

Screening for Autism Spectrum Disorders in a Developmental Clinic in the Western Cape:  
Using the Modified Checklist for Autism in Toddlers (M-CHAT)

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## Abstract

ASD has an estimated prevalence of 1 in 68, making it one of the most common neurodevelopmental disorders in children. Furthermore, its prevalence is increasing; therefore, there is a rising demand for screening tools to help achieve beneficial early diagnosis and intervention outcomes. However, there is a lack of literature around ASD and ASD screening tool validity in South Africa. This thesis adapted and assessed the use of South African English, Afrikaans and IsiXhosa versions of the 23-item Modified Checklist for Autism in Toddlers (M-CHAT) screening tool, for a Western Cape state hospital. The M-CHAT was completed by parents ( $N=255$ ) of children between the ages of 1.5 and 4.99 years, at the Red Cross Children's Hospital developmental clinic. The demographic variables of Child's Age or Sex, Income and Mothers Education did not significantly affect the M-CHAT scores. Furthermore, on qualitative inspection, neither Home language nor Ethnicity of the child appeared to affect the screening scores. Final M-CHAT scores and high internal consistencies were similar across the three M-CHAT language versions, likely indicating their equivalence in flagging ASD. Even the extended age range (4.01-4.99 years) included in this study, did not appear to affect the M-CHAT scores. The M-CHAT follow-up interview was important in determining the ASD risk outcome. Overall, 67% failed the M-CHAT initially, thus requiring follow-up questioning, and of those, 40% changed their outcome and subsequently passed. Interestingly, filling out the M-CHAT in a first or second language did not affect the percentage requiring the follow-up nor the proportions changing their outcome after follow-up. The items which were poor or good discriminators between those eventually passing or failing overall were investigated. The good discriminating items were not necessarily the same as the originally suggested critical items. Thus, new critical items and the possible removal of unnecessary items for this context may need further investigation. For phase 2, a small subgroup ( $n=38$ ) filling in the English M-CHAT took part in formal ASD diagnostic assessments, using the Autism Diagnostic Observation Schedule (ADOS/ADOS-2). Preliminary investigations into the English M-CHAT's predictive abilities are promising. A cut-off of 3/23 items overall indicates high sensitivity (.84) and adequate specificity (.69). The adapted cut-off of 1/6 critical items results in good sensitivity (.76) and high specificity (.92). The promising results warrant further investigations into the predictive validity of all 3 language versions of the M-CHAT. This thesis takes the first steps in validating the use of the M-CHAT in this low SES context and indicates positive prospects for its future use in state clinics in the Western Cape, and ultimately South Africa.

## Introduction

Autism Spectrum Disorder (ASD) has been recognised as a highly prevalent (Matson & Kozlowski, 2011) and severe disorder (Brentani et al., 2013). Its symptoms are present from infancy or early childhood and they continue to impact the person throughout their lifetime, with strain also being put on families, healthcare systems and society (Ganz, 2007; Howlin, Goode, Hutton, & Rutter, 2004).

Western Europe and North America have been the prominent areas for conducting epidemiological studies (Sotgiu et al., 2011). Thus there is very little, if any, information specifically regarding South Africa's ASD prevalence (Malcolm-Smith, Hoogenhout, Ing, Thomas, & de Vries, 2013). However, epidemiological information, primarily from developed countries, indicates an ASD prevalence of about 1 in 68 (Centers for Disease Control and Prevention [CDC], 2014), making it one of the most prevalent neurodevelopmental disorders in children (Fombonne, 2009; Yama, Freeman, Graves, Yuan, & Campbell, 2012). Furthermore, this ASD prevalence has been increasing in recent years; possibly due to a true rise in incidence, increased awareness of the disorder or changes in the diagnostic criteria (Elsabbagh et al., 2012; Fombonne, 2009). Although current prevalence estimates are mostly based on knowledge from developed countries, ASD is thought to be prevalent in all countries, cultures and socioeconomic strata around the world (Elsabbagh et al., 2012).

Epidemiological data on ASD are not available for South Africa, or other African countries (Bakare & Munir, 2011a; Malcolm-Smith et al., 2013). However, it is reported that between the three main state hospitals around Cape Town, 10 new ASD diagnoses are made per week (Bateman, 2013). Thus, ASD appears to be relatively common in South Africa. Furthermore, the prevalence of ASD worldwide appears to be similar, at around 1% (Baird et al., 2006; Elsabbagh et al., 2012; Fombonne, 2009), even in countries such as Sri Lanka (Perera, Wijewardena, & Aluthwelage, 2009). Therefore, it is likely that South Africa has a similarly high ASD prevalence, particularly as ASD is a neurodevelopmental disorder. It is also likely that those in African countries and in low SES populations, such as in the current study, have a decreased awareness of ASD and therefore, these populations are often severely underdiagnosed (Bakare & Munir, 2011b; Grinker et al., 2012; Samms-Vaughan, 2014). Thus, screening tools are particularly necessary in these settings, as parents are likely unaware of ASD and its symptoms.

Screening is necessary for flagging children at high risk for ASD so that they can

receive a formal diagnosis and start accessing essential ASD intervention services. The earlier the diagnosis the better, as the benefits from interventions are said to be optimal when begun at the youngest possible age (Committee on Educational Interventions for Children with Autism & National Research Council, 2001; Dawson et al., 2012; Harris & Handleman, 2000; Landa & Kalb, 2012; Myers, Johnson, & The Council on Children with Disabilities, 2007; Rogers et al., 2012; Webb, Jones, Kelly, & Dawson, 2014). However, South Africa's overburdened healthcare systems and long waiting lists for ASD diagnoses are preventing this beneficial early access to intervention from occurring (Malcolm-Smith et al., 2013). Thus, screening would help to quickly identify those in particular need and have their services prioritised.

In the following literature review, I will describe the new ASD diagnostic criteria, as well as ASD's core symptoms and their ages of onset. This information is helpful in determining appropriate screening measures for detecting ASD at various ages of symptom onset, and for making the finer distinctions between ASD and other developmental disorders. The benefits and limitations of screening will be discussed, with particular consideration of the overburdened healthcare system in South Africa. I will then investigate the cross-cultural application of a well recognised screening tool for young children, the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999; Robins, Fein, Barton, & Green, 2001), and its probable use and validity in South Africa. With ASD prevalence increasing, it is vital that screening tools are introduced so that earlier diagnosis and access to intervention can start to occur. However, considering this country's incredibly diverse population, it is especially important that any screening tool is validated in groups with different languages and socioeconomic status (SES), before use at healthcare sites.

## **Literature Review**

### **ASD: Diagnostic Changes**

The definitions for ASD diagnostic criteria have recently undergone substantial changes in the newly published Diagnostic and Statistical Manual of Mental Disorders (DSM) - 5<sup>th</sup> Edition (DSM-5; American Psychiatric Association [APA], 2013a). Furthermore, there are also proposed changes for ASD criteria in the 11<sup>th</sup> edition of the International Classification of Diseases (ICD-11; World Health Organisation [WHO], 2016). However, although both the DSM-5 and ICD-11 frameworks appear similar (Lord & Jones, 2012), the DSM-5 has recently been published and thus research has primarily focussed on this, rather than the ICD-11 (due for release in 2018). The previous ASD criteria, the newer criteria, and

the implications of the changes will be discussed below.

The diagnostic criteria of the DSM-IV (APA, 1994) or its text revised version (DSM-IV-TR; APA, 2000), which have been used in the majority of ASD studies to date, are first discussed. These criteria and the criteria from the 10<sup>th</sup> edition of the International Classification of Diseases (ICD-10; WHO, 1992) used the diagnostic term Pervasive Developmental Disorder (PDD), instead of ASD, to group a number of related disorders. The DSM-IV-TR criteria indicated that PDDs were neurodevelopmental disorders characterised by three areas of impairment: 1) social interaction, 2) communication, and 3) the restriction of interests, or repetition of behaviours (APA, 2000). Both the DSM-IV frameworks and the ICD-10 criteria are similar and required these impairments to be present before the age of 3 years. Furthermore, they broke PDD down into subgroups; including Asperger's syndrome, Autism Disorder, Childhood Disintegrative Disorder (CDD), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and Rett's syndrome (APA, 1994, 2000). However, further research regarding the domains of impairment, the age of diagnosis and the applicability of the subtypes, resulted in new changes to the ASD criteria in the DSM-5, and in the proposed ICD-11 revisions.

Firstly, the DSM-5, notes only two areas of impairment, rather than three; the first is social and communication deficits combined and the second is repetitive or restricted behaviours (RRBs; APA, 2013a). In the social and communication domain deficits need to be present in all 3 areas; 1) non-verbal communication, 2) understanding, developing, and maintaining relationships, and 3) social-emotional reciprocity. In addition, in the RRB domain, deficits must be shown in at least 2/4 of the following areas; 1) severe over- or under-reactions to sensory stimuli or unusual sensory interest in the environment (newly added), 2) abnormally intense fixated interests, 3) repetitive or stereotyped motor movements, and 4) the excessive need to adhere to routines or rituals (APA, 2013a). Harstad et al. (2014) agree that this 2-factor model is psychometrically better than the 3-factor model. It is thought that this framework's use of a smaller number of broader criteria, allows diagnoses to be more applicable to those of different language levels, cultures and ages (Lord & Bishop, 2015). In addition, the age at which these symptoms need to be present has been modified.

The ASD symptoms now need to be present in the early developmental period according to the DSM-5 (although some symptoms may only be recognised later with greater demands placed on the child; APA, 2013a). This is in contrast to the DSM-IV frameworks where specific symptoms had to be present before age 3 (APA, 2000). Therefore, the DSM-5 allows for early diagnosis while still allowing diagnoses where symptoms are recognised later

(APA, 2013b). The third significant change to the criteria is regarding the ASD subtypes.

The DSM-5 collapses the Autism, Asperger's syndrome, PDD-NOS and CDD subgroups into a single category, of Autism Spectrum Disorder, while excluding Rett Syndrome (APA, 2013a), as Rett syndrome's specific genetic cause has been identified (Amir et al., 1999). Thus, individual differences are now rather indicated by the severity or degree of required support (Lord & Bishop, 2015). This change was made because the DSM-IV categories were argued to have unreliable boundaries defining the ASD subtypes (Lord, Petkova, et al., 2012; Wing, Gould, & Gillberg, 2011). DSM-IV diagnoses appeared to depend on clinical preference or the clinic visited rather than individual characteristics (Lord, Petkova, et al., 2012). However, some disagree, for example after reviewing many studies Tsai and Ghaziuddin (2014) concluded that DSM-IV PDDs could successfully be broken down into different subtypes. Furthermore, the merge may also upset those with milder symptoms or Asperger's disorder, as a label of ASD appears to have greater stigma attached to it (Wing et al., 2011). Therefore, there is still much controversy arising from the merging of these categories. In addition to the collapse of categories, the new Social Communication Disorder (SCD) added to the DSM-5 needs consideration.

SCD, an additional disorder, not considered part of the ASD spectrum, was introduced. These cases have social communication deficits similar to those with ASD, but without the RRBs. This category will ensure that children without the RRBs continue to have access to services. However, others say this could result in clinicians using this diagnosis rather than ASD as it requires less documented information and seems a milder form (Lord & Bishop, 2015). After all these new changes to the DSM-5 it is important to consider other difficulties that may arise, such as suggestions that the DSM-5 criteria are set at too high a threshold.

It has been argued that criteria are more stringent for the DSM-5 than the DSM-IV/DSM-IV-TR (Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012; Smith, Reichow, & Volkmar, 2015). Thus, some milder or higher functioning cases may lose their diagnosis (Mayes et al., 2014; Smith et al., 2015), or younger children may be missed (Barton, Robins, Jashar, Brennan, & Fein, 2013). However, Lord and Bishop (2015) argue that many studies comparing the DSM-IV and DSM-5 have used existing DSM-IV data, which are unlikely to include details regarding the added symptoms in the DSM-5. Therefore, the apparent decrease in sensitivity for the DSM-5 may not be a fair reflection of its abilities (Lord & Bishop, 2015). Furthermore it is possible that previous diagnostic criteria were too lenient, resulting in some false positives being identified in younger children (Kozlowski, Matson,

Worley, Sipes, & Horovitz, 2012). Therefore, the DSM-5's increased specificity would hopefully eliminate these false positives. Specific studies carried out since the release of the DSM-5 ASD criteria, are discussed below.

Only recently have studies been published using the final DSM-5 criteria rather than the draft criteria, and there have been mixed results. Mayes et al. (2014) found that in a sample with ASD and other disorders, the DSM-5 identified 16% fewer Autism cases and 90% fewer PDD-NOS cases. They therefore concluded that the new criterion reduced the numbers diagnosed at the 'milder' end of the ASD spectrum. However, the PDD-NOS group was small, only consisting of 10 cases (Mayes et al., 2014). In addition, Lord, Petkova, et al. (2012) mention that the diagnoses of milder forms of PDD are in any case particularly unreliable. Another study including 6577 children diagnosed with ASD using the DSM-IV-TR, found 81.2% to be diagnosed using the DSM-5. However, 96.1% of the cases were within one criterion of meeting the DSM-5 diagnosis (Maenner et al., 2014). Kim et al. (2014) found even higher agreement between those diagnosed with the DSM-IV and the DSM-5, with over 90% of PDD cases retaining their diagnosis. Furthermore, when combining those diagnosed with either ASD or SCD on the DSM-5, only 2% of PDD cases would 'lose' their diagnosis (Kim et al., 2014). Therefore, the divergence in the continuity of diagnoses across the two frameworks appears to decrease when relaxing one of the DSM-5 criteria, often in the social communication domain (Smith et al., 2015), or when considering the number that would receive an SCD diagnosis rather than ASD (Kim et al., 2014). Although there are advantages and disadvantages to both frameworks, it is essential for clinicians and researchers to be aware of the effects that changing criteria may have on screening tools and the interpretation of research.

It is also important to consider the potential effects of the above changes on the validity and efficacy of the M-CHAT screening tool. However, the changes are recent, thus to my knowledge there are not yet published studies specifically comparing the M-CHAT's validity using the DSM-IV/5 criteria. Importantly, it does not seem that the M-CHAT was intended to differentiate the ASD subtypes but rather to flag those under the umbrella term of ASD. Therefore, the collapse of categories in the DSM-5 should not affect the M-CHAT screening tool significantly. In addition, the M-CHAT covers all the domains required for a DSM-5 diagnosis, including the newly added sensory criteria. The DSM-5 has also tried to include criteria which are more applicable to younger children (Lord & Bishop, 2015). Therefore, the M-CHAT is likely more in line with the new criteria. Nevertheless, it is important to remember that ASD populations may differ when diagnosed using different

criteria, thus one must be cautious when interpreting and comparing newer and older literature on ASD and screening tools.

### **ASD: Early Signs and Symptoms**

ASD is a neurodevelopmental disorder, however at present the diagnostic criteria (mentioned above) are all behaviourally defined. This is as a result of the limited understanding of ASD's pathophysiology (Barbaro & Dissanayake, 2009). Therefore, it is difficult to diagnose and differentiate ASD, especially across different ages (Ventola et al., 2006). Nonetheless, it is important to try and take note of behaviours that differentiate ASD and their presence across age ranges, in an attempt to best diagnose ASD.

The age at diagnosis is important, as it seems best to diagnose ASD early (Webb et al., 2014), but one also needs to be aware of the possible decreased stability of the diagnosis in young children (Woolfenden, Sarkozy, Ridley, & Williams, 2012). However, early diagnoses are thought to be relatively reliable (Chawarska, Klin, Paul, & Volkmar, 2007; Cox et al., 1999; Guthrie, Swineford, Nottke, & Wetherby, 2013; Lord et al., 2006). Autism symptoms can present as early as 8 months (Dumont-Mathieu & Fein, 2005) and diagnoses made at 19 (Guthrie et al., 2013) or 20 (Cox et al., 1999) months are considered reliable. Some studies have found that a small number do lose their diagnoses over time (Sutera et al., 2007), but this is more for those diagnosed with ASD's other than Autism Disorder at a younger age (Woolfenden et al., 2012). Nevertheless, it appears that screening should still be carried out at an early age, as studies have found the ASD diagnosis to remain somewhat stable, especially for the more severe cases (Woolfenden et al., 2012). In addition, even if the ASD diagnosis changes, ASD traits were likely present previously and thus needing attention. For accurate early screening and diagnosis to take place, it is important to identify the early diagnostic markers of ASD.

These early indicators typical of ASD, within infancy and toddlerhood, are usually impairments in communication and social attention, according to the review by Barbaro and Dissanayake (2009). Early communication deficits in ASD include a lack of vocal communication, joint attention, gaze shifting and behaviour to show or request things. Social attention impairments include a lack of social interaction and interest in others, lack of suitable facial expressions and imitation of others, decreased orienting to name calling, as well as the avoidance of eye contact (Barbaro & Dissanayake, 2009). Barbaro and Dissanayake, (2012) found that the four key markers of ASD in children between 12-24 months were deficits in eye contact, pointing, showing and pretend play. Mars, Mauk, and

Dowrick, (1998) note similar findings for children aged 12-30 months, with the addition of decreased alternating gaze indicating ASD, and without deficient pretend play being a key indicator. Other studies found symbolic play (Dereu et al., 2010) or imaginative skills to be decreased (Barbaro & Dissanayake, 2009). Dietz, Swinkels, van Daalen, van Engeland, and Buitelaar (2006) furthermore found that decreased reactions when spoken to, as well as a lack of interest in others and smiling directly were indicative of ASD. Others have additionally found unusual sensory behaviours as early indicators (Dereu et al., 2010; Zwaigenbaum et al., 2005). Therefore, there are a few specific early ASD diagnostic markers, of which most appear to be in the social and communication domains, with the addition of some sensory behaviours.

### **ASD: Long-Term Effects, Age of Diagnosis and Best Prognosis**

There are many long-term effects of ASD on individuals, families, education, healthcare systems and society. These range from large financial burdens (Ganz, 2007) to developmental outcomes and behaviours which can be overwhelming for the child and those around them (Committee on Educational Interventions for Children with Autism & National Research Council, 2001). However, the significant negative effects appear to be somewhat diminished through earlier diagnosis, which leads to earlier service access and intervention, thus resulting in improved outcomes (Committee on Educational Interventions for Children with Autism & National Research Council, 2001; Johnson, 2008; Webb et al., 2014).

In the United Kingdom and United States, society spends several billion dollars on Autism per annum, these costs occur from childhood and even more so into adulthood (Ganz, 2007; Knapp, Romeo, & Beecham, 2009). They are even more substantial when the child has both ASD and intellectual disability (Knapp et al., 2009). Furthermore, in the US, having a child with ASD resulted in significant income loss for families; on average this was 14% of their reported income (Montes & Halterman, 2008). In South Africa the financial burdens are likely to be even greater as ASD healthcare services are very limited, especially in the state sector (Malcolm-Smith et al., 2013). Thus, families themselves will need to cover the costs associated with ASD, especially where only private ASD services are available. The high expenditure associated with ASD, is likely to have large negative long-term effects on all systems in which the child is involved.

In addition to the costs, ASD's associated behaviours can also be overwhelming for families (Karst & Van Hecke, 2012), especially when the children are undiagnosed and not yet accessing intervention programmes. Therefore, a suitable ASD diagnosis early on would

help families to understand and cope better with the child (Shattuck & Grosse, 2007). In addition, acquiring a 'diagnostic label' could help gain access to intervention services (Stahmer & Mandell, 2007) or medical aid support (Shattuck & Grosse, 2007). Thus, earlier diagnosis should help families to quickly understand their child's behaviours and to promptly access intervention services to improve outcomes.

Early intervention can result in a variety of developmental improvements in language ability or communication, social interactions, symbolic play, adaptive behaviours, as well as academic ability and IQ (Dawson et al., 2010; Kasari, Freeman, & Paparella, 2006; Myers et al., 2007; Yoder & Stone, 2006). Improvements are thought to result due to the plasticity of a younger, developing brain (Dawson, 2008). The improvements from early intervention are likely to decrease the need for other services as the child gets older, thus decreasing long-term emotional burdens and ASD service costs for families and societies (Johnson, 2008).

However, even with all these supposed benefits from early diagnosis, the typical age of ASD diagnosis is still late. The average age of ASD diagnosis in the US differs between studies, some finding it to range from 3.1-7.2 years across the different ASD subtypes (Mandell, Novak, & Zubritsky, 2005), and others finding an average age of 5.4 (Mandell et al., 2010) and 5.7 years (Shattuck et al., 2009). Nevertheless, critical early diagnosis is often delayed until school (Mandell et al., 2005), especially when symptoms from other developmental disorders overlap (Carlsson et al., 2013). This late age of diagnosis is particularly worrying when considering that parents first note concerns at a significantly earlier age (Daniels & Mandell, 2013).

Furthermore, note that the delay in diagnosis mentioned above is for developed countries and thus age at diagnosis may be even older for other contexts, including South Africa. The age of diagnosis is often later for those from low SES backgrounds (Mandell et al., 2010, 2005), and there are mixed reports regarding the diagnostic age across ethnicities. However, in most of these situations, it is only severe cases that are diagnosed early enough, while others are potentially missed altogether (Mandell et al., 2009, 2010). There are many factors possibly influencing the diagnostic age in these populations.

In low and middle income groups the age of ASD diagnosis overlaps with short-term survival issues (such as malnutrition, or HIV and its associated illnesses etc.), thus these may be prioritized over attending to developmental concerns. However, it is essential to realise that the environments negatively affecting survival, often have long-term negative effects on the survivors, such as developmental disorders (Grinker et al., 2012). Furthermore, more children are now surviving infectious and communicable diseases. Thus, one needs to

prioritise looking into the lifelong effects of disorders such as ASD (Bakare, Munir, & Bello-Mojeed, 2014), and to work on decreasing the diagnostic age. In addition to this, in Africa, there is low ASD awareness which may be further affecting diagnosis.

ASD diagnoses seem even later in Africa, possibly due to decreased ASD awareness in healthcare workers (Newton & Chugani, 2013) and parents (Bakare & Munir, 2011b), and at times the disorder is even blamed on spiritual causes (Newton & Chugani, 2013). Studies on age of diagnosis in Africa are limited, but one study in Nigeria found the average age to be greater than 8 years (Bakare & Munir, 2011b). The age of diagnosis is likely delayed in South Africa too, as many of the factors mentioned above may operate in our context, especially in low SES healthcare settings. Thus, it is essential that this age of diagnosis is brought down, for earlier intervention access and for long-term burdens to be somewhat relieved.

### **Screening: Benefits and Limitations**

Screening is of utmost importance as it can quickly attend to concerns and helps to achieve early diagnosis and intervention outcomes (Robins, 2008), thus hopefully ameliorating some of ASD's long term effects (Johnson, 2008). Screening is especially necessary in middle and low income areas where ASD children are often completely underserved or receive services too late (Grinker et al., 2012). Therefore, the benefits and limitations of screening will be discussed further.

Without using screening tools, ASD is often missed by paediatricians and teachers. In the Robins (2008) study only 19% of the confirmed ASD cases had been recognised by paediatricians. This is even more likely to occur in developing countries such as South Africa where healthcare resources are limited. In addition, most crèches in South Africa have too many children to identify mild autism symptoms (Grinker et al., 2012). This likelihood of missing ASD cases increases without screening, and is even more likely when diagnosing across different populations.

Many children across low SES or different ethnic groups are thought to be identified later. However, screening could help to decrease this discrepancy in the age of diagnosis across diverse groups, by also flagging at an early age, those that would usually be missed (Herlihy et al., 2014). Earlier screening and diagnosis could thus result in more equal opportunities for earlier access to beneficial interventions in all population groups (Robins et al., 2014). Thus, screens should be routinely used across all populations when monitoring childhood development to quickly and easily flag all those at high risk.

Screening is a non-invasive, quick way of attending to parental concerns that prevents

practitioners from spending unnecessary time analysing every child for ASD (Scherzer, Chhagan, Kauchali, & Susser, 2012). It is important for the right types of assessment to be prioritised for ASD, however, referrals do not always give enough of an indication about whether the child has suspected ASD or another developmental disorder (Allen, Silove, Williams, & Hutchins, 2007). Carrying out full diagnostic assessments at routine follow-up would take too long, especially as the behaviourally defined ASD diagnostic tools are very comprehensive, costly and time consuming to administer. In addition these tools require highly skilled and trained professionals, which are limited in South Africa's state developmental clinics, where diagnoses can be done. South Africa's healthcare system in particular is already so overburdened; with long waiting lists, therefore, it would be extremely difficult to conduct full diagnostic assessments on all children for potential ASD. Thus, those needing their assessments prioritized should first be 'flagged' with screening tools. Effective screening could result in shortened waiting lists for beneficial autism services (Gray & Tonge, 2005; Khowaja, Hazzard, & Robins, 2015) by ensuring that unnecessary over-referrals for diagnosis are avoided. However, although there are many benefits to screening, it is also important to consider the balance between how well screens predict ASD, the costs to administer them and the services available after screening is complete.

Screening tools also come with risks, such as identifying false positives (Kozlowski et al., 2012), as they do not provide a diagnosis. Screens are rather mechanisms for flagging those at high risk (Canal-Bedia et al., 2011). Thus, a formal diagnosis by highly skilled professionals is still required. However, if resources for diagnosis are limited, parent anxiety arising from ASD screening would likely be further exacerbated (Allen et al., 2007). Furthermore, even once the diagnosis is made; there may be limited intervention resources (Malcolm-Smith et al., 2013). For example, in South Africa there are only 9 schools specific to ASD in the entire country (Bateman, 2013), of which only 5 appear to be state schools. Thus, one needs to weigh up the benefits of early screening and the subsequent services available to cope with those screening positive. In addition one needs to consider the ages to which the screen applies.

The limitations of the age at which screening occurs in children, are important to consider. Screening too early may result in one missing ASD cases when regression (usually between 18 and 24 months) and Asperger's disorder impairments occur later (Dumont-Mathieu & Fein, 2005). Furthermore, developmental trajectories may also change with age (Charman et al., 2005); raising concerns as to whether the same screening tool can be used for children younger and older than 2 years. For example, a constant finding is that children

with ASD of 2 years or younger, have more negative symptoms (a lack of social behaviours and communication), compared to positive symptoms (increased preoccupation with routines and higher repetitive behaviour frequencies) (Pandey et al., 2008; Rogers, 2000). Thus, ASD screens may possibly need to be administered at two time points above and below 2 years to flag children with various ages of symptom onset.

It is important to remember that screening tools based on behavioural criteria are unlikely to have perfect sensitivity and specificity, especially across a range of ages. Thus, Robins (2008) mentions that it would be harmful to clinical services if one were to wait until screens presented perfect results before using them. Furthermore, false positives may also indicate cases with some kind of a delay where further evaluation would still be beneficial (Robins et al., 2001). Thus, there will always be the need to balance false negatives and false positives (Robins, 2008) and to consider whether unnecessarily assessing false positives is feasible (Eaves, Wingert, & Ho, 2006).

### **M-CHAT Screening**

This study was planned and most data collected before the release of the M-CHAT revised with follow-up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) validation literature which was published in 2014 (Robins et al., 2014), hence the initial M-CHAT with follow-up will be the focus of this research. The details and implications of the revision will be considered in the discussion. The M-CHAT screening tool was modified from the original CHAT (Checklist for Autism in Toddlers; Baron-Cohen, Allen, & Gillberg, 1992). It is one of the most esteemed ASD screening tools (Snow & Lecavalier, 2008) and is widely used internationally (Canal-Bedia et al., 2011; Inada, Koyama, Inokuchi, Kuroda, & Kamio, 2011; Robins et al., 2014). The M-CHAT is free and requires no formal training or prior ASD knowledge to administer it (Robins, 2008). Thus, for a low cost, it reaches larger populations (Charman et al., 2001), allowing the identification of more high risk cases. The M-CHAT also screens in very young children where a diagnosis is thought to be most beneficial.

The M-CHAT was developed to screen for ASDs in toddlers; the original validation study used toddlers aged 18-30 months (Robins et al., 2001). However, the M-CHAT is now applicable to children from 16 months, (Kleinman et al., 2008; Pandey et al., 2008; Robins, 2008; Ventola et al., 2007) up until 48 months (Snow & Lecavalier, 2008; Yama et al., 2012). Thus, it screens a range of young children very easily, with few items to complete.

It is a parent report checklist that is very quick to complete, only requiring yes/no responses about the child's behaviour. The M-CHAT consists of 23-items, of which 6 are

classified as critical items (items 2, 7, 9, 13, 14, and 15). It has a high internal consistency of .85 for the total checklist and .83 for the critical items (Robins et al., 2001), thus consistently identifying ASD traits. All questions except items 11, 18, 20 and 22, require a 'yes' response to indicate a pass or no ASD risk. The screen is failed when any 3 items overall are failed or when two out of six critical items are failed (Robins et al., 2001). However a recent large-scale M-CHAT study has indicated that when using the cut-off of 3 or more failed items, without the critical items, the outcomes are similar (Chlebowski, Robins, Barton, & Fein, 2013). A failure on the M-CHAT indicates ASD risk (Robins et al., 2001).

If a child fails the M-CHAT after the initial questions are filled out, a follow-up interview is conducted with the parents, over the phone. During this, each of the initially failed items is repeated to parents, to verify and obtain examples of the behaviours in question and to check whether they are still present. The follow-up interview questions are in the form of a structured flow-chart for each item. If the child still fails after the follow-up, using the previously mentioned criteria, it is recommended they go for formal ASD diagnostic testing. The follow-up interview appears to be essential in increasing the predictive validity of the M-CHAT (Robins, 2008).

The follow-up interview increases the positive predictive value (PPV; the number of cases screening positive and subsequently diagnosed with ASD) of the M-CHAT significantly. Robins et al. (2001) found that the PPV increased with the inclusion of the follow-up; it went from .36-.68 for a cut-off of 3/23 items and from .64-.79 for a cut-off of 2/6 critical items. Kleinman et al. (2008) similarly found that in an overall mixed high and low risk sample, the PPV changed from .36 to .74 when including the follow-up. Although the improvement in PPV from including the follow-up was much greater in the low risk sample (.11 to .65), the PPV after follow-up is still much higher in the high-risk sample (.60 to .76; Kleinman et al., 2008). In another low risk population the PPV improved considerably, from .06 to .54 with the follow-up (Chlebowski et al., 2013). Even though PPV values are dependent on the ASD prevalence in the population (Canal-Bedia et al., 2011) and are thus higher in high risk populations, follow-up interviews are still critical in all populations. The follow-up interviews increase specificity (detecting a lack of the disorder) and decrease false positives (Pandey et al., 2008).

In the case of screening tools, differentiation between true and false negatives is more crucial than discriminating between true and false positives. At least those screening positive are likely to still be evaluated, but those screening negative will not and may miss the chance for early intervention (Matson, Kozlowski, Fitzgerald, & Sipes, 2013). Thus, in the pre-

diagnostic phase it seems worth having a few false positives, rather than missing out altogether on identifying a child with ASD.

Although false positives can be costly and cause unnecessary parent anxiety (Charman & Gotham, 2013), at least they may indicate an at risk group for other developmental disorders (Chlebowski et al., 2013; Robins et al., 2001). In many of the M-CHAT validation studies, the false positives were seldom typically developing children, but rather those with another developmental disorder (Chlebowski et al., 2013; Robins et al., 2001). Chlebowski et al. (2013) found 98% of the false positives on the M-CHAT to have significant developmental concerns. Therefore, in all these cases, further evaluation after the M-CHAT would still have been useful, as these children are likely needing interventions. However, the effects of false positives versus false negatives still need to be weighed up, and cut-off scores determined for the population in which the screen is to be used.

The initial M-CHAT cut-off values were set at a lower level to increase sensitivity (ability to detect the disorder) and to minimise false negatives (Kozlowski et al., 2012), as high sensitivity is typically wanted for a screen such as this, to optimize early identification (Robins & Dumont-Mathieu, 2006). However, it is noted that in some cases both non-ASD children with atypical development and ASD children fail using the originally suggested cut-off scores. However, their scores are quite different, thus, current cut-off scores are possibly too low (Kozlowski et al., 2012). Although, when differentiating ASD from typically developing children, the current cut-offs may be appropriate. Therefore, cut-offs possibly need to be altered for different populations (Kozlowski et al., 2012).

The M-CHAT appears to effectively maximise sensitivity, first of all, as well as specificity across most different populations. However, direct comparisons of these different versions can be challenging as they differ in terms of the number of items used, cut-off scores, age ranges and whether the follow-up was administered. In addition, true sensitivity and specificity are seldom stated; it is usually only those screening positive for ASD and not those screening negative who are diagnostically evaluated (Sunita & Bilszta, 2013). In the original M-CHAT validation, both the critical 6-item and the 23-item sensitivities and specificities were extremely high, with values of .95 and .99 (6-items) and .97 and .99 (23-items), respectively (Robins et al., 2001). Kleinman et al. (2008) also noted a high sensitivity of .91 (23-items). However, Snow and Lecavalier (2008) noted slightly lower overall levels of sensitivity (6-items=.70, 23-items=.88) and especially specificity (6-items and 23-items =.38), which increased slightly when rather using a critical item cut-off of 1/6 items. These lower values are possibly due to a small sample size and the specificity is probably especially

low as it was carried out in a high-risk sample, where it needed to make the very fine distinction between ASD and other developmental and language disorders. Therefore, in some populations the M-CHAT criteria may need to change, to ensure not only high sensitivity but also specificity.

When screening in a sample with other developmental disorders, high specificity on the M-CHAT may also be necessary (Snow & Lecavalier, 2008). The shared symptomology, especially in the early stages of development, between ASD and other intellectual or developmental disabilities makes it difficult to differentiate the disorders from one another (Fernell, Eriksson, & Gillberg, 2013; Ventola et al., 2007). It is in such cases that one needs to be especially careful of the specificity. Otherwise, it may not be worthwhile to use the screen for ASD in high-risk samples, if all those with developmental delays are flagged, rather than only ASD. Fortunately, the M-CHAT does usually appear to have adequate specificity, based on its previous use. However, symptoms and key M-CHAT items differentiating ASD from other developmental delays are still important to investigate and be aware of.

If screens are to specifically flag ASD, its core symptoms need to be included in tools such as the M-CHAT. In South Africa in particular, HIV/AIDS prevalence rates are especially high, thus, it is critical that screens differentiate ASD from other developmental delays, often resulting from HIV/AIDS (Grinker et al., 2012). Ventola et al. (2007) investigated the symptom presentation differences amongst the following three groups of children failing the M-CHAT; 1) ASD, 2) global developmental delay as well as 3) developmental language disorder groups. They could distinguish ASD from the other groups based on 4 items which were all related to social responsiveness and joint attention (ability to follow a point, pointing to request and for interest, and responding to name). In the Luyster et al. (2011) study of the M-CHAT, in children born before the 28<sup>th</sup> week of gestation, there were also 4 discriminating items, however, only 2 of these overlapped with those identified by Ventola et al. (2007; pointing for interest and ability to follow a point). The other 2 items related to the imitation of others and bringing objects to show (Luyster et al., 2011). However, these are all still related to social and communication deficits which, as mentioned earlier, are thought to indicate an early ASD diagnosis (Barbaro & Dissanayake, 2009; Fernell et al., 2013). Thus, it seems that there are core ASD symptoms, such as those above, by which the M-CHAT is able to specifically distinguish ASD. However, one also needs to be aware that symptoms may change across age ranges.

Children's symptoms may differ at various stages of the rapid early developmental

phase. One needs to ensure that screens primarily include prominent early social and communication markers for earlier diagnoses. However, some repetitive behaviours, which usually develop later (Moore & Goodson, 2003) should also possibly be included in screens. This would hopefully ensure accurate screening in older children too. Fortunately, the M-CHAT screen covers all of these behaviours. However, one possibly requires variations in M-CHAT cut-off scores across the different age ranges (Matson, J., Nebel-Schwalm, & Matson, M., 2007). When investigating the M-CHAT across various ages, Yama et al. (2012) found an increased rate of positive screens in the age group older than 48 months. They concluded that this was not due to the older group being at higher risk for ASD but rather due to some M-CHAT items possibly no longer being applicable to this age group, resulting in increased failed responses; however, the older group's sample size was very small. Pandey et al. (2008) found that overall in a mixed high and low risk sample, the older toddlers (24-30 months) had a slightly higher PPV for ASD on the M-CHAT than did younger toddlers (16-23 months), with values of .79 and .66 respectively. Although, when analysing the high-risk group alone, the PPV between the younger (.79) and older groups were similar (.74; Pandey et al., 2008). It is thought that accurately screening younger toddlers seems most challenging due to their limited interactions with friends, thus, making social and language deficits hard to see (Matson, Wilkins, & González, 2008). However, the M-CHAT was designed for young children and should cater for both younger and older toddlers.

In summary, the M-CHAT is a quick, easy and affordable way to flag those at high risk for ASD (Robins, 2008). In addition, many M-CHAT studies indicate promising results in terms of the tools' ability to identify those at risk for ASD, especially when including the follow-up (Pandey et al., 2008). However, further considerations are required in terms of the M-CHAT cut-off scores, its use across different age groups and developmental disorders, as well as the validity of its cross-cultural application.

### **Cross-Cultural Application of the M-CHAT**

Although ASD prevalence seems similar across different countries (Baird et al., 2006; Fombonne, 2009), the rates have sometimes differed across ethnicity and culture. However, these differences may reflect methodological problems when assessing ASD cross-culturally. Variations may result from culturally determined behaviour and SES possibly influencing the ASD diagnosis (Norbury & Sparks, 2013). Therefore, it is vital to be aware of the possible effects of applying a behaviourally defined screening tool across various cultures. Cultural norms can influence a family's perceptions, acceptance, and expectations of certain

behaviours and development. Therefore, problematic and stereotypical behaviour can be difficult to diagnose in the same way for all populations (Grinker et al., 2012).

Differing cultural perceptions of eye contact, pointing and lack of interest are some examples of behaviour needing consideration when diagnosing ASD. In many African cultures, little eye contact with unfamiliar adults is a sign of respect (Mulaudzi, 2005); but researchers may interpret it as an ASD symptom. However, this discrepancy could be clarified by the parents; as they would note that younger children may still look appropriately at adult faces but without making culturally inappropriate eye contact (Grinker et al., 2012). These ideas about eye contact are also noted in Asian and Latin-American cultures. Furthermore, some cultures also see pointing as rude, thus it is discouraged (Albores-Gallo et al., 2012). Other cultures, such as the Japanese, interpret a lack of interest in another child as shyness, rather than a sign of ASD (Inada et al., 2011). This indicates that there are cultural variations in the acceptability of certain behaviours; thus, these need further exploration and consideration when validating the M-CHAT for particular contexts.

The validation of screening tools cross-culturally even needs to occur when tests of the same language are administered to different populations. Tests require ‘cultural translations,’ as the same concepts may be represented by alternate words in different cultures (Norbury & Sparks, 2013). For example Canal-Bedia et al. (2011) created a new Spanish version for use in Spain, as the Latin-American Spanish version was not culturally appropriate and used slightly different vocabulary. However, caution must be taken to avoid culturally adapting the screening tool so much, that it eventually tests something completely different (Norbury & Sparks, 2013). It is critical to pilot newly translated versions in the population of interest in order to establish optimal tool utility (Soto et al., 2014) and cut-off scores.

The M-CHAT has been effectively modified and translated into Spanish (separate versions from Spain, the Western Hemisphere or Latin America, and Mexico), Arabic, Japanese, Turkish, and Swedish versions. These versions resulted in successful outcomes, similar to the original M-CHAT study. However, to allow optimal validity for cross-cultural use, various adaptations and cut-off scores were used for each sample (Albores-Gallo et al., 2012; Canal-Bedia et al., 2011; Eldin et al., 2008; Inada et al., 2011; Kara et al., 2012; Kimple, Bartelt, Wysocki, & Steiner, 2014; Nygren et al., 2012). The Spain-Spanish (Canal-Bedia et al., 2011) and Arabic versions (Eldin et al., 2008) used the original cut-off scores suggested by Robins et al. (2001), which resulted in similarly high sensitivity and specificity values. No further adaptations of the M-CHAT, other than translations, were required for

Arab countries (Eldin et al., 2008). However, the Spain-Spanish version made minor modifications by rewording 3 items and including culturally relevant examples of toys. They also suggested a cut-off of 5 to decrease false positives (Canal Bedia et al., 2011). The Mexican-Spanish version made minor cultural adaptations such as explaining what ‘peek-a-boo’ was, as there was no word for that game in Spanish (Albores-Gallo et al., 2012). The Japanese version used a cut-off of 2/23 items instead of 3/23 to yield the highest sensitivity (.75) and specificity (.89). They also created a shortened 9-item version, resulting in adequate specificity (.89) but slightly lower sensitivity (.65; Inada et al., 2011). The Turkish M-CHAT was successful, resulting in a PPV of .75. However, in Turkey, it was most successful when healthcare workers read through questions with parents to clarify any confusion. This study also found that different items had more diagnostic power than the originally suggested critical items (Kara et al., 2012). The Swedish M-CHAT only required minor adjustments when translating, resulting in an acceptable sensitivity value, using the originally suggested cut-off scores (Nygren et al., 2012). Therefore, in all these cases the M-CHAT appeared cross-culturally valid.

The above cross-cultural applications only required minor adjustments for their respective populations. However, the application and translation of the M-CHAT into Sinhala in Sri Lanka was not as successful in terms of its sensitivity (.25) and PPV values (.13), but its specificity was adequate (.70). The researchers ascribed these low values to a number of possibilities; the first being, mothers not recognising social and communication behaviours as abnormal due to cultural ideas. Secondly, yes/no type answers possibly resulted in parents tending towards the answer indicating typical development when in doubt, especially when considering the social stigma around ASD (Perera et al., 2009). Another US study in a very low SES rural sample suggested that the M-CHAT (English and Spanish-Western Hemisphere versions) required further modifications for use in low SES, low education, and minority groups. They found that low maternal education and minority group status resulted in slightly higher M-CHAT scores, however, diagnostic evaluations were not analysed for this sample (Scarpa et al., 2013). Although these reflect somewhat more negative results on the M-CHAT’s application, it is critical to note that both studies appear not to have used the follow-up interview which is known to significantly improve the M-CHAT outcomes (Kleinman et al., 2008; Robins et al., 2001).

In summary, different populations have contrasting ideas on what constitutes acceptable behaviour, thus behaviourally defined tests are likely to need cultural adaptations for the population of interest. Most of these M-CHAT modifications have been successful,

but not all; therefore, initial validation of new versions is essential. Furthermore, the follow-up is critical, especially in different populations where there may be more misunderstandings, thus, clarifications on items using the follow-up are even more of a necessity (Kimple et al., 2014). South Africa is particularly diverse in terms of language and culture, therefore, validity testing of adapted versions of the M-CHAT is especially important. However, previous promising outcomes point towards the M-CHAT's likelihood of being a valid and useful tool in South Africa too.

### **Summary and Rationale for Research**

ASD affects around 1% of the child population (Baird et al., 2006), with significant effects on the children and their families throughout their lifetimes (Ganz, 2007). With the increasing prevalence of ASD (Elsabbagh et al., 2012; Fombonne, 2009), there is an increasing critical demand for screening, diagnosis and intervention. Introducing the routine use of early screening tools at healthcare sites in the Western Cape is a crucial first step towards achieving earlier diagnosis and intervention in South Africa. However, to my knowledge, no screening tools seem to have yet been formally validated for this context. Therefore, confirmation of the validity of screening tools such as the M-CHAT for this linguistically and culturally diverse population in South Africa is vital.

The M-CHAT does not result in an ASD diagnosis, but it has indicated promising outcomes in terms of flagging individuals at high-risk for ASD in numerous different settings. However, further clarification of its finer discriminating abilities in samples with developmental disorders will also be valuable. The M-CHAT is particularly useful as it is free, quick and easy to fill out and requires minimal resources in terms of administration. These are all essential components when finding an ideal screening tool for the overburdened healthcare system in South Africa, where the primary users are from low SES backgrounds.

Quickly flagging children at high risk helps prioritise those most in need of assessment, and prevents unnecessary diagnostic assessments from being carried out. Therefore, the long waiting lists for services would hopefully be decreased. Early screening ensures that children receive a timely diagnosis, which may be necessary for access to educational and intervention services. The earlier these services are accessed, the better the long-term outcomes for individuals, families, healthcare and education systems, as well as for society overall.

## Specific Aims

This thesis aimed to translate, adapt and preliminarily validate the M-CHAT screening tool for use in a high-risk sample in the Western Cape, South Africa. Initial pilot data had indicated the M-CHAT's success in discriminating children with ASD from neurotypical children in this context (Stephens, 2012). Therefore, in this thesis, a more stringent test of the M-CHAT's ability to differentiate ASD from other developmental disorders across different population groups was assessed. The screen's preliminary validation took place at a state hospital developmental clinic where it is likely to be used in future, with the aim of rendering ecologically valid results.

Phase 1 of the study included the translation, adaptation and administration of the M-CHAT, which was the focus of this thesis. The main aim was to examine the use of the culturally adapted and translated South African (SA) English, Afrikaans and IsiXhosa versions of the M-CHAT (see Appendices A, B and C) in great detail, as it was essential that all language versions were equally and correctly understood by the sample. Therefore, in each case the M-CHAT was investigated overall and across the 3 language versions.

It was also examined across age ranges: the current study included the previously validated M-CHAT age range of (1.5 years- 4.00 years), as well as an extended age range (4.01 years – 4.99 years). This extended range was to examine the M-CHAT's potential use in older children. This was necessary as it is not clear which instruments are most appropriate around this age (Allen et al., 2007), regression may occur later, and the age of ASD diagnosis in South Africa is likely later than in other countries, thus screening possibly needs to occur until a later stage.

Investigations into the effect of important demographic characteristics on M-CHAT scores were carried out. Furthermore, the necessity of the follow-up interview in this context and the patterns of items failed were further investigated, to see how these compared to other studies. In addition, any problems with administration were noted so that these could be attended to before routine use of the tool.

This thesis presents only preliminary results from phase 2. This information provides diagnostic assessments to investigate the M-CHAT's predictive abilities for ASD. This analysis offers an exploratory investigation into how well the SA English M-CHAT predicted ASD. The aim was to clarify previous findings that the M-CHAT should sufficiently discriminate ASD from other developmental disorders, but in the Western Cape, South Africa. Additionally, preliminary cut-off points, sensitivity, and specificity for this high-risk

Western Cape population were examined and compared to previous M-CHAT validation studies.

## **Methods**

### **Design and Setting**

This study is part of a larger project aiming to adapt and validate screening tools for ASD in the Western Cape, South Africa. The research reported on in this thesis examined whether adapted and translated versions of the M-CHAT are suitable in this context. It also looked at whether these M-CHAT versions are capable of distinguishing ASD from other developmental disorders in young South African children.

This study used a quasi-experimental cross sectional design. In phase 1, investigations into the effects of demographic variables on M-CHAT scores were carried out and the results compared across the three M-CHAT versions (SA English, Afrikaans and IsiXhosa). In the original study, Robins et al. (2001) used the M-CHAT for 18-30 month old children; however, it is found to be valid up until 48 months (Eaves et al., 2006; Snow & Lecavalier, 2008; Yama et al., 2012). This current study's age range was extended even further, to include children up to 59 months (4.99 years). Therefore, the M-CHAT's appropriateness for the original age range suggested by the literature (1.5-4.00 years) and the extended age range (4.01-4.99 years) used in this study was also investigated.

Preliminary data from phase 2 of the larger protocol are also presented. For the research reported here, this constitutes a preliminary investigation into the extent to which M-CHAT scores successfully predict ASD vs. non-ASD risk, in a high risk sample. In a subset of participants filling in the English M-CHAT, we examined the extent to which children screening positive for ASD on the M-CHAT were in fact formally diagnosed with ASD, using the Autism Diagnostic Observation Schedule (ADOS (Lord, Rutter, DiLavore, Risi, 1999)/ADOS-2; (Lord, Luyster, Gotham, & Guthrie, 2012; Lord, Rutter et al., 2012)).

### **Ethical Considerations**

This study followed the ethical guidelines of the University of Cape Town (UCT) codes for research with human subjects and of the Declaration of Helsinki (2008). Ethical approval for the larger study was obtained from the UCT Faculty of Health Sciences Human Research Ethics Committee (see Appendix D), and the School of Child and Adolescent Health at Red Cross Hospital (see Appendix E). Further approval from the UCT Department of Psychology Ethics committee was obtained.

**Consent and confidentiality.** We made it explicit from the outset that declining or discontinuing participation at any stage would have no negative consequences for the parent or the child in terms of care and treatment at the participating state clinic. The researchers explained the process of the study to the parents and parents were encouraged to ask questions. They were informed that all information would be kept strictly confidential, that it was only available to the researchers on the project, and that individuals would not be identifiable in any write-ups of the data. Furthermore, they were told that their data would be stored securely. Parents were also informed that they would receive feedback on their child from the clinic doctors, when the results were available.

We obtained written consent from the parent to take part in the screening (phase 1) and these informed consent forms were completed in the parent's language of choice (English, Afrikaans or IsiXhosa; see Appendices F, G and H). Parents who consented to the screen were also asked whether they would consent to be contacted for further research (see Appendices I, J and K). Only parents who provided this consent were contacted for phase 2 of the study. We then obtained further written consent for both the parent and their child's participation in the diagnostic assessment, as well as consent for this to be video recorded (see Appendix L).

**Risks and benefits.** There was no added risk when participating in the study. Screening took place at the hospital, on the day of the parent's normal visit. Children of parents completing the screen were not removed from any waiting lists for assessment. Those participating in the diagnostic assessments were remunerated in terms of transport costs to the clinic, as well as being provided with a snack and drink in-between testing. We also took breaks in-between assessment tasks to prevent fatigue.

Doctors of the participants were given the information (via the developmental clinic head, Assoc. Prof. Donald) from the screening and diagnostic assessments. When giving screening results to doctors, they were reminded that it was a screening result and not a formal diagnosis, and that its validity for use in South Africa was still under investigation. However, it was considered useful clinical information and could be used to indicate whether to investigate high ASD risk further. The diagnostic assessment results were also given to the doctors; this provided useful extra information or clarification on the child's ASD diagnosis. The outcome was communicated to the parents, via the doctors, to provide detailed information about their child's current developmental status. If the child was found to be on the autism spectrum, the parents were given an information leaflet about the disorder (see Appendix M). This leaflet gives information explaining ASD symptoms, as well as what the

next steps for the child are i.e. support groups, schools and interventions. The children on the spectrum would also then be referred by the doctors to occupational and speech therapy at the Red Cross Children's Hospital. The diagnostic assessment results may have caused some concern for parents, especially if they were unaware of their child being on the ASD spectrum. However, parents were already at this tertiary level clinic due to concerns about their child's development and the information was conveyed by doctors who regularly manage cases of developmental disorders. Moreover, this information would benefit the child and family, as they could then seek treatment and support to achieve the best possible outcomes for the child.

Several participants did not consent to future research, or recruitment into phase 2. In these cases, concerning M-CHAT results were still conveyed to the doctors at the developmental clinic, thus, diagnostic assessments could be prioritized, if necessary.

**Dissemination of results and benefits to society.** Once the larger project is complete, it will be written up and posters will be made. Posters will portray the research results in community accessible terms, and will be displayed at the Red Cross Children's hospital. If the screening tools investigated in the larger project (the M-CHAT and Social Communication Questionnaire (SCQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999) are valid in this context, their use can continue at Red Cross. They will also be made available to other health care professionals in the Western Cape. Information sessions about the screening tools will be held. This educates others on the validity and benefits of their use in flagging young children at high risk for ASD. Screening tool use can assist children in gaining earlier access to diagnosis and intervention, to ensure optimal developmental outcomes. Without this beneficial early ASD screening, cases may go unnoticed and only be flagged at a later stage, where intervention outcomes may not be as successful.

## **Procedure**

Please see Figure 1 below for an overview of the procedure followed for phase 1 and phase 2 of the study.

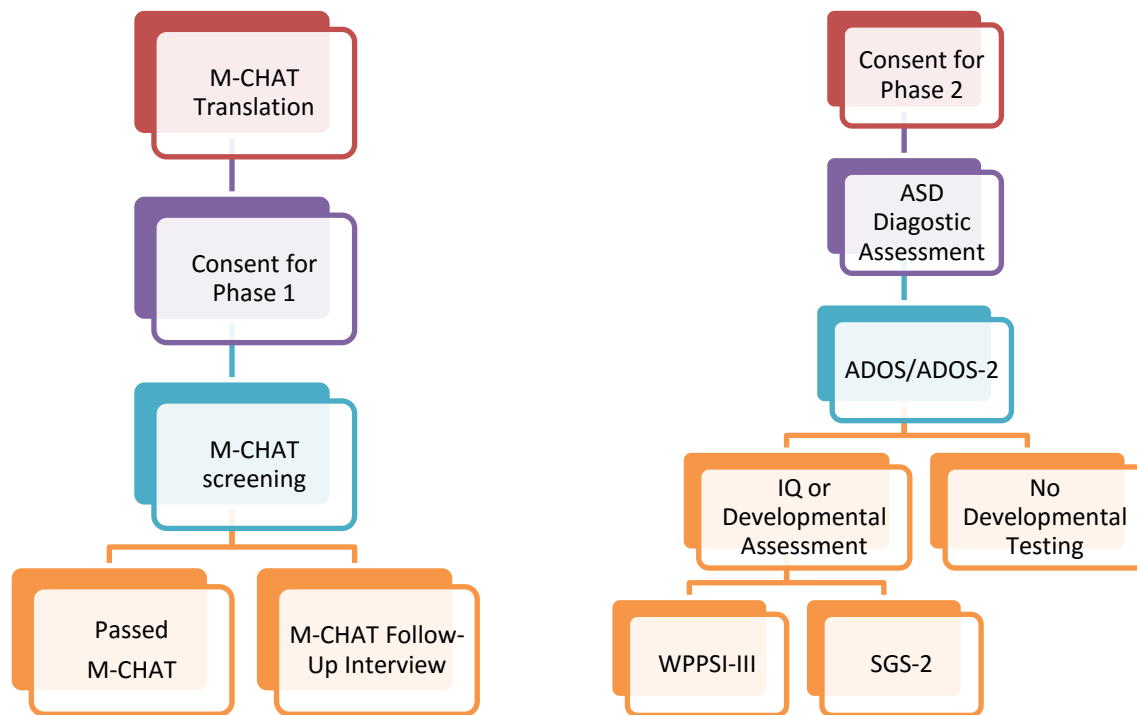


Figure 1. Overview of the steps involved in phase 1-screening (left) and phase 2-diagnostic assessment (right) of the study.

### Phase 1.

**Translation.** We had written permission from the M-CHAT authors to translate the instrument. The English M-CHAT version was adapted for South Africa. The Afrikaans and IsiXhosa versions were adapted, translated, and back translated. The translations are simple; using phrases familiar to the Western Cape population. A consensus meeting including researchers, translators, and community members was also held to ensure that the language for each item was appropriate, and that each item still asked the same question in each language version. Following this, it seemed that each version was easily understood and correctly interpreted.

Items 3 and 11 were adapted in all versions by giving different examples of the behaviours, to increase understanding. For example, in item 3 (*Does your child like climbing on things, such as on chairs or other things?*); the example of the behaviour was changed from climbing up ‘stairs’ to climbing on ‘chairs or other things,’ because stairs are seldom found in most South African houses. In item 11 (*Does your child ever seem oversensitive to noise [e.g. blocks ears]*), the example changed from ‘plugging ears’ to ‘blocking ears,’ to ensure that the behaviour is more easily understood.

Equivalence across all languages was also ensured as far as possible. For example,

initially item 16 of the Afrikaans version was phrased as ‘*can* your child walk?’ but the English version was phrased, ‘*does* your child walk?’ The Afrikaans version asked whether the child is able to walk, whereas the initial English version rather asked whether they choose to walk. Therefore, the Afrikaans version was re-worded for equivalence.

The versions were also adapted by using familiar phrases and examples. For example, the IsiXhosa version offers examples of culturally specific games for item 8. The English version of item 8 (*Does your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling or dropping them?*) offers ‘cars or blocks’ as examples of toys. However, the IsiXhosa version also offers the examples of ‘cars, blocks, washing pegs or any other small things.’ These examples seemed more relevant to IsiXhosa speaking children as they often do not have their own toys/ blocks, but rather play with any small objects around the house.

In the IsiXhosa culture, due to cultural norms, assessing eye contact is problematic. It can be regarded as disrespectful for children to make eye contact with an adult. Therefore, item 10 (“*Does your child look you in the eye or face for more than a second or two, in an appropriate way?*”) was adapted from “*Does your child look you in the eye for more than a second or two?*” for the IsiXhosa M-CHAT. Thus, it was changed to the way the child looks at the eyes *or* face of an adult because it is likely that a child will look at an adults face but not in their eyes, out of respect. It also mentions that this must be done ‘in an appropriate way’ to account for instances where the child does not look appropriately or as often as one would expect for a neurotypical child, thus possibly indicating ASD.

The M-CHAT follow-up interview was also adapted and translated for the South African context. The vocabulary and examples that changed on the initial M-CHAT screen questions (as mentioned above) were adapted in the same way for the follow-up interview. However, the questions and examples in the flow charts below the main question in query, were translated as directly as possible from the original follow-up. If there was not a direct translation for a word, the word closest was indicated, with a second translation in brackets for clarification. Due to limited resources, these translations have not yet been back translated; however, the translators for the forward translations were familiar with the context in which they would be used.

**Recruitment and screening.** Researchers fluent in the Western Cape languages approached parents/caregivers in the waiting room at the Red Cross Hospital Developmental Clinic. These parents were attending this clinic because of concerns about their child’s development. Parents were given a brief description of what the study would entail. If

wanting to take part, they were asked what their home-language was and were given a detailed information sheet in their preferred language of English, Afrikaans or IsiXhosa. On each occasion researchers offered to read through the information and questions with parents, in case they had poor levels of education: they could then choose whether to do it themselves or with the researchers' help. Parents were encouraged to ask questions and those choosing to participate gave written informed consent to take part in the screening (phase 1). They were then given a socio-demographic questionnaire (see Appendices N, O and P) and the M-CHAT to fill in (all in their language of choice). Researchers remained on hand, providing input and explanations to parents requiring it, in an attempt to ensure that parents understood the questionnaires and hence provided valid answers.

If the child screened at risk for ASD on the M-CHAT, the follow-up interview was conducted, either straight away or over the telephone, to check whether the problematic behaviours were indeed present. Failed questions indicating ASD risk were repeated and specific examples of the behaviour in question were obtained. This clarified confusion that parents may have had, regarding the behaviours to look for. If we could not reach parents telephonically, we would try to follow them up on their next clinic visit, provided the child was not yet past the defined age range. Problems that parents had in understanding any items on the M-CHAT were noted.

## **Phase 2.**

***Diagnosis confirmation.*** On the original consent form, parents were also asked if they would consent to being contacted for future research. For phase 2 of this study, only English participants were eligible to take part, as the Afrikaans and IsiXhosa versions of the diagnostic tools are not yet available (for the larger study, full groups of each language version will be contrasted). The aim was to include equal numbers of children in the following groups; high risk for ASD, close to the western normed cut-off scores, and no risk for ASD, according to the M-CHAT scores.

Parents providing consent to be contacted further, were invited to take part in the formal diagnostic assessments with their child, and  $n=28$  agreed to this. These took place in private rooms at the University of Cape Town (UCT) Child Guidance Clinic. Parents were given information about the assessment beforehand. They were reminded that they could withdraw at any stage without negative consequences. They were also asked for further consent to take part in these assessments and for the session to be filmed. In this phase, the M-CHAT screening results were confirmed against a well-established, 'gold standard'

diagnostic measure, the ADOS/-2 (Luyster et al., 2009). Qualified researchers trained in the ADOS-2 (researchers for the ASD assessment were blind to M-CHAT scores), Wechsler Preschool and Primary Scale of Intelligence, third edition (WPPSI-III; Wechsler, 2002) and Schedule of Growing Skills, second edition (SGS-II; Bellman, Lingam & Aukett, 1996), conducted the assessments. The ADOS-2 was administered first, with the parent and the child in the room. There was then a 30-minute snack break before the IQ or global developmental assessments were administered to the child. All assessments took no longer than 3 hours in total and parents could ask questions at the end of the session.

In addition to the phase 2 participants described above, participants that took part in the pilot phase of this project ( $n=10$ ) were diagnosed using the original ADOS (Lord et al., 1999), at the UCT Child Guidance Clinic. The children in this group had their ASD diagnosis and were then subsequently asked if they would give consent to filling in the M-CHAT too. They did not take part in the IQ/developmental assessments. This small group was included to increase the available numbers in the preliminary phase 2 analyses.

Diagnostic results were made available to the Doctors (via Assoc. Prof. Donald- head of the Development Clinic) at the Red Cross Children's Hospital, for improved case management. These doctors would put the information in the child's hospital folder and inform parents of the results, along with detailed feedback about the developmental status of their child.

## **Participants**

**Phase 1- screening.** The recruitment of the  $N=255$  parents/caregivers concerned about their child's cognitive or social development took place at the Red Cross Children's Hospital Developmental Clinic. This recruitment took place every second week between September 2012 and October 2013 and again between February 2014 and March 2015. A break was taken in recruitment because the same patients repeatedly came in for follow-ups at the clinic. Therefore, we waited a few months for a sufficient intake of new patients, before recommencing recruitment.

The parents had to have a child between the ages of 1.5 years – 4.99 years to take part. We extended the maximum suggested age found in the literature for the M-CHAT from 4.00 years to 4.99 years, to investigate its utility in a slightly older age range. This was to see whether the M-CHAT could successfully flag older individuals. Furthermore, it is not clear which screening instruments are most appropriate for this age (Allen et al., 2007). Although the M-CHAT is valid from 16 months, we decided to only include participants from 18

months, to facilitate comparisons with most other studies, as some studies only investigate the M-CHAT from 18 months. In the original age range suggested by previous literature (1.5-4.00 years), there were  $n=158$  participants and in the extended age range (4.01-4.99 years) there were  $n=97$  participants.

All parents in the clinic waiting room were invited to take part. Participants were only selected when their child fitted the age range, but not based on any other demographic criteria. We felt it more important to have a population representative of those using this clinic, rather than having equal numbers within each demographic profile. However, this is a state-funded hospital; thus, it is likely that the demographic breakdown of this sample is largely representative of a low SES population.

Participants with sensory deficits were excluded, because the M-CHAT has some questions that assume that a child can see or hear. Participants were also excluded where parents could not be reached for the follow-up interview (due to incorrect numbers or changing numbers from phones being lost or stolen), where forms were incomplete or in cases where children were significantly overage for the follow-up, due to difficulties in contacting them. Due to these factors, 26 participants were excluded. Due to prolonged difficulties in contacting some participants, a few had children slightly overage at the follow-up, however, if the children were still less than 5 years, 6 months, they were included ( $n=6$ ).

Ideally, we would have preferred to only include undiagnosed participants visiting the clinic for the first time as the M-CHAT would typically screen such cases. These cases would be ideal as the parents are likely to have less ASD knowledge and the children are unlikely to already be part of intervention programmes. Therefore, M-CHAT scores would have been unlikely to be affected by these factors. However, there were few first time visitors during the long period of recruitment.

**Phase 2- diagnostic assessment.** The diagnostic phase of the study included 38 parents in total. Of those parents at Red Cross giving consent to take part further,  $n=28$  came in with their children for the diagnostic assessment, using the ADOS-2 at the UCT Child Guidance Clinic. The other  $n=10$  children had formal diagnoses, using the ADOS, from the initial pilot study. All participants in this phase had completed the English M-CHAT as the ADOS/-2 assessment is currently only available in English.

## Measures

### Phase 1.

***Socio-demographic questionnaire.*** This short questionnaire asks parents details such

as household income and assets, parental education, as well as child's age, race and home-language. There were additional questions around whether the child had a formal diagnosis and regarding any concerns parents may have had with their child's development.

**Modified Checklist for Autism in Toddlers (M-CHAT).** The M-CHAT (Robins et al., 2001) is a self-report parent questionnaire, consisting of 23 yes/no items, which takes 5-15 minutes to complete (Robins, 2008). It indicates children at high risk for ASD by enquiring about crucial aspects of the child's observable behaviour. Children can fail using the following cut-offs; 2/6 critical items failed or any 3/23 items failed (Robins et al., 2001). Those failing receive a follow-up interview (see Figure 2), either face-to face or telephonically. These questions are presented in a flow-chart format, where initially failed items are re-administered to see if behaviours are still present, and specific examples of the behaviours are acquired. As mentioned earlier, the follow-up decreases false positives and increases specificity (Robins et al., 2001). The psychometric properties and cross-cultural applications of the M-CHAT were discussed earlier. These reveal its promising cross-cultural validity, and likely applicability in South Africa.

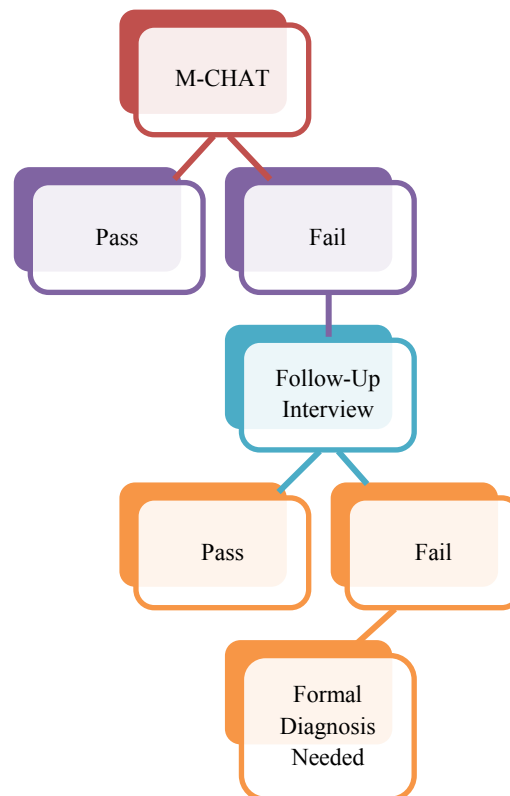


Figure 2. The process of administering the M-CHAT.

## **Phase 2.**

***Autism Diagnostic Observation Schedule-2 (ADOS-2).*** The ADOS-2 (Lord, Luyster, et al., 2012; Lord, Rutter, et al., 2012) is a standardized semi-structured assessment tool which takes 40-60 minutes to administer. It caters for ages from 12 months into adulthood and is a revised version of the original ADOS. This revised algorithm demonstrates a high predictive validity (Lord, Luyster, et al., 2012; Lord, Rutter, et al., 2012) with improved sensitivity and specificity values (McCrimmon & Rostad, 2014).

It uses different planned activities to elicit behaviours relating to ASD, by assessing the child's communication, social interactions, imagination/play and restricted and repetitive behaviours. The two main domains measured are Social Affect (SA) and Restrictive and Repetitive Behaviour (RRB). One of five modules is completed by the child, depending on their developmental level and language capability (Lord, Luyster, et al., 2012; Lord, Rutter, et al., 2012). The ADOS-2 is the global gold-standard measure for ASD diagnosis. In order to administer it, clinicians first need to undergo the clinical training (McCrimmon & Rostad, 2014); for this study researchers had achieved research reliability.

Each module involves interactive activities using different materials (e.g. remote control toys, bubbles and snacks). In this study, given the young age range, only the toddler module and modules 1 and 2 were used. The Toddler Module (12-30 months), for children not using phrase speech consistently, consists of activities that are loosely structured and involve highly motivating materials. This Toddler Module focuses on the 'range of concern,' because of the uncertainty of ASD diagnoses at such a young age (Lord, Luyster, et al., 2012), however, it has been found that the ranges do appear to sufficiently predict diagnoses later on (Guthrie et al., 2013). Module 1 (31 months and up) is for older children not consistently using phrase speech. Module 2 is for a child of any age that uses phrase speech, without being verbally fluent. Observed behaviours from the assessment are coded ('3' indicates marked abnormality and '0' indicates no abnormality). The child's score is then calculated using an algorithm. This indicates a placement in the 'range of concern' or the classification of autism, autism spectrum or non-spectrum (Lord, Luyster, et al., 2012; Lord, Rutter, et al., 2012).

*Toddler Module.* This module indicates high sensitivity and specificity levels, with values above .86 (McCrimmon & Rostad, 2014). It also demonstrates high test-retest reliability (.64-.88) and high inter-rater reliability (.87-.97). However, in the Toddler Module, the RRB domain (.50) has a lower internal consistency than the SA domain (.88-.90; McCrimmon & Rostad, 2014). Although, the lower RRB internal consistency is somewhat

expected because RRBs are not as evident at this young age (Moore & Goodson, 2003).

*Module's 1-3.* The sensitivity (.60-.95) and specificity (.75-1.0) values are high and were specifically improved for modules 1 and 2. The internal consistency for modules 1-3 in the SA domain are high (.87-.92) and the RRB domain indicates a moderate reliability (.51-.66). These modules also demonstrate high test-retest reliability (.68-.92) and very high inter-rater reliability (.92-.98; McCrimmon & Rostad, 2014).

***General cognitive ability or developmental level.*** In phase 2 of the study, the WPPSI-III (Wechsler, 2002) or SGS-II (Bellman et al., 1996) were administered. ASD is not necessarily associated with intellectual disability (ID)/developmental delay (DD), however, when it is, it is difficult to distinguish from pure ID/DD. Therefore, an IQ or global developmental assessment is important for indicating the extent to which IQ or DD confounds the M-CHAT result and whether the screen distinguishes ASD with ID/DD from pure ID/DD.

*The Wechsler Preschool and Primary Scale of Intelligence, third edition (WPPSI-III).* The WPPSI-III provides estimates of intellectual functioning in particular cognitive domains, and an estimate of general intellectual ability. It is for children aged 2 years, 6 months to 7 years, 3 months but deals with two separate age bands, for children above and below 4 years. The tests for each age band differ in terms of difficulty, time of administration, verbal expression reliance and score structure (Wechsler, 2002).

There are three types of subtests in the WPPSI-III: core, supplemental and optional. Combinations of subtest batteries result in different IQ measurements, such as full scale (FSIQ), performance (PIQ), verbal (VIQ) and processing speed IQ (PSIQ), as well as general language composite (GLC). When PIQ, VIQ and FSIQ are required, core subtests are administered (Wechsler, 2002), thus, only the core subtests were used here.

The FSIQ, GLC, PIQ and VIQ split-half reliabilities were high in the normative sample (.93-.96). Test-retest reliability was also excellent, with the coefficients above or equal to .90 for the PSQ, VIQ and FSIQ. There was a range of .84-.87 for the PIQ stability coefficients. The reliability coefficients of the subtests range from .84-.95 and in autistic disorder, they range from .94-.98. Results seem to support the validity and clinical utilisation of the WPPSI-III in clinical groups (Wechsler, 2002).

The items on this version have been reviewed by the developers to try and exclude bias in terms of SES, ethnicity and gender for the US population (Wechsler, 2002). This should act to improve its applicability to the diverse South African population.

*Schedule of Growing Skills- second edition (SGS-II)*. This instrument measures child development in children aged 0-5 years. Therefore, in this study it was used for children too young or too delayed for the WPPSI-III. The SGS-II can be part of an interview and observation with parents and their children. The assessment is based on nine developmental areas: active posture, passive posture, manipulative (fine motor), locomotor (gross motor), hearing and language, speech and language, visual, self-care, social and interactive social skills. There is a further subdivision of these skill areas into 'skill sets.' The most advanced items reached in each skill set are added together to give a total score for the skill area. The total scores identify an estimated age of functioning, within each developmental area (Bellman et al., 1996).

### **Data Analysis**

IBM SPSS version 22 was used for all statistical analyses. All assumptions for the analyses were investigated and in the few cases where these were violated, alternate statistical analyses were used or the data was log transformed to ensure normality. Instances where this occurred will be mentioned in the relevant sections below. Because a large number of statistical analyses were carried out, an adjusted p-value was used. The Bonferroni correction method would have been too conservative for exploratory data (Sainani, 2009); therefore a more lenient adjusted  $p$ -value of .01 was used throughout.

**Phase 1 - screening.** In the analyses one had to consider the outcomes for 1) the total sample, 2) across the 3 M-CHAT versions (SA English, Afrikaans and IsiXhosa) and 3) across the 2 age ranges (the 'original age range' suggested by previous literature and the 'extended age range' included in this study). Furthermore, in each case there were two possible final M-CHAT scores, using either the overall 23-item score or the critical 6-item score.

**Demographic characteristics.** The demographic variables per age group were investigated. The demographic characteristics which were continuous variables (child's age, household income, and mothers education) were compared (using ANOVA) across the 3 M-CHAT versions. This investigated differences in these characteristics across each version, to see whether the M-CHAT versions differed significantly on certain variables. In cases where there was non-homogeneity of variance, the Welch statistic was used instead of the F statistic. The categorical variables (child's sex, ethnicity, and home language) did not contain enough participants in each of the categories (multiple expected frequencies were <5) to carry out formal statistical analyses, therefore, they were descriptively analysed.

*M-CHAT language chosen based on home language.* This was a descriptive investigation into the home languages of participants and which M-CHAT version they chose to fill out.

***M-CHAT score comparison.*** Within each age range, the final M-CHAT scores were compared across the three M-CHAT versions (using ANOVA). The final scores for the M-CHAT were also compared across the two age ranges within each M-CHAT version (using independent t-tests). This indicates whether the M-CHAT scores are similar across the different M-CHAT versions, per age group, as well as across each age group within each M-CHAT version. In these analyses, both final M-CHAT scores were log transformed [ $\log(\text{M-CHATscore}+1)$ ] to ensure a normal distribution.

***Correlation of demographics to M-CHAT score.*** Each of the demographic variables (except ethnicity and home language) was correlated with the two final M-CHAT scores. This was investigated within each age range (all M-CHAT versions combined), and within each M-CHAT version (all age ranges combined). Where there were significant correlations, these were further investigated. For example, the Afrikaans M-CHAT group was broken down into the two separate age ranges to see the effects of age on the 6-item score. These analyses investigated whether any particular demographic variables had a relationship with the M-CHAT scores. Again both final M-CHAT scores were log transformed [ $\log(\text{M-CHATscore}+1)$ ] to ensure a normal distribution.

***Correlation of final M-CHAT scores to one another.*** The relationships between the two M-CHAT final scores (overall 23-items and the critical 6-items) were investigated. These correlations were carried out for each age range and then for each M-CHAT version separately. Both final M-CHAT scores were log transformed [ $\log(\text{M-CHATscore}+1)$ ] to ensure a normal distribution.

***Descriptive examination of relationship between home language and ethnicity with final M-CHAT scores.*** The home language and ethnicity variables consisted of more than two categories each; therefore, they were not included in the correlational analysis because the order in which they were entered would have affected the outcome. Thus, the M-CHAT score averages and ranges were descriptively investigated within each category of the variables of home language and ethnicity.

***Internal consistency.*** Cronbach's alpha measured the internal consistency for the 23-items and for the 6 critical items of the M-CHAT in each set of analyses. This was calculated for the total sample (ages and M-CHAT versions combined), for each age range (M-CHAT versions combined), for each M-CHAT version (both age ranges combined), as well as across

the age ranges within each M-CHAT version. However, the extended age range in the Afrikaans and IsiXhosa versions could not be investigated due to insufficient numbers in these groups. The internal consistency indicates whether the questionnaire reflects what it set out to measure, in this case, autistic traits. Item-total correlations were investigated to look for indications of problem items that should possibly be removed or re-worded for this context.

***Analysis of each M-CHAT item.*** An M-CHAT item-by-item analysis was conducted (similar to the analysis carried out by Robins et al. (2001)) within each of the following groups: a) participants requiring no follow-up, b) participants passing the M-CHAT after follow-up, and participants that c) failed the follow-up. The percentage failure of each of the 23 M-CHAT items, within each of the groups was calculated. From this, we could gauge which items seemed most pertinent and which were failed too often or too seldom, therefore, which items were possibly not indicating ASD sensitively enough.

The percentage of participants failing particular M-CHAT items initially and then passing on follow-up was also investigated for all 23-items. This may indicate instances where initial questions are not clear enough from the outset, thus the correct answers were only clarified through the follow-up examples.

***Investigation into changes in outcome after follow-up.*** An investigation into the necessity of the follow-up interview was carried out. This assessed the percentage requiring a follow-up and how often participants' outcome changed (high to low ASD risk) after the follow-up had been administered. This was investigated for the overall sample, as well as using the sample that filled out the SA English M-CHAT.

Of those filling out the SA English M-CHAT, many indicated a home language other than English, therefore the effects of this on the number of follow-ups needed and the number of outcomes that changed after follow-up were investigated. This observed whether filling out the M-CHAT in a 2<sup>nd</sup> language was problematic in terms of requiring too many follow-ups or too many participants changing their outcome after the follow-up, possibly indicating difficulties with understanding the initial M-CHAT screening questions.

**Phase 2 – diagnostic assessment.** In the following analyses for the diagnostic assessment data, there were only English speaking participants. The ADOS/-2 was the tool used to determine the diagnostic outcome. In each case the statistical analyses were performed separately for the overall 23-item M-CHAT score and then for the critical 6-item M-CHAT score. No transformations for normality were required in this sample of participants.

**Demographic characteristics.** The demographic characteristics in the ASD and non-ASD groups were investigated. Where the demographic variables were continuous rather than categorical variables, *t*-tests were carried out to measure their differences across the ASD and non-ASD groups. It was noted where equal variances were not assumed. The categorical variables were descriptively analysed due to small numbers in each category.

**M-CHAT score comparison in ASD and non-ASD.** The average final M-CHAT scores between these two groups were investigated using independent *t*-tests. The tests were 1-tailed, because it was assumed that the M-CHAT scores would be higher in the ASD group compared to the non-ASD group.

**Descriptive comparison of diagnosis using either the 23-item score or the 6-item score.** The number of participants that passed (low ASD risk) or failed (ASD risk) the M-CHAT and those that were diagnosed as ASD or non-ASD were investigated. This was carried out separately for the 23-item M-CHAT score and then for the 6-item M-CHAT score to identify which score seemed better in correctly flagging those individuals at high risk for ASD. From this, positive and negative predictive values could also be calculated.

**M-CHAT's ability to distinguish ASD with ID/DD from pure ID/DD.** The results from the IQ and developmental assessments (WPPSI-III and SGS-II) were qualitatively analysed to investigate whether an intellectual or global developmental delay was present in the ASD and non-ASD cases. The M-CHAT outcomes for the ASD and non-ASD cases with and without ID/DD, were investigated. Participants failing the M-CHAT but in the non-ASD group were specifically investigated, in terms of whether an ID/DD was present or not, as this may have affected their M-CHAT scores. This attempted to see whether the M-CHAT could effectively distinguish between ASD with ID/DD and pure ID/DD.

**M-CHAT's ability to predict ASD.** Binary logistic regression established whether the number of failed M-CHAT items could successfully predict ASD or non-ASD. Screening measure scores were predictor variables and diagnostic assessment outcomes (ASD vs. non-ASD), the outcome variable. Logistic regression was performed separately for all 23 M-CHAT items, and for the 6 critical items.

All assumptions for logistic regression were upheld. The Nagelkerke  $R^2$ , as well as the Cox & Snell  $R^2$  indicate the relationship strength between the M-CHAT score and diagnostic classification. The Wald criterion showed whether predictors significantly contributed to the outcome's prediction. Finally, the Odds Ratio value indicated the likelihood of an ASD classification with a one-unit increase in the M-CHAT score.

**Preliminary cut-off point analysis.** To determine cut-off scores resulting in the best

sensitivity and specificity, Receiver Operating Characteristic (ROC) analyses were used. ROC curves allow a visual depiction of the sensitivity and specificity at different cut-off points. These aspects of the M-CHAT were investigated as an indication of its utility in the Western Cape. It is essential to establish optimal cut-off scores for the screen in this context.

This was carried out separately using all 23-items and only the 6 critical items. Area under the ROC curve values greater than .50 indicate that the M-CHAT is predicting the diagnostic outcome better than by chance (Fawcett, 2006). The larger the area under the curve (AUC), the better the M-CHAT was in predicting ASD or non-ASD.

## **Results & Discussion**

This project in particular focuses more on the first phase of the study, in terms of the adaptations of the M-CHAT and its applicability to this Western Cape context. There is a smaller, nevertheless important focus on the second phase of the project, to begin investigating how well the M-CHAT predicts ASD and non-ASD in this sample from a developmental clinic. There were many aspects requiring investigation in this thesis, therefore the discussion of each set of findings is integrated with results. This is both to facilitate understanding and to avoid repetition.

The results and discussion will cover the following:

- The response rate and the demographic profile of the sample.
- The differences in demographic characteristics across the three M-CHAT versions in each age range and their effects on the M-CHAT score.
- The extended age range's impact on the M-CHAT scores, compared to the original age range suggested by previous literature.
- The internal consistency of the 23-item and 6-item M-CHAT score.
- An item-by-item analysis of the M-CHAT and the necessity of the follow-up interview.
- The ability of the M-CHAT to differentiate ASD from non-ASD, and the optimal cut-off points for this sample of children with suspected developmental disorders.
- An overview regarding strengths and difficulties of the M-CHAT and its use, as shown by this study, will be discussed.
- Finally, the limitations and directions for future research will be discussed.

## **Phase 1 – Screening**

**M-CHAT rate of responding.** In the waiting room, the majority of children were above the age range (even above the extended range included in this study) for the M-CHAT. Of those fitting the criteria, about 80% agreed to take part. Although a larger number ( $n=281$ ) took part initially, only 255 participants completed the M-CHAT; usually due to difficulties in contacting participants for the follow-up interview.

Most participants willingly took part but some declined for various reasons. The most common reason for declining was where IsiXhosa caregivers needed help with the forms, on days where the IsiXhosa translator was not available. Other parents had children needing full supervision in the waiting room. At times, the person bringing the child was not the primary caregiver and could not give accurate information about the child and their typical behaviour. Furthermore, nurses from children's homes were not allowed to give personal details about the child. A select few also felt the forms did not apply to them, after reading through them. Other parents did not feel like taking part that day.

A response rate of 80% is high (Baruch & Holtom, 2008) for this study considering that it was voluntary, with no immediate rewards for taking part. However, the sample may be slightly less representative of children requiring their caregivers full attention at all times, of IsiXhosa speakers who could not read without assistance and of participants from children's homes.

There were some cases where the forms were not completed before participants were called into the doctor's rooms. Where most of the form had been filled out, attempts were made to phone the participants in order to complete the questions. However, some participants did not indicate the correct contact details.

Furthermore, incomplete form numbers were increased by those not reached for their follow-up interview, to obtain a final M-CHAT score. This was usually due to lost or stolen phones and numbers changing; which has also been a barrier in other low SES samples (Khowaja et al., 2015). These difficulties then resulted in children being overage for the M-CHAT. The total number excluded for incomplete forms was  $n=26$ .

**Demographic characteristics.** The sample was obtained from the Red Cross Children's Hospital Developmental Clinic in Cape Town, where participants would be representative of a typical Western Cape provincial community clinic setting. A total of 255 participants completed the forms: 158 in the original age range suggested by previous literature, and 97 in the extended age range.

To determine the validity of the SA English, Afrikaans and IsiXhosa versions of the M-CHAT in the Western Cape, separate investigations into the demographic characteristics across the three language versions were carried out, first for the original age range (1.5-4.00 years; Table 1), then for the extended age range (4.01-4.99 years; Table 2). This was to inspect the demographics of those filling out each M-CHAT version to see where demographic differences lay, as these could potentially affect the scores on the different versions. Additionally, a descriptive investigation into the M-CHAT version chosen, in relation to the participants' reported home language, was carried out (Table 3).

Table 1

*Demographic Characteristics Across M-CHAT Version in Original Age Range*

Demographic characteristics	Total sample original age range ( <i>n</i> =158)	M-CHAT version			Test of significance		ESE
		SA English ( <i>n</i> =107)	Afrikaans ( <i>n</i> =24)	IsiXhosa ( <i>n</i> =27)	ANOVA		
					<i>F</i>	<i>p</i>	
Child's age (years) & Age range	2.95 (0.70)	2.92 (0.69)	2.99 (0.77)	3.07 (0.67)	0.57	.569	.01
	1.44 <sup>a</sup> -4.00	1.44 <sup>a</sup> -4.00	1.59-3.98	1.75-3.98			
Child's sex (Female:Male)	53: 105	36:71	7:17	10:17			
Child's ethnicity (Black: Coloured: White: Other)	51:95:10:2	25:72:9:1	0:23:1:0	26:0:0:1			
Child's home language (English: Afrikaans: English & Afrikaans: Xhosa: English & Xhosa: Other)	81:21:8:36:2:10	72:4:7:15:0:9	6:17:1:0:0:0	3:0:0:21:2:1			
Income (R per annum)	33479.58 (32571.97)	35928.54 (34510.61)	34737.18 (33521.56)	23012.33 (21361.47)	2.36 <sup>b</sup>	.107	.01
Mother education (years completed)	11.40 (1.83)	11.64 (1.40)	10.84 (3.22)	10.85 (1.78)	2.62 <sup>b</sup>	.089	.03

*Note.* ESE= estimate of effect size. For Age, Income and Mothers education, the means are provided with standard deviations in parentheses. For child's Sex, Ethnicity, and Home Language, raw numbers are provided. The sample size for Income is *n*=120 and for Mother's Education it is *n*=146. Where there are categorical variables, there were not sufficient numbers in each category across each M-CHAT version to permit statistical analyses (multiple expected frequencies < 5).

<sup>a</sup>One participant was 20 days younger than the minimum age for the M-CHAT and the parents wanted to participate, therefore they were included.

<sup>b</sup>The Welch statistic was used when data variability was not homogenous.

Table 2

*Demographic Characteristics Across M-CHAT Version in the Extended Age Range*

Demographic characteristics	Total sample extended age range ( <i>n</i> =97)	M-CHAT version			Test of significance		ESE
		SA English ( <i>n</i> =73)	Afrikaans ( <i>n</i> =14)	IsiXhosa ( <i>n</i> =10)	ANOVA		
					<i>F</i>	<i>p</i>	
Child's Age (years) & Age range	4.55 (0.92)	4.53 (0.31)	4.63 (0.25)	4.57 (0.21)	0.89 <sup>a</sup>	.427	.01
Child's sex (Female:Male)	27:70	23:50	3:11	1:9			
Child's ethnicity (Black: Coloured: White: Other)	22:70:4:1	12:56:4:1	0:14:0:0	10:0:0:0			
Child's home language (English: Afrikaans: English & Afrikaans: Xhosa: English & Xhosa: Other)	59:12:4:18:0:4	56:4:1: 8:0:4	3:8:3:0:0:0	0:0:0:10:0:0			
Income (R per annum)	32564.71 (31554.10)	35296.74 (33523.46)	29325.45 (23593.28)	13375.25 (16798.07)	3.39 <sup>a</sup>	.063	<.01
Mother education (years completed)	10.97 (2.31)	11.17 (2.19)	10.00 (3.65)	10.50 (1.08)	1.36	.261	.01

*Note.* ESE= estimate of effect size. For age, Income and Mother's Education, the means are provided with standard deviations in parentheses. For child's Sex, Ethnicity, and Home Language, raw numbers are provided. The sample size for Income is *n*=70 and for Mother's Education it is *n*=92. Where there are categorical variables, there were not sufficient numbers in each category across each M-CHAT version to permit statistical analyses (multiple expected frequencies < 5).

<sup>a</sup>The Welch statistic was used when data variability was not homogenous.

**Age.** This indicated the child's age when the M-CHAT was filled out by parents (not the age at follow-up, as not all children were followed-up). There were fewer children at the lowest end of the original age range, possibly due to clinic waiting lists being long.

**Original age range.** The mean age of the children in the previously validated age range was 2.95 years (SD = 0.70; see Table 1). Average age did not differ across the English, Afrikaans and IsiXhosa M-CHAT versions,  $F(2, 155) = 0.57$ ,  $p = .569$ ,  $\omega^2 = .01$ . Omega indicates a negligible effect.

*Extended age range.* In this age range, from 4.01-4.99 years, the mean age was 4.55 years (SD = 0.92; see Table 2). Average age did not differ across the English, Afrikaans and IsiXhosa M-CHAT versions, *Welch's F* (2, 20.98) = 0.89,  $p = .427$ ,  $\omega^2 = .01$ . Omega indicates a negligible effect.

**Sex.** In both age ranges, the sex of the children for whom the form was filled out, included a higher number of males compared to females across all three M-CHAT versions.

*Original age range.* In this age range were many more males (n=105), than females (n=53), indicating a ratio of 1:2.0 for female to male. This ratio was similar across the three M-CHAT versions: for the English M-CHAT there were 36 females and 71 males (ratio=1:2.0); for the Afrikaans M-CHAT there were 7 females and 17 males (ratio=1:2.4); and for the IsiXhosa M-CHAT there were 10 females and 17 males (ratio=1:1.7). Although statistical analyses could not be carried out due to low numbers in some of the groups, it is clear that for each M-CHAT version, there are about twice as many male children compared to female children.

*Extended age range.* In this age range once again there were many more males (n=70), compared to females (n=27), indicating a ratio of 1:2.6 for female to male. This ratio was similar across the English and Afrikaans M-CHAT versions: for the English M-CHAT there were 23 females and 50 males (ratio=1:2.2); and for the Afrikaans M-CHAT there were 3 females and 11 males (ratio=1:3.7). However, for the IsiXhosa version there was 1 female and 9 males (ratio=1:9). Even though the sex imbalance seems more pronounced in the older IsiXhosa group, the number of participants in that group was too small to reach any conclusions. Although statistical analyses could not be carried out due to low numbers in some groups, it still seems that for the majority there are about 2 or 3 times as many male children compared to female children, especially for the English and Afrikaans versions.

*Overview of sex.* In general there were about 2-3 times as many males compared to females for whom the form was filled out. This was true for all M-CHAT versions, except the small IsiXhosa group in the extended age range. The majority ratio is interesting to note because it is in contrast to population statistics for children aged 0-4 years in the Western Cape, which indicates similar numbers of males (50.7%) and females (49.3%; Statistics South Africa, 2014b). However, ASD appears to be 5 times more common in males than in females (CDC, 2014). In addition, ADHD is diagnosed twice as often in males (Visser et al., 2014) and Cerebral Palsy is also slightly more common in males (Autism and Developmental Disabilities Monitoring [ADDM] Cerebral Palsy Network, 2013). Therefore, in a tertiary

level developmental clinic, given these higher incidences of these developmental disorders in the male population, it is likely that more males are brought in for evaluation.

**Ethnicity.** The ethnicity of the children for whom the form was filled out, differed across the three M-CHAT versions (Tables 1 and 2).

*Original age range.* The majority of participants in this age range were Coloured ( $n = 95$ ), then Black ( $n = 51$ ), with few White ( $n = 10$ ) and very few in the ‘other’ group, where participants were neither Coloured, Black, nor White ( $n = 2$ ).

Even though statistical analyses could not be performed on these groups across the three M-CHAT versions, it is clear that ethnicity and M-CHAT version seem to be linked (Table 1). The majority of participants filling in the English M-CHAT were Coloured (67.3%), then Black (23.4%), with very few in the White (8.4%) and ‘other’ groups (0.9%). For the Afrikaans M-CHAT, the Coloured participants also filled out the large majority (95.8%), with only 1 participant in the White group (4.2%). For the IsiXhosa M-CHAT, the Black group then made up the largest majority (96.3%), with 1 participant in the ‘other’ group (3.7%).

*Extended age range.* The majority of participants in this age range were Coloured ( $n = 70$ ), then Black ( $n = 22$ ), with few White ( $n = 4$ ) and just one in the ‘other’ group ( $n = 1$ ).

Again, even without statistical analyses, it is clear that ethnicity and M-CHAT version seem to be linked (Table 2). The majority of participants filling in the English M-CHAT were Coloured (76.7%), then Black (16.4%) with few in the White (5.5%) and ‘other’ groups (1.4%). For the Afrikaans M-CHAT; there were only Coloured participants (100%) and for the IsiXhosa M-CHAT, there were only Black participants (100%).

*Overview of ethnicity.* The ethnicity of participants differed across the three M-CHAT versions. However, in South Africa, ethnicity and language are highly correlated to one another; therefore, this is not unexpected.

The majority of the sample overall were Coloured (64.7%), with fewer Black participants (28.6%), few White (5.5%) and very few of ‘other’ ethnicities (1.2%). In the Western Cape, according to statistics, the Coloured population make up the majority (53.9%), then Black (26.7%), with few being White (18.4%) or Indian (1.0%; Statistics South Africa 2014b). Therefore, the proportions of ethnicity in the sample are fairly representative of the Western Cape population, except for the sample’s slightly higher numbers in the Coloured population and lower numbers in the White population. This can probably be explained by economic factors: Kaus (2013) found that the Black and Coloured populations in South Africa had a decreased expenditure on health services, compared to the White population. In

addition, 77% of the White population have medical aid compared to 20.3% of the Coloured and 10.6% of Black populations (Statistics South Africa, 2014a). Therefore, those with medical aid are likely to use private medical care, rather than being on long waiting lists at state hospitals, leading to reduced presence of Whites at state hospitals.

***Home language and M-CHAT language.*** In the total sample, more participants reported English as their home language compared to Afrikaans or IsiXhosa. A few also reported both English and Afrikaans, or English and IsiXhosa, and those in the ‘other’ group spoke none of the above-mentioned home languages. The majority of participants also completed the English M-CHAT compared to the Afrikaans and IsiXhosa M-CHAT’s. The reported home language mostly matched M-CHAT version. However, in a number of cases, participants whose home language was not English still filled out the English M-CHAT. The M-CHAT version chosen, based on home language can be found in Table 3 below.

Table 3

*M-CHAT Version Chosen Based on Home Language for the Total Sample*

Home language	All participants (N=255)	M-CHAT version		
		SA English (n=180)	Afrikaans (n=38)	IsiXhosa (n=37)
English	140	128	9	3
Afrikaans	33	8	25	0
IsiXhosa	54	23	0	31
English & Afrikaans	12	8	4	0
English & IsiXhosa	2	0	0	2
Other	14	13	0	1

*Note.* For all variables, raw numbers are provided.

Even though 180 participants filled out the English M-CHAT, only 71.11% of these indicated a home language of English. Of the rest, 4.44% indicated a home language of both English & Afrikaans, 4.44% were Afrikaans speaking, 12.78% were IsiXhosa speaking, and 7.22% spoke languages other than English, Afrikaans or IsiXhosa, such as French or Chichewa.

Only 65.79% of participants filling in the Afrikaans M-CHAT reported Afrikaans as their home language. The rest reported English & Afrikaans, 10.53% or English, 23.68%.

For the IsiXhosa M-CHAT, 83.78% reported a home language of IsiXhosa, and 5.41% a home language of English & IsiXhosa. A further 8.11% of people reported English and 2.70% had a home language other than those mentioned above.

Statistical analyses were not conducted on this data; however, of note is that from the total number of IsiXhosa home language speakers, only 57.41% chose to fill out the IsiXhosa M-CHAT. This is a much lower percentage than expected. In comparison, a large number of Afrikaans home language speakers (76.76%) filled in the Afrikaans M-CHAT and 91.43% of English home language speakers filled in the English M-CHAT. Even across the original and extended age ranges, home language mostly corresponded with the M-CHAT version, but with a large number of IsiXhosa speakers choosing to fill out the English M-CHAT.

*Overview of home language and M-CHAT version.* The majority of the sample reported English as their home language; the second largest number reported IsiXhosa, with fewer reporting Afrikaans. It was expected that participants would fill out an M-CHAT corresponding to their home language, but the large number of IsiXhosa home language speakers filling out the English M-CHAT was certainly noteworthy in all cases. It is interesting to note that the actual distribution of first language in the Western Cape is opposite to the sample's distribution. In the Western Cape, the majority of the population are Afrikaans speaking (49.6%), followed by IsiXhosa (24.7%) and then English (20.2%; Statistics South Africa, 2011). The differences in home language distribution and M-CHAT version chosen in this sample may have occurred for a number of reasons.

Some caregivers reported that their personal home language is different to the language spoken at home with their child; therefore, caregivers may have differed in terms of whether this detail was filled in according to themselves or their child. This may have occurred most where the caregiver's own home language was Afrikaans or IsiXhosa but where the child was at an English school, thus English was spoken at home. Additionally, in South Africa, English is still perceived by some, to indicate affluence and education (Slabbert & Finlayson, 2000 as cited in Hornberger & Vaish, 2009), thus participants may indicate English as a home language and choose the English M-CHAT because of its perceived status.

In terms of the M-CHAT version chosen, it is possible that fewer participants chose the Afrikaans and IsiXhosa M-CHATs because the study was first explained in the waiting room in English and then participants were individually asked about their home language and if they would prefer the information in Afrikaans or IsiXhosa. In addition, the IsiXhosa interpreter was not always available for data collection, due to financial constraints. Although most parents indicated that English was better for them, it is not clear whether this was just to

make it easier for the researchers. However, some parents reported that even though not their home language, they were most comfortable in English because of it being widely spoken at school and in the work place. Furthermore, even though they may speak Afrikaans or IsiXhosa conversationally, the ‘higher’ and medical terms in these languages can be difficult to understand. In addition, at Red Cross Hospital, the majority of doctors are English speaking rather than Afrikaans or IsiXhosa (Levin, 2006), thus parents possibly indicated English preference because of a preconceived idea that English is spoken at Red Cross. All these many factors may contribute to the distribution of home language and M-CHAT version chosen.

**Income.** This variable indicates the income in a year, of the entire household in which the child lives. It is measured in Rands per annum and is measured across each M-CHAT version (Tables 1 and 2).

*Original age range.* On average the household income for the younger age range was R33 479.58 (SD = R32 571.97). Mean annual household income did not differ significantly across M-CHAT version, *Welch's F* (2, 40.47) = 2.360,  $p = .107$ ,  $\omega^2 = .01$ , Omega indicates a negligible effect.

*Extended age range.* On average the household income for the older age range was R32 564.71 (SD=R31 554.10). Even though the annual income seemed to differ slightly across M-CHAT version, this was not significant: *Welch's F* (2, 14.16) = 3.39,  $p = .063$ ,  $\omega^2 = <.01$ , Omega indicates a negligible effect.

*Overview of income.* Breaking down annual household income results in a low average income of <R2800 per month. This relatively low value can be expected as the participants are from a state-funded clinic primarily offering care to low SES populations, who cannot afford private healthcare. The samples' similar income values across the three M-CHAT versions were also then expected.

**Mother's Education.** This variable indicates the level of schooling reached by the child's mother or in some cases the child's primary caregiver. This was measured by the number of years of school completed.

*Original age range.* On average, the mothers completed 11.40 years of schooling (SD = 1.83; Table 1). Although the English M-CHAT group seemed to indicate higher maternal education levels, this was not significantly different to the education levels in the Afrikaans and IsiXhosa M-CHAT groups, *Welch's F* (2, 32.30) = 2.61,  $p = .089$ ,  $\omega^2 = .03$ . Omega indicates a negligible effect.

*Extended age range.* On average, the mothers completed 10.97 years of schooling (SD = 2.31; Table 2). Mothers' education was not significantly different across the English, Afrikaans and IsiXhosa M-CHATs,  $F(2, 89) = 1.36, p = .26, \omega^2 = .01$ . Omega indicates a negligible effect.

*Overview of mother's education.* On average the mothers or primary caregivers had reached a level of schooling equivalent to Grade 10 or 11 and this was similar across the three M-CHAT versions. Although one cannot determine the quality of the level reached, in the Western Cape specifically, there are high levels of literacy, at 81.7% (Western Cape Government, 2012). Therefore, these high levels of literacy and the adequate average level of education reached by parents in this study, indicates that the M-CHAT scores were unlikely to have been largely affected by the mother's education or illiteracy.

**M-CHAT scores across version in each age range.** The final M-CHAT scores were compared across the different language versions in each of the age ranges, to identify whether they vary. The M-CHAT score is the number of items failed, which indicates risk for ASD. We hoped that they did not vary across the versions as all versions should be equally well understood after their adaptations. These investigations were carried out separately within each age range so that the extended age range results would not be influencing overall scores. The investigation was carried out separately for the two M-CHAT scores, using the overall 23-item score and then the critical 6-item score. See Table's 4 and 5 below.

Table 4

*Average M-CHAT Scores Across M-CHAT Version in the Original Age Range*

M-CHAT Score	Total sample 1.5-4.00 years (n=158)	M-CHAT version			Test of Significance		ESE
		SA English (n=107)	Afrikaans (n=24)	IsiXhosa (n=27)	ANOVA		$\omega^2$
					F	p	
M-CHAT average score and range for 23 items	3.75 (4.17) 0-18	4.02 (4.36) 0-18	3.75 (3.79) 0-12	2.70 (3.61) 0-13	1.55 <sup>a</sup>	.215	.01
M-CHAT average score and range for critical 6 items	0.94 (1.55) 0-6	1.02 (1.65) 0-6	0.88 (1.36) 0-4	0.67(1.27) 0-5	0.49 <sup>a</sup>	.614	.01

*Note.* ESE= estimate of effect size. For the M-CHAT scores, the means are provided with standard deviations in parentheses. Below the mean scores, the score range is provided.

<sup>a</sup>The ANOVA for M-CHAT score across M-CHAT version was calculated using the  $\log(\text{M-CHAT score} + 1)$  to ensure normal distribution of M-CHAT scores.

Table 5

*Average M-CHAT Scores Across M-CHAT Version in the Extended Age Range*

M-CHAT score	Total sample 4.01-4.99 years (n=97)	M-CHAT Version			Test of Significance		ESE
		SA English (n=73)	Afrikaans (n=14)	IsiXhosa (n=10)	ANOVA		$\omega^2$
					F	p	
M-CHAT average score and range for 23 items	2.90 (2.98) 0-14	3.15 (3.22) 0-14	1.79 (1.63) 0-5	2.60 (2.37) 0-7	1.37 <sup>a</sup>	.260	.01
M-CHAT average score and range for critical 6 items	0.55 (1.07) 0-4	0.60 (1.13) 0-4	0.21 (0.43) 0-1	0.60 (1.27) 0-4	0.63 <sup>a</sup>	.536	.01

*Note.* ESE= estimate of effect size. For the M-CHAT scores, the means are provided with standard deviations in parentheses. Below the mean scores, the score range is provided.

<sup>a</sup>The ANOVA for M-CHAT score across M-CHAT version was calculated using the  $\log(\text{M-CHAT score} + 1)$  to ensure normal distribution of M-CHAT scores.

**Overall M-CHAT score with 23 items.** The original cut-off score for the 23 items is a failure on 3 or more items (Robins et al., 2001), which indicates ASD risk.

*Original age range.* The mean final M-CHAT score for all 23 items, was 3.75 (SD = 4.17). In this age range, when using the originally suggested cut-off score, 57.6% of children would have passed and 42.4% would have failed, indicating risk for ASD. There was a greater range in the M-CHAT score for the SA English M-CHAT compared to the Afrikaans and IsiXhosa M-CHAT's, however, a much larger number of participants filled out the SA English version. Although the average IsiXhosa score seems lower than the Afrikaans and English M-CHAT scores, the overall mean M-CHAT 23-item score (using the log transformation) was not significantly different across versions  $F(2, 155) = 1.55, p = .215, \omega^2 = .01$ . Omega indicates a negligible effect.

*Extended age range.* The mean M-CHAT score for all 23 items was 2.90 (SD = 2.98). In this extended age range, 64.9% of children would have passed using the 3-item cut-off and 35.1% would have failed, indicating risk for ASD. There was again a greater range in the M-CHAT score for the SA English M-CHAT, however, a much larger number of participants filled out this version. Although the average Afrikaans M-CHAT scores seem lower than the English and IsiXhosa M-CHAT scores, the mean M-CHAT 23-item score (using the log transformation) was not significantly different across versions  $F(2, 94) = 1.37, p = .260, \omega^2 = .01$ . Omega indicates a negligible effect.

**Overall M-CHAT score with 6 critical items.** The original critical item cut-off score as suggested by Robins et al. (2001) was a failure on 2 or more critical items, to indicate ASD risk.

*Original age range.* The mean critical 6-item M-CHAT score was 0.94 (SD = 1.55). In the original age range, when using the original cut-off scores, 78.5% would have passed the 2 item cut-off and 21.5% would have failed, indicating risk for ASD. The M-CHAT score range was similar across all the M-CHAT versions in the original age range. The mean number of M-CHAT critical items failed (using a log transformation) was not significantly different across the three M-CHAT versions  $F(2, 155) = 0.49, p = .614, \omega^2 = .01$ . Omega indicates a negligible effect.

*Extended age range.* The mean critical item M-CHAT score was 0.55 (SD = 1.07). In the extended age range, when using the original cut-off scores, 74.6% would have passed the 2 item cut-off and 25.4% would have failed, indicating risk for ASD. The M-CHAT score range was similar for the English and IsiXhosa M-CHATs, but smaller for the Afrikaans M-CHAT. However, the mean number of M-CHAT critical items failed (using a log

transformation) was not significantly different across the three M-CHAT versions in the extended age range,  $F(2, 94) = 0.63, p = .536, \omega^2 = .01$ . Omega indicates a negligible effect.

**M-CHAT scores across the original and extended age ranges for each version.** In order to assess whether there were any variations in the *final M-CHAT scores* between the two age ranges, an independent t-test was used. This was carried out between each of the age ranges but for each M-CHAT version separately. The analyses were separated across version so that the version filled out would not influence the score changes between age ranges. The results are displayed in Table 6 below.

Table 6

*Difference in Final M-CHAT Score Between the Original and Extended Age Ranges for Each M-CHAT Version*

M-CHAT version	M-CHAT final score (log(score+1))	Test of significance		ESE
		<i>t</i> -test		<i>r</i>
		<i>t</i>	<i>p</i>	
SA English	23-item	0.932	.367	.07
	6-item	1.818	.071	.14
Afrikaans	23-item	1.379	.176	.22
	6-item	1.901	.066	.31
IsiXhosa	23-item	-.418	.678	.07
	6-item	0.181	.858	.03

*Note.* ESE= estimate of effect size. For the *t*-test, the log(M-CHAT score +1) was used, to ensure a normal distribution of the M-CHAT scores.

The results from the above analysis indicate that there were also no significant differences in the M-CHAT final scores (separately considering the 23-item and the 6-item M-CHAT scores) across the two age ranges within any of the M-CHAT versions, as all the *p* values were above .01 (in fact they were all  $> .05$ ).

**M-CHAT score overview.** It is encouraging that the 23-item and 6-item M-CHAT scores are similar both across the three different M-CHAT versions, as well as across the two age ranges. Therefore, the M-CHAT versions adapted and translated for this context result in similar scores, thus they are likely to be measuring the same thing, and each version appears equally understandable to parents. This implies that there are no hidden demographic factors within each M-CHAT version impacting on scores. In addition, the extended age range (4.01-

4.99 years) did not indicate significantly different final M-CHAT scores on any of the versions. However, this should be confirmed in larger samples, as the Afrikaans M-CHAT resulted in some small effects between the age ranges (see Table 6 above), although these could be due to more high risk ASD children in one of the Afrikaans age ranges.

**Percentage failing the M-CHAT.** On the M-CHAT, a child fails or screens positive for ASD by failing either of the two cut-off scores. However, in the total sample no one failed the M-CHAT on the 6-item score alone, they either failed on both the 23-item and 6-item M-CHAT score, or the 23-item score only. Therefore, the 23-item score determined the final M-CHAT ASD risk classifications. Chlebowski, et al. (2013) also found this and queried whether the critical item score was even necessary. Additionally, Snow & Lecavalier (2008) found the 23-item score to have the best sensitivity. Therefore, when comparing the number of positive cases identified in each of the age ranges, the 23-item M-CHAT score seems most useful and indicated a slightly larger percentage failing the M-CHAT in the original age range compared to the extended age range. This slightly larger percentage failing can be due to more high-risk individuals or those that have not yet undergone intervention in the younger original age range. It is also important to remember that the originally suggested cut-off scores and the choice of critical items may first need to be adapted for this particular context, when a larger sample is available.

**Demographic characteristics and their relationship to M-CHAT score and relationship of the two final M-CHAT scores to one another.** The relationships between the different demographic characteristics and the M-CHAT scores (overall 23-items and 6-critical items) were directly investigated to see if there were any influences of these on the M-CHAT scores. Correlations between the variables of child's age, household income, mother's education, and child's sex, with M-CHAT overall 23-item score and M-CHAT critical 6-item score were investigated. The correlations did not include the categorical variables of home language, M-CHAT version and ethnicity, as these had more than two categories, therefore the order in which they were entered would have affected the outcome. Consequently, these variables were analysed descriptively. Child's sex could be investigated in the correlations as it was only made up of 2 categories, thus the ordering of categories was not misleading (Field, 2009). The correlations were first investigated overall (all language versions combined) across the original (Table 7) and extended age ranges (Table 8) and thereafter across the three M-CHAT versions of SA English (Table 9), Afrikaans (Table 10) and

IsiXhosa (Table 11). In all correlations below, the M-CHAT final scores were based on the  $\log(\text{M-CHAT score}+1)$  transformation, to normalize the distribution of the data.

Table 7

*Correlations Between Demographic Characteristics and M-CHAT Scores (Original Age Range)*

Variable associated with M-CHAT	Overall 23-item M-CHAT score		Critical 6-item M-CHAT score	
	Pearson's correlation ( <i>r</i> )	<i>p</i>	Pearson's correlation ( <i>r</i> )	<i>p</i>
Age	.02	.816	.01	.952
Income	-.09	.319	-.12	.195
Mother Education	.13	.108	.10	.230
Sex	.10	.231	.06	.431
Overall 23-item M-CHAT score	-	-	.83	<.001

Table 8

*Correlations Between Demographic Characteristics and M-CHAT Scores (Extended Age Range)*

Variable associated with M-CHAT	Overall 23-item M-CHAT score		Critical 6-item M-CHAT score	
	Pearson's correlation ( <i>r</i> )	<i>p</i>	Pearson's correlation ( <i>r</i> )	<i>p</i>
Age	.05	.616	-.11	.278
Income	.19	.111	.26	.029
Mother Education	-.12	.256	-.11	.281
Sex	.07	.488	-.00	.973
Overall 23-item M-CHAT score			.71	<.001

***Correlation of demographic variables to M-CHAT final scores in each age range.***

From both tables above it can be concluded that the demographic variables of child's age, mother's education, income, and child's sex were not significantly correlated with either of the M-CHAT scores, in either of the age ranges, as all correlations were above the  $p = .01$  level.

***Correlation of the two final M-CHAT scores to one another in each age range.*** The 23-item score and the critical 6-item scores in each age range, were strongly and significantly positively correlated, Pearson's correlation  $r = .83$ ,  $p < .001$  (original age range) and  $r = .71$ ,  $p < .001$  (extended age range). As expected, when the overall 23-item score is high, so is the critical 6-item score. In the original age range the scores share 69.06% of their variability and in the extended age group they share a slightly lower amount of variability, 49.84%.

There were no significant correlations between the demographic characteristics and the M-CHAT scores in either age range. Therefore, the same demographic characteristics and their relationship to the final M-CHAT scores within each of the three M-CHAT versions were investigated. This was to see whether the demographic make-up of each M-CHAT version was affecting the M-CHAT score. The two age ranges were grouped into one for each M-CHAT version, to identify any significant correlations. See Table's 9,10 and 11.

Table 9

*Correlations Between Demographic Characteristics and SA English M-CHAT Scores*

Variable associated with M-CHAT	Overall 23-item M-CHAT score		Critical 6-item M-CHAT score	
	Pearson's correlation ( $r$ )	$p$	Pearson's correlation ( $r$ )	$p$
Age	.00	.955	-.05	.473
Income	-.08	.364	-.09	.294
Mother education	-.02	.805	-.01	.902
Sex	.06	.438	.02	.764
Overall 23-item M-CHAT score			.81	<.001

Table 10  
*Correlations Between Demographic Characteristics and Afrikaans M-CHAT Scores*

Variable associated with M-CHAT	Overall 23-item M-CHAT score		Critical 6-item M-CHAT score	
	Pearson's correlation ( <i>r</i> )	<i>p</i>	Pearson's correlation ( <i>r</i> )	<i>p</i>
Age	-.33	.040	-.45	.005
Income	.15	.437	.41	.026
Mother education	.03	.885	.05	.791
Sex	.12	.473	-.07	.670
Overall 23-item M-CHAT score			.77	<.001

Table 11  
*Correlations Between Demographic Characteristics and IsiXhosa M-CHAT Scores*

Variable associated with M-CHAT	Overall 23-item M-CHAT score		Critical 6-item M-CHAT score	
	Pearson's correlation ( <i>r</i> )	<i>p</i>	Pearson's correlation ( <i>r</i> )	<i>p</i>
Age	.09	.598	-.09	.593
Income	.10	.625	.07	.748
Mother education	.20	.233	.10	.569
Sex	.22	.198	.22	.186
Overall 23-item M-CHAT score	-	-	.75	<.001

***Correlation of demographic variables to M-CHAT final scores in each M-CHAT version.*** From Tables 9, 10, and 11 above it can be concluded that the demographic variables of child's age, income, mother's education, and child's sex were not significantly correlated with either of the final M-CHAT scores, in the English or IsiXhosa versions. The correlations for these were all above the  $p < .01$  significance level. In the Afrikaans version, income, mother's education and child's sex were not correlated to the M-CHAT final scores either. However, in the Afrikaans version, child's age was significantly negatively correlated to the M-CHAT 6-item score ( $r = -.45, p = .005$ ), but not to the M-CHAT 23-item score. Age

shared 19.98% of the variance with the 6-item score for the Afrikaans version and as age increased, the M-CHAT score decreased.

Due to this significant correlation between age and the 6-item M-CHAT score, the Afrikaans version's correlation of age with the M-CHAT score was investigated further to see whether this was also present within the age ranges filling out the Afrikaans versions (see Table 12 below). There were no concerns in the English and IsiXhosa groups; therefore, they were not investigated further.

Table 12

*Correlations Between Age and Afrikaans M-CHAT 6-Item Scores in the Original and Extended Age Ranges*

Variable associated with M-CHAT	Critical 6-item M-CHAT score	
	Pearson's correlation ( $r$ )	$p$
Age (Original Age Range)	-.44	.030
Age (Extended Age Range)	-.03	.918

*Correlation of age to final 6-item M-CHAT score in the Afrikaans age ranges.* When exploring the correlation between *age* and the 6-item M-CHAT score further, it appears there are no significant correlations (Table 12). This is true in both the original and the extended age range for the Afrikaans version, as no correlations have a significance less than  $p = .01$  and the  $r$  values are not particularly high. However, splitting this into age ranges reduces the range for each correlation, thus one is unlikely to see a pattern with a significant correlation. One would not expect age to correlate with M-CHAT score in the original age range; it is rather the extended age range that needs verification. Thus looking at the combined age range correlation from above is probably best. However, with such a small sample, and without diagnostic classification, it is not possible to explain this correlation definitively. Even though the combined age range correlation is significant- this may be due to other factors such as less high-risk children in the small extended age range.

***Correlation of the two final M-CHAT scores to one another in each M-CHAT version.*** In Tables 9, 10, and 11 above, the overall 23-item score and the critical 6-item score, in each of the M-CHAT versions, were always significantly positively correlated with one another, Pearson's correlation  $r = .81, p < .001$  (SA English),  $r = .77, p < .001$  (Afrikaans) and  $r = .75, p < .001$  (IsiXhosa). As expected, when the overall 23-item score is high, so is the critical 6-item score. For the SA English M-CHAT the two scores share 65.61% of their

variability, for the Afrikaans M-CHAT they share 59.14% and for the IsiXhosa M-CHAT they share 55.65%.

*Descriptive examination of the relationship between home language and ethnicity with final M-CHAT scores.* The relationships between home language and ethnicity with the final M-CHAT scores had to be qualitatively assessed, as the numbers per group were too small to be statistically assessed (see Tables 13 and 14 below).

Table 13

*M-CHAT Score Averages and Ranges Across Home Language*

Home language	M-CHAT final score	<i>n</i>	Minimum	Maximum	Mean
English	23-items	140	0	17	3.61
	6-items	140	0	6	0.86
Afrikaans	23-items	33	0	9*	2.42*
	6-items	33	0	3*	0.39*
IsiXhosa	23-items	54	0	17	3.04
	6-items	54	0	5	0.65
English & Afrikaans	23-items	12	0	12	3.67
	6-items	12	0	4	0.75
English & IsiXhosa	23-items	2	2*	2*	2.00*
	6-items	2	0	1*	0.50
Other	23-items	14	0	18	5.50*
	6-items	14	0	6	1.57*

*Note.* \* indicates noteworthy values.

*M-CHAT scores per home language.* This was descriptively assessed (see Table 13). The Afrikaans home language scores showed a smaller range, and lower mean values than the other home languages. However, the values are still not strikingly different. These slightly lower values for the 6-item score especially, also support the possibility mentioned previously, that there are fewer cases at high risk in the older Afrikaans group. The ‘other’

group also showed slightly higher mean M-CHAT scores, however, there were only 14 participants in this group, thus the results may have been skewed due to sampling error. The English, IsiXhosa as well as English & Afrikaans home language groups indicated similar M-CHAT scores and ranges to one another. The English & IsiXhosa home language group was too small to investigate.

Table 14  
*M-CHAT Score Averages and Ranges Across Ethnicity*

Ethnicity	M-CHAT final score	<i>n</i>	Minimum	Maximum	Mean
Black	23-items	73	0	18	3.55
	6-items	73	0	6	0.85
Coloured	23-items	165	0	17	3.41
	6-items	165	0	6	0.77
White	23-items	14	0	8*	3.29
	6-items	14	0	2*	0.79
Other	23-items	3	0	5*	2.00*
	6-items	3	0	1*	0.33*

*Note.* \* indicates noteworthy values.

*M-CHAT scores per ethnicity.* The white group in the ethnicity analysis had a smaller range of M-CHAT scores when considering both the 23-items and the critical 6-items, however, this group consisted of a very small number of 14 participants. The Black and Coloured groups had similar mean M-CHAT scores and ranges for both of the final M-CHAT scores. The other group was too small to investigate. See Table 14 above.

***Overview of demographic characteristics' relationship to M-CHAT score.*** In summary, it is encouraging that the M-CHAT scores do not appear to be largely affected by any of the demographic characteristics. The correlations indicated that this was true in almost all cases, across age ranges and across M-CHAT versions. This is in contrast to the Scarpa et al. (2013) study in a low SES population where low maternal education and minority group status resulted in slightly higher M-CHAT scores.

The only correlation possibly requiring further investigation in a larger sample is the negative relationship between age and the 6-item M-CHAT score in the Afrikaans M-CHAT version. However, when this was assessed further, by breaking down the Afrikaans M-CHAT scores into the age ranges, it was no longer significant. It seems likely that the significance is rather due to a decreased number of ASD children in the extended age range. However, this could not be empirically tested in a larger sample in this study, as an approved Afrikaans ADOS/-2 is not yet available.

The effects of ethnicity and home language on the M-CHAT scores were only analysed descriptively. However, there were no apparent large differences in M-CHAT score across any of the categories within these variables. Some categories had slightly different mean scores or ranges, but mostly in cases where there were smaller numbers of participants in that group. A smaller number of participants in a group is likely to affect the range of scores (due to sampling error) thus, one cannot conclude that there are any particularly concerning effects of ethnicity or home language on the M-CHAT scores.

The M-CHAT is a behaviourally defined screening tool, thus it can be difficult to apply it across populations that differ culturally. However, it has been successfully adapted and translated for a variety of other contexts. In addition, in this South African context with a wide variety of languages and cultures, the M-CHAT scores did not appear to be affected by demographic characteristics, indicating its likely cross-cultural validity.

**Internal Consistency.** Internal consistency is a measure of the reliability of one's scale. For example, if a questionnaire consistently reflects the construct it sets out to measure, it is reliable. The most commonly used measure of this is Cronbach's alpha ( $\alpha$ ; Field, 2009), therefore, it was used to assess the internal consistency of the M-CHAT, in identifying autistic traits. The acceptable alpha values recommended, range from .7 to .9 (Tavakol & Dennick, 2011). A few analyses were carried out; firstly the internal consistencies overall (age ranges combined) and in the original age range for each M-CHAT version were investigated. The extended age range was investigated for the SA English M-CHAT but the numbers were not sufficient for the Afrikaans ( $n=14$ ) or IsiXhosa ( $n=10$ ) M-CHATs. Internal consistency was then investigated in each age range overall (all M-CHAT versions combined) and finally by using the total sample (all M-CHAT versions and age ranges combined). In each case, two separate analyses were used, the first for the overall 23-item score, and the second for the critical 6-item score. The internal consistency was measured using item responses from the first time that the M-CHAT was answered, i.e. before the

follow-ups had taken place, as not all participants needed the follow-up. Please find results in Table 15 below.

Table 15

*Internal Consistency Measured Across M-CHAT Version, Age Range, and in the Total Sample*

Sample analysed	Cronbach's $\alpha$ for 23-item M-CHAT	Cronbach's $\alpha$ for critical 6-item M-CHAT
SA English total sample	.86	.77
English original age range	.88	.83
English extended age range	.77	.61
Afrikaans total sample	.84	.72
Afrikaans original age range	.86	.76
IsiXhosa total sample	.78	.74
IsiXhosa original age range	.78	.71
Original age range (all M-CHAT versions)	.87	.80
Extended age range (all M-CHAT versions)	.75	.64
Total sample (all ages, all M-CHAT versions)	.84	.76

***Internal consistency of the final M-CHAT scores.*** In all cases, the 23-item M-CHAT score had a higher internal consistency than the 6-item score. However, this is expected because as the number of items increases, so does the alpha value (Cortina, 1993). All internal consistencies were acceptable for the overall 23-item M-CHAT score, according to Tavakol & Dennick (2011). The majority of internal consistencies for the 6-item scale were also above the recommended value, despite it being such a very short scale.

***Investigation into the scales with reliability  $\alpha < .7$ .*** The extended age range in the overall sample and in the SA English version sample showed slightly lower reliabilities ( $\alpha < .7$ ) when using the 6-item M-CHAT scale. Therefore, they were investigated further to determine particular items of concern.

***SA English extended age group.*** The corrected item-total correlations indicated concerning values for item 9 (.241), item 14 (.118), and item 7 (.290), which were all below .3, indicating poor correlations with the overall score. However, when determining the effect of their deletion on Cronbach's alpha, only the removal of item 14 increased the Cronbach's

alpha ( $\alpha = .610$  to  $\alpha = .633$ ). This is not a substantial change in alpha; therefore, it does not appear necessary to delete this item.

*Overall extended age group.* The corrected item-total correlations again indicated concerning values for item 9 (.145) and item 14 (.277), which were below .3, indicating poor correlations with the overall score. However, when determining the effect of their deletion on Cronbach's alpha, in contrast, only removal of item 9 would increase alpha ( $\alpha = .635$  to  $\alpha = .663$ ). This is once again not a substantial change in the alpha; therefore, it does not appear necessary to delete this item.

*Internal consistency overview.* The internal consistencies in this study were high, the 23-item alpha values ranging from .77 to .87, were similar to other M-CHAT validation studies. Some of the 6-item alpha values, ranging from .61 to .83, were similar and others slightly lower than other studies, however, they were still acceptable. The internal consistencies found for other M-CHAT validation studies for the 23-item and 6-item scales respectively were .85 and .83 (Robins et al., 2001), .85 and .84 (Kleinman et al., 2008) as well as .80 and .74 (Snow & Lecavalier, 2008). The validation of translated and culturally adapted versions of the M-CHAT had slightly lower values of internal consistency such as .76 (23-items) and .70 (6-items) for the Mexican version (Albores-Gallo et al., 2012) and .56 (23-items) for the Japanese version (Inada et al., 2011). Furthermore, the results from the current study are in stark contrast to another study in a rural low SES population group in the US, where the internal consistencies were particularly poor, especially in cases of low maternal education and minority status (Scarpa et al., 2013). The internal consistency values in the current study are especially high compared to other studies where the M-CHAT had been cross-culturally adapted or where it had been validated in low SES populations. It is encouraging that the M-CHAT kept its high level of internal consistency even after being translated and adapted for use in this multicultural, low SES South African context.

*Lower reliability in extended age range.* The slightly lower internal consistency for the 6-item scale in the extended age range was for items asking whether the child responds to their name when called, pointing for interest and showing objects to parents. Item appropriateness can change due to changes in ASD symptomology throughout development and as repetitive behaviours become more apparent in 4-5 year olds (Moore & Goodson, 2003). Although it is possible that these items may be slightly less evident in older children, this seems unlikely with regards to these specific items. Furthermore, the deletion of these problem items did not significantly increase the Cronbach's alpha. In addition, the internal consistency values were still not particularly poor, especially considering that it was such a

short scale, with values only slightly below the acceptable value of .7 (Tavakol & Dennick, 2011). Thus, they are not particularly concerning, even in this older age range.

**Item-by-item analysis: percentage failure per group outcome.** The item-by-item analysis investigates the percentage of failed questions on the M-CHAT (before follow-ups had taken place), for each of the final group outcomes. The final group outcomes are described as “no follow-up needed” (M-CHAT passed on initial administration), “passed M-CHAT after follow-up” (M-CHAT failed initially but passed after follow-up), and “failed follow-up.” This analysis helps identify which M-CHAT questions are most pertinent to those who will eventually pass or fail the M-CHAT and which items are failed too often or too seldom, thus, not necessarily indicating ASD risk. The percentage of each item failed per final group outcome is indicated in Table 16 below. Additionally, the overall (all group outcomes combined) percentage of items failed initially and then passed on follow-up can be found in the final column of the table.

Table 16  
*Percentage of Participants Failing an M-CHAT Item Across Group Outcome*

M-CHAT item	% failed each item per group			Overall % failed item initially and passed on follow-up
	“No follow-up needed”	“Passed M-CHAT after follow-up”	“Failed follow-up”	
1	2.44	12.50	7.92	4.71
2*	2.44	9.72	35.64	5.49
3	1.22	8.33	17.82	4.31
4	1.22	18.06	32.67	8.63
5	0.00	8.33	46.53	6.67
6	2.44	12.50	39.60	4.31
7*	1.22	13.89	42.57	3.92
8	2.44	22.22	53.47	9.02
9*	1.22	18.06	38.61	6.67
10	7.32	18.06	29.70	12.94
11	34.15	38.89	60.40	24.71
12	1.22	1.39	7.92	1.96
13*	3.66	20.83	48.51	15.69
14*	0.00	4.17	30.69	3.53
15*	0.00	5.56	41.58	3.53
16	1.22	18.06	21.78	3.14
17	2.44	11.11	53.47	3.92
18	23.17	38.89	50.50	22.35
19	3.66	25.00	39.60	12.16
20	6.10	27.78	44.55	9.80
21	0.00	6.94	38.61	4.71
22	23.17	50.00	71.29	24.71
23	7.32	19.44	43.56	10.59

Note. \*Critical 6-items

***Poor discriminating items.***

*Items failed most across all group outcomes.* When comparing the % failing each item between those that eventually passed or failed the M-CHAT, items 11 (*Does your child ever seem oversensitive to noise (e.g., blocking ears?)*), 18 (*Does your child make unusual finger movements near his/her face?*) and 22 (*Does your child sometimes stare at nothing or wander with no purpose?*) show high failure rates in all the groups, not only those failing overall. Item failures indicate ‘ASD risk,’ thus, one would not want all participants to fail items; only those at risk for ASD should fail. Therefore, these items do not seem to discriminate well between those at risk and those not at risk, because they were often failed, whether the M-CHAT was failed overall or not. Regarding items 11 and 22; overall 24.17% of participants initially failed the item but passed after follow-up. With item 18, 22.35% of participants also failed initially but passed after follow-up. An unnecessary initial failure on items warrants many unnecessary follow-up interviews to be conducted, which is not optimal, especially in the under-resourced South African healthcare setting.

Other studies have also found these same items to be easily misunderstood or failed too often. Harrington, Bai, and Perkins, (2012) found items 11,18 and 22, as well as item 20 to be problematic. Kimple et al. (2014) assessed two Spanish versions and the same items were also failed too often, however, in addition to these, Canal-Bedia et al. (2011) also found item 23 to be problematic. The Swedish M-CHAT validation, also flagged items 11 and 22 (as well as item 23) as items where the follow-up was particularly important (Nygren et al., 2012).

A possible explanation for these problematic items may be that the initial questions are misunderstood or unclear. For example, with item 11 (*Does your child ever seem oversensitive to noise (e.g. blocking ears?)*), parents often answered ‘yes’ because their children are somewhat sensitive to noises, however, not to *everyday* noises but rather to loud noises. Therefore, only when the specific types of everyday noises and the emotional reactions along with those were queried in the follow-up, did parents realise what the question was actually asking. Therefore, the initial M-CHAT questions should be adapted to give extra examples of the behaviour in question, rather than requiring the follow-up to clarify this. Interestingly, the new M-CHAT-R/F does just this, in this revised version Item 11 (mentioned above) is rephrased as “*Does your child get upset by everyday noises? (FOR EXAMPLE: does your child scream or cry to noise such as a vacuum cleaner or loud music?)*).

Additionally, it is interesting to note that the items mentioned above make up 3 out of 4 items requiring a reverse response of “no” to indicate “not at risk.” Therefore, if there is a response bias for parents answering yes/no, they may fill this in incorrectly, especially as item 11 is the first to require a “no.” Once again, the new M-CHAT-R/F tried to improve this by reordering the items, with a reverse response already required on item 2 (Robins et al., 2014). It is difficult to ascertain which reasons resulted in these items being failed too often; however, it appears to be relatively common for them to be problematic.

*Items not failed in the “failed follow-up” group.* Items 1 (*Does your child enjoy being swung, bounced on your knee, etc.?*) and 12 (*Does your child smile in response to your face or your smile?*), were seldom failed in any of the groups, even the group failing the M-CHAT overall. Therefore, they also did not discriminate well between those that would eventually pass or fail the M-CHAT.

This could also be due to some misunderstandings of these questions. However, because items which are passed are not followed-up, parents’ understanding of these items was seldom clarified. The high percentages passing these could also be due to buffer questions in the M-CHAT (Robins et al., 2001) which hide the aim of the test. Robins and Dumont-Mathieu, (2006) mention that item 1 is one of these, as it queries a motor skill that is usually intact in ASD individuals, thus it does not differentiate ASD from non-ASD. However, item 12 is not noted as a buffer item and it is unlikely to be one as it queries a behaviour previously shown to distinguish ASD from other developmental disorders (Trillingsgaard, Sørensen, Němec, & Jørgensen, 2005). Although, Ventola et al., (2007) also found that the pass rates on both these M-CHAT items (1 & 12) were relatively high (especially item 1) and not significantly different between toddlers with ASD and those with other developmental disabilities.

To confirm these poor discriminating items, an actual ASD or developmental disorder diagnosis on the participants would be required in order to confirm whether those actually failing the M-CHAT were diagnosed with ASD or not. Furthermore, larger numbers in the Afrikaans and IsiXhosa groups may be useful, to check whether the M-CHAT version played a part in which items were passed or failed too often.

***Good discriminating items.*** Items 5 (*Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?*), 15 (*If you point at a toy across the room, does your child look at it?*), and 17 (*Does your child look at things you are looking at?*) were all particularly good at discriminating those that passed or failed the M-CHAT overall. Many more participants in the group failing the M-CHAT overall, failed these

items. In addition, overall these items had a lower number of participants failing initially and then passing on follow-up. Therefore, it is likely that the questions were correctly understood the first time.

One would expect that the most discriminating items would make up some of the critical items. However, of the 3 most discriminating items here, only item 15 was one of the previously suggested critical items (Robins et al., 2001). Item 15 was also one of the best discriminators when differentiating ASD from other developmental disabilities (Ventola et al., 2007). Items 5 and 15 were found to be the best discriminators in a Chinese sample (Wong et al., 2004), and items 5, 15 and 17 (in addition to items 2, 7, 9, 10, 14, 19 and 21) showed high diagnostic power in a Turkish sample (Kara et al., 2012). There are many factors which can affect the choice of M-CHAT critical items; whether the sample is from a general or clinic population, the age range included, and the cultural differences of the sampling groups (Albores-Gallo et al., 2012).

Therefore, in this particular South African clinic population, items 5, 15, and 17 seem most useful in distinguishing those that failed the M-CHAT. In addition, they appear to be well understood on the initial questioning, with fewer changed responses at follow-up. Therefore, it is possible that these items are more appropriate to this context and that a new set of critical items may be required. Furthermore, it will also be important to verify this with ASD diagnoses; especially when sampling from a developmental clinic where many symptoms may overlap between ASD and other developmental disorders (Ventola et al., 2007). An additional investigation across the 3 M-CHAT versions would also yield important results.

One final consideration when interpreting all these items is it that the percentage failure of each item was dependent on the initial questions, and not on follow-up questions. Nevertheless, unnecessarily failing items initially is also problematic, as it requires resource-consuming follow-up interviews. In addition, the initial item failure was still analysed in terms of the final outcome group (after follow-up) and an indication of any overall large changes in responses at follow-up were still examined.

***Qualitative comments on items.*** When conducting the research, some items were flagged, in addition to those mentioned above, in terms of being failed more often than expected or being culturally inappropriate. Firstly, in a developmental clinic, item 16 (“*Does your child walk?*”) and item 3 (“*Does your child like climbing on things, such as on chairs or other things?*”) may be failed because some children in this setting are slow to walk and others are in a pram/wheelchair, thus they cannot walk or climb. Therefore, some M-CHAT

scores may be increased and indicate ASD risk, when these items may not be specifically indicative of ASD in these children. This is especially true for item 16 which is a ‘buffer’ item that most children are meant to pass (Robins et al., 2001). These are also not the only items frequently failed by those with developmental disorders other than ASD, in fact Ventola et al. (2007) found that only 4 M-CHAT items successfully discriminated ASD from other developmental disabilities, namely items 6 (pointing for help), 7 (pointing for interest), 14 (responding to name), and 15 (following a point)- all related to joint attention. Luyster et al. (2011) also found the M-CHAT to be failed more frequently when hearing, vision, cognitive or motor problems were present. Although the current study excluded children with hearing or visual deficits, in a developmental clinic it is likely that children will have motor or cognitive difficulties, thus affecting their scores. Therefore, it is particularly important to validate the M-CHAT and determine the cut-off scores in these developmental clinic settings.

Regarding cultural appropriateness, in the IsiXhosa M-CHAT item 10 (regarding eye contact) was adapted to make it less about only specifically looking the parent in the eye, but also looking towards their face, in an appropriate way. This was necessary because many African cultures consider it disrespectful for children to look adults in the eyes (Mulaudzi, 2005). For example, in the Zulu culture, by age two it is expected that children look at adults in the face but without eye contact (Grinker et al., 2012). However, two parents queried this adaptation, as they believed that young IsiXhosa children are still expected to look their parents in the eyes. However, these parents were possibly more Westernized, therefore eye contact was more expected. In future, it would be useful to ask more IsiXhosa parents what they think of this question. Furthermore, investigating all the items separately across the 3 M-CHAT versions would be useful.

**Investigation into changes in outcome after follow-up.** Previous literature notes the importance of administering the M-CHAT follow-up questions to increase the M-CHAT’s internal reliability and specificity (Pandey et al., 2008; Robins et al., 2001). This section investigates how often the participants’ outcome changed overall (high or low risk for ASD) once the follow-up had been administered. This was first investigated overall, with all age ranges and M-CHAT versions combined. It was then investigated for the SA English M-CHAT version where more participants than expected filled out the English M-CHAT without speaking English as their home language. Therefore, of those completing the English M-CHAT, the changes in outcome after follow-up were compared across the English home language group and the group with a home language other than English. This was to assess

whether filling in the M-CHAT in a non-home language resulted in more misunderstandings of the initial questions, thus resulting in more follow-ups and subsequent changes in outcome after follow-up.

***Final outcome changes after follow-up in overall sample.*** In the total sample, 67% of participants required the follow-up interview. After the follow-up, 27% continued to fail the M-CHAT, and 40% changed from a fail to a pass.

***Final outcome changes on the English M-CHAT after follow-up for those with and without English as a home language.*** Out of those choosing to fill in the English M-CHAT 28% indicated a home language other than English. Of all the non-English home language speakers, 64% required a follow-up; after follow-up 22% continued to fail and 42% changed from a fail to a pass. These proportions were similar to English home language speakers, where 65% required a follow-up; of those, 21% continued to fail and 44% changed from a fail to a pass. Therefore, answering the SA English M-CHAT in a non-home language did not change the proportions requiring a follow-up or the proportions changing their outcome after follow-up, likely indicating that the initial questions were equally well understood. Furthermore, these proportions were also similar to those in the overall sample including all M-CHAT versions.

***Changes After Follow-Up.*** In the current study, a large number of participants changed their outcome (ASD to no ASD risk) after follow-up. However, these proportions were similar to the original M-CHAT validation (Robins et al., 2001). Therefore, this possibly indicated that the M-CHAT adaptations on the initial questionnaire were understood by a similar proportion of people. When comparing the current study to other M-CHAT cross-cultural validations, a smaller proportion in the current sample changed from a fail to a pass after follow-up and this sample indicated fewer false positives before follow-up (Canal-Bedia et al., 2011; Kara et al., 2012). This may be due to cultural adaptations to the initial questions in the current study being understood more clearly the first time, requiring less clarification at follow-up. However, one must be cautious comparing this study to the others as they did not sample from purely high-risk populations where there are likely to be more participants failing, but incorrectly, due to the overlapping symptoms of another developmental disorder. In future, the interpretations of the current follow-up findings need to be validated with actual diagnoses. This will determine the extent to which the M-CHAT is identifying ASD, whether its results are confounded by symptoms of other developmental disorders or to what extent questions are initially misunderstood by parents. However no matter the reason for follow-up, from this study and from previous research, it is clear that the

follow-up is essential in identifying those that eventually pass or fail the screen, to decrease the number of false positives (Kleinman et al., 2008; Pandey et al., 2008).

The large numbers changing their outcome after the follow-up are likely due to misunderstandings on the initial items but they do not appear to be affected by filling out the M-CHAT in a second language. However, in a few cases, outcomes may also change in the extended periods between filling in the M-CHAT and completing the follow-up (where telephone contact was difficult). In these extended periods, symptoms may change, due to increasing age or participants undergoing ASD interventions. Although the follow-up is important, administering it requires extra resources in terms of interpreters, phone calls, and time.

In South Africa's overburdened healthcare system, follow-up telephone calls are not feasible. In this context resources are limited and there are large difficulties getting hold of people telephonically, thus the reason why  $n=26$  participants were unreachable. Therefore, it is a positive that the current study indicated fewer participants requiring the follow-up compared to others. However, it is still important to ensure that even more questions are initially easily understood to decrease the number of follow-ups required.

In an attempt to decrease the need for follow-ups, the new M-CHAT-R/F (which was validated after this study commenced) has tried to make the questions more easily understood the first time by simplifying the wording and offering examples of behaviours. Additionally, the new scoring algorithm, allows children in the high-risk range (failing 8+ items) to bypass the follow-up, thus further decreasing the number of follow-up interviews being carried out (Robins et al., 2014). These changes would likely be particularly useful in the overburdened South African context.

## **Phase 2 – Diagnostic Assessment**

**Demographic characteristics.** This diagnostic phase of the study was a preliminary investigation into the predictive abilities of the M-CHAT. Of the 38 participants described below, 28 came in for a full diagnostic assessment, after filling out the M-CHAT at the Developmental Clinic and consenting to take part in phase 2. The full diagnostic assessment consisted of the ADOS-2, and an IQ or developmental assessment (WPPSI-III or SGS-II). However,  $n=2$  of these participants did not take part in the developmental assessments due to time constraints. Because the number formally diagnosed was so low, an additional 10 participants from the initial pilot study for this project were also included in this analysis: they were assessed using the ADOS but scored using the new scoring algorithm from the

ADOS-2 (when it became available). Therefore, the diagnoses are unlikely to be affected and are likely comparable to the diagnoses made on the other 28 participants. In the additional 10 cases there were no assessments of IQ or development.

For this phase we tried to get equal numbers in each of the following M-CHAT outcome groups: high ASD risk, close to cut-off and low ASD risk. However, this was not always possible so we had to work with which parents were available to come in for the diagnostic assessment.

Furthermore, the phase 2 sample only contains participants completing the English M-CHAT because at present, there are no approved Afrikaans or IsiXhosa versions of the ADOS/-2. In the sample,  $n=5$  of the parents reported home languages different to English; however, they were all fluent in English and these parents reported that the children were competent in English too. Descriptive statistics for phase 2 can be found in Table 17 below.

Table 17

*Demographic Characteristics of the Phase 2 Sample in ASD and Non-ASD Groups*

Demographic characteristics	Total phase 2 sample (N=38)	ASD diagnostic outcomes		Test of significance		
		ASD (n=25)	Non-ASD (n=13)	t-test		ESE
				t	p	r
Child's Age (years)	3.65 (1.00)	3.82 (0.91)	3.32 (1.10)	-1.48	.147	.24
Range of age	1.57-4.94	1.57-4.94	1.87-4.90			
Child's Sex (Female:Male)	9:29	6:19	3:10			
Ethnicity (Black: Coloured: White)	2:31:5	2:19:4	0:12:1			
Home language (English: English & Afrikaans: Xhosa: Other)	33:3:1:1	22:1:1:1	11:2:0:0			
Income (Household R per annum)	34611.57 (33236.68)	44074.00 (36676.60)	18525.45 (18526.48)	-2.40	.024 <sup>a</sup>	.44
Mother's education (years completed)	12.00 (1.04)	12.08 (1.06)	11.80 (1.03)	-0.72	.480	.13

*Note.* ESE=estimation of effect size. For Age, Income and Mother's Education, the means are provided with standard deviations in parentheses. The sample size for Income was  $n=27$  (ASD:  $n=17$ , non-ASD:  $n=10$ ) and  $n=34$  for Mother's Education (ASD:  $n=24$ , non-ASD:  $n=10$ ). Age represents the age of the child when the caregiver filled out the M-CHAT. For child's Sex, Ethnicity, Home Language, raw numbers are provided. With the categorical variables, there were not sufficient numbers in each category across ASD and non-ASD to permit statistical analyses (multiple expected frequencies  $< 5$ ).

<sup>a</sup>Equal variances were not assumed.

The table above indicates the differences in demographic variables between the ASD and non-ASD groups. These were measured using an independent samples t-test (2-tailed), for the continuous variables. The categorical variables were descriptively analysed. There were no significant differences in the age of the children between the ASD and non-ASD groups ( $t(36) = -1.48, p = .147$ ). The large majority of participants were Coloured (81.58%), with very few White (13.16%) or Black participants (5.26%). In terms of sex, again there were many more males (76.32%) compared to females (23.68%). All the participants had filled out the English M-CHAT, however, 86.84% had a home language of English, 7.89%

spoke both English & Afrikaans at home, 2.63% spoke IsiXhosa and 2.63% spoke French at home. Household income was not significantly different between the groups, when using the adjusted significance of  $p < .01$ , ( $t(25) = -2.40, p = .024$ ). There were also no differences in the mother's education between the two groups ( $t(32) = -0.72, p = .480$ ).

In summary, mean age, income and mother's education were similar across the ASD and non-ASD groups. In addition, within the variables of sex, ethnicity, and home language, the individual categories making up each variable had similar ratios to one another when looking across the ASD and the non-ASD groups. Therefore, we can be relatively certain that the M-CHAT score variability is not due to uncontrolled differences in demographic variables across the ASD and non-ASD groups. Furthermore, earlier statistics also indicated that demographic characteristics appear to have limited effects on M-CHAT scores.

### M-CHAT scores across ASD and non-ASD groups.

Table 18

*M-CHAT Scores of the Phase 2 Sample Between ASD and Non-ASD Groups*

M-CHAT final scores	Total phase 2 sample (N=38)	ASD diagnostic outcomes		Test of significance		
		ASD (n=25)	Non-ASD (n=13)	t	t-test p	ESE r
M-CHAT score overall- 23 items	4.68 (3.48)	5.72 (3.26)	2.69 (3.09)	-2.76	.005	.42
Range of M-CHAT score overall- 23 items	0-13	1-13	0-11			
M-CHAT score critical- 6 items	1.24 (1.62)	1.68 (1.57)	0.38 (1.39)	-2.50	.009	.38
Range of M-CHAT score critical- 6 items	0-6	0-6	0-5			

*Note.* ESE=estimate of effect size. For the M-CHAT scores, the means are provided with standard deviations in parentheses. Other cells indicate the range of M-CHAT scores.

Table 18 above describes the differences in final M-CHAT scores across the ASD and non-ASD groups. These differences were measured using 1-tailed independent samples *t*-tests. The ASD group had significantly higher final scores than the non-ASD group for the 23-items ( $t(36) = -2.76, p = .005$ ) and the 6-items ( $t(36) = -2.50, p = .009$ ), both with a medium effect. This is expected, as increased M-CHAT score indicates increased ASD risk.

Unexpectedly, the M-CHAT scores fall within similar ranges in the two groups; however, the high scores in the non-ASD group are due to one non-ASD participant scoring particularly high. If one excluded that participant's score from the non-ASD range, the range for the 23-items would be 0-7 and for the 6-items, all other participant scores were 0. Thus, in general there was still a lower score range in the non-ASD group compared to the ASD group.

**Descriptive comparison of diagnosis using either the 23-item or the 6-item score.**

Table 19

*Comparison of M-CHAT Outcome vs. Formal Diagnosis*

M-CHAT screening	Diagnosis	
	ASD	Non-ASD
23 Items		
ASD risk (fail)	21	4
Non-ASD risk (pass)	4	9
6 Items		
ASD risk (fail)	11	1
Non-ASD risk (pass)	14	12

The 23-item M-CHAT score results in a larger number of correct classifications into the diagnostic groups (see Table 19 above). Using the 23-items, the majority failing the screen were also diagnosed as ASD and the majority passing the screen, were not diagnosed with ASD. However, with the critical 6-item M-CHAT score, the majority failing the screen were diagnosed as ASD; but many that passed the M-CHAT were also diagnosed as ASD, rather than non-ASD. Thus, by using this 6-item score alone one may miss out on flagging high risk individuals for assessment, which would be problematic. Some participants may possibly have had a diagnosis and intervention before filling in the screen, resulting in lower M-CHAT scores. However, the 23-item score was still more accurate and sensitive (which is vital for screening measures) in indicating ASD or non-ASD risk. As mentioned earlier, there were also no participants failing only on the 6-item score and not on the 23-item score. Additionally, one of the largest M-CHAT studies also found that the 23-item cut-off was best and the results were not improved by the 6-item score (Chlebowski et al., 2013).

Overall and when using the 23-item cut-off, the M-CHAT indicates a positive predictive value (PPV) of .84 and a negative predictive value (NPV) of .69. Although PPV relies on ASD prevalence (Canal-Bedia et al., 2011), this PPV is still higher than other studies in high risk samples, which indicate PPV's of .76 (Kleinman et al., 2008), .74-.79 (Pandey et al., 2008), and .75 in the Turkish combined high and low risk sample (Kara et al., 2012). Interestingly, Khowaja, et al. (2015) also found that PPVs across maternal education and racial groups were similar to one another (although lower than the values in the current study). Thus on future analyses of the other M-CHAT versions, one can be hopeful that their PPVs will be similarly high, as these demographic factors did not affect PPV. However, although the values in the current study are high, PPV is likely to be increased in a high risk sample (Pandey et al., 2008), in addition, the numbers in the non-ASD group are small and so drawing accurate conclusions can be difficult.

**M-CHAT's ability to distinguish ASD with ID/DD from pure ID/DD.** This section qualitatively investigates the effects of Intellectual Disability (ID) or Developmental Delay (DD) on the M-CHAT outcome. This is to determine whether the M-CHAT can distinguish ASD with ID/DD from pure ID/DD. However, for the rest of this section, the use of "DD" will indicate ID/DD. In this sample, many children were markedly delayed and therefore had to do the SGS-2 rather than the WPPSI-III IQ test. Therefore, we had to establish a cut-off indicating DD on each of the instruments; on the WPPSI-III this was where the child had a Full Scale IQ < 70 (due to ongoing research at the University of Cape Town, this seems to be a more appropriate DD cut-off in the low SES Western Cape population) and on the SGS-2 it was where the child fell in the "abnormal" development range for the majority of the domains of functioning.

The IQ or developmental assessments were completed by 26 participants. All those with ASD also had a DD, and of these participants, 76.9% failed the M-CHAT. Of those that had neither a DD nor ASD, only 14.3% failed the M-CHAT and of those that had a DD but were non-ASD, a larger proportion of 50% failed the M-CHAT. Therefore, in non-ASD participants, larger percentages failed the M-CHAT when they had a DD. This is somewhat expected as children with ASD share many features with other developmental disorders (Ventola et al., 2007).

Because of quite a high failure rate in the non-ASD DD group, the M-CHAT is possibly incorrectly flagging DD as ASD. This could be the case as other M-CHAT studies such as that by Chlebowski et al. (2013), found that in a low risk sample, the M-CHAT had a

PPV of .54 for ASD and a PPV of .98 for all developmental concerns needing intervention. However, in the current study a much larger percentage of ASD participants still failed the M-CHAT, compared to non-ASD participants with a DD. Thus, it seems the M-CHAT is still best at flagging ASD in this sample. However, this analysis needs to be carried out in a much larger sample as there were only 3 non-ASD participants with a DD and 1 participant with neither ASD nor DD.

**Logistic regression of M-CHAT score to predict ASD vs. non-ASD.** Although numbers were small in this exploratory investigation, this analysis was run to see whether the M-CHAT seems successful in predicting ASD risk, as confirmed by formal diagnoses on the ADOS/-2. Two logistic regressions were run, with ASD classification as the outcome variable and the final M-CHAT scores (23-items and 6-items separately) as the predictor variables. Note that one participant was assessed using the ADOS-2 Toddler Module which results in a ‘range of concern,’ rather than an ASD diagnosis.

**23-item M-CHAT and ASD prediction.** When the model included the final 23-item M-CHAT score, it predicted ASD and non-ASD risk significantly better than when only the constant was included,  $\chi^2(1) = 7.95, p = .005$ . The  $b = 0.36$  ( $SE = 0.16$ ) value indicates that a one unit change in the predictor results in a 0.36 change in the logit of the outcome variable. However, the Wald statistic ( $Wald = 5.43, p = .020$ ) is not significant at the  $p < .01$  level, therefore the  $b$  coefficient for the M-CHAT 23-item score is not making a significant contribution to the prediction of the outcome. However, the less stringent alpha value may be more appropriate for this exploratory investigation, in which case the M-CHAT score would be significantly contributing to the outcome. The odds ratio of 1.43 indicates that as the number of M-CHAT items failed increases by 1, the odds of being in the ASD group is 1.43 times more likely. However, the  $R^2$  values ( $R^2 = .19$  (Cox & Snell),  $.26$  (Nagelkerke)) do not indicate a particularly strong relationship between the 23-item M-CHAT score and the ASD classification.

If one were to delete the one outlier in the non-ASD group, who failed many items on the M-CHAT, the *Wald* value would then be significant, even at the  $p < .01$  level. Thus, the  $b$  coefficient for the 23-item M-CHAT score would then be making a significant contribution to the prediction of the outcome, but with only slightly higher  $R^2$  values ( $R^2 = .32$  (Cox & Snell),  $.45$  (Nagelkerke)).

**Critical 6-item M-CHAT and ASD prediction.** When the model included the critical 6-item M-CHAT score, it predicted ASD and non-ASD risk significantly better than when

only the constant was included  $\chi^2(1) = 7.51, p = .006$ . The  $b = 0.88$  (SE = 0.43) value indicates that a one unit change in the predictor, results in a 0.88 change in the logit of the outcome variable. However, the Wald statistic ( $Wald=4.23, p=.040$ ), is not significant at the  $p<.01$  level, therefore the  $b$  coefficient for the 6-item score is not making a significant contribution to the outcome prediction. However, again, with the less stringent alpha for this exploratory investigation, the M-CHAT score would then significantly contribute to the outcome. The odds ratio value is 2.42, indicating that as the number of M-CHAT items failed increases by 1, the odds of being in the ASD group is 2.42 times more likely. The  $R^2$  values ( $R^2 = .18$  (Cox & Snell),  $.25$  (Nagelkerke)) do not indicate a particularly strong relationship between the 6-item score and the ASD classification. However, if one were to again delete the outlier in the non-ASD group, then every participant in the non-ASD group would have had a 6-item score of 0.

It is important to note that phase 2 has a very small number of participants; therefore, power is likely reduced, thus possibly affecting the statistics. The power values for the 23-items and the 6-items are around .07 and .31 respectively. These low power values possibly indicate why the expected results did not come across as strongly as anticipated. Due to the large number of statistical analyses used throughout this study, a significance value of  $p < .01$  was being used. However, if using the conventional significance value of  $p < .05$ , one could have concluded that both the M-CHAT 23-item score and the critical 6-item M-CHAT score were significantly contributing to the prediction of ASD or non-ASD, as  $p < .05$  in both instances. In addition, the results would have improved further by the removal of the outlier. Therefore, this exploratory investigation seems to indicate that the M-CHAT would be capable of predicting ASD but confirmation in a larger sample is still needed.

**Preliminary cut-off point analysis.** Receiver Operating Characteristic (ROC) analyses were conducted to determine cut-off scores resulting in optimal sensitivity and specificity. ROC curves allow a visual depiction of the sensitivity and specificity at different cut-off points on the M-CHAT. These can be found in figures 3 and 4 below.

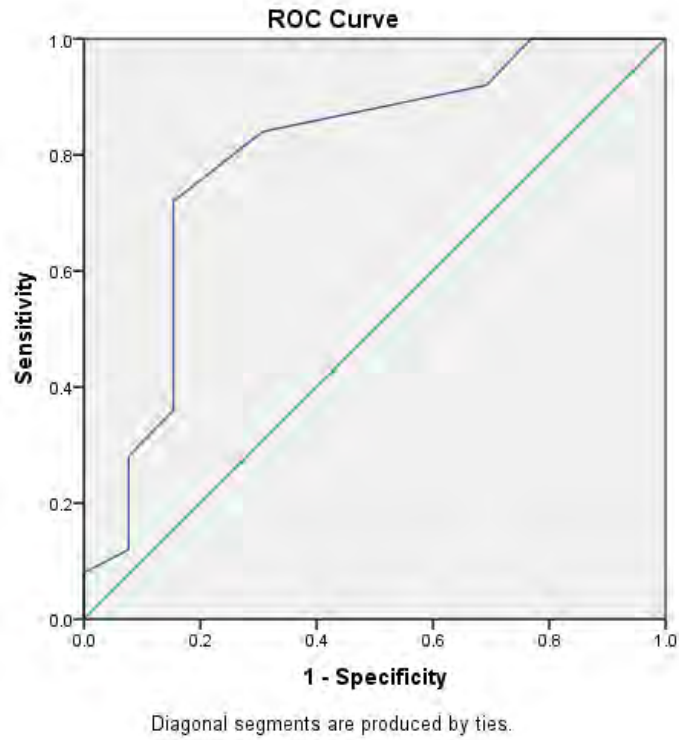


Figure 3. ROC curve of M-CHAT results when using all 23-items

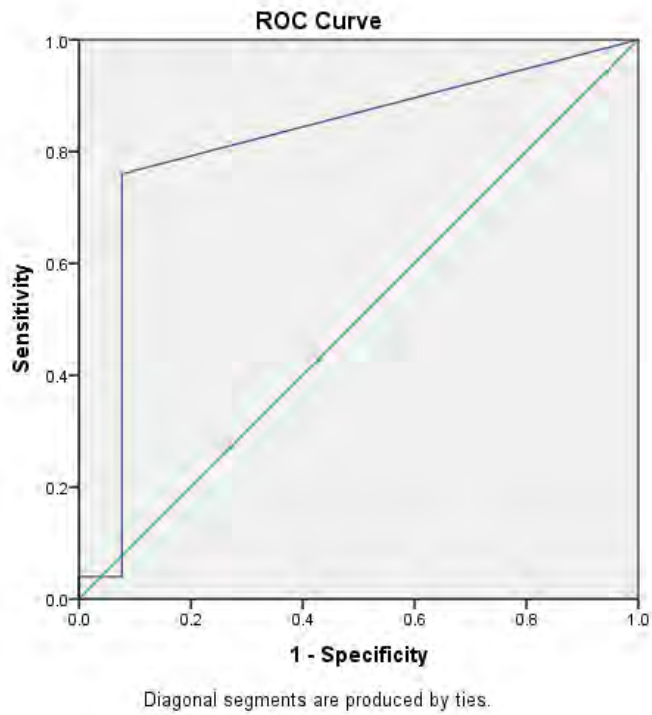


Figure 4. ROC curve of M-CHAT results when using critical 6-items

**Overall 23-item M-CHAT ROC analysis.** The ROC curve in figure 3 indicates the 23-item analysis. The area under the curve (AUC) was .80, indicating that the M-CHAT score predicted ASD/non-ASD much better than by chance.

**Critical 6-item M-CHAT ROC analysis.** The ROC curve in figure 4 indicates the critical 6-item analysis. The AUC was .82; again indicating that the M-CHAT score predicted ASD/non-ASD much better than chance.

Table 20

*Cut-Off Point Analysis for the 23-Item M-CHAT*

Cut-off point (if > than or equal to)	Sensitivity	Specificity
.5	1.00	.231
1.5	.920	.328
<b>2.5</b>	<b>.840</b>	<b>.692</b>
3.5	.720	.846

Table 21

*Cut-Off Point Analysis for the 6-Item M-CHAT*

Cut-off point (if > than or equal to)	Sensitivity	Specificity
<b>.5</b>	<b>.760</b>	<b>.923</b>
1.5	.440	.923
2.5	.240	.923

The following section investigates the cut-off points, by looking at the sensitivity and specificity of each of the M-CHAT final scores. The sensitivities and specificities resulting from different cut-off points are indicated in Table 20 for the 23-item score and in Table 21 for the 6-item score.

**Overall 23-item M-CHAT cut-off, sensitivity and specificity.** Table 20 and Figure 3 to indicate that a cut-off point of 2.5 is most useful. Therefore, any values greater than or equal to 2.5 should result in a classification of ASD risk. Thus on the M-CHAT, where scores are only in whole numbers, the cut-off point is reached when 3 questions or more are failed. This is the same cut-off originally suggested when using all 23-items (Robins et al., 2001). In

this case the sensitivity is high (.840) and the specificity is also adequate (.692). This cut-off was chosen, as the M-CHAT is a screening tool, therefore, a higher sensitivity is more important than a high specificity, although one would ideally like them both to be as high as possible, especially in a developmental disorder population.

**Critical 6-item M-CHAT cut-off, sensitivity and specificity.** Table 21 and Figure 4 for the 6-item M-CHAT score indicate that a cut off of 0.5 is best. Therefore, a score above or equal to 0.5 should result in an ASD risk classification. Again, the M-CHAT scores are in whole numbers, thus, the cut-off is reached when 1 critical item is failed. In this case both the sensitivity (.760) and the specificity were high (.923). Although, a higher sensitivity is ideal for a screening tool, if one were to make the cut-off point 1 unit higher, the sensitivity would have dropped too low to .440. Future studies should also investigate whether a new set of critical items is more applicable to this context.

**Comparisons to other studies.** It is difficult to make direct comparisons of sensitivity and specificity with other studies as they differ in terms of whether the follow-up was administered, the age ranges included and the cut-off scores used. In addition, true values are difficult to determine because most often only those failing the M-CHAT are evaluated, thus those passing the screen are not evaluated to check for missed cases. That is one of the strengths of the current sample: although it is small, the diagnostic assessments were completed by those that both passed or failed the M-CHAT. Thus, the sensitivity and specificity values in the current sample are particularly meaningful.

In comparing other studies, both the original M-CHAT study (Robins et al., 2001) and the Kleinman et al. (2008) study indicated high values of sensitivity (.87 and .91, respectively) and the original study found a high specificity (.99), in a mixed sample of low and high risk participants (Robins et al., 2001). Kleinman et al. (2008) had a particularly accurate sensitivity as they followed-up some screened participants 1.5-2 years later to check diagnoses and missed cases. On other cross-cultural adaptations, the M-CHAT maintained its high sensitivity and specificity. In a low risk sample, the Spanish M-CHAT indicated a sensitivity and specificity of 1 and .98 (Canal-Bedia et al., 2011), and the Japanese M-CHAT had a sensitivity of .75 and specificity of .89 for the cut-off of 2/23 items (Inada et al., 2011). In a high risk sample, the Arabic version found high sensitivity (.86) and specificity (.80; Eldin et al., 2008). The current study sample indicates a similar sensitivity to other studies for both the 23-item and 6-item cut-offs. For the 23-items, specificity was adequate yet slightly lower, likely due the high-risk sample, where it was harder to differentiate those with other developmental disorders. However, the 6-item specificity was similar to other studies and

likely higher than the 23-item specificity because the critical items are specific to ASD, thus allowing better discrimination between ASD and other developmental disorders. In addition 3/4 of the items found by Ventola et al. (2007) to be best at differentiating ASD and other developmental disabilities, are also critical items.

In this study no participants failed on the 6-item cut-off alone, they either failed the 23 item cut-off only or both. Therefore, the high true sensitivity using the 23 item score indicates that the M-CHAT is likely to correctly flag those at risk for ASD, without missing many cases. High sensitivity is preferred for screening, as one would rather over identify possible cases, because even if they do not have ASD, many may have another developmental disorder requiring intervention. Eaves et al. (2006) mentioned that sensitivity may be more important for low risk population screening, but indicated concerns regarding the M-CHAT's ability to identify ASD in high risk samples. However, the current sample has shown that specificity is also adequate despite the high-risk population.

### **General Discussion**

This study was part of a larger project investigating the use of ASD screening tools in the Western Cape, South Africa. However, this thesis specifically focussed on assessing the use of the M-CHAT in this diverse population. ASD diagnosis in developed countries occurs relatively late and is likely even later in developing countries. Late diagnosis is especially likely in South Africa as government hospitals are overburdened and have long waiting lists for appointments. In addition, short-term survival issues may overlap with the age of early ASD diagnosis. Thus, without screens, ASD is often missed by paediatricians and teachers. This is problematic as early diagnosis and intervention are said to result in the best possible outcomes and decreased ASD expenditure. Therefore, the validation of ASD screening tools for young children in South Africa is essential in achieving this. Although this study took place at Red Cross Children's Hospital, it is hoped that these screening tools will be implemented at primary care clinics around the Western Cape, where undiagnosed ASD cases are even more likely.

In the following section, I will highlight the main findings from phase 1 and phase 2 of this study. In addition, I will consider the implications of these findings on the M-CHAT's application for this context.

## Phase 1

**Effects of demographic characteristics.** Consideration of the demographic characteristics of this sample was important as South Africa is extremely diverse and this diversity could affect M-CHAT scores. Because this study was carried out in a population where it is likely to be used, the information is extremely valuable and a true reflection of the M-CHAT's applicability. The sample was from a low SES background and although the mother's education was generally adequate, one cannot be sure of the schooling quality. However, the fact that income and mother's education had no effects on the M-CHAT scores is extremely promising, especially as low SES populations are likely most in need of screening. Nevertheless, it is important to note that standard self-administration was not always used; instead researchers were on hand to read through questions with parents. Although simplified wording in the M-CHAT-R/F could decrease this need, in future, parents are still likely to require help reading and understanding questions. Another consideration was the age at which the M-CHAT was administered.

Child's age was not found to affect the M-CHAT score. Thus the screen seems to successfully flag those at an early age (from 1.5-4.00 years), and those in an extended older age range (up to 4.99 years). The inclusion of the older age group is important in South Africa where clinics are overburdened and where parents and healthcare workers are less aware of ASD: thus children may be older when first seen at tertiary hospitals. Therefore, screening needs to cover a wider age range, ensuring that older cases are not missed, and to flag cases where regression may have occurred. In addition to score equivalence across ages, equivalent results across sex and ethnicity are also important.

Neither sex, nor ethnicity appeared to affect the M-CHAT scores. However, ethnicity was highly correlated with language, which is often expected in South Africa.

It is positive that M-CHAT scores did not differ across the three M-CHAT versions nor did they appear to differ across home language. Therefore, it seems each M-CHAT version was equally well understood. Furthermore, all versions showed good internal consistency. Thus, they are likely all reliably measuring autistic traits, with especially high values compared to other M-CHAT cross-cultural validations. Therefore, all three M-CHAT versions should continue to be used for this population in future.

**M-CHAT versions of choice.** This study showed that the English M-CHAT will likely be the most common version of choice in the Western Cape. It was chosen by English home language speakers as well as, surprisingly, by many English second language speakers. Unexpectedly, the results show that filling out the screen in a first or second language does

not affect the percentage changing their ASD-risk outcome after the follow-up. Furthermore, it is possibly fortunate that higher proportions are likely to choose the English version, as most healthcare staff at Red Cross are English first language speakers (Levin, 2006), thus many members would be available to help English-speaking parents. It is also likely that some healthcare staff (although fewer) are able to speak Afrikaans or IsiXhosa; they could assist the smaller numbers filling in non-English versions. However, if rolled out beyond the Red Cross Clinic, it is likely that more healthcare staff are Afrikaans or IsiXhosa speaking. Thus, the version of choice may change in other settings. In addition to three different versions for this context, there are specific items which appear more applicable.

**Item applicability and decreasing follow-ups.** Specific items that were either failed too often or too seldom, by all outcome groups, were identified. It may be worth considering the elimination of these items in this context, as they were not particularly discriminatory between those eventually passing or failing the M-CHAT. However, diagnostic confirmations on more cases are needed before deciding on item removal. In addition, many of the items which were failed too often were initially failed and subsequently passed on follow-up. Thus, indicating that the follow-up is important in clarifying the final outcome. However, the follow-up also requires many extra resources. Therefore, ways to eliminate unnecessary initial item failure are essential to consider, in order to reduce the resource burden required to administer the M-CHAT, as this was of great concern. Potential methods of doing this will be discussed in later subsections.

## **Phase 2**

Although phase 2 was a preliminary analysis of the SA English M-CHAT, there are indications that it has good predictive ability for ASD diagnoses using the ADOS/-2. This was even true in a developmental clinic sample, where all children have some sort of developmental difficulties. The promising results indicate that further diagnostic investigations in larger samples for each M-CHAT version should be carried out. For this population, the optimal cut-off for 23-items remained at 3 but the critical 6-item cut-off was optimal when decreased to 1. However, the critical items may be unnecessary, because the final 23-item score, rather than the 6-item score, determined the final ASD-risk outcome in all cases. However, earlier item analysis also showed that the items best at discriminating those passing or failing overall were slightly different to the originally suggested critical items. Thus, more confirmatory diagnostic assessments would help in determining whether other critical items are better for this context.

Even though some of those with non-ASD DDs were incorrectly flagged as ASD (50%), it still appears that the M-CHAT was better at correctly predicting ASD. In the ASD group with DDs, the M-CHAT correctly flagged 77% with ASD. Furthermore, the M-CHAT is only a screening tool and is not expected to provide a final diagnosis. Moreover, other studies found that those incorrectly flagged with the M-CHAT were often not typically developing, so further follow up was still required.

Overall, most results were positive, when considering the M-CHAT's use in the Western Cape, South Africa, which is very diverse. This research indicates that the M-CHAT should be valid for 'at risk' populations in state-funded clinics in the Western Cape. The M-CHAT-R/F is also not that different to the original M-CHAT, thus adapting it using the vocabulary deemed suitable for the South African population should result in it working equally well, if not better, with its simplified wording and extra examples. Although further diagnostic assessments are still required, the M-CHAT did not appear to be affected by the diversity found in this context and even appeared to make some of the finer distinctions between ASD and other DDs.

I will now discuss, in more detail, practical suggestions for future administration of the M-CHAT in Western Cape state-funded clinics. This will take into account the difficulties and limitations experienced in this study, as well as investigating possible changes from the new M-CHAT-R/F, which could be useful.

### **Difficulties and Suggestions for the Application of the M-CHAT**

It is important to think about the real world application of the M-CHAT in Western Cape community clinics. Although literacy rates in the Western Cape are relatively high and the mother's education higher than expected in this sample, there are still some parents with very low levels and quality of education. Furthermore, parent education may be even lower in primary care clinics. Therefore, in low SES samples it is likely that some parents will need help from interpreters when completing the M-CHAT, as was the case during data collection. Self-report as practiced in developed countries, does not appear feasible in this context. Interpreters were particularly necessary in the IsiXhosa group, as many parents mentioned the difficulty in reading long and complex IsiXhosa written words, and the ease in understanding it when spoken. Therefore, interpreters would be necessary but could be very costly. Alternatively, healthcare professionals at each site could help participants; but there would need to be someone fluent in each language available. Although the majority of the doctors at Red Cross are first language English speaking (Levin, 2006), some of the nurses may be

Afrikaans or IsiXhosa speaking and could therefore assist parents filling out the screen. In addition, extra resources are needed to administer the follow-up.

The follow-up interviews also need to be administered in each of the three languages. The many phone calls are costly and time consuming, and many participants are lost or phoned much later, exceeding the screen's age limits. This is due to lost or stolen phones and numbers changing. Thus, the follow-ups should rather be completed immediately, in the clinic. Even though the new M-CHAT-R/F would help somewhat with decreasing the number of follow-ups needed, follow-ups are still required. However, Kara et al. (2012) found fewer false positives when healthcare workers administered the M-CHAT in the waiting room, where questions could immediately be clarified, without using the follow-up. Thus, if there are sufficient healthcare workers fluent in each of the languages this may be an option. However, it would require larger time commitments from these healthcare professionals as they would need to read through the screen with every parent rather than just those needing a follow-up or needing help reading through. Although, Kara et al., (2012) mention that the time required is still negligible. Healthcare staff would also likely need good ASD knowledge to identify questions needing further clarification.

Although the M-CHAT administration should not typically require training, it may be useful for healthcare workers/interpreters to have prior guidance around ASD. This would be especially useful in this context, if administering the follow-up, as ASD knowledge is likely limited in the Western Cape. Although most of the follow-up questions follow a simple flow chart and have a checklist of behaviours to query, there are a few instances where parents are asked to come up with their own behavioural examples. The current study's IsiXhosa interpreter sometimes struggled to judge whether parent's examples indicated ASD or not, without first asking one of the other researchers. Thus, if the IsiXhosa interpreter had more knowledge around ASD, it would have been easier and quicker to realise whether a response indicated ASD or whether the checklist of behaviours should rather be run through with the parent, as was done for the English and Afrikaans versions, where the researchers were more knowledgeable on ASD. Once trained and familiar with this process, the M-CHAT and follow-up interview are very quick and easy to administer.

In this Western Cape context, it will likely be better to have healthcare staff read through and clarify the initial M-CHAT with parents, as they did in the Kara et al. (2012) study. However, in addition, standard administration of the follow-up should still be used (but administered immediately after the M-CHAT), rather than only relying on clarifying answers on initial questioning, without the follow-up. Use of the follow-up would help to ensure valid

and reliable M-CHAT final scores across staff and clinics, and is very quick to administer. Furthermore, even if initial questions are read aloud, parents may feel embarrassed to query a question's meaning and just answer with a yes/no. In these cases where they incorrectly fail, the standard follow-up would help to clarify this, whereas healthcare workers may not automatically query given answers without the follow-up. Although extra resources would likely be required for implementing the M-CHAT, one would rather deal with the costs of carrying out some further training and slightly extending the roles of current staff, than having potentially invalid screens.

A further possible way of preventing the need for an interpreter in each language and to prevent irregularities in the way the screen is administered, may be to have an electronic version. The M-CHAT and the necessary follow-up questions could be read out aloud electronically to parents, in their language of choice, and answers selected on a touch screen. If clarifications are needed, healthcare staff could assist parents. Harrington, et al. (2012) investigated the use of an electronic version (not read out aloud) of the M-CHAT on an iPad, in a low SES sample. They found many benefits to this method of administration; reduced human error in scoring, uniformity in follow-up administration, decreased false positives and better parent satisfaction. Importantly, the use of the electronic technology did not appear problematic, thus, it could potentially work in the Western Cape community clinics too. This would decrease the costs of trained interpreters, in the long run it could decrease printing costs, and all information could be stored electronically. However, realistically, the cost of setting up and maintaining this type of equipment is not feasible in such low SES clinics, which are already severely underequipped and lacking technical support.

### **M-CHAT and M-CHAT-R/F**

One of the biggest challenges with the M-CHAT in this study and others is the false positive rate, especially after the initial questioning. False positives after initial questioning result in many unnecessary, costly follow-ups being conducted. This was one of the issues the M-CHAT-R/F attempted to tackle (Robins et al., 2014).

Literature on the M-CHAT-R/F validation became available in 2014<sup>1</sup>, after this study was designed and data collection commenced in 2012. Therefore, this study focuses on the initial M-CHAT outcomes, while making comparisons with the newer version. The M-CHAT-R/F changed the M-CHAT in a number of ways; wording was simplified, examples of

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<sup>1</sup> Although the revised M-CHAT-R/F was developed in 2009, the validation literature on the new tool was, to my knowledge, only available in 2014.

behaviours were given, unnecessary items were removed, and questions were re-ordered to decrease positive response biases (Robins et al., 2014). Many of these changes have taken control of the recommendations that the current study would have made, as mentioned in earlier parts of the discussion. This is especially true in terms of adding examples to the initial items; it is likely that many more items would have been passed initially, if these were available from the outset. In addition, reordering the items requiring a reverse response could reduce the number of failed items from positive response biases. These are all likely to decrease the need for resource-burdening follow-ups.

However, when it comes to item removal, only one of three items removed in the new version coincided with problem items identified for this context. Thus, it may be useful for South Africa to create its own revised M-CHAT by removing non-discriminatory items specific to this context.

The new version has also changed the scoring to some extent. Scores after initial questioning are grouped into low (0-2), medium (3-7), and high risk (8+). Within each score range there are recommendations given. For example, when scoring in the low risk range; if the child is < 24 months, re-administer the screen after their 2<sup>nd</sup> birthday, otherwise take no further action (Robins et al., 2014). This would help ensure that those screened very young are re-screened when symptoms possibly become more apparent. Specific South African risk ranges could also be determined, and those in the ‘high risk range’ could bypass the follow-up, as is the case with the M-CHAT-R/F, again further decreasing the number of follow-up interviews.

Overall it appears the M-CHAT-R/F has made important changes and would likely also be applicable to the South African context, as it asks the same questions, but in simplified ways and by using more examples. However, it would possibly be important to make adaptations, such as the removal of items and the setting of score ranges, using a South African sample, to determine its applicability.

### **Limitations and Future Directions**

In addition to the difficulties in administration and the changes to the screen that may be useful in future, there were some other aspects possibly affecting the results. Firstly, the number of participants needs to be increased, especially in the Afrikaans and IsiXhosa groups, and for the phase 2 English sample. Increased numbers for phase 1 would have allowed statistical analyses of the effects of home language and ethnicity, which, in the current sample, had too few participants in each category. However, data collection took

place over a long time (every second week from September 2012-October 2013 & February 2014-March 2015) and these numbers represent the families seen in the clinic over that time. In addition, when Afrikaans and IsiXhosa ADOS/-2 versions become available, these groups need to be formally diagnosed. Increased numbers of actual diagnoses are essential to determine the real predictive abilities of the M-CHAT within a sample with many other developmental disorders, and for determining critical items and cut-off scores for this diverse context.

Secondly, the majority of children taking part were undiagnosed but some had a diagnosis. Thus, some may have had improved M-CHAT scores, if part of an intervention programme. However, the age of diagnosis in the US is still late, with an average age of around 64.9 months (Mandell et al., 2010) and 68.4 months (Shattuck et al., 2009). The children in the current sample would fall below this age, thus the majority are unlikely to be diagnosed and undergoing intervention programmes. This is especially true in South Africa where age of diagnosis is likely later, and access to interventions is limited. It is difficult to know whether changes in outcome between initial questioning and follow-up were because of children in intervention programmes, because symptoms change as children age, or because parents misunderstood the initial questions. In future if follow-ups are conducted immediately, these influences would not affect the final score.

Thirdly, some parents had a researcher reading through the screen with them and others did not. Although everyone was given this option, some may have felt embarrassed to do this or to ask questions; thus, results could be affected. Because the M-CHAT consists of yes/no answers, it is difficult to know if parents understood the question or just picked a random answer. Additionally, the primary researchers only spoke English and Afrikaans but not IsiXhosa. Thus, even though the IsiXhosa interpreter was shown how to administer the M-CHAT, the instructions and help given to IsiXhosa participants may have differed somewhat. However, slight differences in explanations are likely to happen with routine use of the M-CHAT in clinics, thus this may make the investigation more ecologically valid.

In addition, some adaptations for the IsiXhosa M-CHAT were not made to the other language versions. For example, in item 8 on the IsiXhosa version, the examples of small toys used were 'washing pegs or any other small things,' in addition to the originally stated 'cars or blocks.' This was changed because most IsiXhosa children are unlikely to have their own cars/blocks but rather play with objects around the house. Furthermore, the IsiXhosa version of item 10, asking about eye contact, included looking at the parent's eyes *or* face, in an appropriate way, rather than only looking at the eyes, as this is seen as disrespectful. These

changes were made to specifically suit the IsiXhosa population; therefore, they were not changed on the English or Afrikaans versions. However, in hindsight it would have been useful to make these changes on all versions because a number of IsiXhosa home language speakers still filled in the English M-CHAT. Thus, they would not always have received the exact same examples. However, these few changes to the IsiXhosa version were minor and unlikely to have significantly affected the scores in this study.

Lastly, the ADOS/-2 diagnostic instrument, used here, is not yet specifically validated for the South African context. Therefore, it would have been useful for clinicians to check the reliability of the diagnoses. This could have been achieved by clinicians reviewing the assessment material, and making a consensus diagnosis. We had hoped to do this; but resources were not available in time for write-up of this thesis. However, the ADOS/-2 is considered the gold-standard measure for ASD-diagnoses, therefore likely still correctly identifying ASD.

Although one cannot determine the extent to which the above factors affected scores, it is unlikely that their impact was large. However, it is still useful to bear them in mind when interpreting the applicability of the M-CHAT. Future studies should take note of whether the M-CHAT was read aloud, whether the child was previously diagnosed or taking part in interventions, and whether the follow-up interview was conducted immediately or not. Studies with larger samples in the English, Afrikaans and IsiXhosa groups, as well as actual diagnoses are going to be important for establishing the true validity of the M-CHAT in the Western Cape.

However, despite these considerations for future studies, it is important to reflect on the positive aspects of the current research. The current results are a real representation of the M-CHAT's validity in the low SES population in which it is likely to be used in future. Although the Afrikaans and IsiXhosa numbers were low, these group sizes are representative of those in the clinic waiting room. Furthermore, the M-CHAT scores seemed unaffected by varying demographic characteristics, they appeared equivalent across all three M-CHAT language versions, and indicated good predictive abilities.

### **Conclusion**

ASD is highly prevalent, and has a lifelong impact on the child and their families. Therefore, aiming for the best possible outcomes from early intervention is essential. Fortunately, the M-CHAT screens very young children, allowing for earlier diagnosis and hence access to services. This screen is especially beneficial in this Western Cape low SES

context as it is free, quick to administer and requires little training. This study took the first steps in assessing the applicability of three different language versions of the M-CHAT for this diverse population, with promising results. It is the hope that this will ultimately lead to the routine use of this ASD screen in clinics around the Western Cape, and ultimately, South Africa.

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*Appendix A*

## South African (SA) English M-CHAT

Please fill out the following about how your child usually is. Please try to answer every question. If the behaviour is not usual (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.? 

YES	NO
-----	----
2. Does your child take an interest in other children? 

YES	NO
-----	----
3. Does your child like climbing on things, such as on chairs or other things? 

YES	NO
-----	----
4. Does your child enjoy playing peek-a-boo/hide-and-seek? 

YES	NO
-----	----
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things? 

YES	NO
-----	----
6. Does your child ever use his/her index finger to point, to ask for something? 

YES	NO
-----	----
7. Does your child ever use his/her index finger to point, to indicate interest in something? 

YES	NO
-----	----
8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them? 

YES	NO
-----	----
9. Does your child ever bring objects over to you (parent) to show you something? 

YES	NO
-----	----
10. Does your child look you in the eye for more than a second or two? 

YES	NO
-----	----
11. Does your child ever seem oversensitive to noise (e.g., blocking ears)? 

YES	NO
-----	----
12. Does your child smile in response to your face or your smile? 

YES	NO
-----	----

13. Does your child imitate you? (e.g., you make a face-will your child imitate it?) 

YES	NO
-----	----
14. Does your child respond to his/her name when you call? 

YES	NO
-----	----
15. If you point at a toy across the room, does your child look at it? 

YES	NO
-----	----
16. Does your child walk? 

YES	NO
-----	----
17. Does your child look at things you are looking at? 

YES	NO
-----	----
18. Does your child make unusual finger movements near his/her face? 

YES	NO
-----	----
19. Does your child try to attract your attention to his/her own activity? 

YES	NO
-----	----
20. Have you ever wondered if your child is deaf? 

YES	NO
-----	----
21. Does your child understand what people say? 

YES	NO
-----	----
22. Does your child sometimes stare at nothing or wander with no purpose? 

YES	NO
-----	----
23. Does your child look at your face to check your reaction when faced with something unfamiliar? 

YES	NO
-----	----

## Appendix B

## Afrikaans M-CHAT

Voltooi asseblief die volgende vraelys oor hoe jou kind se gedrag gewoonlik is. Probeer om elke vraag te beantwoord. As die gedrag selde gebeur (u het dit nog net een of twee keer gesien), antwoord dat u kind dit *nie* doen *nie*.

1. Hou jou kind daarvan om geswaai te word, of om op jou knieë te ry, ensovoorts?	JA	NEE
<b>2. Is jou kind geïnteresseerd in ander kinders?</b>	<b>JA</b>	<b>NEE</b>
3. Hou jou kind daarvan om bo-op goed te klim, soos byvoorbeeld om op stoele of ander goed te klim?	JA	NEE
<b>4. Hou jou kind daarvan om wegkriupertjie of “waar's hy/daar's hy?” te speel?</b>	<b>JA</b>	<b>NEE</b>
5. Speel jou kind ooit verbeelding speletjies, soos byvoorbeeld om te maak asof hy/sy op die foon praat of om 'n pop te versorg, of ander verbeeldingspel?	JA	NEE
<b>6. Gebruik jou kind ooit sy/haar wysvinger om na iets te wys om daarvoor te vra?</b>	<b>JA</b>	<b>NEE</b>
7. Gebruik jou kind ooit sy/haar wysvinger om na iets te wys waarin hy/sy geïnteresseer is?	JA	NEE
<b>8. Kan jou kind op die regte manier met klein speeldinge (soos karre of blokkies) speel, sonder om net daarmee te vroetel, die speelgoed te laat val, of dit in die mond te sit?</b>	<b>JA</b>	<b>NEE</b>
9. Bring jou kind ooit vir jou (die ouer) dinge om dit vir jou te wys?	JA	NEE
<b>10. Kyk jou kind jou ooit in die oë vir meer as net 'n sekonde of twee?</b>	<b>JA</b>	<b>NEE</b>
11. Is jou kind ooit oormatig sensitief vir geraas? (byvoorbeeld druk ore toe)	JA	NEE
<b>12. Reaggeer jou kind ooit met 'n glimlag as jy na hom/haar kyk of vir hom/ haar glimlag?</b>	<b>JA</b>	<b>NEE</b>
13. Boots jou kind jou na? (byvoorbeeld as jy 'n gesig trek, sal jou kind dit		

namaak?)	JA	NEE
<b>14. Reaggeer jou kind op sy/haar naam wanneer jy roep?</b>	<b>JA</b>	<b>NEE</b>
15. As jy na 'n speelding aan die anderkant van die kamer wys, sal jou kind daarna kyk?	JA	NEE
<b>16. Stap jou kind?</b>	<b>JA</b>	<b>NEE</b>
17. Kyk jou kind na goed waarna jy kyk?	JA	NEE
<b>18. Maak jou kind snaakse vingerbewegings/handgebare naby sy/haar gesig?</b>	<b>JA</b>	<b>NEE</b>
19. Probeer jou kind jou aandag trek na sy/haar doenighede?	JA	NEE
<b>20. Het jy al ooit gewonder of jou kind doof is?</b>	<b>JA</b>	<b>NEE</b>
21. Verstaan jou kind wanneer mense praat?	JA	NEE
<b>22. Staar jou kind soms in die verte in of dwaal hy/sy soms doelloos rond?</b>	<b>JA</b>	<b>NEE</b>
23. Kyk jou kind na jou gesig om te sien hoe jy reaggeer wanneer hy/sy op iets onbekend afkom?	JA	NEE

*Appendix C*

IsiXhosa M-CHAT

Nceda ugwalise oku kulandelayo ngomntwana wakho nangendlela asoloko eyiyo/aziphata ngayo. Nceda uzama ukuyiphendula yonke lemibuzo. Ukuba yindlela engeqhelekanga (uyibone kanye, okanye kabini),nceda uphendule ngokungathi umntwana akayenzi.

1. Ingaba umntwana wakho uyakuthanda ukujingiswa, ukuxhunyiswa edolweneni njalo njalo? Ewe Hayi
2. Ingaba umntwana wakho unomdla kwabanye abantwana? Ewe Hayi
3. Ingaba umntwana wakho uyakuthanda ukukhwela ezitulweni okanye ukunyuka ngezinto? Ewe Hayi
4. Ingaba umntwana wakho uyakuthanda ukudlala umdlalo wokuzifihla ubuso uphinde uziveze /ukuzimela uphinde uvele (undize)? Ewe Hayi
5. Ingaba umntwana wakho ukhe azenze ngathi uyazenzisa umzekelo ukuthetha efowinini okanye ukukhathalela unopopi/unodoli okanye ezinye izinto nje athanda uzenzise ngazo? Ewe Hayi
6. Ingaba umntwana wakho wakhe/ukhe asebenzise lomnwe wokukhomba ukukhomba, okanye ukucela into? Ewe Hayi
7. Ingaba umntwana wakho wakhe/ukhe asenbenzise lomnwe wokukhomba ukukhomba ebonisa ukuba unomdla kwinto ethile? Ewe Hayi
8. Uyakwazi umntwana wakho ukudlala kakuhle ngezinto/ithoyi zokudlala ezincinci umzekelo (imoto okanye ibloko,ipegs nokuba zeziphi izinto ezincinci umntwana wakho adlala ngazo) ngaphandle kokuzitya okanye azicofacofe okanye aziwise? Ewe Hayi
9. Ingaba umntwana wakho uzisa izinto kuwe (kubazali) ukukubonisa into? Ewe Hayi
10. Ingaba umntwana wakho ukujonga ngqo emehlweni okanye ebusweni imizuzwana emibini okanye omnye ngedlela engaqhelekanga? Ewe Hayi

11. Ingaba umtwana wakho akayithandi kwaphela ingxolo? Umzekelo(Avale iindlebe xa kungxolwa)? Ewe Hayi
12. Ingaba umtwana wakho uyakuncumela xa ejonge ubuso bakho okanye xa umncumela? Ewe Hayi
13. Ingaba umtwana wakho uyakulinganisa umzekelo (xa udlala ngobuso-angakulinganisa)? Ewe Hayi
14. Ingaba umntwana wakho uyasabela xa umbiza? Ewe Hayi
15. Ukuba ukhomba into yokudlala okanye ithoyi kwelinye icala endlwini, ingaba umtwana uyayijonga? Ewe Hayi
16. Uyahamba umntwana wakho? Ewe Hayi
17. Ingaba umtwana wakho uyazijonga izinto ozijongileyo? Ewe Hayi
18. Ingaba umntwana wakho ushukumisa umnwe ngendlela engaqhelekanga apha ngasebusweni? Ewe Hayi
19. Ingaba umtwana wakho ufuna ukuba usoloko uhoyene naye kwimidlalo yakhe/ xa edlala? Ewe Hayi
20. Ingaba seke wazibuza ukuba umntana wakho ingaba sisithulu na? Ewe Hayi
21. Ingaba umntwana wakho uyaqonda/uyava ukuba abantu bathini? Ewe Hayi
22. Ingaba umtwana wakho ukhe ajonge nje ajame ungazi ukuba ujonge ntoni, ahamba-hambe kungekho nobangela? Ewe Hayi
23. Ingaba umtwana wakho ujonga ubuso bakho ajonge ukuba uzakuthini na? xa athe wajongana nento/ imeko angayiqhelanga? Ewe Hayi

isiXhosa version by Sizwe Zondo, 01/03/12

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*Appendix D*

Ethical Approval From the UCT Faculty of Health Sciences

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

pp TuBurgess

**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.

s.thomas

*Note.* Ethical approval was renewed annually.

*Appendix E*

## Approval for Red Cross War Memorial Children's Hospital

**Western Cape  
Government**

Health

Dr TA Blake  
Manager: Medical Services  
Email: Thomas.Blake@pgwc.gov.za  
Tel: +27 21 658 5788 fax: +27 21 658 5166  
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,

A handwritten signature in black ink, appearing to read 'Thomas Blake'.

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

*Appendix F*

## English Phase 1 Informed Consent Form

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 G*

## Afrikaans Phase 1 Informed Consent Form

Geagte Ouer(s),

Ons kontak u omdat u kind 'n patiënt 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 H*

## IsiXhosa Phase 1 Informed Consent Form

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 I*

## English Phase 1 Consent to be Contacted

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 J*

## Afrikaans Phase 1 Consent to be Contacted

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 or 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 K*

## IsiXhosa Phase 1 Consent to be Contacted

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 L*

## 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 M

### Autism Spectrum Disorder Information Sheet

#### 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 N*  
English Demographic Questionnaire

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 O*  
Afrikaans Demographic Questionnaire

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              Asiaties  
                          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  
       pediatrisiese 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 = Tersiëre opvoeding, Universiteit / technikon / 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 Mikroolfoond	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.



**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 ongunya okhathelela(yakha isangqa kwinani elifanelekileyo)**

	Umama	Utata	Umntu ongunya 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.) 7 iminyaka(ibanga lesi7/u5) = ugqibe amabanga aphantsi	3.	3.	3.
4.) 8-11 iminyaka(ibanga 8-11/ u6-9) =Amanye amabanga aphezulu (zange agqibe amabanga aphezulu)	4.	4.	4.
5.) 12 iminyaka(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. 3.	2. 3.
3.Une account okanye amakhadi etyala ezivenkileni		