 6 years and confirmed that the child was not hearing- or sight-impaired, they were asked what their home language was. If it was one of the three in which the SCQ was available, they were given a questionnaire pack. If the parents' home language was not English, Afrikaans or isiXhosa, they were asked which of those languages, if any, would be most preferable. The researcher then asked the parent whether they would like to fill in the questionnaire alone or whether they would prefer the interviewer to read through it with them. Although the SCQ was designed as a self-report questionnaire, to be filled in independently by the parent or caregiver of the child in question (Berument et al., 1999), we decided to deviate from standard administration due to the high levels of illiteracy in the South African population. This is discussed in further detail in the Measures section below.

Each questionnaire pack contained a consent form (see Appendix G, Appendix H and Appendix I), a form asking if they would agree to be contacted regarding further stages of the study (see Appendix J, Appendix K and Appendix L), a demographic questionnaire (see Appendix M, Appendix N and Appendix O) and the SCQ (see Appendix A, Appendix B and Appendix C). Both the consent page and that asking for permission to contact them later reiterated that taking part or declining to take part in the study would not impact the services received at the clinic.

**Measures.** The forms contained in the pack are further described below.

**Demographic questionnaire.** This brief questionnaire asked parents to provide information regarding basic demographic data (e.g. the age of their child, family income, race, and home language), as well as details of the clinical presentation of their child's developmental disorder.

There was a section which required the parents to provide information relating to their socioeconomic status (SES). The raw scores from this information on SES were standardised

and summed. A popular way to arrange the data is to divide the summed data into tertiles, representing low, medium and high SES groups (Myer, Stein, Grimsrud, Seedat, & Williams, 2008). This however assumes that the spread of SES is broad and that high medium and low SES individuals are equally represented. This sample was largely low SES and not representative of the overall population. This is due to the fact that parents who can afford the fees of the private health sector are likely to visit private practitioners in order to avoid the long wait for appointments that is associated with the state-funded health care sector. The data was therefore not divided into tertiles and was instead calculated as a score out of one hundred based on the scores on the SES questions answered. An additional reason for this was in order to keep the data on SES continuous, rather than losing information by turning it into a categorical variable.

***Social Communication Questionnaire.*** The SCQ (Berument et al., 1999) is a 40 item questionnaire. The items ask whether the child displays certain behaviours and the child-in-question's primary caregiver must answer with yes or no.

As discussed in the literature review, the psychometric properties of the SCQ are good. Sensitivity and specificity were found to be 1.00 and 0.62 in a population similar in age and diagnostic status to that used in this study (Allen et al., 2007). This means that all children with ASD were correctly identified and 62% of non-ASD children were correctly identified by the SCQ.

There are two versions of the SCQ; Lifetime and Current. The Current version of the SCQ focuses on the previous 3 months of the child's life, whereas the Lifetime version focuses on the child throughout his/her lifetime, with specific focus on the period between 4 and 5 years of age (Lee et al., 2007). On each version, the total score ranges from 0 to 39, with higher scores indicating more symptoms connected with autism (Berument et al., 1999). Because the Lifetime version focuses on the period between the individual's 4<sup>th</sup> and 5<sup>th</sup> birthday, it requires that the individuals be above the age of 5 years. Because this study tested only children below the age of 6, we followed the example of Lee et al. (2007) who, based on advice of a SCQ developer, used only the Current version.

The SCQ is designed to be self-administered by the child's primary caregiver. In a Western Cape context however, many parents come from disadvantaged backgrounds and the incidence of illiteracy is high. Statistics South Africa (2012) reported that 8.6% of the South African adult population (around 4 million individuals) have received no schooling and 12.3% (around 6 million individuals) have only received some primary school education. Because of the likelihood of individuals not having the required literacy level and perhaps

feeling hesitant to ask for help, all parents were offered assistance in filling out the form. Parents who chose to fill the form in without assistance were encouraged to ask the researchers if they did not understand any part of the questionnaire pack.

Scoring was done by a researcher, blind to the child's diagnostic status, directly after the parent finished the questionnaire pack. As the parent was usually still in the waiting room when the questionnaire was marked, the researcher was able to ask them to fill in any questions that they had left out. When the parent had left the question blank due to confusion about the question, the researcher provided assistance in understanding the question. The number of positive answers with regards to the presence of autistic symptoms was summed. A higher score indicates more symptoms of autism.

***Translated versions of the SCQ.*** The SCQ was developed in the United Kingdom as an English questionnaire. The language and content of the SCQ therefore needed to be adapted in order to appropriate for a South African context and translated into the other two main languages of the Western Cape, Afrikaans and isiXhosa. This process of translation is discussed below.

**The translation process.** The SCQ was firstly translated from English into Afrikaans and isiXhosa by academics who lecture in isiXhosa and linguistics and do translation work at the University of the Western Cape. This is a university in which many of the students come from impoverished backgrounds (Breier, 2010). The translators were given instructions to use language that could be easily understood by people from all SES groups.

The translated versions were then back-translated. Back-translation can be a successful translation technique for a variety of languages (Brislin, 1970). It involves translating the translated version of the questionnaire back into the original language. This serves to verify that the original translation is adequately similar to the original version. If not, the translation is amended. The Afrikaans version was back-translated by a first-language Afrikaans speaking PhD student and the isiXhosa by a freelance first-language isiXhosa translator. Translation is improved when the translators are familiar with the concepts discussed in the document they are translating (Brislin, 1970). The PhD student had a great deal of clinical experience doing interviews with parents from this demographic grouping and assessments with children, and additionally has many years of research experience in ASD. The isiXhosa back-translator was from a community of similar SES as the parents at Red Cross, has experience with children and has experience translating in low SES settings. Both the original Afrikaans and isiXhosa translations, despite our request for simple accessible language, reportedly used very formal language and therefore the back-translators subsequently

replaced the formal words with more widely understood ones. The translations were further amended to better correspond with the English version.

A focus group was then held with the isiXhosa back-translator, three researchers, the Afrikaans back-translator and an Afrikaans individual who is familiar with the language of low and middle SES groups in the Western Cape. This method is described by Brislin (1970) as the “committee technique”. The source language version, in this case English, was open to revision. The changing of the original version is known as “decentering” (Brislin, 1970). Both these techniques can improve translation quality (Brislin, 1970). The instructions and each question were examined and comparisons were made between the three languages. This was to ensure that each question had the exact same meaning in all three languages. The three language versions were further simplified in order to eliminate unnecessarily complicated words and sentences. The instructions were changed in the English and then the Afrikaans and isiXhosa accordingly.

In order to simplify the SCQ and make it accessible to people with differing levels of education, the instructions and various questions were amended in order to make the language simpler. The changes to the English version are shown below. Where original words have been deleted, they are indicated in bold. Where new words were added they have been bracketed and italicised:

“Thank you for taking the time to complete the questionnaire. This questionnaire **focuses on** (*asks about*) the behaviour of your child in the last three months. Please answer each question with a yes or a no. A few questions ask about several **related types of** (*similar*) behaviours; please answer yes if any of these behaviours have been present. **Although you may be uncertain** (*Even if you are uncertain*) about whether some behaviours were present or not, please answer *yes* or *no* to every question on the basis of what you think.”

“6. Does she/he ever use words that she/he seems to have invented or made up herself/himself put things in odd, indirect ways; **or use metaphorical ways of saying things** (e.g. saying hot rain for steam)?”

“8. Does she/he ever have things that she/he seems to have to do in a very particular way or order or **rituals** (*routines*) that she/he insists that you go through?”

“9. Does her/his facial expression usually **seem appropriate to** (*match*) the particular situation, as far as you can tell?”

“11. Does she/he have any interests that **preoccupy** (*take up a lot of*) **her/him** (*her/his time*)

and might seem odd to other people (e.g. traffic lights, drainpipes or timetables)?”

“12. Does she/he ever seem to be more interested in parts of a toy or an object (e.g. spinning the wheels of a car), rather than in using the object as it **was intended** (*is meant to be used*)?”

“16. Does she/he ever have any **complicated** (*unusual*) movements of her/his whole body, such as spinning or repeatedly bouncing up and down?”

“21. Does she/he ever **spontaneously** (*just*) copy you (or other people) or what you are doing (such as vacuuming or mending things)?”

“22. Does she/he ever **spontaneously** (*just*) point at things around her/him just to show you things (not because she/he wants them)?”

“24. Does she/he nod her/his head to **indicate** (*show*) yes?”

“25. Does she/he shake her/his head to **indicate** (*show*) no?”

“28. Does she/he ever show you things that interest him/her to **engage** (*catch*) your attention?”

“34. Does she/he ever **spontaneously** (*just*) join in and try to copy the actions in social games, such as The Mulberry Bush, Wheels on the Bus or London Bridge is Falling Down, On-On or clapping game?”

“35. Does she/he play any pretend or make-believe games (*like playing house*)?”

“36. Does she/he seem interested in other children of **approximately** (*about*) the same age **whom** (*that*) she/he does not know?”

“37. Does she/he **respond positively** (*react well*) when another child approaches her/him?”

“39. Does she/he ever play **imaginative** (*pretend*) games with another child in such a way that you can tell that each child understands what the other is pretending?”

“40. Does she/he play **cooperatively** (*nicely*) in (*group*) games **that need some form of joining in** with a group of other children, such as hide-and-seek or ball games?”

Words and examples foreign to South Africa were removed, expanded upon or replaced with examples familiar in a Western Cape context. An example of this is listing the South African soap opera *Generations* as an interest. This was in order to ensure that the questions were relevant to a Western Cape population. The amendments in the English version of the SCQ are listed below.

“11. Does she/he have any interests that take up a lot of her/his time and might seem odd to other people (e.g. (*robots*) (traffic lights), **drainpipes** (*taps*) or **timetables** (*counting*))?”

“13. Does she/he ever have any special interests that are unusual in their intensity, but

otherwise appropriate for her/his age and peer group (e.g. trains or dinosaurs (, *soccer teams, Generations*))?”

“18. Does she/he ever have any objects (other than a soft toy (, *teddy bear*) or **comfort** blanket (*that she/he likes*)) that she/he has to carry around?”

“21. Does she/he ever just copy you (or other people) or what you are doing (such as (*sweeping,*) vacuuming, (*washing dishes, cleaning the yard*) **gardening** or mending things)?”

“34. Does she/he ever just join in and try to copy the actions in social games, such as The Mulberry Bush, (*Ring-a-Rosy, Wheels on the Bus,*) **or** London Bridge is Falling Down, (*On-On or clapping games*)?”

Simplifications and adaptations such as those above were used in the Afrikaans and isiXhosa translations. The final translations had slightly different examples in order to conform to the corresponding culture of the different language speakers. One example of this in question 13, although the English and isiXhosa versions give the television programme *Generations* as an example of an interest, the Afrikaans version lists *7de Laan*, a popular Afrikaans soap-opera. A second example of this is the differing games mentioned in Question 34. English examples were replaced by popular Xhosa games in the isiXhosa version and a popular game played by Afrikaans children was added to the Afrikaans version.

**Data Analysis.** Data was analysed using version 21 of IBM SPSS Statistics.

**Descriptive statistics.** The distribution of age, race, gender, home language, the language version of the SCQ filled in (form language), SES and SCQ scores were explored in the sample. The differences in age, race, gender, home language, SES and SCQ scores across the English, Afrikaans and isiXhosa SCQ versions were investigated. This was done using chi-squared tests of contingency and ANOVAs.

**Correlations and regression.** Correlations between SCQ score and the continuous variables of age and SES, and the dichotomous variable of gender were examined. This was in order to determine whether SCQ score was associated with these demographic variables.

SCQ score as an outcome was regressed on age, gender, SES and dummy coded categorical variables of home language and form language. This is a crude measure of whether the SCQ score is affected by any demographic variables.

**Internal reliability.** The internal reliability (also known as internal consistency) was measured by calculating Cronbach’s alpha. Cronbach’s alpha demonstrates the amount of inter-correlation between test items. It is a measure of whether the test measures one common

thing, in this case ASD symptoms. This value was compared against those found by other validation studies.

***Factor analysis.*** Factor loadings were computed for each of the 39 questions on the SCQ. This was used to determine the factor structure underlying the SCQ in this Western Cape population. The results were compared to the factor solutions found in the initial validation study by Berument et al. (1999) and to factor structures found by Gau et al. (2011) and Magyar et al. (2012).

***Qualitative analysis.*** Problems that presented during the interview process were reflected on. This information was used to provide additional detail regarding the applicability of each language version of the SCQ to the Western Cape context.

## Phase 2 – Diagnostic Assessment

At the time of write-up of this thesis, the second phase of the larger study was taking place. Preliminary results of from Phase 2, as well as some assessments conducted in the Red Cross Hospital's developmental clinic, were used to assess relationship between diagnoses and scores on the SCQ.

**Participants.** Participants,  $N = 18$ , were drawn from those children whose parents had taken part in Phase 1 of the study and had agreed to be contacted for further research. Twelve of the 18 participants were children who had been assessed in Phase 2 of the larger study at the time of write-up. In this second phase of the larger study, participants are selected in accordance with their scores on the SCQ and three groups of around twenty children each are established. One group consists of children who, according to the SCQ, show a very high likelihood of having ASD ( $n = 20$ ). A second group consists of children with SCQ scores that fall close to cut-off scores established in Western countries ( $n = 20$ ). The third group consists of children who, according to the SCQ, have little chance of having ASD ( $n = 20$ ). Although these groups will be established for each SCQ language version, at the time of writing up this thesis, only the English version of the SCQ was being tested. The 12 children were therefore all English first-language speakers.

In addition to these 12 participants, ADOS assessments conducted with six participants by paediatricians at the developmental clinic were used. Doctors at the developmental clinic perform assessments in the course of patient treatment when it is not clear whether the child in question has ASD or if they feel the family need a formal assessment in order to better accept the diagnosis (Dr. K. Donald, personal communication, October 20, 2013). These six assessed by the paediatricians were added to the 12 children thus far assessed in Phase 2, making a sample of 18 children

**Procedure.** Parents of the potential Phase 2 participants (i.e. those who provided consent to future contact and whose children fell in one of the three groups described above) were contacted by a researcher and asked if they were willing to participate in this phase of the study. If they agreed, an appointment was set up in which a number of assessments were conducted. The appointment took place at the Child Guidance Clinic (CGC), the clinic run by the Psychology department of the University of Cape Town. It has a number of rooms for assessment, equipped with recording devices. The clinic quite near the Red Cross Children's Hospital and is close to various forms of public transport.

At the appointment, consent was obtained from the parent (see Appendix P) and, where possible, assent was obtained from the child (see Appendix Q). The child first took

part in a play assessment, the Autism Diagnostic Observation Schedule, 2<sup>nd</sup> edition (ADOS-2; Lord et al., 2000). The parent was then interviewed using the Autism Diagnostic Interview - Revised (ADI-R; Lord et al., 1994), while the child was assessed using the Wechsler Preschool and Primary Scale of Intelligence, 3<sup>rd</sup> edition (WPPSI-III; Wechsler, 2002), or the Schedule of Growing Skills, 2<sup>nd</sup> edition (SGS-II; Bellman, Lingam, & Aukett, 1996) if the child did not have the verbal skills to complete the WPPSI-III. The ADOS and ADI-R are standard assessments used in combination to diagnose ASD, and both were administered by research-trained professionals, blind to the screen results. This entire appointment lasted around 3-4 hours.

The parents were reimbursed their travelling costs. Results were then given to the collaborating doctor at Red Cross, Dr Donald, to be used in case management and feedback. Because diagnostic assessment is standard in the Red Cross developmental clinic the participants who do not consent to participate in this phase of the research still received the standard diagnostic assessments.

The six children with whom ADOSs were conducted as part of their assessments were assessed by doctors working at the developmental clinic of the Red Cross Children's Hospital. These assessments took place between 2011 and 2013. Because the children assessed at the developmental clinic did not receive ADI-R interviews and cognitive assessments, only the results of the ADOS are analysed for this subset.

### **Measures.**

***Autism Diagnostic Observation Schedule.*** The Autism Diagnosis Observation Schedule, second edition (ADOS-2; Lord et al., 2012) is a standardised direct assessment that is conducted by a formally trained individual who uses specific presses to elicit behaviours in the domains of social interaction, communication and repetitive-stereotyped patterns of behaviour. The assessment battery takes the form of specific tasks and playtime for the child, which is observed by the professional and rated according to whether the behaviour follows autistic patterns. Ultimately, the results of this behavioural observation are used to formulate a diagnosis of autistic disorder, other ASD, or unaffected (Lee et al., 2007).

The ADOS is relied on globally and is seen as the gold-standard of autism diagnostics (Filipek et al., 2000). The ADOS validation study (Lord et al., 2000) showed excellent interrater reliability, test-retest reliability and internal consistency. The ADOS effectively differentiated between autism and other ASDs. Sensitivity and specificity scores were excellent. Both specificity and sensitivity scores ranged from 93-100% across the four modules of the ADOS when differentiating between cases of autism and non-spectrum cases.

The major difference between the ADOS and the ADOS-2 is the revised scoring algorithm, developed by Gotham, Risi, Pickles, and Lord (2006). This algorithm was validated in a study of 1 630 children between the ages of 14 months and 16 years with ASD and other developmental disorders. Gotham et al. (2006) found that the newer algorithm better differentiated between ASD diagnoses.

The ADOS assessments in Phase 2 are administered by researchers who have many years of experience working with children with ASD. These researchers have received both clinical and research training in the ADOS. The researchers are blind to the child's SCQ score and any possible diagnosis the child may have received.

The ADOS assessments conducted as part of assessment at the Red Cross Children's Hospital were administered by paediatricians. These doctors have been trained in clinical administration of the ADOS and two have received research training in the ADOS. Paediatricians conduct the ADOS assessments on children when they are unsure whether they meet the criteria for ASD (personal communication, Dr. K. Donald, October 20, 2013).

**Data Analysis.** Once the whole of Phase 2 is completed, a complete analysis of descriptive statistics, logistic regression, receiver operating characteristic curves, optimum sensitivity and specificity scores and predictive power of items and of the SCQ as a whole will be conducted. This will be performed for each language version of the SCQ. However, due to the small amount of data available at the time of this write-up, only preliminary exploration of the data on the English version of the SCQ was conducted.

**Descriptive statistics.** Age, race, gender, home language and SES were explored for this group.

**Logistic regression.** Scores on the SCQ were correlated with results from the diagnostic assessments. A logistic regression was used to determine whether the SCQ can reliably predict the presence of ASD in this small sample.

## Results

### Response Rate

Two hundred and twenty eight Social Communication Questionnaires were completed, with a response rate of 70%. The most common reason given for declining to take part in the study was that the caregiver needed to watch the child while they were in the waiting room. The fact that some parents declined may be therefore due to the fact that their children required stricter supervision. Nevertheless, there were many caregivers who came to the clinic with another adult who supervised the child while the caregiver completed the form as well as caregivers who were there without another adult who nonetheless completed the form.

A second common reason for declining was that the caregiver needed help understanding the form, but did not speak English or Afrikaans. This occurred with isiXhosa speakers on the days that the translator was not in the clinic. IsiXhosa speakers were recruited into the sample ( $n = 59$ ) when the translator was at the clinic (one of the two data collection days per week).

A third reason why people did not take part was because they had not spent enough time with the child to be familiar with their behaviours. This usually occurred when a more distant relative brought the child to the clinic, rather than the mother, father or guardian.

Finally, nurses or personnel from children's homes brought in children. Although some of these personnel did fill in the forms, others reported that they were not allowed to give out information on the children from the home.

For these reasons the sample may be less representative of children who require constant supervision and who arrived with only one caregiver, who reside in institutional homes, speak isiXhosa, and whose caregivers are less confident with reading

A response rate of 70% can be regarded as acceptable in this study, due to the number of mitigating factors associated with participation. Participation in this study was voluntary and the potential participants could therefore freely choose not to take part. Potential participants were not familiar with the researchers who explained the study. They likely felt less obligated to take part than if their doctor or another service provider had approached them; however this might have introduced the element of perceived coercion in recruitment and was therefore avoided. Furthermore, there were no immediate rewards associated with taking part and no negative consequences of not doing so that could sway potential participants to take part. Some potential participants were unable to complete the forms

before being called to their appointment by the paediatrician. Considering these mitigating factors, 70% participation from the potential sample is adequate (Baruch, 1999).

### Sample Characteristics

The overall sample was made up of an unselected series of cases from the Red Cross Children's Hospital's developmental clinic. There was no attempt to stratify precisely on demographics, as the purpose was to have a sample that represented the population that attends community clinics in the Western Cape. The distribution of *age, race, gender, home language, form language* and *SES* in the sample of 228 children was examined. Table 1 summarises the spread of these demographic variables across the sample. Means and frequencies are presented for the sample as a whole, as well as broken down into the three language versions of the SCQ in order to ascertain whether the samples for each were equivalent.

Table 1

#### *Demographic Characteristics of the Samples Broken Down by Language Group*

Variable	All subjects (N=228)	SCQ groups			Test of significance on SCQ groups	
		English SCQ (N=161)	Afrikaans SCQ (N=28)	isiXhosa SCQ (N=39)	ANOVA <i>F</i>	<i>p</i>
Age (years)	4.73 (0.86)	4.74 (0.84)	4.77 (0.84)	4.70 (0.97)	0.06	.947
Age range (years)	3.00-5.97	3.00-5.95	3.13-5.97	3.17-5.95		
SES (score out of 100)	69.59 (16.94)	73.44 (15.77)	57.58 (14.31)	63.22 (17.79)	17.95	<.001
SCQ score	12.94 (6.00)	12.01 (6.47)	12.46 (4.51)	13.41 (4.86)	0.21	.892
SCQ score range	0-32	0-32	5-24	2-22		
Gender (male: female)	153:75	103:58	22:6	28:11	2.77	.250
Race (Black:Coloured:White:Other)	77:132:8:11	36:107:8:10	3:25:0:0	38:0:0:1	92.68	<.001
Home language (Eng:Afr:Xho:Eng&Afr:Other)	121:27:59:9:12	117:6:20:6:12	4:21:0:3:0	0:0:39:0:0	257.93	<.001

*Note.* For age, SES and SCQ score, means are provided with standard deviations in parentheses.

### **Participant characteristics of the full sample.**

**Age.** Participants, that is, children about whom the SCQ was answered, ranged in age from 3.00 to 5.97 years. This age range was chosen in order to test the lower and upper limits of the Current version of the SCQ (suitable for children below the age of 6 years). The mean age was 4.73 years, with a standard deviation of 0.86.

**Gender.** Both male and female children were included in this study. A total of 153 participants were male and the remaining 75 were female. The ratio of males to females was thus 2.04:1.

**Race.** Parents were asked to report the race of their child. The majority of the sample, 58% ( $n = 132$ ), was classified as *Coloured*. This was followed by 77 individuals who were classified as *Black*, making up 34% of the sample. Only 3% of participants ( $n = 8$ ) classified their children as *White*. The remaining 5% ( $n = 11$ ) were made up of individuals who were classified as *Indian*, “*Other*” or in which the answer was left blank.

**Socioeconomic status.** SES was measured using annual income of the adults in the home of the participant, highest level of education obtained by the mother and father of the participant and number of common household items and amenities present in the participant’s home. For each participant the scores of each question answered were standardised, the standardised scores were then summed and divided by the number of questions answered and a score out of one hundred was created, where 100 indicated higher SES. This method was used in order to be able to compare SES levels even when certain questions were left out. This occurred in many cases, as many parents chose not to answer the question on income. The variable was kept in continuous form rather than transformed into tertiles. This allowed for small, subtle differences to be explored, which are lost when continuous data is categorised. Furthermore, the continuous nature of the data allowed for correlations and regressions to be performed and easily interpreted.

In order to achieve the maximum score on this questionnaire a household would need an annual income of over R90 000, parents would need to have attended a tertiary education institution and the household would need running water, a built-in kitchen sink, a hired cleaner, a sound system, a landline telephone and other similar appliances. The parent filling in the questionnaire would need to shop at supermarkets, have a bank account and have some form of credit account. This form measures differences between predominantly low SES to middle SES participants, due to the relatively basic items in the item inventory and the low income level options. The average middle-class family would score very high on the questionnaire and in order to score low, parents must earn very little, have low levels of

education and few amenities and household items in their house. The mean SES score in the sample was 69.59 with a standard deviation of 16.94.

**SCQ.** Scores on the SCQ ranged from 0 to 32, with the highest possible score being 39 (with high scores indicating high risk of ASD). The mean score was 12.94 with a standard deviation of 6.00. Just over a third, 38.2%, of the 228 participants were flagged as possible ASD, scoring 15 and above, the cut-off recommended by Berument et al. (1999). Of the 228 participants, 63.2% were flagged as possible ASD using the cut-off score of 11 recommended by Lee et al. (2007) and Snow and Lecavalier (2008). Thus a large portion of the sample, 25%, lies in the grey area between the two cut-off scores.

**Home language.** Home language, also known as mother tongue, is the language that an individual speaks in their home environment. In the demographic form, caregivers were asked what the home language of their child was. The most common in the sample was *English*, which 54% ( $n = 122$ ) of the sample reported as a home language. This was followed by *isiXhosa*, which was reported as a home language by 26% of the sample ( $n = 59$ ), and *Afrikaans*, which was the home language of 12% of the sample ( $n = 27$ ). There was not an option of English and Afrikaans, but nine people (4%) wrote in that their home language was both English and Afrikaans. The remaining 4% reported having a home language other than English, isiXhosa and Afrikaans. Most of these people were from other African countries, and spoke Chichewa (from Malawi) or French (from central African countries).

**Form language.** The most frequently chosen language form chosen by parents was English,  $n = 161$ . This was followed by isiXhosa,  $n = 39$  and Afrikaans,  $n = 28$ . One hundred and sixty individuals chose to answer the English questionnaire, despite the fact that only 121 parents reported English as their home language. Four of the latter group chose to fill in the Afrikaans version of the SCQ. This is further explored in the next section.

**Differences in participant characteristics between language versions.** In order to determine whether the participants who filled in different language versions were equivalent, Analyses of Variance (ANOVAs) and chi-squared tests of contingency were performed on the demographic variables. Differences in descriptive statistics between individuals who filled out the different language versions of the SCQ were examined. The results of these analyses are presented in Table 1.

**Age.** The mean age for the children in the English, Afrikaans and isiXhosa groups was 4.74 (SD = 0.84), 4.77 (SD = 0.84) and 4.70 (SD = 0.97) respectively. Age ranged from 3.00

to 5.95 years in the English group, 3.13 to 5.97 years in the Afrikaans group and 3.17 to 5.95 years in the isiXhosa group. There was no significant difference between those who filled in English, Afrikaans and isiXhosa forms on *age*,  $F = 0.06$ ,  $p = .947$ . The effect size was very small,  $\eta^2 < .001$ .

**Gender.** In each of the language groups there were more male than female children. In the English group there were 103 male and 58 female participants, a ratio of 1.78 males to every female. In the isiXhosa group there were 28 male and 11 female participants, a ratio of 2.55 males to every female. In the Afrikaans group there were 22 male and six female participants, a ratio of 3.67 males to every female. A chi-squared analysis showed that the distribution of males and females did not differ significantly across the groups,  $\chi^2(2) = 2.77$ ,  $p = .250$ . Effect size was small, with Cramer's  $V = .110$ .

**Race.** The English language group had the most racially mixed group of children. One hundred and seven of these 161 participants classified their children as *Coloured* (66%). Thirty six participants classified their children as *Black* (22%), eight classified their children as *White* (5%) and the remaining ten were classified as "other" (6%). The six percent were made up of *Indian* participants, participants who chose the option "*Other*" and participants who did not answer the question. In the Afrikaans group, 25 of the 28 participants classified their children as *Coloured* (89%) while the remaining three were classified as *Black* (11%). In the isiXhosa group, 38 of the 39 participants classified their children as *Black* (97%), while the remaining participant did not disclose their race.

There were significant differences in race between all of the language versions of the SCQ,  $\chi^2(6) = 92.69.81$ ,  $p < .001$ , demonstrating that the groups had significantly different race distributions. Effect size was large, with Cramer's  $V = .456$ . This was expected, as in South Africa language and race are highly related.

Analysis of the residuals showed that within the English language version group, there were significantly fewer Black people, with a standardised residual of -2.5, well over the necessary 1.96 that shows significance at  $p < .05$ . There was no significant over- or under-representation of Coloured, White or "Other" individuals. In the isiXhosa language version there were significantly more Black people, with a standardised residual of 6.9 and significantly fewer Coloured people, with a standardised residual of -4.7,  $p < .001$ . These are very high numbers, showing substantial differences. Once again, there was no significant under- or over-representation of White or Other individuals, however this is likely due to the low numbers of White and Other individuals (8 and 6 respectively). In the Afrikaans

language version group, there was a significantly high number of Coloured people, with a residual of 2.1, and a significantly lower number of Black people, with a residual of -2.1,  $p < .05$ . The representation of White and Other participants was within the normal range. Analysis of the residuals showed that there were several large differences between the groups, likely because of strong associations between specific race groups and home language.

**SES.** The English group had the highest mean *SES*, 73.44 (SD = 15.77). They were followed by the isiXhosa group, with a mean of 63.22 (SD = 17.79). The Afrikaans group had the lowest mean of 57.58 (SD = 14.31).

There were significant between-group differences in *socioeconomic status*,  $F(2) = 17.95$ ,  $p < .001$ ,  $\eta^2 = .139$ . The differences in SES between the isiXhosa and Afrikaans groups were not significant,  $p = .400$ . However, the differences between English and Afrikaans,  $p = .006$ , and English and isiXhosa,  $p < .001$ , groups were significant. The Afrikaans and isiXhosa groups had significantly lower SES than the English group.

Table 2

*Language Version Chosen According to Reported Home Language*

Reported home language	All subjects (N=228)	Language versions of the SCQ6		
		English SCQ (n=161)	Afrikaans SCQ (n=28)	isiXhosa SCQ (n=39)
English	121	117	4	0
Afrikaans	27	6	21	0
isiXhosa	59	20	0	39
Afrikaans and English	9	6	3	0
Other	11	11	0	0
Missing	1	1	0	0

**Home language.** A breakdown of reported home language and form language chosen is displayed above in Table 2. Home language of the children was largely divided by form language.

The majority, 73%, of the individuals who filled out the English SCQ, reported *English* as a home language, ( $n = 117$ ). Twelve percent ( $n = 20$ ) of the individuals who chose to fill in English forms reported *isiXhosa* as their child's home language. Four percent, six individuals, reported *Afrikaans* as their child's home language and another six individuals reported *Afrikaans and English* as a home language. The final 7%, made up of 12 individuals, reported that their home language was neither English, Afrikaans nor isiXhosa.

Of the participants that chose to fill out an Afrikaans SCQ, 75%, 21 individuals, reported *Afrikaans* as their child's home language. Fourteen percent, four individuals, reported *English* as a home language and the remaining three individuals, 11%, reported both *English and Afrikaans*. All 39 of the individuals who filled out the isiXhosa form reported that their child's home language was *isiXhosa*.

Form language was largely dependent on home language and there were therefore significant differences between all groups,  $\chi^2(8) = 257.93, p < .001$ . Effect size was large, with Cramer's  $V = .754$ .

Analysis of the residuals showed that, within the English version group, English as a home language was significantly over-represented and isiXhosa and Afrikaans as home languages were significantly under-represented, with standardised residuals of 3.5, -3.3 and 3.0 respectively, all significant at  $p < .001$ . Within the isiXhosa version group, isiXhosa was significantly over-represented and English and Afrikaans were significantly under-represented, with standardised residuals of 9.1, -4.6 and -2.2,  $p < .05$ . Lastly, in the Afrikaans version group, the home language of Afrikaans was significantly over-represented, while English and isiXhosa were significantly under-represented, with residuals of 9.7, -2.8 and -2.7,  $p < .001$ . These results are to be expected, as most people would choose to answer a form in their home language, the language they in which they feel most fluent. The language spoken at home, their child's home language, is highly likely to be the parent's home language, with exceptions occurring in institutional homes and when parents speak different languages.

It is noteworthy that only 39 of the 59, or 66%, of the participants whose reported home language was isiXhosa chose to fill in the isiXhosa SCQ. This is much lower than the 78% of Afrikaans speakers who filled out the Afrikaans SCQ (21 out of 27 Afrikaans participants) and the 97% of English participants who filled out the English SCQ (117 out of 121 English speakers).

**SCQ score.** The mean *SCQ scores* for the English, Afrikaans and isiXhosa groups were very similar; 12.01 (SD = 6.47), 12.46 (SD = 4.51), and 13.41 (SD = 4.86) respectively. Although the isiXhosa group had a slightly higher mean, ANOVA showed that the *SCQ scores* were not significantly different between groups,  $F(2) = 0.21, p = .892$ . The effect size was very small,  $\eta^2 = .002$ .

### Demographic Predictors of SCQ Score

**Correlations.** Correlations between the demographic variables *age*, *gender*, *SES* and *SCQ score* were run. This was done in order to assess whether demographic variables were associated in any way with SCQ score. Although *gender* was a categorical variable, it had only two categories and therefore did not create a deceptive ordering of categories. Furthermore, Bollen and Barb (1981) suggested that when exploring data, Pearson's correlation can be justifiably used. *Home language* and *form language* were however not included in this correlation analysis due to the fact that they are multi-category variables and the outcome of these variables would be dependent on the order in which they were classified. The results of the correlations are given in Table 3.

Table 3

*Summary of Correlations between SCQ Scores and Demographic Variables*

Variable associated with SCQ score	Pearson's correlation	<i>p</i>
Age	-.071	.142
Gender	-.113	.044
SES	-.123	.033

Note. \* is significant when  $p < .05$ .

*Age* was not significantly related to SCQ score, with  $p = .142$ . *Gender* was significantly negatively correlated with *SCQ score*,  $-.113$ ,  $p = .044$ , meaning that being male (coded as 0, female was coded as 1) was associated with higher SCQ scores. *SES* was also significantly negatively correlated with *SCQ score*,  $-.122$ ,  $p = .033$ . Thus, participants with lower SES scored higher on the SCQ, indicating a higher possibility of ASD.

**Linear regression.** A linear regression was conducted in order to determine the strength of the relationship between *SCQ score* as the outcome variable and *age*, *gender*, *SES*, *race*, *home language* and *form language*. *Home language* and *form language*, the two multi-category variables, were converted into dummy variables before being inserted in the regression.

The results are presented in Table 4. The resulting regression model was not statistically significant,  $F(10, 195) = 1.118$ ,  $p = .350$ . The variables explained, at best, only 5.4% of the variance in *SCQ scores*,  $R^2 = .054$  and *adjusted R*<sup>2</sup> = .006. The only significant predictor of *SCQ score* was *SES*, which was negatively related to SCQ score. As with the

correlation, this indicates that people who score lower on the SES measure score higher on the SCQ. However, a simple regression of *SES* onto *SCQ* score was not significant,  $p = .66$ .

Table 4  
*Summary of Linear Regression for SCQ Scores and Possible Predicting Variables*

Variable	<i>b</i> ( <i>SE</i> )	<i>B</i>	<i>t</i>	<i>p</i>	95%CI	
					Lower	Upper
Constant	18.244 (4.546)		9.787	< .001	9.276	27.208
Age	-0.622 (0.501)	-.089	-1.242	.216	-1.610	0.366
Race	-1.577 (0.921)	-.117	-1.748	.082	-2.136	.128
SES	-0.062 (0.028)	-.174	-2.213	.028*	-0.117	-0.007

Note:  $R^2 = .054$ ,  $p = .350$ . \* significant at  $p < .05$

### Internal Reliability

Internal reliability, also referred to as internal consistency, is a measure of the correlation between items in a test. It demonstrates whether the test truly measures one general construct, in this instance, autistic traits. If this is the case items should correlate well with one another (Bland & Altman, 1997).

The first item on the SCQ asks whether the subject speaks in phrases. If not, the next six items are not applicable and must be left out. When scoring, the six blank items are left out and therefore subjects do not receive higher scores (indicative of ASD risk). This method helps to increase specificity, as delayed speech, which is common in ASD but not pathognomonic on its own, does not count against the child when scoring is done. However, this method creates problems when calculating internal consistency. This is due to the fact that calculations of internal consistency cannot be produced when there are items missing. I therefore present two estimations of internal consistency. One is the internal consistency of the questionnaires in which all items were filled in (i.e. in which the children could speak in phrases). The other is the internal consistency of all completed questionnaires, but only of items 8 through to 40 (i.e. the items compulsory for all children, including those who are non-verbal).

This analysis examines the Cronbach's alphas of each language version of the SCQ. Cronbach's alpha is a statistic that measures the internal consistency of a test (Cronbach, 1951). It is a widely used measure and a score of between 0.70 and 0.90 is thought to demonstrate acceptable internal reliability (Tavakol & Dennick, 2011).

**The English SCQ.** The analysis of all 39 items, excluding the children who could not speak in phrases, resulted in a Cronbach's alpha of 0.82 ( $n = 95$ ). This is a good score and demonstrates good internal consistency. The Cronbach's alpha for items 8-40 (including 43 non-verbal children),  $n = 138$ , was 0.89, again reflecting good internal consistency. This was very similar to the alpha of 0.91 reported by Berument et al. (1999).

**The isiXhosa SCQ.** The analysis of all 39 items, excluding the children who could not speak in phrases, resulted in a Cronbach's alpha of 0.79 ( $n = 19$ ). This shows modest internal reliability. The Cronbach's alpha for items 8-40 (including 12 non-verbal children),  $n = 31$ , was 0.76, slightly lower than the alpha which included all the items. This may indicate that the first eight items are important in the test; however this can only be speculated as the sample sizes in these calculations are small which leads to less accuracy in the estimation of internal reliability (Yurdugul, 2008). The alpha is nevertheless in the acceptable range prescribed by Takavol and Dennick (2011).

**The Afrikaans SCQ.** The analysis of all 39 items, excluding the children who could not speak in phrases, resulted in a Cronbach's alpha of 0.71 ( $n = 16$ ). This is an acceptable alpha; however the sample size was very small, making the alpha less reliable (Yurdugul, 2008). The Cronbach's alpha for items 8-40 (including six non-verbal children),  $n = 22$ , was 0.76. This sample was larger, as was the alpha. This is similar to the same alpha in the isiXhosa sample.

Overall, these alphas are largely adequate, demonstrating good internal consistency in all language versions of the SCQ.

### **Factor Structure of the SCQ**

Factor analysis is one of the most common measures used in developing, refining and evaluating clinical instruments (Floyd & Widaman, 1995). It is used to determine which underlying latent variables are measured by the items on a questionnaire. These factors are named according to the characteristics shared by the items loading on the factor. Principal component analysis (PCA) and principal factor analysis (PFA) are widely used in order to determine factor structure in questionnaires and tests (e.g. Boelen, van den Bout, & de Keijser, 2003; Karp, 1996; Lessiter, Freeman, Keogh, & Davidoff, 2001; Yao, Chung, Yu, & Wang, 2002) and have been used previously to examine the latent structure underlying the SCQ (for example by Berument et al., 1999; Gau et al., 2011; Magyar et al., 2012).

In this study, principal component analysis was used to determine the possible number of factors and these factor solutions were then explored using principal factor

analysis, as recommended by Streiner (2013). Principal component analysis (PCA) determines the largest number of factors possible with eigenvalues above one. The optimal number of factors is then chosen, by examining amount of variance explained, eigenvalues and the scree plot on which factors are plotted according to their eigenvalues. If the chosen solution has fewer factors than that suggested by PCA, principal factor analysis is then used to force an analysis of the chosen factor model. The results of principal factor analysis are used to show the fit of the model, the item loadings and amount of variance explained.

Unfortunately, factor analysis could not be conducted on the isiXhosa or Afrikaans versions, as the sample sizes were too small. Floyd and Widaman (1995) suggest ratios of either 4:1 or 5:1 participants to items, and for the isiXhosa and Afrikaans versions the ratio were 1:1 and 0.7:1 respectively. Only the factor structure of the English version of the SCQ, which had a ratio of 4.1:1, was explored.

Principal component analysis factoring without rotation was used in order to determine the number of factors measured by the SCQ. Rotation aims to fit the items as highly as possible and on as few factors as possible (Floyd & Widaman, 1995). The varimax rotation option was chosen in each of the factor analyses conducted in this study, however in the case of PCA the model was not improved by rotation so the unrotated factors were used.

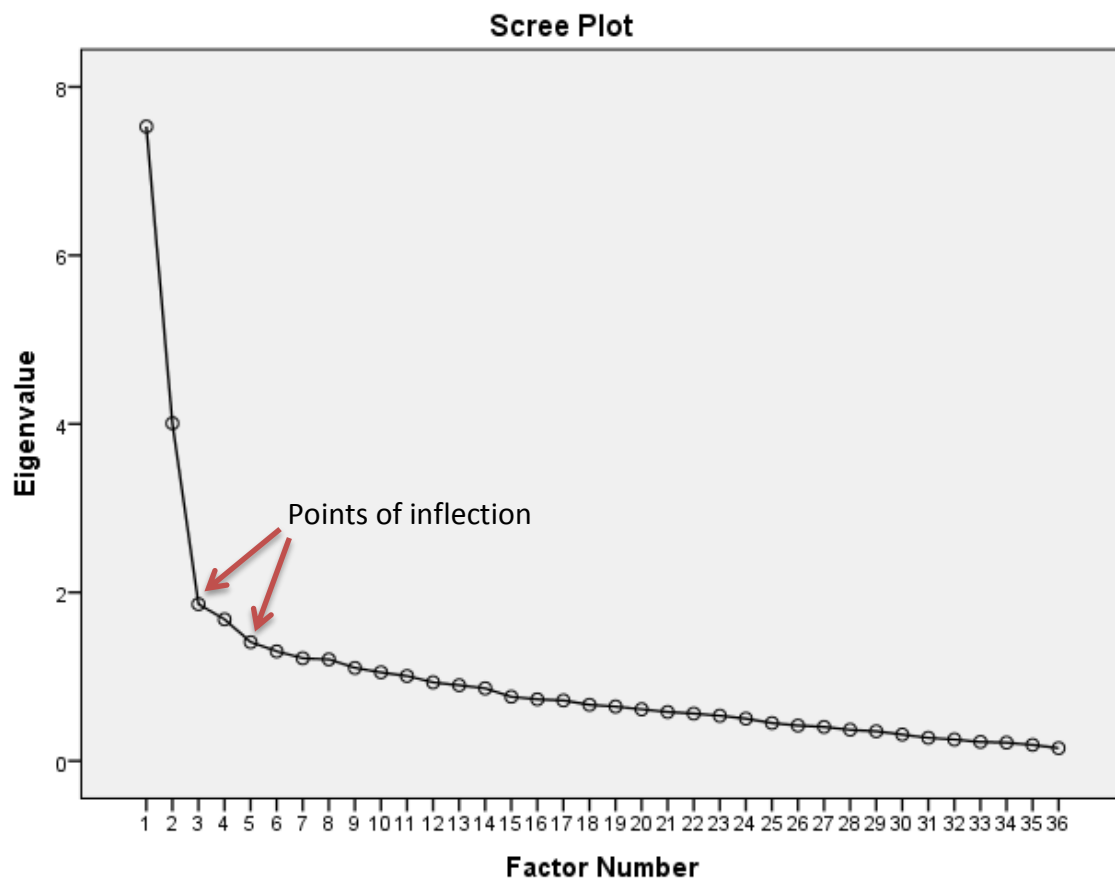
When conducting a PCA on the English version of the questionnaire, Bartlett's test of sphericity was significant,  $\chi^2 (741, n = 161) = 1461.58, p < .001$ , verifying that the correlations between the items were large enough to perform a factor analysis. The Kaiser-Meyer-Olkin (KMO) measure demonstrated good sampling adequacy,  $KMO = .75$ . However, three of the 39 KMO values for individual items were below the acceptable level of .50, one of which was below 0.40. Additionally, the determinant was below the necessary value of .0001. This indicated that there may be a problem of multicollinearity, in which more than one question measures the same construct.

The three items with KMO values below 0.5, question 2 (conversation), 4 (inappropriate questions) and 22 (pointing to express interest), were deleted, as recommended by Field (2009) and the factor analysis was rerun. The KMO measures once again demonstrated good sampling adequacy,  $KMO = .78$  and all KMOs for individual items were above .50. Bartlett's test of sphericity was significant,  $\chi^2 (630, n = 161) = 1349.21, p < .001$ . However, the determinant was once again below the minimum value and therefore multicollinearity may still be a problem.

Eleven factors were found with eigenvalues over Kaiser's criterion of one, which together explained 64.93% of the total variance. Eigenvalues demonstrate the amount of

variance accounted for by the factor. The sum of these values adds up to the total number of items (Floyd & Widaman, 1995). Therefore, eigenvalues below the value of one account for less variance than an individual item (Floyd & Widaman, 1995). One method of choosing factors is accepting all factors with eigenvalues above one. However Zwick and Velicer (1986) warn that this method can overestimate the number of factors.

Another possible method of factor selection is examination of the scree plot, which plots the factors according to their eigenvalue (Floyd & Widaman, 1995). A point of inflection demonstrates a change in the slope of the scree plot. The point of inflection signals that the factors before the point of inflection are most relevant. In the scree plot for this analysis, shown in Figure 1, two points of inflection were found. One suggested a two factor solution and the other a four factor solution. Both of these models were explored using principal factor analysis.



*Figure 1.* Scree Plot of Eigenvalues

**Four factor model.** Because the initial validation study by Berument et al. (1999) favoured a four factor solution, we chose to explore the same solution in order to compare

item loadings between these studies. This solution was explored using principal factor analysis and varimax rotation with Kaiser normalisation, forcing a four factor solution.

**Factor structure.** The four factor model explained 35.1% of the variance. This is less than the 42.4% found by Berument et al. (1999). The results of the current analysis and the analysis by Berument et al. (1999) are presented in Table 5. The four factors found in the current study were: *repetitive and stereotyped behaviours* (made up of repetitive and stereotyped behaviour and language use), *social interaction, communication* and *social play*. The *repetitive behaviours* domain accounted for 10.9% of the variance (eigenvalue 3.92), much more than that found by Berument et al. (1999) where this factor accounted for 4.5% (eigenvalue 1.74). The second factor was *social interaction* which explained 10.7% of the variance (eigenvalue of 3.84). This is much less than in the initial validation study where this factor explained 24.3% of the variance (eigenvalue 9.7). More similar was the factor of *communication* which accounted for 6.9% (eigenvalue 2.47) in the present data, compared to 8.7% (eigenvalue 2.46) in the initial validation study. The final factors differed between studies. Factor four in this study was made up of predominantly *social play* items whereas it was made up of *abnormal language* items in the initial validation study. This factor accounted for 6.6% of the variance (eigenvalue 2.36) in the current study and 5% (eigenvalue 1.94) in the initial study.

Table 5

*Factor Structure in a Four Factor Model for Current and Initial Validation Study*

Factor number	Factor domain	Study	% of variance	Eigenvalue	Alpha	Cumulative % of variance
1	Repetitive & stereotyped behaviour	Current	10.9	3.92	0.74	10.9
		Initial	4.5	1.74	0.67	4.5
2	Social interaction	Current	10.7	3.84	0.79	21.6
		Initial	24.3	9.7	0.91	28.8
3	Communication	Current	6.9	2.47	0.68	28.5
		Initial	8.7	3.38	0.71	37.5
4	Social play	Current	6.6	2.37	0.62	35.1
	Abnormal language	Initial	5	1.94	0.79	42.5

**Item loadings.** Berument et al. (1999) first labeled 37 of the 39 items according to one of the three factors that they intended the SCQ to measure. These were *social interaction, communication* and *repetitive behaviour*. The two items they did not label were *self-injury*

and *attention to voice*. These groupings are referred to below as factor labels. They then ran a factor analysis in which items were found to load on one of four factors. These were the three initial labels of *social interaction*, *communication* and *stereotyped behaviour* as well as a domain of *abnormal language*. These are referred to below as initial factors loaded upon. Each item therefore has a label, loads on and is therefore categorised under a particular factor from the initial validation study and now loads on a factor from the current validation study. The differences in these loadings are examined below and shown graphically in Table 10.

*Items loading on the repetitive and stereotyped behaviour domain.* Items on repetitive and stereotyped behaviours were well placed in the first factor of the current study. The category was made up of 14 items, nine of which were initially labeled by Berument et al. (1999) as repetitive or stereotyped behaviours in their validation. These items are shown in Table 6. One item loaded on repetitive and stereotyped behaviour in the study by Berument et al., as well as in this study, but was initially labelled as social interaction. The four remaining items that loaded on repetitive and stereotyped behaviour in the current study were all initially labeled as communication. Three of these four items loaded on abnormal language in the original validation study. One item was labeled as repetitive behaviour, found to load on communication by Berument et al., but then classed as stereotyped in the current study. The alpha of the category was satisfactory, 0.74.

Table 6

*Items Loaded on the Repetitive, Stereotyped Behaviour Domain*

Item number	Item	Initial domain label	Initial factor loaded on	Current factor loaded on
7	Verbal rituals	Repetitive behaviour	Stereotyped behaviour	Repetitive, stereotyped behaviour
10	Use of other's body to communicate	Social interaction	Stereotyped behaviour	Repetitive, stereotyped behaviour
11	Unusual preoccupations	Repetitive behaviour	Stereotyped behaviour	Repetitive, stereotyped behaviour
12	Repetitive use of objects	Repetitive behaviour	Stereotyped behaviour	Repetitive, stereotyped behaviour
8	Compulsions and rituals	Repetitive behaviour	Stereotyped behaviour	Repetitive, stereotyped behaviour
15	Hand and finger mannerisms	Repetitive behaviour	Communication	Repetitive, stereotyped behaviour
14	Unusual sensory interests	Repetitive behaviour	Stereotyped behaviour	Repetitive, stereotyped behaviour
3	Stereotyped utterances	Communication	Abnormal language	Repetitive, stereotyped behaviour
18	Unusual attachment to objects	Repetitive behaviour	Stereotyped behaviour	Repetitive, stereotyped behaviour
13	Circumscribed interests	Repetitive behaviour	Stereotyped behaviour	Repetitive, stereotyped behaviour
16	Complex body mannerisms	Repetitive behaviour	Stereotyped behaviour	Repetitive, stereotyped behaviour
5	Pronoun reversal	Communication	Abnormal language	Repetitive, stereotyped behaviour
6	Neologisms	Communication	Abnormal language	Repetitive, stereotyped behaviour
23	Gestures	Communication	Social interaction	Repetitive, stereotyped behaviour

*Items loading on the social interaction domain.* The category of social interaction was made up of ten items, all of which were found to load on the factor of social interaction by Berument et al. (1999). These items are shown in Table 7. Two of these items were those that were not labeled under any of the three categories of behaviour, but the remaining eight were labeled as social. This convergence displays positive similarities between this study and the initial validation study. The alpha of the category was satisfactory, 0.79.

Table 7

*Items Loaded on the Social Interaction Domain*

Item number	Item	Initial domain label	Initial factor loaded on	Current factor loaded on
37	Response to children's approaches	Social interaction	Social interaction	Social interaction
36	Interest in children	Social interaction	Social interaction	Social interaction
27	Social smiling	Social interaction	Social interaction	Social interaction
17	Self-injury	None	Social interaction	Social interaction
26	Eye gaze	Social interaction	Social interaction	Social interaction
30	Seeking shared enjoyment	Social interaction	Social interaction	Social interaction
40	Group play	Social interaction	Social interaction	Social interaction
29	Offering to share	Social interaction	Social interaction	Social interaction
38	Attention to voice	None	Social interaction	Social interaction
28	Showing and directing attention	Social interaction	Social interaction	Social interaction

*Items loading on the communication domain.* The category of communication was made up of six items, of which three were originally labeled as social. These items are shown in Table 8. One of these three then loaded on communication in the initial study, however the other two loaded on social interaction in the initial study. The remaining three items were labelled as communication, two of which loaded on communication in the initial study. The other item labeled as communication was then found to load on the social factor in the initial study. The alpha for this factor was fairly low, 0.68.

Table 8

*Items Loaded on the Communication Domain*

Item number	Item	Initial domain label	Initial factor loaded on	Current factor loaded on
24	Nodding to mean "yes"	Communication	Communication	Communication
25	Head shaking to mean "no"	Communication	Communication	Communication
31	Offering comfort	Social interaction	Social interaction	Communication
21	Imitation	Communication	Social interaction	Communication
32	Quality of social overtures	Social interaction	Social interaction	Communication
20	Social chat	Social interaction	Communication	Communication

*Items loading on the social play domain.* The category of social play was made up of six items that were largely labeled as social interaction by Berument et al. (1999) and were found in the initial validation study's factor analysis to fit into the social category. These items are shown in Table 9. The exceptions were imitative social play, which was originally labeled as

communication, loaded on the social factor in the initial study, but found to fit in social play in this study; and inappropriate facial expression which was initially labeled as social, classed as communication, but found here to fit into social play. The alpha of the category was low, 0.62. This demonstrates that this factor was not a very good one as an alpha of above 0.80 is considered good (Cicchetti, 1994) and an alpha of 0.70 is considered acceptable (Takavol & Dennick, 2011).

Table 9

*Items Loaded on the Social Play Domain*

Item number	Item	Initial domain label	Initial factor loaded on	Current factor loaded on
33	Range of facial expressions	Social interaction	Social interaction	Social play
19	Friends	Social interaction	Social interaction	Social play
34	Imitative social play	Communication	Social interaction	Social play
9	Inappropriate facial expressions	Social interaction	Communication	Social play
35	Imaginative play	Communication	Social interaction	Social play
39	Imaginative play with peers	Social interaction	Social interaction	Social play

*Strength of item loadings.* The loadings of each item on the four factors are shown below in Table 10. In order to be significant, loadings should be above .30 or .40 (Floyd & Widaman, 1995). Thirty five out of the thirty six items had loadings above .30. Thirty of the thirty six had loadings above .40.

Seven of the items did not load cleanly on one factor. The item on *neologisms* loaded almost equally on repetitive, stereotyped behaviour (.345) and social play (.340). Both *seeking shared enjoyment* and *group play* loaded primarily on social interaction (.469 and .465) but also on social play (.364 and .398). The question on *showing and directing attention* loaded almost equally on social interaction and communication, .413 and .412 respectively. *Offering comfort* loaded on social interaction (.329) and communication (.476). The item on *social chat* loaded on communication (.320) and social play (.295). Finally, *imaginative play* loaded on social interaction (.322), communication (.298) and social play (.327). Some of the items described above do logically fit into more than one domain. An example of this is the item of *shared enjoyment* fitting into the social interaction and the social play categories. However, a large majority of the items that load on more than one factor do not seem related to one of the two factors and this four factor model therefore looks problematic.

Table 10

*Item Loadings in a Four Factor Model*

Item number	Item	Initial domain label, initial factor designation and current factor designation	Factor loading Factor 1: Repetitive & Stereotyped Behaviour	Factor loading Factor 2: Social	Factor loading Factor 3: Communication	Factor loading Factor 4: Social Play
7	Verbal rituals	R, SB, RSB	<b>.668</b>	.119	-.307	.269
10	Use of other's body to communicate	S, SB, RSB	<b>.651</b>	.125	.086	.130
11	Unusual preoccupations	R, SB, RSB	<b>.558</b>	.211	.009	-.004
12	Repetitive use of objects	R, SB, RSB	<b>.546</b>	.226	.086	.056
8	Compulsions and rituals	R, SB, RSB	<b>.545</b>	.080	-.111	-.040
15	Hand and finger mannerisms	R, C, RSB	<b>.500</b>	<b>.407</b>	.317	.167
14	Unusual sensory interests	R, SB, RSB	<b>.498</b>	.272	.051	.018
3	Stereotyped utterances	C, AL, RSB	<b>.495</b>	.132	-.197	.264
18	Unusual attachment to objects	R, SB, RSB	<b>.482</b>	.011	.138	-.020
13	Circumscribed interests	R, SB, RSB	<b>.463</b>	.066	-.189	-.165
16	Complex body mannerisms	R, SB, RSB	<b>.448</b>	<b>.426</b>	.161	-.122
5	Pronoun reversal	C, AL, RSB	<b>.422</b>	-.057	-.068	.188
6	Neologisms	C, AL, RSB	<b>.345</b>	-.103	-.144	<b>.340</b>
23	Gestures	C, S, RSB	<b>-.288</b>	.030	.081	-.001
37	Response to children's approaches	S, S, S	-.035	<b>.678</b>	-.028	.278
36	Interest in children	S, S, S	.138	<b>.672</b>	.068	.263
27	Social smiling	S, S, S	.204	<b>.539</b>	.144	.037
17	Self-injury	-, S, S	.285	<b>.528</b>	.064	.020
26	Eye gaze	S, S, S	.099	<b>.484</b>	.208	.058
30	Seeking shared enjoyment	S, S, S	-.070	<b>.469</b>	.115	<b>.364</b>
40	Group play	S, S, S	.205	<b>.465</b>	.050	<b>.398</b>
29	Offering to share	S, S, S	.053	<b>.441</b>	.128	.182
38	Attention to voice	-, S, S	.281	<b>.420</b>	.131	.160
28	Showing and directing attention	S, S, S	-.048	<b>.413</b>	<b>.412</b>	-.005
24	Nodding to mean "yes"	C, C, C	-.076	.227	<b>.691</b>	.044
25	Head shaking to mean "no"	C, C, C	-.121	.128	<b>.563</b>	.045
31	Offering comfort	S, S, C	.006	.329	<b>.476</b>	.211
21	Imitation	C, S, C	-.049	.040	<b>.443</b>	.244
32	Quality of social overtures	S, S, C	-.056	-.002	<b>.357</b>	.189
20	Social chat	S, C, C	.066	.155	<b>.320</b>	.295
33	Range of facial expressions	S, S, SP	.098	.167	.312	<b>.650</b>
19	Friends	S, S, SP	-.046	.225	.113	<b>.465</b>
34	Imitative social play	C, S, SP	.119	.256	.192	<b>.463</b>
9	Inappropriate facial expressions	S, C, SP	-.003	.165	.301	<b>.429</b>
35	Imaginative play	C, S, SP	.108	<b>.322</b>	<b>.298</b>	<b>.329</b>
39	Imaginative play with peers	S, S, SP	.152	.287	.163	<b>.329</b>
Eigenvalue			3.92	3.84	2.46	2.37
% variance			10.89	10.67	6.86	6.59
Alpha			0.74	0.79	0.68	0.62

NOTE: S, social domain; C, communication domain, R, SB &amp; RSB, stereotyped and repetitive behaviour domain; SP, social play.

## Two factor model.

**Factor structure.** Principal factor analysis and varimax rotation with Kaiser normalisation was used to explore a forced two factor solution. The results of the two factor model, which explained 28.23% of the variance, are displayed in Table 11. The first factor was made up of social-communicative items, which explained 15.79% of the variance (eigenvalue 5.68). The second factor was made up of stereotyped and repetitive behaviours and included repetitive and abnormal language use. It explained 12.44% of the variance (eigenvalue 4.48). The Cronbach's alphas were good: that for social-communication was 0.86 and that for repetitive-stereotyped behaviour was 0.77.

Table 11  
*Factor Structure in a Two Factor Model*

Factor number	Factor domain	% of variance	Eigenvalue	Alpha	Cumulative % of variance
1	Social interaction	15.8	5.68	.86	15.8
2	Abnormal language and repetitive, stereotyped behaviour	12.4	4.48	.77	28.2

**Strength of item loadings.** Item loadings are displayed below in Table 12. Item loadings were high with 35 out of 36 items with a factor loading above .30. Thirty two of these had factor loadings above .40 and the items were more cleanly loaded onto two rather than four factors. Only two items had loadings over .30 on both factors. The first item was *hand and finger mannerisms*, a repetitive factor which loaded highest on social interaction. The item loaded .512 on social-communication (SC) and .489 on abnormal language and repetitive stereotyped behaviour (ALRSB). The second item was *self-injury*, an item which was not originally classified by Berument et al. (1999). Self-injury loaded almost equally on SC and ALRSB, .378 and .376 respectively. In addition, only one item categorised as social in the four factor model fell into the repetitive and stereotyped behaviour category. This is a much better fit than that of the previous model.

Table 12  
*Item Loadings in a Two Factor Model*

Item number and domain designation	Item	Initial domain label, initial factor designation and current factor designation	Factor loading Factor 1 “social- communication”	Factor loading Factor 2 “abnormal language and repetitive, stereotyped behaviour”
31	Offering comfort	S, S, SC	<b>.599</b>	-.026
36	Interest in children	S, S, SC	<b>.589</b>	.295
33	Range of facial expressions	S, S, SC	<b>.578</b>	.101
24	Nodding to mean “yes”	C, C, SC	<b>.565</b>	-.184
30	Seeking shared enjoyment	S, S, SC	<b>.544</b>	.050
35	Imaginative play	S, S, SC	<b>.543</b>	.124
37	Response to other children's approaches	S, S, SC	<b>.540</b>	.165
15	Hand and finger mannerisms	R, C, SC & ALRSB	<b>.512</b>	<b>.489</b>
40	Group play	S, S, SC	<b>.510</b>	.322
28	Showing and directing attention	S, S, SC	<b>.509</b>	-.051
34	Imitative social play	C, S, SC	<b>.492</b>	.158
9	Inappropriate facial expressions	S, C, SC	<b>.486</b>	-.009
26	Eye gaze	S, S, SC	<b>.461</b>	.161
29	Offering to share	S, S, SC	<b>.448</b>	.138
27	Social smiling	S, S, SC	<b>.443</b>	.285
25	Head shaking to mean “no”	C, C, SC	<b>.436</b>	-.221
39	Imaginative play with peers	S, S, SC	<b>.435</b>	.193
19	Friends	S, S, SC	<b>.430</b>	.020
20	Social overture	S, C, SC	<b>.428</b>	.035
38	Attention to voice	S, S, SC	<b>.417</b>	.342
21	Imitation	C, S, SC	<b>.404</b>	-.134
17	Self-injury	-, S, SC & ALRSB	<b>.378</b>	<b>.376</b>
32	Quality of social overtures	S, S, SC	<b>.300</b>	-.133
7	Verbal rituals	S, SB, ALRSB	-.004	<b>.744</b>
10	Use of other's body to communicate	S, SB, ALRSB	.167	<b>.617</b>
11	Unusual preoccupations	R, SB, ALRSB	.118	<b>.567</b>
3	Stereotyped utterances	C, AL, ALRSB	.073	<b>.563</b>
8	Compulsions and rituals	R, SB, ALRSB	-.057	<b>.555</b>
12	Repetitive use of objects	R, SB, ALRSB	.203	<b>.543</b>
14	Unusual sensory interests	R, SB, ALRSB	.197	<b>.517</b>
13	Circumscribed interests	R, SB, ALRSB	-.167	<b>.486</b>
16	Complex body mannerisms	R, SB, ALRSB	.296	<b>.459</b>
5	Pronoun reversal	C, AL, ALRSB	-.006	<b>.407</b>
18	Unusual attachment to objects	R, SB, ALRSB	.061	<b>.405</b>
6	Neologisms	C, AL, ALRSB	-.005	<b>.350</b>
23	Gestures	C, S, ALRSB	.079	<b>-.282</b>
Eigenvalue			5.68	4.48
% variance			15.8	12.4
Alpha			0.86	0.77

NOTE: S, social domain; C, communication domain; R & SB, stereotyped and repetitive behaviour domain; SC, social-communication domain; ALRSB, abnormal language and repetitive, stereotyped behaviours.

## Exploration of Phase 2 Data

Logistic regression was used to explore the Phase 2 data that had been collected in the study so far. This was used to determine whether the SCQ can effectively predict whether or not children have ASD. The analysis used *ADOS result* as the outcome variable, using participants whose diagnoses were tested and confirmed using the ADOS-2. *SCQ score* was the predictor variable.

Eighteen participants had ADOS assessments. Six of these assessments were performed by doctors working at the developmental clinic at the Red Cross Children's Hospital. All six of the children assessed were found to have ASD. The remaining 12 participants were assessed in Phase 2 of the larger study, as explained in the Methods section. Eight of these 12 participants were found to have ASD.

**Descriptives.** The descriptive characteristics of the sample are displayed in Table 13. Participants in this small group ( $N = 18$ ) ranged in age from 3.01 to 5.81. The mean age was 4.56 years ( $SD = 0.72$ ). Socioeconomic status scores ranged from 47 to 100, with a mean of 72.35 ( $SD = 14.59$ ). Fourteen of the participants were classified as Coloured, two were classified as Black and two were classified as White. Thirteen of the 18 participants were male. Of these 13 males, 10 received a diagnosis of ASD. Of the five female participants, four were found to have ASD. Two participants listed their home language as isiXhosa, one as English and Afrikaans and the remaining 15 participants as English. All but one of the participants filled in the English version of the SCQ, the other filled out the isiXhosa version of the SCQ. This individual's ADOS assessment was conducted by a doctor at the developmental clinic. The SCQ scores in this sample ranged from 2 to 28, with a mean of 16.00 ( $SD = 7.18$ ).

Table 13.

### *Demographic Characteristics of the Sample Broken Down by Language Group*

Variable	Participants ( $N=18$ )
Age (years)	4.56 (0.72)
Age range (years)	3.01-5.81
SES (score out of 100)	72.35 (14.59)
SCQ score	16.00 (7.18)
SCQ score range	2-28
Gender (male: female)	13:5
Race (Black:Coloured:White)	2:14:2
Home language (Eng:Afr:Xho:Eng&Afr)	15:0:2:1

*Note.* For age, SES and SCQ score, means are provided with standard deviations in parentheses.

**Predictive ability of the SCQ.** A logistic regression was run with *ADOS diagnosis* as the outcome variable and *SCQ score* as the predictor variable ( $N = 18$ ). The results of this analysis are shown below in Table 14. *SCQ score* was demonstrated to successfully predict *ADOS result*. The use of *SCQ score* significantly improved the predictive model, with  $\chi^2(1) = 11.189, p = .001$ . Cox and Snell's  $R^2$  of .463 showed a moderate relationship between the two variables, while Nagelkerke's  $R^2$  of .709 indicated a strong predictive relationship between *SCQ score* and *ADOS result*. The process of logistic regression attempts to predict the probability of an outcome, in this case a diagnosis of ASD, using values of the predictor, in this case SCQ scores (Field, 2009). Values are plotted and a probability line is drawn, in which the centre is used as a cut-off point. Overall prediction success of the cut-off point in this logistic regression was 81.3% (50% for non-ASD and 92.9% for ASD). Two of the four participants not diagnosed as ASD were misclassified. One of the fourteen participants diagnosed as ASD was misclassified.

The Wald criterion demonstrated that ASD classification was significantly predicted by SCQ,  $p = .049$ . The Odds Ratio value indicated that when SCQ score is raised by one unit (one point) the odds ratio is 1.557 times as large and therefore classification of ASD is 1.557 times more likely. Overall, this small sample suggests that scores on the SCQ significantly predict ADOS results.

Table 14.

*Summary of Logistic Regression Using SCQ score as a Predictor and ADOS result as the Outcome*

Variable	B (SE)	Wald criterion	p	Odds Ratio	95% CI for Odds Ratio	
					Lower	Upper
Constant	-4.237 (2.539)	2.785				
SCQ score	.443 (.218)	4.121	.049	1.557	1.015	2.386

A more qualitative examination of the data revealed that the four non-ASD cases scored 2, 5, 10 and 10 on the SCQ. ASD cases scored between 6 and 28, however only one ASD case scored below 10, with the other cases scoring 15 and above. Using a cut-off score of 11, 12, 13, 14 or 15, all four non-ASD cases would have been correctly identified and 13 of the 14 ASD cases would have been correctly identified. This indicates that in this analysis of a very small sample ( $N = 18$ ), the commonly recommended cut-off score of 11 (Lee et al., 2007; Snow & Lecavalier, 2008) would have successfully classified 17 of the 18 participants. The one outlier was a 4 year old Coloured male whose home language was English, whose parent filled out an English SCQ and who was assessed in Phase 2 of the larger study. He scored 6 on the SCQ but when assessed with the ADOS was classed as autistic.

## **Discussion**

The aim of the larger study, which has been described in the introduction and methods sections of this thesis, is to examine the SCQ in the Western Cape population in a context similar to which it will be used. This thesis examines the first phase of the larger study: the adaptation, translation and administration of the SCQ. In this section results of the analysis of the completed SCQs are firstly discussed; in particular the demographic profile of the clinic population, the relationship between SCQ scores and demographic variables, and the internal consistency and factor structure of the SCQ. Secondly, observations on issues in administration of the SCQ are examined. Thirdly, strengths and limitations of this study are considered. Lastly, matters that have emerged and could be further explored are put forward.

### **Demographic Profile of the Clinic Population**

The sample was gathered from patients at the Red Cross Children's Hospital's developmental clinic. The Red Cross Children's Hospital is a state-funded hospital which is open to all children in South Africa. State clinics and hospitals are well known for their long waiting lists, due to high demand by the large number of poor South Africans. This is in stark contrast to private health care facilities which have much shorter waiting lists. Low SES individuals are dependent on the state-funded health system as they cannot afford private health care. State clinics are therefore most in need of screening measures as the long waiting lists cause further delay in the diagnostic process. Screening measures have the potential to identify high-risk individuals whose assessments could be prioritised as well as possibly decreasing the number of individuals waiting for assessment by identifying which individuals are not at risk. The state hospitals and clinics are therefore one of the primary environments in which the SCQ could be used. Examining the demographic profile of this sample therefore gives insight into the population in which the SCQ may be used.

Two hundred and twenty eight caregivers completed SCQs. The sample of children about whom the SCQs were answered consisted of children above the age of 3 and below the age of 6 years who attended the developmental clinic at the Red Cross Children's Hospital when data collection occurred on a Monday or Tuesday, between September 2012 and June 2013. All adult caregivers at the clinic were approached and 70% of the caregivers whose children fitted the participant criteria filled in the SCQ.

**Race.** In this sample, 33.8% of the children were Black, 57% were Coloured and 3.5% were White. The Western Cape population is made up of 32.9% Black people, 48.8% Coloured people and 15.7% White people (Statistics South Africa, 2012). This is not proportionally representative of the Western Cape population, with whites under-represented and coloured people over-represented. As discussed above, due to the lack of an isiXhosa translator one day of data collection per week, isiXhosa people are likely to be less represented in this sample than in the clinic population. Despite the fact that the Red Cross Hospital's catchment area includes areas where White people reside, they were under-represented. This is likely due to the fact that many more Coloured and Black people live in poverty and therefore have lower SES than White people (Statistics South Africa, 2012) . Attendance at this clinic is referral based and based on SES. People of low SES are more likely to be in the state hospital system than people who can afford medical aid and private health care. Therefore, although not representative of the entire Western Cape population, the demographics are likely representative of the population using state-funded health care services in this region.

**Gender.** The percentage of females was lower in this sample, 32.9%, than in the Western Cape population where females make up just over 50% of the population (Statistics South Africa, 2012). This may well be due to the fact that ASD is much more common in males than females. It is estimated that males are five times more likely to be diagnosed with ASD than females (Center for Disease Control and Prevention, 2012). Furthermore, gender bias in other disorders may have an effect on the clinic population. For example, Attention-Deficit/Hyperactivity Disorder, stated as the child's diagnosis by a number of parents, is more than twice as common in males than females (Pastor & Reuben, 2008). This unequal prevalence in ASD and ADHD may lead to more boys than girls attending the developmental clinic, which in turn would result in more parents of boys taking part in the study.

In summary, this sample consisted of a majority of Coloured individuals, followed by Black individuals and then by White individuals. More boys than girls were part of the sample. SES was relatively low, with a mean of 69.59 out of a possible 100, with 100 indicating a modest salary, some tertiary education and the possession of basic household items and access to credit. Finally, the most common home language was English, followed by isiXhosa and Afrikaans. The breakdown of demographic variables between the three language version groups is explored below.

### **Demographic Differences in the Samples Completing Each Language Version**

The characteristics of the groups who filled in the English, Afrikaans and isiXhosa versions of the SCQ were examined. The differences between groups in age, gender and SES were assessed in order to determine whether the groups had similar demographic profiles. The more equivalent the three groups are, the more reliable comparisons between these groups would be. Mean age, SES, SCQ score and gender distribution were examined in order to assess the group equivalence. Race was examined in order to establish the spread of this variable. Home language was examined in order to determine whether individuals chose to fill in the forms according to their home language and to determine which language versions were chosen by bilingual individuals and individuals who spoke a language other than English, isiXhosa or Afrikaans.

When comparing the sub-samples who completed each language version of the SCQ there were no significant differences between these groups for the variables of age and gender. This indicates that the distribution of age and gender was equivalent across the groups. Thus group differences on other variables, such as SCQ score or internal reliability, cannot be ascribed to the effects of age or gender.

**Race.** There were significant differences in the race of the participants using the different language versions of the SCQ. The English language version sample consisted of significantly fewer Black people. The isiXhosa language version sample consisted of significantly more Black people and significantly fewer Coloured people. The Afrikaans language version sample consisted of a significantly higher number of Coloured people and a significantly lower number of Black people. This is to be expected, as in South Africa language is largely divided by race. Black South Africans generally speak “African” languages. In the Western Cape the most common of these is isiXhosa. Coloured and White South Africans generally speak English or Afrikaans.

**Home language.** Home language also differed significantly between subsamples, as individuals are likely to choose the language version of the SCQ based on the language they feel most comfortable with. This is generally their home language, but can be the language in which they were schooled.

It was very interesting to find that many of the parents who took part in the study did not speak English as a home language, yet chose to fill in the English version of the SCQ.

This was especially striking in the isiXhosa speaking sample. Twenty of the 59 isiXhosa speakers (34%) chose to fill in the English version, with only 66% filling in the isiXhosa version of the SCQ. Six of the 27 Afrikaans speakers chose to fill in the English version. Two thirds (six out of nine) of the participants who listed both English and Afrikaans as their home languages filled in the English version. All the participants who had a home language other than English, Afrikaans or isiXhosa chose to fill in the English form. This may be due to the fact that, although the researchers were competent in Afrikaans, there was not an Afrikaans first-language speaker to provide assistance to Afrikaans participants and on certain days there was not an isiXhosa first-language speaker to provide assistance to isiXhosa participants. This indicates the importance of providing not only screening measures in the spoken languages of an area, but also providing assistance in these languages.

Alternatively, the choice by these individuals to fill out the form in English - or name English as their home language, in the case of four individuals who filled out Afrikaans forms SCQs - may be due to the fact that in South Africa, speaking English is seen as a sign of educational accomplishment and may be seen as a matter of pride (Gough, 1996).

**Socioeconomic status.** There were also significant differences between language version groups on SES. The mean SES of the English version group was significantly higher than that of the Afrikaans and the isiXhosa version groups. The reasons for this are likely twofold. Firstly, language spoken is partly determined by race. The English group contained all the White individuals in the sample. Due to historical and socio-political factors, White people remain the richest, most well-educated population in South Africa (Statistics South Africa, 2012). This concentration of White individuals in the English group would likely have increased the average SES of this group.

There were, however, Black and Coloured individuals who felt competent enough in English to choose to fill out the English SCQ. These individuals may also have brought up the SES score. The second reason sheds light on this. Due to the system of Bantu Education that was in place during Apartheid, schools designated for White children were supplied with many resources and became strong, good quality institutions. Schools for Black and Coloured people were neglected. This imbalance in resources still affects the school system (Lemon & Battersby-Lennard, 2009; van der Berg, 2007). There are well-established, good quality predominantly English-medium schools in previously White areas and poorer quality English, Afrikaans and isiXhosa schools in previously Coloured and Black areas. Individuals

who have attended an English medium school are therefore likely to have received a better education and therefore have a higher SES due to the opportunities that come with better education. It is possible that the Coloured and Black individuals who chose to fill out English SCQs may have been more comfortable with English because their school was English medium, they had attended an English tertiary education institution or worked in an English environment.

The significant differences across groups on home language, race and SES result in the groups not being equivalent. We therefore cannot say with certainty that any differences between the different language versions of the SCQ are due to the differences in the actual screening measure, as variables such as race or SES may have had an influence on the outcomes.

Nevertheless, despite these differences between the samples in each language version of the SCQ, there were no significant differences between SCQ scores on each of the language versions. This is a very important result, which suggests that the adapted version of the English SCQ and the translated isiXhosa and Afrikaans versions are alike and is a positive indication that these language versions of the SCQ are equivalent across different cultural groups. This positive result indicates that the further testing of these versions of the SCQ should be followed through. The possible effect of the demographic variables on SCQ score is explored below.

### **The Effect of Demographic Variables on SCQ Score**

In order to establish possible relationships between demographic variables and SCQ score and possible biases in the SCQ, correlations between SCQ score and age, SES and gender were explored. A multiple regression was run with SCQ score as an outcome and age, SES, gender, home language and form language as predictors. This served to determine whether the scores on the SCQ are unduly influenced by demographic variables.

In order to evaluate whether there may be biases in the SCQ, the prevalence of ASD in relation to these demographic variables is taken into account. However, due to a lack of research on ASD in Southern Africa, we know little about ASD in the South African population. Autism spectrum disorder has been shown to be genetically based (Muhle, Trentacoste, & Rapin, 2004), and present in various populations across the world (Matson et

al., 2011). We therefore assume that the prevalence of ASD and effect of demographic variables in South Africa is likely to be similar to that found around the world, but the following interpretations are nonetheless offered with caution.

**Age.** In this study it was found that age was not significantly correlated with SCQ score. Furthermore, age was not a significant predictor of SCQ score. This result indicates that SCQ scores are not significantly different across the age range of 3 to below 6 years, despite the developmental changes that occur. This is an encouraging result as we assume that age should not affect diagnosis, due to the fact that ASD is a pervasive disorder that is present throughout the individual's life. Age could, however, affect scores on the SCQ, due to the differences in behaviours across time and due to the appearance of certain behaviours only at later stages in development. Nevertheless age should not affect SCQ score to the degree that sensitivity and specificity rates are affected due to the age of the child.

**Gender.** This study found that gender was negatively correlated to SCQ score, indicating that being a male (labelled 0, female labelled 1) resulted in significantly higher SCQ scores. However gender was not predictive of SCQ score. It is likely that in this sample of children suspected of having developmental disorders, there were more boys than girls with ASD. We expected gender to be correlated with SCQ score. This is due to that fact that males are four times more likely than females to be diagnosed with ASD (Center for Disease Control, 2012). This result is therefore a positive indication that SCQ scores reflect higher prevalence of ASD in males. Nevertheless the current result does not rule out a gender bias in the screening instrument.

Only two of the studies on SCQ discussed in this thesis mentioned gender differences. This is likely due to the very low number of females in many of the validation studies. Berument et al. (1999) reported no significant gender differences in SCQ score. However Gau et al. (2011) found significant differences in SCQ scores between all male and female participants as well as between the participants with ASD. Gau et al. suggested that this may reflect either boys presenting with more severe autistic symptoms than girls or an observation and report bias. This could be further explored in Phase 2 of the larger study.

**Socioeconomic status.** This study found that socioeconomic status was negatively correlated with SCQ score, indicating that individuals with higher SES had lower scores on the SCQ (fewer behaviours associated with ASD). Similarly, when regressed against SCQ score, race, age, form language, home language and gender were not significant predictors.

Only SES was shown to predict SCQ, but explained only a very tiny amount of variance (at most 5.4%). This finding may reflect a bias of the SCQ against low SES individuals. Alternatively, it could reflect a higher prevalence of ASD in low SES individuals in a state-funded developmental clinic.

Previous findings on the relationship between socioeconomic status and prevalence have been mixed. Some studies have found a relationship between ASD and SES while others have reported no relationship. Findings of a relationship are thought by some to be a result of ascertainment, or sampling, bias (Newschaffer et al., 2007). Bhasin and Schendel (2007) and Larsson et al. (2005) both conducted large, population-based studies into the relationship between ASD and SES. Larsson et al., who conducted the study in Denmark, found no relationship. Bhasin and Schendel, who conducted the study in the USA, found a positive relationship between income level and ASD prevalence. Both studies drew attention to the fact that in Denmark health care is free and accessible for the whole population. This suggests that the relationship between SES and ASD may be mediated by accessibility and quality of health care. One such manifestation of the mediation may be a sampling bias that occurs due to the setting in which data collection takes place.

Bhasin and Schendel (2007) suggested that the positive relationship between ASD and SES may be caused by sampling bias, as data was collected in smaller, private clinics. The negative relationship between SES and SCQ score found in this study may have been related to the fact that data collection took place in a state-funded clinic. When faced with a child with very severe symptoms of ASD, middle SES parents may choose to visit private health care facilities in order to get services more quickly. Low SES parents would not be able to afford private health care and therefore more low SES children who would score high on the SCQ would be at the state-funded clinic. Alternatively, low SES parents, given the difficulty of accessing services due to costs in time and transportation, may only take very severe cases for assessment. This predominance of severe cases would raise the average SCQ scores for low SES participants. Nevertheless, this is only speculation on the mediation between SES and the accessibility and quality of health care, we cannot rule out the explanation that the SCQ is biased against children from low SES backgrounds.

Socioeconomic status was significantly related to SCQ score *and* significantly different between the samples of each language version. This suggests that, in this study, comparisons between the three language versions of the SCQ may be inconclusive, due to the

uncontrolled variable of SES. In order to compare these versions, future studies may wish to gather a large sample in each group and select a subset from the groups that are matched on SES.

In sum, this analysis showed both strong and weak characteristics of the SCQ versions in a Western Cape population. SCQ score was significantly higher in males. This is not unusual as there is a higher rate of ASD in males. Another positive sign is that SCQ scores were not affected by age. However, SCQ scores were affected by SES, which may indicate a bias. This suggests a need for further research on the relationship between the SCQ's validity in samples that vary in SES. Below, I discuss the more promising results, on the internal reliability of the SCQ.

### **The Internal Reliability of the SCQ**

In this study, I analysed the reliability of the adapted English SCQ, and the new Afrikaans and isiXhosa versions of the SCQ, in a population of children suspected to have developmental problems. Internal reliability, or consistency, is used to determine the degree to which a measure, in this case the SCQ, assesses a construct, in this case ASD.

Due to limitations in the scoring of the SCQ, two estimations of internal consistency were calculated for each language. The first alpha was calculated using only the children whose parents reported that they could speak in phrases, which allowed analysis for all 39 of the items (including questions involving speech). The second alpha was calculated using all the children sampled for only the last 32 compulsory items, leaving out the first seven items that are only filled in if the child speaks in phrases. The overall internal consistency estimates were 0.82 ( $n = 95$ ) and 0.89 ( $n = 138$ ) for the English version, 0.79 ( $n = 19$ ) and 0.76 ( $n = 31$ ) for the isiXhosa version and 0.71 ( $n = 16$ ) and 0.76 ( $n = 22$ ) for the Afrikaans version.

These are acceptable alphas according to some researchers (e.g. Takavol and Dennick, 2011); however according to others (e.g. Cicchetti, 1994) an alpha above 0.80 is desirable, which only the English version has. This may indicate that the English version is superior to the isiXhosa and Afrikaans translations. However, estimates of internal consistency in the isiXhosa version and certainly in the Afrikaans version are likely to be less reliable due to the small samples sizes (Yurdugul, 2008). Moreover, due to the significant difference in SES, race and home language across the groups, differences in the internal reliability of each

version could be due to differences in the versions or differences in these extraneous variables. Nevertheless, all three language versions of the SCQ demonstrated acceptable levels of internal reliability in a Western Cape clinic population. The fact that the items in the SCQ are suitably interrelated indicates that the SCQ is likely measuring one thing, in this case, behaviours associated with ASD.

Streiner (2013) however warns that scores of 0.90 and above may indicate redundancies in test items, suggesting that the test could be shortened. The English 32-item version had a very high alpha of 0.89, which, according to Streiner, could suggest that certain items may be redundant. Bland and Altman (1997), on the other hand, suggest that for a clinical instrument, an alpha of 0.90 should be a requisite. Although the use of the SCQ is clinical, it is a screening questionnaire rather than a diagnostic tool and therefore an alpha below 0.90 may still be acceptable.

**Internal reliability estimates found in other studies.** The internal reliability values of the English version are compared to previous reliability results. Two studies, Berument et al. (1999) and Snow and Lecavalier (2008) examined the overall internal consistency of the English SCQ. Berument et al. (1999) found the highest alpha, 0.91. They examined a sample of 200 individuals who took part in previous research projects. They ranged in age from 2 to 40 years old. These individuals all had diagnoses. One hundred and sixty had diagnoses of ASD and the remaining 40 had various other diagnoses, as varied as Rett syndrome and conduct disorder. The alpha may be larger than those found in this and other studies due to the fact that the majority of the participants had established diagnoses of ASD, and therefore were familiar with the disorder. Nevertheless, in the current study, the alpha for the full English sample using 32 questions was 0.89, very close to Berument et al.'s findings.

Snow and Lecavalier (2008) examined a sample of 65 children aged 2.5 to just below 6 years who were suspected of having ASD, the majority of which were then found to have ASD. Their population was more similar in age and diagnostic status to the sample in this study than that of Berument et al. (1999). The alpha found by Snow and Lecavalier, 0.81, was very similar to the alpha found in the current study's full item analysis of the English version, 0.82.

The adapted version of the English SCQ examined in the current study thus shows internal reliability estimates similar to those found in other studies. The internal reliability estimates of the isiXhosa and Afrikaans versions of the SCQ are lower than that of the current

study's English version as well as internal reliability estimates found in other studies. However, firm conclusions cannot be drawn from this, due to the small sample sizes of the isiXhosa and Afrikaans SCQs. It is therefore suggested that further research be performed on larger samples of the IsiXhosa and Afrikaans versions of the SCQ.

**Internal reliability estimates of the factors of the SCQ.** These interpretations of the overall internal reliability are limited by the fact that, although this screening device measures the single category of behaviours associated with ASD, it can be broken down into various types of behaviours. It is therefore important to examine the internal consistency of the individual factors that make up the screen.

In the four factor model suggested in this study, two factors had acceptable alphas, while the remaining two factors had low alphas. The factors of *repetitive and stereotyped behaviour* and *social* had good internal reliability, with alphas of 0.74 and 0.79 respectively. The factors of *communication* and *social play* had poor internal reliability, with alphas of 0.68 and 0.62 respectively. In the two factor model suggested in this study, both factors had good internal reliability. *Social-communication* had an alpha of 0.86 and *stereotyped, repetitive behaviour* had an alpha of 0.77. The internal reliability of the two factor model is very strong when compared against the internal reliability estimates found in previous studies.

Berument et al. (1999) reported internal consistencies of 0.91 for social interaction, 0.79 for abnormal language, 0.71 for communication and 0.67 for stereotyped behaviours. Snow and Lecavalier (2008) found lower internal consistencies, likely due to the difference in sample characteristics. They found 0.70 for social interaction, 0.47 for communication and 0.76 for stereotyped behaviours. Gau et al. (2011) examined a Mandarin version of the SCQ in a sample of 922 children, who ranged in age from 2-18 years. Of the 922 children, 682 had been diagnosed with ASD and the remaining 240 were siblings of the children with ASD. Gau et al. found high internal consistencies. Social interaction had an alpha of 0.91, communication had an alpha of 0.73 and stereotyped behaviours had an alpha of 0.84. These studies show varied results, with some factors having high internal reliability and other factors which do not have satisfactory internal reliability. It is important to examine the individual internal consistencies of factor models not only to assess the strength of the model, but to assess the internal reliability of the instrument as a whole and get a clearer picture of the strong and weaker factors. The factors found in this study are discussed below.

## **The Underlying Constructs Measured by the SCQ**

There has been much attention on the constructs underlying autism spectrum disorders (for example Acevedo & Loewenstein, 2007; Gau et al., 2011; Miranda-Linné & Melin, 2002; Posserud, Lundervold, & Gillberg, 2006; Snow, Lecavalier, & Houts, 2009; Stella, Mundy, & Tuchman, 1999; Tadevosyan-Leyfer et al., 2003). The interest in the underlying factors of diagnostic and screening tools is driven by the aim to improve diagnostic and classification systems as well as to provide information for the increasingly popular ASD genetic studies (Snow et al., 2009). An example of improving diagnostic systems can be seen in the recent changes, based on factor analysis, to the widely used Diagnostic and Statistical Manual of Mental Disorders (Volkmar & Reichow, 2013).

In this study, I performed a factor analysis on the English version of the SCQ. This was done, firstly, in order to determine whether the items on the SCQ had been understood and had measured what they set out to assess. This can be seen when items load in a logical fashion, alongside items that measure similar behaviours. Secondly, factor analysis was performed in order to determine whether the SCQ used in a Western Cape population had similar results to the SCQ used in other populations. Three other studies have conducted factor analyses on the SCQ, one set in the UK, one set in China and one set in the USA (Berument et al., 1999; Gau et al, 2011; Magyar et al 2012). Lastly, a factor analysis demonstrated the number of factors measured by the SCQ. There have been various findings on the number of categories of symptoms underlying ASD. The most recent development in this area is the change in the DSM from three to two categories of symptoms. Two of the three DSM-IV diagnostic categories, social interaction and communication, were combined to form one category of social-communication in the DSM-5. The third DSM-IV factor of repetitive, stereotyped behaviour and restricted interests and activities became the second factor of the DSM-5 diagnostic criteria.

The findings of factor analyses in this study pointed to four and two factor models. As mentioned earlier, the SCQ aims to measure the presence of symptoms and behaviours associated with ASD. These can be divided up into various types of symptoms or behaviours. The questions that measure each of these factors should have good internal consistency, as they are measuring the same construct. The four factor model found alphas of 0.79 for social interaction, 0.68 for communication, 0.74 for stereotyped behaviours and 0.62 for social play. The two factor model showed very good alphas. The domain of social-communication had an

alpha of 0.86 and the domain of stereotyped and repetitive behaviour and language had an alpha of 0.77. This demonstrates that the items loading on the factors were highly correlated and the factor was in fact measuring one type of behaviour. The two factor model had better alphas than those in the four factor model and the factor solutions of Berument et al. (1999) and Gau et al. (2011). This lends credence to the strength of the two factor model.

The four and two factor models in the current study contained all but three questions, whose KMO values were too low to include. The low KMO values show a lack of sampling adequacy, suggesting that these items may fit in the factor analysis if more data is gathered. These three items had low communalities. Communality measures the variance shared with the underlying factors (Floyd & Widaman, 1995) and therefore items with low communality do not explain sufficient variance and will not load acceptably highly on the underlying factors. The three questions with unacceptably low KMO values and low communalities covered *conversation*, *inappropriate questions* and *pointing to express interest*. An explanation for low communality may be that the items measure constructs that were not otherwise measured. It is also possible that these items were not understood and were therefore answered randomly; however there are other possible explanations that are more specific to the questions. Before exploring the two potential factor structures of the SCQ, I will briefly discuss the three problematic questions that were excluded.

The SCQ item of *conversation* asks whether the child and caregiver have conversations in which the child builds on what the adult has said. Although this item measures whether the child is sociable enough to partake in conversation (i.e. measuring social reciprocity) it also measures whether the child is mentally or developmentally capable of having a conversation. The item can therefore measure two different constructs; language capability and social reciprocity. This may be a reason for the low KMO and communality values. Additionally, slow development of speech is not pathognomonic to autism and is likely a symptom in many of the children who visit the developmental clinic. The item may therefore only be indicative of ASD in cases where children have the necessary language skills to be able to maintain a conversation, but still do not. This is another possible reason that the communality and KMO values were low.

The item of *pointing to express interest* is one of a couple of items that enquires about pointing behaviour. The fact that only this item had low KMO and communality values indicates that it is the aspect of pointing to items of interest, rather than the ability to point,

that is problematic. This may be because this item can measure more than one type of behaviour. It can measure whether the child is interested in interacting with the caregiver (this is measured in other items in the questionnaire) or it can measure the ability or habit of pointing which is also dealt with in other SCQ items. The ambiguous nature of this item may therefore be a reason for the low KMO and communality values.

The item on inappropriate questions asks whether the child often asks *inappropriate personal questions or makes inappropriate comments*. This item is likely to be affected by culture and customs of the various individuals who filled in the English version. This included Coloured, Black and White individuals who spoke Afrikaans, English, isiXhosa and languages spoken in other parts of Africa. Some cultures may be much stricter regarding personal questions asked by young children and may have stronger views on what is inappropriate. Whether “inappropriate” behaviour is noticed, how common these inappropriate questions are and how this is mediated by age of the child may therefore differ between cultures. This variation between cultures may have rendered the question useless. Another explanation for the low KMO and communality values may be due to the frequency at which most young children make inappropriate remarks or ask inappropriate questions, because they are unaware that their comments are upsetting to others. The fact that this behaviour is common amongst young children and not only present in children with autism may result in lower KMO and communality values than items that are more obviously pathognomonic and less common at this age. This question may be more suitable for identifying older individuals with ASD.

The items that were identified as problematic should be further explored in Phase 2. The predictive power of these items, as well as the possibility of high degrees of similarity between items and possible redundancy of some items should be explored. In Phase 1, these items were not further explored and were deleted from the factor analysis in order to create the best possible factor solution. As discussed, two possible factor solutions were found. The four factor model will be discussed first.

**The four factor model.** Factor analysis of the English SCQ resulted in a scree plot which displayed two possible solutions. One of these solutions consisted of four factors, the same number found in the initial validation study by Berument et al. (1999). The current study’s four factor model was compared to that found by Berument et al. (1999). There were a number of differences in the results obtained in these two studies.

Firstly, although both the current study and the study by Berument et al. (1999) produced four factor solutions, the factors produced did not cover the same areas of behaviour. Berument et al. found factors of *social interaction, communication, stereotyped behaviours* and *abnormal language*. The current study found three of the same factors, namely *social interaction, communication* and *stereotyped behaviour*; however the fourth factor covered items regarding *social play*. A factor similar to social play has been found in a factor analysis of ASD diagnostic tools (van Lang et al., 2006). The three common factors were the three areas used in diagnostic requirements by the DSM-IV. Similar to the current study's factor model, in the DSM-5 abnormal language use falls under the area of stereotyped, repetitive behaviour and restricted interests. Similar to Berument et al.'s factor solution, social play falls under the social part of social-communication in the DSM-5.

The second difference was in the amount of overall variance explained. The variance explained in this study was less than that explained in the study by Berument et al. (1999). The four factors in Berument et al.'s study accounted for 42.5% of the overall variance, whereas the current study explained only 35.1% of the variance.

Thirdly, the common factors of stereotyped behaviour, social interaction and communication not only accounted for different amounts of variance, but their relative strengths were very different between the studies. In the initial validation study the factor of social interaction accounted for the most variance (24.3%), followed by communication (8.7%), abnormal language (5%) and lastly repetitive behaviour (4.5%). In this study repetitive behaviour explained the most variance (10.9%), followed closely by social interaction (10.7%), communication (6.9%) and social play (6.6%).

The differences in the factors and their respective variances between this study and the initial validation study are likely due to the differences in the populations studied. Results of a factor analysis may not be generalised to populations other than the sample used (Field, 2009). Berument et al. (1999) used a sample of children as well as adults who were already diagnosed with various disorders (Chandler, 2007). This study used a sample of only children between the ages of 3 years and 5 years 11 months who were suspected of having developmental disorders, some of whom had diagnoses, while others did not. The fact that all participants in Berument et al.'s sample already had diagnoses may have affected the way in which the questions were answered. This additional knowledge of the diagnosis of the participants as well as the knowledge about ASD gained after diagnosis may have contributed

to the higher percentage of explained variance in the initial validation study. Some signs of autism measured by the SCQ, such as language ability and social interaction problems may become clearer and appear more problematic with increasing age. It is therefore plausible that items that appear odd even at a young age, such as repetitive and stereotyped behaviours, explained more variance within a younger study in which problems of language delay and social interaction were less apparent and worrying. This may have also contributed to the difference in factors found in the two studies.

The item loadings of the initial and current study were considerably different. One exception to this was the factor of social interaction. All ten of the items that loaded on the current study's factor of social interaction loaded on the social interaction factor of Berument et al. (1999). Furthermore, social interaction had a very good alpha of 0.79.

The domain of stereotyped, repetitive behaviour in the current study was an amalgamation of the factors of stereotyped behaviour and abnormal language from the initial validation study, as well as two other items. This fits well with the DSM-5 groupings, in which stereotyped language falls under the restricted, stereotyped and repetitive behaviour domain. The two other items came from the communication domain and the social interaction domain of the initial study. One of these items was *hand and finger mannerisms*. Movements such as flapping or moving fingers in front of the eyes are types of repetitive behaviour commonly found in children with ASD. This item fell under the communication domain in the study by Berument et al. (1999). However it was more fittingly placed in the repetitive, stereotyped behaviour domain in the current study. The item from Berument et al.'s social interaction domain dealt with *gestures*. This may have been confused with the item on *hand mannerisms* and is perhaps why the factor loaded onto the stereotyped, repetitive behaviour factor. Overall the domain showed good internal consistency with an alpha of 0.74.

There were many differences in the communication domain. Only three of the six factors in this domain were shared between the studies. The other three factors loaded on communication in the initial validation study although one of these, an item on *imitation*, was labelled as communicative. The remaining two items were on *offering comfort* and *the quality of social overtures*, both items that were labelled and loaded on social interaction in Berument et al.'s study. This suggests that in this study, the factors of social interaction and communication were interlinked and not truly distinct domains. Internal consistency was not

very strong, with an alpha of only 0.68. This low internal consistency and unusual item loadings suggests that this is a weak domain in the four factor model.

The least internally consistent domain, with an alpha of 0.62, was social play, which was not a factor in the initial validation study. Four of the six items that made up this factor were related to social play. The fifth and sixth were items that asked about the *range* and *appropriateness* of the child's *facial expressions*. These items were labelled as social interaction by Berument et al. (1999) and fell under social interaction and communication in the initial validation study. This suggests that the social interaction and social play domains are not completely distinct. These items may have loaded on social play because they affect social interaction with peers. Nevertheless, this could be said about many of the other items in this questionnaire which did not load onto social play. Due to the overlap in social play and social interaction, two items loaded on both domains. These items were on seeking shared enjoyment and group play. Another item on social chat loaded on both communication and social play.

Four items did not load cleanly onto one factor. The item on *use of neologisms* loaded onto stereotyped, repetitive behaviours, perhaps due to the amount of items on language use in that factor, as well as on social play. This strange loading indicates that the item may not have been very well understood. Similarly, the items on *showing and directing attention* and *offering comfort* loaded on social interaction and communication; *imaginative play* loaded on these two factors as well as on social play.

These loadings, on what appear to be unrelated factors, suggest a weakness in the four factor model. Only two of the four factors, social interaction and repetitive behaviour, had acceptable alphas, above 0.70. The factors of social play and communication did not have acceptable internal reliability. These issues indicate that the four factor model is not acceptable. The two factor model was found to be a better fit.

**The two factor model.** The factor analysis in the current study also suggested a two factor solution. Although the two factor model explained less variance, 28.2%, than the four factor model, 35.1%, the two factor model had higher alphas and the items loaded much more cleanly. It therefore looked like the more suitable solution.

The two factors in this model were *social-communication* and *stereotyped, repetitive behaviour*, which included the use of abnormal language. Both factors had good internal

consistency. Social-communication had an alpha of 0.86 and repetitive, stereotyped behaviours had an alpha of 0.77. Social-communication was now the stronger factor, as opposed to in the four factor model, explaining 15.8% of the variance while repetitive stereotyped behaviour explained 12.44%. This change in factor strength is likely due to the fact that the domains of social interaction, communication and social play, which explained reasonable variance in the four factor model, were combined in this two factor model. The four factor model domains of social interaction and communication were found to be related, as were the domains of social interaction and social play. It is therefore a good indication that the domains were combined in the two factor model to form social-communication.

As mentioned above, the two factor model's item loadings were higher and more cleanly loaded on specific factors than in the four factor model. Nevertheless, one item did not load above 0.30. This item enquired about *gestures*, a lack of which is one of the manifestations associated with ASD. Gestures loaded slightly higher on repetitive behaviours, despite the fact that it was labelled as communication and categorised as social interaction by Berument et al. (1999). The item on gestures also loaded on repetitive behaviours in the four factor model. This could be an indication that the question was misunderstood by some of the participants who may have interpreted it as referring to flapping and other hand mannerisms associated with ASD. Alternatively, the fact that gestures did not load on social-communication could be due to cultural differences in the use of gestures.

The presence of *hand mannerisms* was one of two items that loaded on both factors. The item on hand and finger mannerisms may have been confused with gestures used when communicating. The second item that loaded on both factors was *self-injury*, which was unclassified by the Berument et al. (1999) study. Although not regarded as a core symptom, this behaviour is frequently found in children with ASD (Aman, 2004). It is therefore logical that self-injury does not load clearly on either one of the factors, both core symptoms in ASD.

**The findings in comparison to other studies on the SCQ.** A two factor structure was not found by Berument et al. (1999) or Gau et al. (2011). Berument et al. found a four factor solution, which was discussed in relation to the current study's four factor model. Gau et al. examined the factor structure of the Mandarin version of the SCQ in a sample of Chinese children. They found a three factor solution made up of the three categories used in the DSM-IV, social interaction, communication and repetitive behaviour. This is not only a different result from that of this study, but also different from the initial validation study.

A two factor solution was identified by Magyar et al. (2012), who conducted exploratory and confirmatory factor analyses of the SCQ when assessing its use in a sample of children with Down syndrome (DS). The study was conducted in the USA and examined the SCQ results of just under 200 children between the ages of 4 and 14 years. The two factors found by Magyar et al. were the same as those found in the current study. However the variance explained by Magyar et al., 54.4%, was much higher than that found in the current study, 28.2%. This may be due to the fact that the participants in the study all had a diagnosis of DS, whereas in the current study, there was no diagnosis common to all participants. The answers given may therefore have been more varied.

The factor of social-communication contributed the highest amount of variance in both this current study and that by Magyar et al. (2012), 15.8% and 39.9% respectively. Social-communication accounted for the large majority of variance in the study by Magyar et al., whereas in the current study the spread of variance between the two factors was more even. Restricted, repetitive behaviours accounted for 12.4% of the variance in this study and 14.6% of the variance in the study by Magyar et al. (2012). This difference may again be due to the differences in samples.

There were many similarities between the current study and that by Magyar et al. (2012). Item loadings between the two studies were very similar. Magyar et al. included only items with loadings equal to or above 0.36. Items two to seven, only filled out for children who speak in phrases, were left out. They also left out two items, one on *quality of social overtures* and the other on *imaginative play with peers*, due to low loadings. These are different to the three items not included in the current study. Of the 29 common items between the two studies, 28 of these items loaded on the same factor in each study. The one item that loaded differently between the studies was an item on *hand mannerisms*. This item loaded across both factors on both studies, but loaded more on repetitive, restricted behaviours in the current study and more on social-communication in the study by Magyar et al. (2012). A second item that loaded on both factors in the current study dealt with *self-injury*. This item also loaded on both factors in the study by Magyar et al. (2012).

This agreement between the two studies, despite differences in age, nationality and diagnostic make-up of the samples, shows a robustness of the two factor model underlying the SCQ. The underlying structure of the SCQ should also be similar to that of other instruments measuring and conceptualisations of ASD symptoms. This is explored below.

**The findings in comparison to other ASD literature.** As discussed in the introduction, changes have recently been made to the symptom domains for ASD in the Diagnostic and Statistical Manual of Mental Disorders. The DSM-IV-TR was released in 2000 and specified the criteria of deficits in social interaction, communication and the presence of repetitive, stereotyped and/or restricted behaviours. In the DSM-5, released in the beginning of 2013, the domains of social interaction and communication were amalgamated to form the domain of social-communication. Requirements for a DSM ASD diagnosis are now: deficits in social-communication and the presence of stereotyped, repetitive and/or restricted behaviour which may include restricted, repetitive, stereotyped language use. These new categories are the same as were found in the two factor model. The factor structure found to underlie the SCQ is therefore the same as that used by diagnosticians. This is a very good reflection on the suitability of the SCQ, as it measures the same criteria as are used in diagnosis.

The SCQ's two factor structure is not only the same as the DSM-5 diagnostic requirements for ASD, but has been found in factor analysis of the ADI-R, the diagnostic measure on which the SCQ was based. Frazier, Youngstrom, Kubu, Sinclair and Rezaei (2008) examined the factor structure of the ADI-R in a population of 1 170 children and adults with ASD. They found a two factor solution, which also consisted of social-communication and stereotyped language and restrictive, repetitive and stereotyped behaviour. More recently Snow et al. (2009) examined the underlying factors of the ADI-R in a sample of 1 861 children with ASD between the ages of 4 and 18 years. They found evidence for a three factor solution, as well as for a two factor solution, with the same factors as were found in this study's two factor model. The two factor solution was found to be stable despite the large range in age of the children (Snow et al., 2009), and this is similarly demonstrated by the fact that a two factor structure was supported in a sample of children and adults.

Frazier et al. (2008) drew attention to the need for future studies that must test more heterogeneous samples, in which a greater proportion of the participants do not have ASD. The study by Snow et al. (2009) used a more varied population by including individuals who were suspected of having ASD but did not meet the diagnostic criteria. This study goes a step further by including children suspected of having any developmental disorder.

Although the fact that a two factor model fitted in a variety of different samples demonstrates strength in the two factor hypothesis, there have been other studies that found

different numbers of underlying factors. There is by no means an agreed upon number of factors that underlie the disorder of ASD. Miranda-Linné and Melin (2002) examined the factor structure of the Autism Behaviour Checklist (ABC), a screening device, and found a five factor structure. Stella et al. (1999) found five different factors underlying the Childhood Autism Rating Scale (CARS). These factors were social-communication, emotional reactivity, social orienting, cognitive and behavioural consistency, and odd sensory exploration.

Not only is there a lack of agreement between different screening measures, but there is a lack of agreement between the same screening measures used in differing samples. Contrary to the findings of Frazier et al. (2008) and Snow et al. (2009), Tadevosyan-Leyfer et al. (2003) examined the factor structure of the ADI-R and found six clusters of items, five of which were internally consistent and showed correlations between siblings –hence indicating a possible genetic base. Tadevosyan-Leyfer et al. nevertheless concluded by suggesting a return to two diagnostic criteria, specifically those originally proposed by Kanner. These are deficits in relating to others, both practically and due to lack of interest, and compulsive repetitive, ritualistic behaviour. These two factors are essentially problems in social-communication and repetitive behaviour; however Kanner suggested that deficits in language should not be a diagnostic criterion due to the variability between individuals with ASD (Kanner, 1943).

There have been various findings on the factor structure of the SCQ and of ASD in general. Nevertheless, the factor structure found in the SCQ in this Western Cape sample is very similar to many international findings. Most pleasing is the fact that the factor structure reflects that of the ADI-R, on which the SCQ is based. This shows that the adapted English SCQ is successfully measuring the same factors in a Western Cape population as the ADI-R, the gold standard in ASD diagnostics. Furthermore, the factor structure reflects the changes in the DSM-5, a very widely used diagnostic manual in both research and practice.

### **The Predictive Ability of the SCQ**

In order to be a successful screening instrument, scores on the SCQ should predict ASD risk. A preliminary analysis was performed on the initial Phase 2 data, as well as some of the ADOS assessments conducted in the Red Cross Children's Hospital's developmental

clinic. A logistic regression demonstrated that scores on the SCQ were predictive of the results of the ADOS assessments, with an accuracy of 81.3%. Cut-off scores of 11, 12, 13 and 14 all resulted in correct classification of 17 of the 18 participants. Due to the very small sample size, more detailed estimates of sensitivity and specificity could not be obtained (Obuchowski, Lieber, & Wians, 2004). Receiver operating characteristic curves and the resulting sensitivity and specificity scores will be conducted with the full data from Phase 2 of this study.

These preliminary results must be interpreted with caution, as the sample size was very small and, besides one exception, only the English version of the SCQ was examined. Further investigation in a larger sample size can demonstrate the exact optimum cut-off score for all three language versions. Nevertheless, these results demonstrate that the English version of the SCQ may potentially be a successful screening tool.

### **Issues in Administration of the SCQ**

Many practical problems emerged during the administration of the study. Awareness of these problems is important when planning the implementation of a screening programme.

**Translation.** Translation of the instrument was the first step in the study. South Africa has 11 official languages and often a mix of more than one of these languages is used in certain areas. Across geographical areas language has developed within populations and new words are used, an example of this is the distinct type of Afrikaans spoken in the Western Cape (McCormick, 2006). Additionally, there are many citizens of other African countries whose only knowledge of a South African language is English which they speak as a second or often third language.

It was a struggle to find translators who understood the importance of the fact that the questionnaire needed to be accessible to a wide range of people, from different areas with different levels of education. The first attempts at translations used very formal language, which would not be familiar to many South Africans. The language used had to be simple and understood and used by people with low socioeconomic status, as these make up the majority of the people who attend state-funded hospitals. It was therefore very important to not only have the versions forward and back translated, but to get the input of individuals who work in low SES environments. This consultation resulted in changes to examples and

wording of the translations as well as the original version of the SCQ. These changes (documented in the Methods section) would not have been obvious from simply forward- and back-translating the measure.

**Administration.** Once the translations of the SCQ were deemed satisfactory, the SCQ was administered to parents at the developmental clinic.

The SCQ was designed as a self-report questionnaire, which parents or guardians fill in on their own (Berument et al., 1999). This, however, is impossible in the Western Cape clinic population. Many South Africans receive little and very poor quality educations. As a result there are South African adults who cannot read. Statistics South Africa (2012) found that 25.5% of the adult South African population has a grade seven level of schooling or less. According to Aitchison and Harley (2006), this results in them being functionally illiterate. Of the 25.5% of illiterate individuals, a third of these people have had no schooling whatsoever (Statistics South Africa, 2012). There are also many individuals not from the Western Cape or South Africa who may only speak English as a second or third language and are likely not to be literate in English. During data collection, researchers were available to read the SCQ to people who asked for help.

If this screening measure is brought into Western Cape clinics, it would be necessary to have nurses available to help parents fill in the questionnaire. This study found that many individuals who listed their home languages as isiXhosa and Afrikaans chose to fill in the English version of the SCQ. During administration of the SCQ, on only one of the two days of data collection per week was an isiXhosa first-language speaker available to provide assistance to participants. The other researchers were both English first-language speakers. It is likely that some Afrikaans and isiXhosa participants chose the English version rather than the language version that they were most proficient in, because the assistance provided was by English first-language speakers. Every day of data collection there were parents from all three language groups. It would therefore essential that nurses sufficiently proficient in all three languages be available.

Furthermore, many parents enquired about the meaning of some of the items in the SCQ and needed assistance in order to clearly understand the behaviours that were in question. It is possible that the SCQ assumes pre-existing knowledge that may be more common in parents in more developed countries. In order to assist with administration of the SCQ, nurses would need to clearly understand the behaviours that the questions on the SCQ

ask about. Nurses would therefore need to be informed on symptoms of ASD. Using nurses who understand the questionnaire and can explain questions or read the SCQ to participants will help ensure that questionnaire is better understood and results are therefore more reliable. However, this means implementation of the screen across state clinics is likely to be more difficult, as it will require prior training for staff.

The lack of literacy and of implicit understanding of the SCQ in the Western Cape context indicates that the SCQ would require higher levels of input, training and expertise than in the countries where it is currently used, such as the United Kingdom and Australia. It is therefore important to determine whether the SCQ is a tool that is useful and valuable enough to warrant these extra costs in time, personnel and training.

### **Strengths and Limitations**

The major strength of this study was that we sampled from the population for whom the SCQ was designed. The sample was suitable for a number of reasons discussed in the paragraphs below.

Firstly, we sampled children between the ages of 3 years and 5 years 11 months. The three existing studies that examined the factor structure of the SCQ used samples of children and teenagers (Gau et al., 2011; Magyar et al., 2012) and children and adults (Berument et al., 1999). The SCQ was designed as a screening device and the majority of the individuals who need diagnosis and therefore screening are children. On average, children in the United Kingdom are diagnosed with what was previously autistic disorder at the age of 5 years and what was previously Asperger's syndrome at the age of 11 years (Howlin & Asgharian, 1999). There is therefore little need for a screening device for teenagers or adults. Furthermore, early diagnosis is ideal due to the apparent benefits of early intervention. The greatest need is therefore in children around or below the age of 5 years, as sampled in this study. The subsequent factor analysis was the first of its kind to sample only young children.

Secondly, Berument et al. (1999) and Gau et al. (2011) sampled children and adults who were already diagnosed with ASD. This may have had an effect on the parents' responses on the SCQ due to their familiarity with the disorder of ASD. When screening measures are used in clinics, before diagnosis, parents are likely to know less about ASD than they would after a diagnosis. Many of the individuals in our sample did not yet have a

diagnosis and this made the sample more similar to the population in which the SCQ would be used.

Lastly, children in the sample were suspected of having, or were diagnosed with, developmental problems. In our small pilot study, the English version of the SCQ had excellent specificity and sensitivity when distinguishing children with ASD from typically developing children. However there are behaviours that are not only typical of ASD, but of the other developmental disorders included in the SCQ. Typically developing children are likely to have fewer of these behaviours than children with developmental disorders. Thus, a more challenging task for the SCQ is to distinguish between children with ASD and children with other developmental disorders. The SCQ is therefore put to a more rigorous test in a population of young, developmentally disordered children, some of whom are undiagnosed.

Although there were many advantages to using this unselected series of cases, there were also limitations to this design that would have been controlled in a matched sample. Firstly, the sample was limited to the individuals between the ages of 3 years and 5 years 11 months who came to the developmental clinic over the 10 months from September 2012 to June 2013. The demographic variables were therefore not equally distributed. Furthermore, because most of these participants chose to fill in the English version of the SCQ, the isiXhosa and Afrikaans versions could not be fully explored. Results of internal consistency analyses would have been more reliable had the sub-sample sizes been larger (Yurdugul, 2008). Factor analyses of these language versions would also have been possible with a larger sample sizes.

Secondly, in application, the SCQ would be used on undiagnosed children whose parents generally did not know much about autism. Therefore the ideal participant on which to test the screening measure would be a child who is visiting the clinic for the first time. First time visitors to the clinic would likely have less knowledge of their child's developmental disorder, and thus in the case of children with ASD, have less knowledge of the symptoms of autism. Unfortunately, there were not enough new cases within the year to make up a feasible sample size on which analyses could be performed. The sample was thus made up of participants with and without diagnoses and parents with varying levels of knowledge on autism.

Thirdly, due to the large numbers of people in the clinic at one time, not every SCQ was administered in the same way. There was not enough time, before the appointments with

doctors started, for the researchers to go through the forms and questionnaires with each parent. Thus, parents had the option to either fill it in on their own, or to fill it in with the assistance of a researcher or interpreter. Although researchers encouraged participants to ask if they were not clear about any of the items, there is a possibility that certain parents who chose to fill them in without assistance may have misinterpreted some of the questions.

Fourthly, parents who did not want to take part in the study did not always give a reason. There may well have been a systematic variable, such as disinterest or lack of literacy that was common amongst the declining parents. The sample may therefore be biased in a way that we are not aware of.

A limitation unrelated to sampling was the use of an interpreter, which may have added bias to the data. An isiXhosa translator helped isiXhosa participants to complete the SCQ. English and Afrikaans participants were helped by one of two other researchers. Because the isiXhosa participants were instructed by a different person to the Afrikaans and English populations, there may be differences in their answers, due to the possible differences in instructions and explanations. Although the isiXhosa translator was trained in the administration of the SCQ, it is still possible that different instructions were given

A final limitation was that there have been no SCQ validation studies on a young, developmentally disordered population examining the factor structure of the screening measure. Although this is a strength, in that this study adds new information to the literature, it also limits the study. There are no results of this kind to which the findings in this study can be compared. Berument et al. (1999) examined the factor structure of the SCQ in a sample of children and adults with developmental disorders, who were already diagnosed. Magyar et al. (2012) examined the factor structure of the SCQ; however the sample was made up of 4 to 14 year olds. Gau et al. (2011) examined the factor structure of a modified version of the SCQ; however the sample was made up of 2 to 18 year olds already diagnosed with ASD. These differences in knowledge of autism and age of participants are likely to affect the answers given to items and therefore the factor structure (Miranda-Linné & Melin, 2002; Stella et al., 1999; Tadevosyan-Leyfer et al., 2003).

## **Future Research**

**Phase 2 of the validation study.** As discussed, Phase 2 of this study aims to determine the predictive power of the SCQ and the optimal cut-off points. There have been

many positive results from this analysis, such as general independence of SCQ score, good internal reliability, good fit of a two factor model and support for the changes to the Diagnostic and Statistical Manual of Mental Disorders. The thus far successful results demonstrate the need to carry on investigating the SCQ as a screening measure in a Western Cape population.

A large percentage of children, a quarter of the sample, scored between 11 and 15, the two recommended cut-off points. The choice of a cut-off score between these points will thus have a large effect on the specificity and sensitivity of the measure. It is therefore very important to determine what the optimal cut-off points for the English, Afrikaans and isiXhosa versions of the SCQ would be in a Western Cape population.

The possibility of multicollinearity surfaced in both the analysis of internal consistency of the English version of the SCQ and in the factor analysis. Cronbach's alpha for the English version of the SCQ was 0.89. This high alpha suggests that there may be a level of redundancy in the items (Streiner, 2013). Furthermore, the value of the determinant was below the acceptable value of .0001, also suggesting possible multicollinearity (Field, 2009). Magyar et al. (2012) found that the SCQ had similar levels of specificity and sensitivity when all 39 questions were examined and when examining only the 32 compulsory questions. Additionally, Oosterling et al. (2009) suggested that certain questions in the SCQ should be left out of the screening device. In order to determine whether the SCQ could be shortened, the predictive power of individual items should be assessed in Phase 2. The predictive power and multicollinearity of the items which were not included in the factor analysis should be thoroughly investigated.

The relationship between SES and SCQ score that appeared in this study should be further investigated in Phase 2. Effects of SES on predictive power could establish whether there is a possible bias in the SCQ.

There have been a number of studies which examined the factor structure underlying screening and diagnostic instruments for ASD. One such study by Posserud et al. (2006) examined the factor structure of another screening measure, the Autism Spectrum Screening Questionnaire (ASSQ). They suggested that information from the separate factors could be used in order to improve the positive predictive power of the measure. Using a flat cut-off on a screening measure is the simplest manner of scoring, but bears the risk of sacrificing additional information, such as scores on the different types of behaviour. Using a combination of individual factor cut-offs may provide a more accurate result in screening for

ASD (Posserud et al., 2006). This method of individual cut-offs for different areas of behaviour is used by two of the most highly regarded ASD diagnostic instruments, the ADOS-2 and the ADI-R. In applying this to the SCQ, individual cut-off points for the two factors could be used when scoring is done. Phase 2 of the study should include an investigation into whether using these individual factor cut-off points, rather than one flat cut-off score, improves sensitivity and specificity of the SCQ.

**Further research.** Further data on the Afrikaans and isiXhosa versions of the SCQ should be gathered in order to determine whether the factor structure is similar to that of the English version. In addition to this, tests of internal reliability could be conducted in order to determine whether internal reliability is acceptable and comparable to that of the English version when using larger samples sizes. Individual analysis of items in the three versions of the SCQ should be conducted in order to refine the questionnaire for use in the Western Cape and investigate the problem of multicollinearity, which would mean that more than one item is measuring one aspect of behaviour. Some of these items would therefore be redundant. Due to the fact that the factor structure is influenced by the sample used, a factor analysis on the SCQ using only children with ASD could determine whether the two factor model found in this study is applicable when used with a purely ASD population. This could potentially confirm the strength of the two factor solution.

The larger study, which this project is part of, is assessing the SCQ as a level two screening device. Even if the SCQ is unsuccessful as screening device in developmental clinics, future research may be interested in investigating the SCQ as a level one screening device. The utility of the SCQ in general clinics could be investigated.

Previous validation studies, such as Oosterling et al. (2009, 2010) have shown that the SCQ may not be successful when used on children below the age of 3 years. There is thus a need for a screening measure that can be used on toddlers. South African researchers may be interested in investigating possible screening measures that could be used in a very young South African population.

## Summary and Conclusion

This thesis explored the first phase of a larger study. This study aimed to test the ability of a much needed ASD screening measure, the SCQ in a Western Cape population, through translation administration and analysis. In Phase 1, this was done through testing the internal reliability, the factor structure and the predictive power of the SCQ. The demographic characteristics of the state-funded hospital sample were examined and issues that arose during translation and administration were examined. In addition, preliminary results of a small sample of the Phase 2 data were examined in order to establish the predictive power of the SCQ.

Examination of the demographic profile of the clinic population provided insight into what the target population of the SCQ may look like. Socioeconomic status was low. Most individuals spoke English, isiXhosa or Afrikaans as a home language, with a small percentage speaking a different home language. This demographic profile reinforced the need for all three language versions of the SCQ, as well as the need for questionnaire language that is understood by people of lower socioeconomic status. Some participants chose to answer the SCQ in English rather than in their home language and many participants required help to understand the behaviour that was discussed in the items of the SCQ. This showed a need for assistance, available in all three languages, when administering the SCQ in the state-funded hospital context in the Western Cape.

The examination of the relationship between SCQ score and the demographic variables was followed by ambivalent results. Very positive results for the SCQ were shown in the lack of relationship between age, form language, home language and SCQ score. Gender was related to SCQ score; however this was expected due to the higher prevalence of ASD in males. Of concern, however, was the fact that SCQ score was found to be negatively related to SES. This may be indicative of a bias in the SCQ and should be further investigated.

The analysis of Phase 1 data found that the English version of the SCQ has good internal reliability and the isiXhosa and Afrikaans versions had adequate internal reliability. The internal reliability of the English version of the SCQ was similar to that found in other studies. Furthermore, the factors found in two factor solution of the English version had very good internal reliability. This demonstrated the consistency of items with each factor to measure the behaviours, in this case social-communication behaviours and repetitive, restricted behaviours and language use. This same two factor solution was found in a factor analysis of the SCQ (Magyar et al., 2012) and in factor analyses of the ADI-R, the diagnostic

instrument on which the SCQ was based. Moreover, the solution fits with the current construction of impairments associated with ASD, evidenced by the changes in the DSM-5 (2013). This agreement in factor analyses lends support to the assertion that this adapted version of the English SCQ measures ASD symptoms as they are currently conceptualised. Furthermore, this version of the SCQ, when used in a Western Cape sample, has similar results to the use of the SCQ when used in an American sample, and to the ADI-R, on which the SCQ is based, when used in various samples.

Upon analysis of preliminary data from Phase 2, the SCQ showed good predictive power of ADOS diagnosis. Possible cut-off points of 11, 12, 13 and 14 showed perfect specificity and good sensitivity. Nevertheless, the sample size was very small and this analysis was merely exploratory. It does suggest that the SCQ may have the potential to be a successful screening measure for ASD in state-funded clinics in the Western Cape.

The results of the study so far have shown that the SCQ appears to measure current conceptualisations of ASD. It is therefore recommended that Phase 2 of the study be performed and a full analysis of sensitivity, specificity, predictive power and optimum cut-off scores is conducted.

This thesis outlined the first phase of a very important study, which assesses an ASD screening measure, the SCQ, in a Western Cape population. Screening can result in earlier diagnosis of ASD, which positively affects the individual's prognosis. It is of utmost importance that this screening need is addressed, as the prevalence rate could potentially be as high as 1% of the population, resulting in 10 000 South African children born with ASD each year. This study has taken the first step in adapting and assessing a much-needed screening device for children who may have ASD.

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## APPENDIX A

## Social Communication Questionnaire (English Version)

Name of subject:  
 Date of birth:  
 Date of interview:  
 Chronological age:  
 Gender:

Thank you for taking the time to complete the questionnaire. This questionnaire asks about the behaviour of your child in the last three months. Please answer each question with a *yes* or a *no*. A few questions ask about several similar behaviours; please answer *yes* if any of these behaviours have been present. Even if you are uncertain about whether some behaviours were present or not, please answer *yes* or *no* to every question on the basis of what you think.

1. Is she/he now able to talk using short phrases or sentences?

YES	NO
-----	----

If no skip to question 8.

2. Do you have a to and fro “conversation” with your child that involves taking turns or building on what you have said?

YES	NO
-----	----

3. Does your child ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases that she/he hears other people use or ones that she/he makes up)?

YES	NO
-----	----

4. Does your child ever use socially inappropriate questions or statements? For example, does she/he ever regularly ask personal questions or make personal comments at awkward times?

YES	NO
-----	----

5. Does your child ever get her/his pronouns mixed up (e.g. saying you or she/he for I)?

YES	NO
-----	----

6. Does your child ever use words that she/he seems to have invented or made up her/himself put things in odd, indirect ways (e.g. saying *hot rain* for *steam*)?

YES	NO
-----	----

7. Does your child ever say the same thing over and over in exactly the same way or insist that you say the same thing over and over again?

YES	NO
-----	----

8. Does your child ever have things that she/he seems to have to do in a very particular way or order or routines that she/he insists that you go through?

YES	NO
-----	----

9. Does your child’s facial expression usually match the particular situation, as far as you can tell?

YES	NO
-----	----

10. Does your child ever use your hand like a tool or as if it were a part of her/his own body (e.g. pointing with your finger or putting your hand on a doorknob to get you to open the door)?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
11. Does your child have any interests that take up a lot of her/his time and might seem odd to other people (e.g. robots (traffic lights), taps or counting)?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
12. Does your child ever seem to be more interested in parts of a toy or an object (e.g. spinning the wheels of a car), rather than in using the object as it is meant to be used?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
13. Does your child ever have any special interests that are *unusual* in their intensity, but otherwise appropriate for her/his age and peer group (e.g. trains, dinosaurs, soccer teams, Generations)?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
14. Does your child ever seem to be *unusually* interested in the sight, feel, sound, taste, or smell of things or people?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
15. Does your child ever have any mannerism or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
16. Does your child ever have any unusual movements of her/his whole body, such as spinning or repeatedly bouncing up and down?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
17. Does your child ever injure her/himself deliberately, such as by biting her/his arm or banging her/his head?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
18. Does your child ever have any objects (*other* than a soft toy, teddy bear or blanket that she/he likes) that she/he *has* to carry around?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
19. Does your child have any particular friends or a best friend?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
20. Does your child ever talk with you just to be friendly (rather than to get something)?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|
21. Does your child ever *just* copy you (or other people) or what you are doing (such as sweeping, vacuuming, washing dishes, cleaning the yard, or mending things)?
- |     |    |
|-----|----|
| YES | NO |
|-----|----|

22. Does your child ever just point at things around her/him just to show you things (not because she/he wants them)? 

YES	NO
-----	----
23. Does your child ever use gestures, other than pointing or pulling you hand, to let you know what she/he wants? 

YES	NO
-----	----
24. Does your child nod her/his head to show *yes*? 

YES	NO
-----	----
25. Does your child shake her/his head to show *no*? 

YES	NO
-----	----
26. Does your child usually look at you directly in the face when doing things with you or talking with you? 

YES	NO
-----	----
27. Does your child smile back if someone smiles at her/him? 

YES	NO
-----	----
28. Does your child ever show you things that interest him/her to catch your attention? 

YES	NO
-----	----
29. Does your child ever offer to share things other than food with you? 

YES	NO
-----	----
30. Does your child ever seem to want you to join in her/his enjoyment of something? 

YES	NO
-----	----
31. Does your child ever try to comfort you if you are sad or hurt? 

YES	NO
-----	----
32. If your child wants something or wants help, does she/he look at you and use gestures with sounds or words to get your attention? 

YES	NO
-----	----
33. Does your child show a normal range of facial expressions? 

YES	NO
-----	----
34. Does your child ever just join in and try to copy the actions in social games, such as *The Mulberry Bush*, *Ring-a-Rosy*, *Wheels on the Bus* or *London Bridge is Falling Down*, *On-On* or *clapping games*? 

YES	NO
-----	----
35. Does your child play any pretend or make-believe games (like playing house)? 

YES	NO
-----	----
36. Does your child seem interested in other children of about the same age that she/he does not know? 

YES	NO
-----	----

37. Does your child react well when another child approaches her/him?

YES	NO
-----	----

38. If you come into a room and start talking to your child without calling her/his name, does she/he usually look up and pay attention to you?

YES	NO
-----	----

39. Does your child ever play pretend games with another child in such a way that you can tell that each child understands what the other is pretending?

YES	NO
-----	----

40. Does your child play nicely in group games with other children, such as hide-and-seek or ball games?

YES	NO
-----	----

## APPENDIX B

## Social Communication Questionnaire (Afrikaans Version)

Deelnemer (kind) se naam:

Geboortedatum:

Datum van onderhoud:

Ouderdom:

Geslag:

Dankie dat u hierdie vraelys invul. Die vraelys vra oor u kind se gedrag gedurende die laaste drie maande. Antwoord asseblief elke vraag met “ja” of “nee”. Daar is 'n paar vrae wat oor dieselfde soort gedrag vra; antwoord asseblief *ja* indien u kind enige van hierdie gedrag getoon het. Antwoord asseblief “ja” of “nee” op elke vraag, selfs al is u nie seker of u die gedrag gesien het nie.

1. Kan jou kind nou in kort uitdrukkings of sinne praat?

JA	NEE
----	-----

Indien nie, gaan na vraag 8.

2. Het julle 'n heen-en-weer-“gesprek” met mekaar waarin julle beurte neem en aanlas op wat die ander gesê het?

JA	NEE
----	-----

3. Gebruik jou kind ooit vreemde uitdrukkings of sê hy/sy dieselfde ding oor en oor op amper presies dieselfde manier (uitdrukkings wat hy/sy ander mense hoor gebruik of wat hy/sy opmaak)?

JA	NEE
----	-----

4. Gebruik jou kind ooit ongeskikte vrae of stellings? Vra jou kind byvoorbeeld gereeld persoonlike vrae of maak hy/sy persoonlike opmerkings op ongemaklike tye?

JA	NEE
----	-----

5. Raak jou kind ooit deurmekaar met voornaamwoorde (sê bv. jy of hy/sy vir ek)?

JA	NEE
----	-----

6. Gebruik jou kind ooit woorde wat hy/sy blykbaar self geskep of opgemaak het of stel hy/sy dinge op vreemde, indirekte maniere (bv. om *warm reën* vir *stoom* te sê)?

JA	NEE
----	-----

7. Sê jou kind ooit dieselfde ding oor en oor op presies dieselfde manier of dring daarop aan dat jy dieselfde ding oor en oor moet sê?

JA	NEE
----	-----

8. Is daar ooit dinge wat jou kind op 'n baie spesifieke manier of volgorde moet doen of roetines wat hy/sy aandrings dat julle moet volg?

JA	NEE
----	-----

9. Pas jou kind se gesigsuitdrukking gewoonlik by die spesifieke situasie?

JA	NEE
----	-----

10. Gebruik jou kind ooit jou hand as 'n instrument (“tool”) of asof dit deel van haar/sy eie liggaam is (bv. wys met jou vinger of plaas jou hand op 'n handvatsel om jou die deur te laat oopmaak)?

JA	NEE
----	-----

11. Is daar enige belangstellings wat jou kind aanhoudend besig hou en vir ander mense vreemd kan lyk (bv. verkeersligte, krane of aanhoudend tel)?

JA	NEE
----	-----

12. Lyk dit ooit asof jou kind meer in dele van 'n speelding of voorwerp belangstel (bv. om die wiele van 'n karretjie te draai), eerder as om die ding te gebruik waarvoor dit bedoel is? 

JA	NEE
----	-----
13. Het jou kind ooit spesiale belangstellings wat *buitengewoon* sterk is maar wat andersins aanvaarbaar is vir haar/sy ouderdom en vriendekring (bv. treine, sokkerspanne, dinosourusse, of *7de Laan*)? 

JA	NEE
----	-----
14. Lyk dit ooit asof jou kind *besonders* baie belangstel in die voorkoms, geluid, gevoel, smaak of reuk van voorwerpe of mense? 

JA	NEE
----	-----
15. Het jou kind enige snaakse handgebare of vreemde maniere om haar/sy hande of vingers te beweeg, soos om haar/sy vingers voor haar/sy oë op en af of heen en weer te beweeg? 

JA	NEE
----	-----
16. Beweeg jou kind ooit haar/sy hele liggaam op ongewone maniere, soos om in die rondte te draai of herhaaldelik op en af te wip? 

JA	NEE
----	-----
17. Maak jou kind haar /hom ooit met opset seer, soos deur haar/sy arm te byt of haar/sy kop te stamp? 

JA	NEE
----	-----
18. Is daar enige goedjies (*behalwe* 'n sagte speelding, teddiebeer of kombesie) wat jou kind *moet* rondra? 

JA	NEE
----	-----
19. Het jou kind spesifieke pêle of 'n beste vriend? 

JA	NEE
----	-----
20. Praat jou kind ooit met jou net om vriendelik te wees (nie net om iets te kry nie)? 

JA	NEE
----	-----
21. Aap jou kind jou (of ander mense) of wat julle doen ooit *vanself* na (soos stofsuig, skottelgoedwas, vee of goed regmaak)? 

JA	NEE
----	-----
22. Wys jou kind ooit vanself na goed om hom/haar net om dit vir jou te wys (nie omdat hy/sy dit wil hê nie)? 

JA	NEE
----	-----
23. Gebruik jou kind ooit gebare anders as om te na iets te wys of jou hand te trek, om jou te laat verstaan wat sy/hy wil hê? 

JA	NEE
----	-----
24. Knik jou kind haar/sy kop om *ja* te sê? 

JA	NEE
----	-----
25. Skud jou kind haar/sy kop om *nee* te sê? 

JA	NEE
----	-----
26. Kyk jou kind reguit na jou gesig wanneer hy/sy dinge saam met jou doen of met jou praat? 

JA	NEE
----	-----
27. Glimlag jou kind terug as iemand vir hom/haar glimlag? 

JA	NEE
----	-----
28. Wys jou kind ooit vir jou dinge waarin hy/sy belangstel om jou aandag te trek? 

JA	NEE
----	-----

29. Sal jou kind soms aanbied om goed met jou tel deel (behalwe kos)?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
30. Lyk dit ooit asof jou kind wil hê jy moet iets saam met hom/haar geniet?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
31. Probeer jou kind ooit om jou te troos wanneer jy hartseer is of seergekry het?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
32. As jou kind iets wil hê of hulp nodig het, kyk hy/sy na jou en gebruik hy/sy gebare met klanke of woorde om jou aandag te kry?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
33. Wys jou kind verskeie gesigsuitdrukkings (bv. hartseer, gelukkig, bang, kwaad, ensovoorts)?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
34. Neem jou kind ooit vanself deel aan en probeer hy/sy om die aksies in groep-speletjies soos *vroteier* of *aan-aan* na te maak?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
35. Speel jou kind verbeeldingspeletjies (soos pophuis speel)?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
36. Lyk dit asof jou kind belangstel in ander kinders van min of meer dieselfde ouderdom wat hy/sy nie ken nie?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
37. Reageer jou kind goed wanneer 'n ander kind hom/haar nader?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
38. As jy in 'n kamer ingaan en met jou kind begin praat sonder om haar/sy naam te noem, kyk hy/sy gewoonlik op en luister hy/sy na jou?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
39. Speel jou kind ooit verbeeldingspeletjies met 'n ander kind sodat jy kan sien altwee verstaan wat die ander een opmaak?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|
40. Speel jou kind lekker in 'n groep saam met ander kinders, soos wegkruipertjie of balspele?
- |    |     |
|----|-----|
| JA | NEE |
|----|-----|

## APPENDIX C

## Social Communication Questionnaire (isiXhosa Version)

Igama lakhe:

Nomhla wokuzalwa kwakhe:

Nomhla wovavanyo/ udliwano ndlebe:

Ukulandelelana kweminyaka:

Isini sakhe:

Enkosi ngokuthatha ixesha uphendule lemibuzo. Lemibuzo ibuza kakhulu ngendlela ebeziphethe ngayo umntwana kwezinyanga zintathu zidlulileyo. Nceda uphendule umbuzo ngamnye ngempendulo engu ewe okanye hayi. Imibuzo emininzi ibuza indlela eyeleleneyo ebeziphethe ngayo okanye (ebeyiyo) nceda uphendule u ewe okanye hayi kuba ibike yakho lendlela yokuziphatha. Nangona ukungaqinisekanga nisekanga ukuba lendlela yokuziphatha ibikhe yakho akanye ingekho nceda uphendule ewe okanye hayi kuyo yonke imibuzo ngendlela ocinga ngayo wena.

1. Uyakwazi ukuthetha ngoku esebanzisa amagama amafutshane okanye uthetha kancinci umve ukuba uthini (umzekelo ndifuna ukutya, ndifuna ukuchama)? 

EWE	HAYI
-----	------
2. Uyakawazi ukuncokola naye, naye ancokole nawe apho ninikana amathuba okanye akwazi ukongeza kulencoko yakho? 

EWE	HAYI
-----	------
3. Ingaba umntwana wakho ukhe asebenzise amagama angaqhelekanga okanye athethe into enye okokoko ngedlela enye(okanye into ayive kwabanye abantu beyithetha okanye azenzele yona)? 

EWE	HAYI
-----	------
4. Wakhe/okanye ukhe asebenzise amagama angafanelekanga okanye imibuzo ekwenza iintloni? umzekelo ukhe asoloko ekubuza imibuzo ngaye amaxesha onke okanye athetha apho kungamelanga athethe khona? 

EWE	HAYI
-----	------
5. Ingaba ukhe abhidanise ukubiza izinto(umzekelo athi mna xa efuna ukuthi wena, yena xa efuna ukuthi mna)? 

EWE	HAYI
-----	------
6. Ukhe/wakhe wasebenzisa lamagama abonakala ngathi uzenzele/uziqambele yena xa efuna ukubeka izinto ngokufanelekanga, ngokungathi uyazihlonipha angazibizi ngamagama azo (umzekelo athi imvula eshushu xa efuna ukhuthi umphunga/inja ebomvu) 

EWE	HAYI
-----	------
7. Ingaba ukhe athethe into enye okokoko ngendlela efana ngqo okanye anyanzelise ukuba mawuthethe ngendlela enye efanayo uyiphinda phinde? 

EWE	HAYI
-----	------
8. Ingaba unezinto afuna ukuba mazenziwe ngendlela ethile okanye ngokwesiqhelo/ okanye anyanzelise ukuba uzenze? 

EWE	HAYI
-----	------
9. Ingaba ubuso bakhe buqhelekile abutshintshi kwimeko ezithile, ngendlela obona ngayo wena? Bubonaka ngendlela eqhelekileyo. 

EWE	HAYI
-----	------

10. Ingaba ukhe asabenzise isandla sakho nje ngesixhobo sokusebenza ngathi siyinxalenye yomzimba wakhe? (umzekelo akhombe umnwe wakho okanye awofake emngxunyeni wesitsixo secango ukulivula)?

EWE	HAYI
-----	------

11. Ingaba ikhona into anomdla kuyo kakhulu, ixesha elininzi ebonakala ingaqhelekanga kwabanye abantu (umzekelo izibane ze robots endleleni, itepu okanye ukubala)?

EWE	HAYI
-----	------

12. Ingaba ubonakalisa umdla omkhulu kumalungu ethoyi okanye nantoni na? (umzekelo ukujikelezisa amavili emoto), endaweni yokuba ayisebenzise ngelendlela/ngohlobo yayenzelwe ukuba mayisebenze ngalo?

EWE	HAYI
-----	------

13. Ingaba ukhe abonakalise enomdla owodwa ongaqhelekanga angahoyi nokuba ungampazamisa, kodwa yindlela efanelekileyo kwiminyaka yakhe nakontanga bakhe (umzekelo itrain/uloliwe, wazi nge Pirates ne Chiefs, no Generations)?

EWE	HAYI
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14. Ingaba ubonakalisa umndla ongaqhelekanga kwizinto azibonayo, nendlela azivangayo, ukungcamla okanye ivumba lezinto okanye abantu?

EWE	HAYI
-----	------

15. Ingaba unedlala enza ngayo izinto ongaqhelekanga okanye indlela aphakamisa ngayo izandla okanye iminwe, enjengokuzi bhabhazelisa okanye ajingise iminwe yakhe phambi kwamehlo akhe?

EWE	HAYI
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16. Ingaba unendlela ongaqhelekanga yoku hambisa okanye ukusebenzisa umzimba wakhe wonke, enjengoku wujikelezisa okanye uphinda phinda axhuma xhume phantsi naphezulu?

EWE	HAYI
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17. Ingaba ukhe /wakhe wazonzakalisa ngamabomi, izinto ezinje ngokuziluma ingalo okanye azibathekise ngentloko?

EWE	HAYI
-----	------

18. Ingaba wakhe /unayo into ethambileyo (ngaphandle kwethoyi ethambileyo enjenge bere okanye ingubo ayithathndayo yakhe) asoloko eyiphethe?

EWE	HAYI
-----	------

19. Ingaba unabo abahlobo okanye omhlobo wakhe osenyongweni (amthanda kakukhulu kunabanye)?

EWE	HAYI
-----	------

20. Ingaba ukhe athethe nawe nje ukuncokola nawe okanye akoncokolele nje (ngaphandle kwexesha apho afuna into kuwe)?

EWE	HAYI
-----	------

21. Ingaba ukhe nje akulinganise into oyenzayo( okanye abanye abantu) okanye lonto oyenzayo( izinto ezinje ngokutshayela ukuvatyhuma, ukuhlamba izitya, ukuklina iyard okanye ukulungisa izinto)?

EWE	HAYI
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22. Ukhe avele nje akhombe izinto ezimqongileyo okanye avele nje akubonise izinto? (engakubonisele kuba ezifuna)

EWE	HAYI
-----	------

23. Ukhe asebenzise amanye amalungu omzimba wakhe, ngaphandle kokhomba okanye akutsale ngesandla, xa efuna ukukuxelela ukuba ufana ntoni?

EWE	HAYI
-----	------

24. Ingaba unqwala intloko yakhe xa ekubonisa ukuba uthi ewe?

EWE	HAYI
-----	------

25. Ingaba ushukumisa intloko yakhe xa ukukubonisa ukuba uthi hayi? 

EWE	HAYI
-----	------
26. Ingaba usoloko ekujonge ngqo ebusweni xa esenza izinto nawe okanye xa ethetha nawe? 

EWE	HAYI
-----	------
27. Ingaba ayamncumela umntu xa encuma naye? 

EWE	HAYI
-----	------
28. Ukhe akubonise izinto anomdla kuzo xa efuna ukuba wena umhoye? 

EWE	HAYI
-----	------
29. Ukhe afune ukunikela okanye ukwabelana ngezinto ngaphandle kokutya? 

EWE	HAYI
-----	------
30. Ingaba ukhe afune ukuba ubenaye xa kukho into ayonwabeleyo/uvuyisane naye? 

EWE	HAYI
-----	------
31. Ukhe azame ukukuthuzela xa uqumbile okanye ukhathazekile okanye isiva kabuhlungu? 

EWE	HAYI
-----	------
32. Ukuba ufuna into okanye ufuna uncedo, ingaba ujongka kuwe okanye uye asebenzise izandla okanye naliphi na ilungu lomzimba okanye ingxolo okanye igama ukufana ukuba umhoye? 

EWE	HAYI
-----	------
33. Ingaba ubonisa intlobo ntlobo zobuso eziqhelekileyo(ingaba indlela asebenzisa ngayo ubuso bakhe iqhelekile)? 

EWE	HAYI
-----	------
34. Ukhe nje azame ukukulinganisa xa usenza imidlalo eqhelekileyo edlalwayo ngabanye abantwana, efuna ukuba akulinganise, imidlalo enje ngo ndize ,cekwa (on on), black toti,opikipiki magelana,ibhola, amapeka, itola,ugqhaphu iznto ezinje ngezo? 

EWE	HAYI
-----	------
35. Ukhe adlale lomdlalo wokuzenzisa okanye wenza umntu akholelwe ukuba uyilonto (ipopiheyisi)? 

EWE	HAYI
-----	------
36. Ukhe abenomdla kubantwana abalingana naye angabaziyo? 

EWE	HAYI
-----	------
37. Uye aphaatheke kakuhle xa omnye umntwana angamaziyo esiza kuye? 

EWE	HAYI
-----	------
38. Ukuba ungena endlini okanye ekamereni ubesewuthetha ungakhange ubize igama lakhe, ingaba uye akujonge abenomdla kuwe akuhoye? 

EWE	HAYI
-----	------
39. Ukhe / wakhe wawudlala umdlalo wokuzenzisa ngezinto nabanye abantwanakangokuba uqonde ukuba bayavana okanye bayaqondana/bayavana ukuba omnye uzenzisa ngantoni? 

EWE	HAYI
-----	------
40. Uyakwazi ukudlala imidlalo apho adlala khona nababanye abantwana, enje ngo ndize, cekwa,black toti, amapeka, itola,ugqhaphu , u on on, isoka? 

EWE	HAYI
-----	------

Appendix D  
Hospital Approval from Red Cross Children's Hospital



Dr TA Blake  
Manager, Medical Services  
Email: thomas.blake@gwc.gov.za  
Tel: +27 21 658 5700 Fax: +27 21 658 5144  
28 AUGUST 2012

**DR S MALCOLM-SMITH**

Dear Dr Malcolm-Smith,

Approval to do research at the Red Cross War Memorial Children's Hospital is hereby granted.

Kindly note that after the conclusion of the study, the hospital should be presented with the results.

Yours faithfully,

signature removed

**Dr Thomas Blake**  
**Chair: Hospital Research Review Committee**

## APPENDIX E

## Ethics Approval from the Faculty of Health Sciences, UCT

HREC Ref 365/2012 - 7Aug2012

UNIVERSITY OF CAPE TOWN



Faculty of Health Sciences  
Human Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021] 406 6411  
e-mail: shuretta.thomas@uct.ac.za

07 August 2012

**HREC REF: 365/2012**

**Dr S Malcolm-Smith**  
Psychology  
Room 4.24  
Humanities Graduate Building  
Upper Campus

Dear Dr Malcolm-Smith

**PROJECT TITLE: EARLY SCREENING FOR AUTISM SPECTRUM DISORDERS IN A WESTERN CAPE COMMUNITY SETTING**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year till the 15<sup>th</sup> August 2013**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.  
(Forms can be found on our website: [www.health.uct.ac.za/research/humanethics/forms](http://www.health.uct.ac.za/research/humanethics/forms))

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

**Please quote the HREC. REF in all your correspondence.**

Yours sincerely

signature removed

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN ETHICS**  
Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938  
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

c:\hrc\...

HREC Ref 355/2012 - 2Aug2012

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CMP/ICH/135/95) and FDA Code Federal Regulation Part 312.50, 56 and 312.

## Appendix F

### Information Sheet on Autism Spectrum Disorders

#### WHAT IS AUTISM?

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder. A lot of research is being done to try find the cause of autism, but as yet we don't have definite answers. We do know that autism is no-one's fault. It is NOT a psychological or emotional disorder. It is NOT the result of bad parenting, and children with ASD do NOT choose to misbehave. Misbehaviours are often reactions to the environment and are expressions of the difficulties these children experience. The incidence of Autism Spectrum Disorders (ASD) seems to be on the increase worldwide with international statistics implying that it now affects 1 per 100 children under the age of 8 years. ASD affects 4 times as many boys than girls. It is important to remember that there is NO social disgrace in having a child with autism or any other form of a disability.

#### WHAT ARE THE SYMPTOMS?

ALL people with ASD are affected to different degrees, by problems in 3 main areas: language and communication, social interaction and repetitive/restricted behaviour. Problems with language include slow development of speech and language. Examples of problems with social interaction include always playing alone, seeming not to care about others, finding it difficult to read body language or understand the need for politeness. Examples of repetitive/restricted behaviours are playing endlessly and unusually with one toy only, or having special interests that become obsessions.

How severe these symptoms are can be very different from one person with ASD to another. This is why the idea of a spectrum in autism was created. People with ASD lie on a spectrum, differing in the types of symptoms they have and how severe these are.

#### ARE THERE INTERVENTIONS?

The earlier your child starts therapies and interventions, the better their outcome is likely to be. There are various therapies that can help your child. Examples are occupational therapy, speech therapy, the Early Start Denver Model and applied behaviour analysis. For a list of services and practitioners visit [www.autismsouthafrica.org](http://www.autismsouthafrica.org) or phone Autism Western Cape.

#### ARE THERE SCHOOLS AVAILABLE?

These are some schools that cater for children on the spectrum:

Alpha School, Woodstock, 021-447-1212

Vera School, Rondebosch East, 021-696-2844

Vista Nova School, Rondebosch, 021-689-5323

For a longer list of schools please visit [www.autismsouthafrica.org](http://www.autismsouthafrica.org).

#### WHERE CAN I GET SUPPORT?

Remember you are not alone. There are many other parents who have gone through, or are going through what you are experiencing.

Please contact Autism South Africa or Autism Western Cape, as they can offer you support, information and guidance. They can also put you touch in parents, schools, regional bodies, support networks and professionals in your area. Even though you may feel shy or nervous, it really does help to speak to other parents of children with autism. You can share your feelings, swap ideas and form new friendships for both you and your child.

Autism South Africa: call 011 484 9909 / 9923, e-mail [info@autismsouthafrica.org](mailto:info@autismsouthafrica.org) or visit [www.autismsouthafrica.org](http://www.autismsouthafrica.org)

Autism Western Cape: call 021 557 3573

## Appendix G

## Phase 1 Parental Informed Consent Form (English Version)

Dear Parent(s),

We are approaching because you are bringing your child to the Red Cross Hospital's developmental clinic. We are conducting a study to see if short questionnaires can be used to screen for developmental disorders. We are asking many different parents to be in our study because we want to see how the questionnaire works on children with different kinds of problems.

If you agree to take part in our study, you will be asked to give us some information about yourself and your family; and to fill in a questionnaire that asks questions about your child's behaviour. This will take about 30 minutes, and you can do it while you wait. Please answer all questions as accurately and honestly as possible.

You do not have to agree to take part in the study. If you agree and then change your mind, you can stop at any time. There will be no negative effects for you or your child. Your decision will not affect the services you receive at the clinic. Neither you nor your child will be discriminated against, lose any privileges, or be treated negatively by the hospital.

We understand that some of the questions asked may be sensitive, but all information will be kept strictly confidential. Only members of the research team will be able to see the information. When we publish this research, you will not be identified in any way.

This study has been explained to me and all my questions have been answered. I consent to participate in this study.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

This study was explained by:

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix H

## Phase 1 Parental Informed Consent Form (Afrikaans Version)

Geagte Ouer(s),

Ons kontak u omdat u kind 'n pasiënt by die Rooikruis Kinderhospitaal se pediatriese kliniek sal wees. Ons is besig met 'n studie om te sien of kort vraelyste gebruik kan word om ontwikkelingsafwykings te vind. Ons vra verskillende ouers om in ons studie te wees, want ons wil sien hoe werk die vraelys op kinders met verskillende soorte probleme. Indien u aan die studie deelneem sal u gevra word om basiese inligting oor u en u familie te verskaf en om 'n siftingsvraelys te voltooi wat spesifieke vrae oor u kind se gedrag vra. Die onderhoud sal ongeveer 30 minute duur.

U mag besluit om nie aan die studie deel te neem nie, of om later uit die studie te onttrek. Daar sal geen slegte gevolge vir u of u kind wees nie. Deelname of onttrekking uit die studie sal geensins die dienste wat u by die kliniek ontvang aantast nie. Ons verstaan dat sekere inligting sensitief mag wees, maar wees asseblief verseker dat alle inligting streng privaat gehou sal word.

Ons wil graag hê dat 'n verskeidenheid kinders aan die studie deelneem, so antwoord asseblief alle vrae so noukeurig en eerlik as moontlik. Daar sal geen diskriminasie teen u of u kind wees as gevolg van die inligting wat u verskaf nie. U sal ook nie enige voorregte by die hospitaal verloor of sleg behandel word as gevolg van die verskafte inligting nie. Indien die resultate van die studie gepubliseer word, sal nóg u nóg u kind enigsins in die publikasie geïdentifiseer word nie.

Die studie is aan my verduidelik en al my vrae is beantwoord.

Naam: \_\_\_\_\_ Handtekening: \_\_\_\_\_ Datum: \_\_\_\_\_

Die studie is verduidelik deur:

Naam: \_\_\_\_\_ Handtekening: \_\_\_\_\_ Datum: \_\_\_\_\_

## Appendix I

## Phase 1 Parental Informed Consent Form (isiXhosa Version)

Bazali abathandekayo

Siza kuwe kuba uzisa umntwana wakho kwiKliniki yokukhula yaseRed Cross. Senza uphando/isifundo ukubona ukuba imibuzo emifutshane ingasetyenziswa na ukubona ingxaki ekukhuleni kwabantwana. Sicela abazali abaninzi abahlukaneyo ukuba babekoluphando okanye isifundo kuba sifuna ukubona lemibuzo isebenza njani kubantwana abanengxaki ezahlukeneyo.

Ukuba uthatha inxaxheba koluphando, uzakucelwa ukuba usinike ulwazi oluncinane ngawe nosapho lwakho, uze uzalalise iphepha lemibuzo, ekubuza imibuzo ethe ngqo ngomntwana nangedlela aziphatha ngayo/nayiyo umntwana wakho. Sizakucela uphendule imibuzo enamani kunye nemibuzo ngedlela aziphatha ngayo umntwana wakho. Sifuna ukubona intlobo ngentlobo zabantwana bethatha indima koluphando, siyakucela ke uphendule yonke imibuzo kakuhle nangokunyanisekileyo kangangoko unako.

Ungazirhoxisa koluphando nanina ufuna. Lonto ayisoze ikwenze ukuba uphatheke kakubi wena okanye umntwana apha ekliniki/esibhedlele. Siyayiqonda ukuba oluphando lungangakuphati kakuhle, siyakuqinisekisa ukuba lonke ulwazi luzakugcinwa emfihlweni. Wena okanye umntwana soze niphatheke kakubi, okanye ungawafumani amalungelo akho, okanye ungaphathwa kakuhle sisibhedlele ngenxa yolwazi abalinikiweyo.

Lonke olu lwazi nenckukacha zizakuba yinxalenye yolwazi ligcinwe. Yonke into esiyifumaneyo ngomntwana izakudityaniswa nengama lakho nelomntwana nenombolo yakho yefowuni. Ngamalungu oluphando odwa azakubanemvume yokubona olulwazi. Ukuba iziphumo zoluphando luthe lapapashwa igama lakho nelomntwana ngeze lichazwe nangeyiphi na indlela. Akukho bungozi bungakwehlela ngothatha inxaxheba koluphando.

Igama: \_\_\_\_\_ isiginitsa: \_\_\_\_\_ usuku: \_\_\_\_\_

Consent was obtained by:

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix J

## Phase 1 Consent to be Contacted (English Version)

We might like to contact you to ask if you would take part in future research relating to child development.

Agreeing now that we can contact you DOES NOT mean you consent to take part in the research. If we do contact you in future, you can choose not to participate. You do not have to take part in the future if you fill in your details now – you can decide if you want to take part in the new research when you hear about it. No matter what you decide there will be no negative effects for you or your child. Your decision will not affect the services you receive at the clinic.

I consent to be contacted about future research.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Your child's name: \_\_\_\_\_

Contact numbers (please give at least two): \_\_\_\_\_

Consent was obtained by:

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

If you have any queries or concerns please feel free to contact

Susan Malcolm-Smith on 021 650 4605

Kirsty Donald at [Kirsty.Donald@uct.ac.za](mailto:Kirsty.Donald@uct.ac.za) or

UCT Faculty of Health Sciences Research Ethics Committee on 021 406 6338.

Thank you for your help!

Autism Research Group

Department of Psychology, University of Cape Town

Developmental clinic - Red Cross Children's Hospital

Division of Adolescent and Child Psychiatry, UCT

## Appendix K

## Phase 1 Consent to be Contacted (Afrikaans Version)

Ons sal dalk weer in die toekoms vir u wil kontak om deel te neem in navorsing oor ontwikkelings *probleme*. U mag besluit om nie deel te neem nie. Die dienste wat u en u kind by die kliniek ontvang sal geensins aangetas word nie. U word ook nie verplig om aan toekomstige navorsing deel te neem as u nou u besonderhede gee nie. Daar sal geen slegte gevolge vir u of u kind wees nie en u sal ook nie enige voorregte by die hospitaal verloor nie.

Ek wil graag benader word oor toekomstige navorsing.

Naam: \_\_\_\_\_ Handtekening: \_\_\_\_\_ Datum: \_\_\_\_\_

Telefoonnomers (verskaf asseblief minstens twee): \_\_\_\_\_  
 \_\_\_\_\_

U kind se naam en van: \_\_\_\_\_

Toestemming is verky deur:

Naam: \_\_\_\_\_ Handtekening: \_\_\_\_\_ Datum: \_\_\_\_\_

Indien u enige vrae of besorgdheid oor die studie het, kontak gerus vir Susan Malcolm-Smith by 021 650 4605, Kirsty Donald by [Kirsty.Donald@uct.ac.za](mailto:Kirsty.Donald@uct.ac.za) of die Universiteit Kaapstad se Mediese Wetenskap Fakulteit Etiese Komitee by 021 406 6338.

Dankie vir u hulp!

Autisme Navorsingsgroep,  
 Sielkunde Departement, Universiteit Kaapstad  
 Rooikruis Kinderhospitaal  
 Tiener en Kinderpsigiatrie Afdeling (DCAP)

## Appendix L

## Phase 1 Consent to be Contacted (isiXhosa Version)

Singakucela ngelinye ixesha ukuba uze nomntwana wakho apha esibhedlele/eklinic ukuze simjonge umntwana xa edlala ngeethoyi nezinye izinto ezilula ukuze sikubuze nemibuzo ngomntwana wakho. Oku kungathatha i yure ezi 3. Oku kungenzeka e Red Cross okanye e Child Guidance Clinic. Uzakuncedwa ngemali yohambo, engange R15 ngalo lonke uhambo oluza apha. Apho singakunika olona nyango lwenene lokuba kwenzeka ntoni, apho ke umntwana angathi afumane unyango noncedo aludingayo. Ukuba awufuni ukuthatha inxaxheba , ayizukudala mahluko kwindlela ozakuphathwa ngayo ekliniki/esibhedlele.

Unga zirhoxisa koluphando/ sifundo nangaliphi ixesha ufuna. Lo nto ayizukufaka ngxakini okanye uphatheke kakubi wena nomntwana apha eklinki/esibhedlele. Lonto ayizukuchaphazela indlela ozakuphathwa ngayo eklinki/esibhedle. Siyaqonda ukuba nolulwazi kungaba yinto engakuphatha kakubi, nceda wazi oku lonke olulwazi luzagcinwa luyimfihlo lusemfihlakalweni. Wena nomntwana asoze niphatheke kakubi ngenxa yokuzirhoxisa koluphando,okanye nivinjwe amalungelo enu, okanye niphathwe kakubi sisbedlele ngenxa yeziphumo abazinikiweyo.

Nceda ugwalise apha ukuba ungathanda ukuba sikuthinte/sikufowunele

Igama: \_\_\_\_\_ isiginitsha: \_\_\_\_\_ usuku: \_\_\_\_\_

Inombolo zemfonomfono: \_\_\_\_\_

Consent was obtained by:

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Ukuba unawo nawuphi umbuzo okanye into engakukholisiyo/ongayiqondiyo ungathandabuzi ukutsalela umnxeba/ ufowunele Susan Malcolm-Smith kule 021 650 4605, okanye Kirsty Donald kule [kirsty.donald@uct.ac.za](mailto:kirsty.donald@uct.ac.za), okanye UCT Faculty of Health Sciences Research Ethics Committee kule 021 406 6338.

Enkosi ngoncedo lwakho!

Nge Autism Research Group

Kwicandelo le Department of Psychology

Kwi Yunivesiti yase Kapa

Appendix M  
Demographic Questionnaire (English Version)

Participant no.: \_\_\_\_\_ Date: \_\_\_\_\_

**A. Child's Information:**

1. Name: \_\_\_\_\_
2. Age: \_\_\_\_\_
3. Date of Birth (dd/mm/yy): \_\_\_\_\_
4. Sex:            Male            Female
5. Ethnicity:    White            Black            Indian            Coloured        Asian  
                  Other            If other please specify: \_\_\_\_\_
6. Home Language: \_\_\_\_\_
  
7. How old was your child when you first noticed that they had developmental difficulties?  
\_\_\_\_\_
8. How old was your child when you first sought help?  
\_\_\_\_\_
9. To whom or where did you first go for help?  
\_\_\_\_\_
10. Do you have any idea which developmental disorder your child has?  
\_\_\_\_\_
11. Does your child have a formal diagnosis?  
\_\_\_\_\_
12. How many times have you visited the Developmental clinic at Red Cross Hospital?  
\_\_\_\_\_

**B. Parent Information:****1. What is the total yearly income of the household in which you live? (Tick the appropriate block):**

[NOTE: This should be total household income, not personal income.]

R 0-R3,500: \_\_\_\_\_

R3,501-R7,500: \_\_\_\_\_

R7,501-R12,500: \_\_\_\_\_

R12,501-R17,500: \_\_\_\_\_

17,501-22,500: \_\_\_\_\_

22,001-30,000: \_\_\_\_\_

30,001-40,000: \_\_\_\_\_

40,001-50,000: \_\_\_\_\_

50,001-60,000: \_\_\_\_\_

60,001-70,000: \_\_\_\_\_

70,001-80,000: \_\_\_\_\_

80,001-90,000: \_\_\_\_\_

more than 90,000: \_\_\_\_\_

**2. Highest level of education reached for mother, father and/or guardian (please circle appropriate number).**

	Biological mother	Biological father	Guardian
1) 0 years (No Grades / Standards) = Never went to school	1.	1.	1.
2) 1-6 years (Grades 1-6 / Sub A-Std 4) = Didn't complete primary school	2.	2.	2.
3) 7 years (Grade 7 / Std 5) = Completed primary school	3.	3.	3.
4) 8-11 years (Grades 8-11 / Stds 6-9) = Some secondary education (didn't complete high school)	4.	4.	4.
5. 12 years (Grade 12 / Std 10) = Completed high school	5.	5.	5.
6. 13+ years = Tertiary education Completed university / technikon / college	6.	6.	6.
7. Don't know	7.	7.	7.

**3. Material and financial resources (please circle appropriate number).**

Which of the following items, in working order, does your household have?

Items	Yes	No
1. A refrigerator or freezer	1.	1.
2. A vacuum cleaner or polisher	2.	2.
3. A television	3.	3.
4. A hi-fi or music center (radio excluded)	4.	4.
5. A microwave oven	5.	5.
6. A washing machine	6.	6.
7. A video cassette recorder or dvd/blu-ray player	7.	7.

Which of the following do you have in your home?

Items	Yes	No
1. Running water	1.	1.
2. A domestic servant	2.	2.
3. At least one car	3.	3.
4. A flush toilet	4.	4.
5. A built-in kitchen sink	5.	5.
6. An electric stove or hotplate	6.	6.
7. A working telephone	7.	7.

Do you personally do any of the following?

Items	Yes	No
1. Shop at supermarkets	1.	1.
2. Use any financial services such as a bank account, ATM card or credit card	2.	2.
3. Have an account or credit card at a retail store (e.g Edgars)	3.	3.

Appendix N  
Demographic Questionnaire (Afrikaans Version)

Deelnemer nommer: \_\_\_\_\_ Datum: \_\_\_\_\_

Demografiese Vraelys

**A. Kind se Inligting:**

1. Naam: \_\_\_\_\_
2. Ouderdom: \_\_\_\_\_
3. Geboortedatum (dd/mm/jj): \_\_\_\_\_
4. Geslag (omsirkel een):                      Manlik                      Vroulik
5. Etnisiteit:              Blank                      Swart                      Indiër                      Kleurling                      Asiatics  
                          Ander                      Indien ander, spesifiseer asseblief: \_\_\_\_\_
6. Huistaal: \_\_\_\_\_
7. Hoe oud was jou kind toe jy agtergekom het dat hy/sy ontwikkelingsprobleme het?  
       \_\_\_\_\_
8. Hoe oud was jou kind toe jy die eerste keer hulp gesoek het?  
       \_\_\_\_\_
9. Na wie of waarheen het jy gegaan om hulp te kry?  
       \_\_\_\_\_
10. Het jy enige idee watter spesifieke ontwikkelingsprobleem jou kind het?  
       \_\_\_\_\_
11. Het jou kind 'n diagnose?  
       \_\_\_\_\_
12. Hoeveel keer het jy by die hierdie kliniek, die Rooikruis Kinderhospitaal se pediatriese kliniek gekuier?  
       \_\_\_\_\_

**B. Ouer se inligting:****1. Wat is die totale jaarlikse inkomste van die huishouding waar jy woon? (Merk die gepaste blokkie):**

[LET WEL: Dit moet die totale huishoudelike inkomste wees, nie persoonlike inkomste nie.]

R 0-R3,500: \_\_\_\_\_

R3,501-R7,500: \_\_\_\_\_

R7,501-R12,500: \_\_\_\_\_

R12,501-R17,500: \_\_\_\_\_

17,501-22,500: \_\_\_\_\_

22,001-30,000: \_\_\_\_\_

30,001-40,000: \_\_\_\_\_

40,001-50,000: \_\_\_\_\_

50,001-60,000: \_\_\_\_\_

60,001-70,000: \_\_\_\_\_

70,001-80,000: \_\_\_\_\_

80,001-90,000: \_\_\_\_\_

meer as 90,000: \_\_\_\_\_

**2. Hoogste vlak van opvoeding van moeder, vader en/of voog (omsirkel asseblief gepaste nommer).**

	Biologiese moeder	Biologiese vader	Voog
1) 0 jaar (Geen grade / Standerds) = Het nooit skoolgegaan nie	1.	1.	1.
2) 1-6 jaar (Grade 1-6 / Sub- A-St 4) = Het nie laerskool klaargemaak nie	2.	2.	2.
3) 7 jaar (Graad 7 / St 5) = Laerskool klaargemaak	3.	3.	3.
4) 8-11 jaar (Grade 8-11 / Sts 6-9) = Deel van hoërskoolonderwys (het nie hoërskool klaargemaak nie)	4.	4.	4.
5. 12 jaar (Graad 12 / St 10) = Hoërskool klaargemaak	5.	5.	5.
6. 13+ jaar = Tersiere opvoeding Universiteit / teknikon / kollege klaargemaak	6.	6.	6.
7. Weet nie	7.	7.	7.

### 3. Materiële en finansiële hulpbronne (omsirkel asseblief gepaste nommer).

Watter van die volgende items, in werkende toestand, het jou huishouding?

Items	Ja	Nee
1. 'n Yskas of vrieskas	1.	1.
2. 'n Stofsuier of poleerder	2.	2.
3. 'n Televisiestel	3.	3.
4. 'n Hoëtroustel of musieksentrum (radio uitgesluit)	4.	4.
5. 'n Mikrogolfoond	5.	5.
6. 'n Wasmasjien	6.	6.
7. 'n Videokassetopnemer of dvd-speler	7.	7.

Watter van die volgende het jy in jou huis?

Items	Ja	Nee
1. Lopende water	1.	1.
2. 'n Huishulp	2.	2.
3. Minstens een motor	3.	3.
4. 'n Spoeltoilet	4.	4.
5. 'n Ingeboude kombuisopwasbak	5.	5.
6. 'n Elektriese stoof of warmplaat	6.	6.
7. 'n Werkende telefoon	7.	7.

Het of doen jy self enige van die volgende?

Items	Ja	Nee
1. Doen inkopies by supermarkte	1.	1.
2. Gebruik finansiële dienste soos 'n bankrekening, OTM-kaart of kredietkaart	2.	2.
3. Het 'n rekening of kredietkaart by 'n kleinhandelaar	3.	3.

Appendix O  
Demographic Questionnaire (isiXhosa Version)

Inombolo yakho: \_\_\_\_\_ Usuku: \_\_\_\_\_

Imibuzo yobalo

**A. ulwazi ngomtwana/ inchukacha**

1. Igama: \_\_\_\_\_
2. Iminyaka: \_\_\_\_\_
3. Usuku lokuzalwa (usuku/inyanga/unyaka): \_\_\_\_\_
4. Isini: indoda                      umfazi
5. Ubuhlanga: mhlophe      mnyama              indiya      owebala      wase      omnye      ukuba  
Ungomnye umhlobo nceda ucacise: \_\_\_\_\_
6. Ulwimi lwase khaya: \_\_\_\_\_
7. Weneminyaka emingaphi umtwana wakho ukuze umqaphale ukuba unengxaki yokukhula ?  
\_\_\_\_\_
8. Weyeneminyaka emingaphi umtwana wakho ukuqala kwakho ukufuna uncedo?  
\_\_\_\_\_
9. Ngubani okanye kuphi apho wafumana khona uncedo?  
\_\_\_\_\_
10. Ingaba unalo na ulwazi lokuba yeyiphi na ingxaki yokukhula anayo umtwana wakho?  
\_\_\_\_\_
11. Ingaba umtwana wakho unaso isigulo esithile anaso osaziyo?  
\_\_\_\_\_
12. Lingakanani ixesha usiza kwi kliniki yokukhula yase sisibhedlele sase Red Cross?  
\_\_\_\_\_

**B: Ulwazi ngomzali****1.Yimalini eniyifumanayo ngonyaka kwikhaya lakho eniphila ngayo?(khetha eyonabhokisi ifanelekileyo)**

[qaphela: le kufuneka ebeyimali yomntu wonke , ingabi yeyakho wedwa]

R 0-R3,500: \_\_\_\_\_

R3,501-R7,500: \_\_\_\_\_

R7,501-R12,500: \_\_\_\_\_

R12,501-R17,500: \_\_\_\_\_

17,501-22,500: \_\_\_\_\_

22,001-30,000: \_\_\_\_\_

30,001-40,000: \_\_\_\_\_

40,001-50,000: \_\_\_\_\_

50,001-60,000: \_\_\_\_\_

60,001-70,000: \_\_\_\_\_

70,001-80,000: \_\_\_\_\_

80,001-90,000: \_\_\_\_\_

ngaphezu 90,000: \_\_\_\_\_

**2. ibanga eliphezulu lemfundo likamama, utata kunye/ nomntu onegunya okhathelela(yakha isangqa kwinani elifanelekileyo)**

	Umama	Utata	Umntu onegunya lokujonga
1. iminyaka(ungafaki mabanga) = zange waya esikolweni	1.	1.	1.
2) 1-6 iminyaka(ibanga 1-6/UA-ku4) = zange agqibe amabanga aphantsi	2.	2.	2.
3)7iminyaka(ibanga lesi7/u5) = ugqibe amabanga aphantsi	3.	3.	3.
4)8-11iminyaka(ibanga 8-11/ u6-9) =Amanye amabanga aphezulu (zange agqibe amabanga aphezulu)	4.	4.	4.
5.12iminyaka(ibanga le 12/ ibanga10)	5.	5.	5.
6.13+iminyaka=izufundo zamabanga aphezulu(dyunivesiti)  Ugqibe idyunivesiti/etkinikhoni/ikholegi	6.	6.	6.
7. Andazi	7.	7.	7.

### 3.Izinto onazo nemali (nceda wakhe isangqa kwinani elifanelekileyo)

Zeziphi kwezizinto zilandelayo, ezisasebenzayo, ingaba indlu yakho inako oku?

Ezizinto	Ewe	Hayi
1. Ifridge okanye ifreezer	1.	1.
2.Ivacuum cleaner okanye into you kupolisha	2.	2.
3.ITv /umabona kude	3.	3.
4.i hi-fi kanye into ekhalisa umcule (hayi unomathotholo)	4.	4.
5.I microwave oven	5.	5.
6.I washing machine	6.	6.
7.I video khasethi recokhoda okanye idvd player	7.	7.

Zeziphi kwezi onazo emzini wakho?

Izinto	Ewe	Hayi
1. I tap yakho	1.	1.
2.Umntu okuncedisayo endlini(okusebenzelayo)	2.	2.
3.Imoto unayo enye	3.	3.
4.unethoyilethi egungxulwayo	4.	4.
5. unekhabhadi ezifakelweyo ezinesinki	5.	5.
6.unesitovu sombane esikhulu okanye i plate	6.	6.
7. Ifowuni esbenzayo	7.	7.

Ingaba wenza oku kulandelayo?

Izinto	Ewe	Hayi
1.Uthenga esuphamakethi	1.	1.
2.usebenzise enye yezi ikhawunti yebhanki,ikhadi leATM okanye ikhadi lecredit	2.	2.
3.Une account okanye amakhadi etyala ezivenkileni	3.	3.

Appendix P  
Phase 2 Parental Consent Form

Dear Parent,

We want to ask your permission to do a play assessment and an assessment of cognitive function (memory, attention, problem solving, etc) with your child. We would also like to ask you some questions about your child's behaviour. This will take 2- 3 hours in total. It will take place at the Child Guidance Clinic at the University of Cape Town. After we have done these assessments, your doctor will let you know the results.

You can choose not to take part. If you agree and then change your mind, you can withdraw from the study at any time. Your decision will have no negative effects for you or your child and will not affect the services you receive at the clinic.

We understand that some of this information may be sensitive, but all information will be kept strictly confidential. Only members of the research team will be able to view the information. When we publish the research, you will not be identified in any way.

We also want to ask your permission to video-record the play session and the interview with you. This recording will be used to make sure these sessions are scored properly. These DVD recordings will be stored in a secure place and only members of the research team will have access to them.

There are no risks involved in taking part in the study. If you or your child get tired during the interview or assessment, you can take breaks at any time. The benefits are that your child may get a formal diagnosis and you will be given advice on what is best to do for your child, and what help you can get.

This study has been explained to me and all my questions have been answered. On behalf of myself and my child, I consent to participate.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I consent to having the play assessment and interview filmed, and that this data will only be used for scoring

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

This study was explained by:

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

If you have any queries or concerns please feel free to contact

Susan Malcolm-Smith on 021 650 4605

Kirsty Donald at [Kirsty.Donald@uct.ac.za](mailto:Kirsty.Donald@uct.ac.za) or

UCT Faculty of Health Sciences Research Ethics Committee on 021 406 6338.

Thank you for your help!

Autism Research Group

Department of Psychology, University of Cape Town

Developmental clinic - Red Cross Children's Hospital

Division of Adolescent and Child Psychiatry, UCT

## Appendix Q

## Phase 2 Child Assent Form

We want to tell you about a research study we are doing. A research study is a way to learn more about something. We would like to find out more about screening devices: a way to find out who needs help as quickly and easily as possible. You are being asked to join the study because you are going to the clinic at Red Cross.

If you agree to join this study, you will be asked to take part in a play session and also to do some pencil and paper tasks and puzzles. You will be asked to do certain tasks with toys, and to play some games. It will take about 2 hours altogether, but you can take breaks at any time.

You do not have to join this study. It is up to you. You can say okay now and change your mind later. All you have to do is tell us you want to stop. No one will be mad at you if you don't want to be in the study or if you join the study and change your mind later and stop.

Before you say **yes** or **no** to being in this study, we will answer any questions you have. If you join the study, you can ask questions at any time. Just tell the researcher that you have a question.

If you sign your name below, it means that you agree to take part in this research study.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

This study was explained by:

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_