## Distribution Agreement

Signature:

______________________________ ____________
Catherine Clay Calhoun Date

# Adapting an Autism Screening Tool for Use among Nepali Refugees at the DeKalb County Refugee Pediatric Clinic

By

Catherine Clay Calhoun
MD/MPH

Hubert Department of Global Health

_________________________________________
Parminder Suchdev, MD, MPH
Committee Chair

# Adapting an Autism Screening Tool for Use among Nepali Refugees at the DeKalb County Refugee Pediatric Clinic

By

Catherine Clay Calhoun

B.S.
The University of Georgia
2009

Thesis Committee Chair: Parminder Suchdev, MD, MPH

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in the Hubert Department of Global Health
2015

# Abstract

Adapting an Autism Screening Tool for Use among Nepali Refugees at the DeKalb County Refugee Pediatric Clinic
By Catherine Clay Calhoun

The Centers for Disease Control and Prevention reports that Autism Spectrum Disorder (ASD) affects 1 in every 68 children.[1] Although awareness, screening and research of ASD continue to improve within the US pediatric population, there remains little knowledge regarding prevalence of ASD within US immigrant and refugee populations.

Early detection of ASD, when followed by a combination of mental health, behavioral and educational therapies, provides children and caregivers with the best skills to manage ASD.[2] Thus, a diagnosis of ASD is a crucial step which allows families and children to access the medical, psychiatric, behavioral, and social services that would be unavailable to them otherwise.[3] The M-CHAT-R/F (Modified Checklist for Autism in Toddlers, Revised with Follow-Up) is a widely-used screening tool, used both internationally and within the United States to assess a child's risk of ASD.

The M-CHAT-R/F questionnaire has been translated into several languages; however, there is currently no ASD screening tool that has been translated into Nepali. Additionally, little is known about the prevalence of ASD among refugee children, such as the Nepali pediatric patients of the DeKalb County Refugee Pediatric Clinic. The goals of this project were three-fold: 1) adapt the M-CHAT-R/F so that it is a culturally appropriate screening tool, 2) conduct qualitative interviews with Nepali caregivers regarding their understanding of child-development and ASD and 3) disseminate the adapted M-CHAT-R/F to other pediatric clinics serving similar populations.

We successfully adapted the M-CHAT-R/F into Nepali for use in the DeKalb County Refugee Pediatric Clinic and similar clinics. Additionally, we found that little knowledge exists among Nepali caregivers regarding ASD and developmental delay. Future validation studies of the Nepali M-CHAT-R/F will aid in epidemiologic research of ASD in refugee populations.

# Adapting an Autism Screening Tool for Use among Nepali Refugees at the DeKalb County Refugee Pediatric Clinic

By

Catherine Clay Calhoun

B.S.
The University of Georgia
2009

Thesis Committee Chair: Parminder Suchdev, MD, MPH

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in the Hubert Department of Global Health
2015

# ACKNOWLEDGMENTS

There are many people who made this project possible. First and foremost, I would like to thank Dr. Susan Reines and Dr. Aly Goodman, both pediatricians at the DeKalb County Refugee Pediatric Clinic. This project was born from their desire to better care for their patients, and I am thankful that they trusted me to help carry their thoughts forward into action. Without their constant support and guidance, this project would have never come to fruition. They both spent countless hours reading (and re-reading) my initial project proposal, helping me schedule patients, and connecting me with various community resources. They were foundational in this effort.

Our team of Nepali translators and interpreters were phenomenal. Chandrama Sharma, Pingala Sharma, and Deo Sharma were invaluable in their dedication and skills. Their dedication to our project extended far beyond the clinic walls. Both met with me individually multiple times throughout the project to help recruit patients, to work on additional translations and to ensure that the project was running smoothly. We are indebted to them. Natalie Hill, the clinic's coordinator and medical assistant, contacted and scheduled patients.

Dr. Parminder Suchdev, my thesis advisor and mentor, initially introduced me to Dr. Reines at the DeKalb County Refugee Pediatric Clinic. His support and mentorship has been constant. He has continually offered advice and guidance throughout this process, helping me navigate the proposal-writing process, as well as applying for student-funding for the process.

# TABLE OF CONTENTS

# CHAPTER 1: INTRODUCTION

## Autism Spectrum Disorder

The Centers for Disease Control and Prevention (CDC) estimated that in 2010, Autism Spectrum Disorder (ASD) affected 1 in every 68 children, though the prevalence may vary across geographic areas and among racial and ethnic groups.[1-3] ASD refers to a spectrum of disorders characterized by deficits in social interaction and interpersonal communication (verbal or nonverbal), often punctuated by repetitive behavior. The exact causes of ASD remain elusive, although research suggests that ASD has strong genetic components that are enhanced by environmental factors, many of which may be prenatal or perinatal exposures.[4] The etiology of ASD is most deeply rooted in early neural development; however, most signs and symptoms of ASD do not become apparent until one to three years after birth.[4] Because of the heterogeneity and, at times, subtlety of signs and symptoms seen in children with ASD, parents and pediatricians alike may have difficulty identifying these concerning behaviors. Language delay, though less specific for ASD than other symptoms, is a common parental concern. More frequently, children with ASD display social deficits, demonstrating difficulty connecting with other children and sharing appropriate emotional states.[4] Children with ASD often prefer to be alone, lacking the desire to form relationships with peers. Children who present with speech delay may demonstrate restricted or scripted speech (from television shows or movies, for example) or repetitive speech. Additionally, speech may not be functional and may lack communicative intent. Although these are considered classic presentations, more subtle forms of speech delay can be seen earlier in a child's development.[4]

ASD is considered a lifetime or chronic diagnosis; however, recent literature is clear that early detection of ASD, when followed by a combination of mental health, behavioral and educational therapies, provides children and caregivers with the best skills to manage ASD.[5] However, access to these therapies is dependent upon a diagnosis of ASD. Thus, a timely diagnosis is a crucial step for families caring for children with ASD, allowing them access to the array of services that would be unavailable to them otherwise.[6]

Although awareness, screening and research of ASD continue to improve within the US pediatric population, there remains little knowledge regarding the prevalence of ASD within US immigrant and refugee populations. In fact, the global medical community's knowledge of ASD is based almost entirely upon research and epidemiologic data from developed, Western countries.[7] This is understandable, given the fact that ASD screening tools have been developed using behavioral norms most appropriate for Western cultures.[7] For example, the recently validated Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F) is one of the most widely-used ASD screening tools (both domestically and internationally) and has been validated for use only within the US pediatric population, with few exceptions.[8]

## ASD Screening: Development of the M-CHAT & the current need for culturally appropriate screening tools

The original M-CHAT questionnaire was developed as an extension of its predecessor, The Checklist for Autism in Toddlers (CHAT).[9] The CHAT consists of thirteen questions, nine of which are answered directly by caregivers; the remaining five questions are answered by the child's health care provider.[9] The CHAT was developed and validated in Great Britain in 1992 as a method to identify the early signs of autism among 18 month-old children.[9] The Modified CHAT, or M-CHAT, is a twenty-three item questionnaire that was developed to broaden scope of symptoms included in the CHAT questionnaire; this allows for the identification of a greater range of children with ASD.[10] The M-CHAT has since been translated into many languages; however, the context of the questions (from either the M-CHAT or the more recently revised M-CHAT, the M-CHAT-R) may not be appropriate for children raised outside of the US or by caregivers with different cultural backgrounds. For example, international validation of the M-CHAT has occurred only in Spain[11] and Japan.[12] In Spain, cross-cultural adaptation of the M-CHAT was required before validation could occur.[11] Other studies reinforce the notion that without appropriate cultural adaptation, the M-CHAT's international use is limited.[13]

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F) is a recently validated, two-stage ASD screening tool designed for use in low-risk toddlers.[14] The M-CHAT-R consists of twenty "yes/no" questions that may be answered directly by the child's caregiver; the follow-up questions (M-CHAT-R/F) are constructed in a flowchart format and are designed to be used only if a child screens positive for ASD.[10] The M-CHAT-R/F is an easily accessible, free ASD screening tool that is widely used worldwide, both for direct patient care as well as academic research purposes. For this reason, the M-CHAT-R/F is the screening tool of choice for many pediatric offices, including the DeKalb County Refugee Pediatric Clinic, located in DeKalb County, Georgia.

Without an ASD screening tool designed for immigrant and refugee children (the M-CHAT or M-CHAT-R, for example), pediatricians caring for this population remain ill-equipped to screen for ASD. This screening is crucial, as it helps to identify children at risk for ASD so that appropriate referrals are made to ensure that medical, psychological, behavioral and social services are available. Additionally, an appropriate screening tool is necessary to gather reliable epidemiologic data regarding ASD in the pediatric refugee population; the absence of such a tool limits the ability of researchers to collect this data. Not surprisingly, no epidemiologic data exist on ASD within pediatric refugee populations residing in the United States. At this time, the burden of developmental delay among refugees – many of whom have suffered traumatic births, poor nutrition and high levels of stress and anxiety – is unknown, although is presumed to be high. Appropriately translated ASD screening tools will aid clinicians and researchers in learning more about and caring for this population.

## Refugees in DeKalb County, Georgia

According to a 2011 report from the Office of Refugee Resettlement, DeKalb County has the 7th highest refugee population in the United States and the largest in the state of Georgia.[15] More recent reports have found that Georgia ranks 8th among states for refugee resettlement with the vast majority of new refugees resettling in DeKalb County.[16] In 2012, Georgia accepted over 2,500 refugees – ranking fifth behind states such as Texas, California, Michigan and Pennsylvania.[17] While the refugees that resettle in the U.S. do so from many different counties of origin, the vast majority of these refugees claim Bhutan (15,021), Burma (14,020) and Iraq (12,122) as their home countries.[17] Many of the Bhutanese refugees live for years in Nepalese refugee camps before resettling to cities like Clarkston Georgia, located in DeKalb County.[18] Therefore, although Nepal is not listed as a country from which the majority of DeKalb County's refugees originate, many of the county's Bhutanese refugees are Nepali-speaking.[18]

The Refugee Clinic at the DeKalb County Board of Health provides health screening for the majority of new refugees entering the county, and the Pediatric Refugee Clinic (DCRPC) is available to provide well and acute care for newly resettled refugee children. Per recommendations of the American Academy of Pediatrics and as required by Medicaid, ASD screening occurs at the 18 and 24 month well-child visits at the DCRPC using the M-CHAT-R/F questionnaire. Direct translations of the original M-CHAT or the more recent M-CHAT-R/F are used when available; however, the M-CHAT-R/F is not available in the two languages most commonly spoken by the children and families who receive care at the clinic (Burmese and Nepali). When translations of the questionnaire are not available, clinic interpreters administer the questionnaire to caregivers verbally. This poses a problem for several reasons. First, the amount of time required to interpret the M-CHAT-R/F through the clinic's interpreter is significant and is not feasible given the demand for interpreter time in the busy clinic setting. Secondly, as already discussed, direct translation of the M-CHAT-R/F is inappropriate, inefficient and inconsistent from interpreter to interpreter. Since many of the clinic's Nepali caregivers have functional literacy skills, the use of a translated M-CHAT-R/F would significantly cut down on the use of interpreter time for non-physician interaction. Thus, the need for an appropriately translated, culturally-significant autism screening tools is great and has yet to have been met for several of the cultures and languages cared for at the DCRPC.

There is widespread recognition of the need for a validated ASD screening tool to be used in this population. In fact, researchers at the Children's Hospital of Philadelphia, one of the country's leading pediatric academic institutions, have adapted the M-CHAT for use in the Burmese refugee population. Clinicians at the DCRPC have identified a similar need in the Nepalese refugee population, which they intend to address through implementation of this project. The two institutions plan to make their respective screening tools available to each other upon completion of the adaptation process.[19]

## Autism Spectrum Disorder in Refugee Patients

Not only are there no data on ASD among US-based refugee populations, there are seldom any data on ASD from the children's country of origin. In poor, developing nations such as Nepal or Pakistan, there are virtually no known data on ASD screening or prevalence rates.[20, 21] This is unlikely to change in the near future, as a 2013 study determined that awareness and knowledge of ASD in Nepal is nearly non-existent.[21] A similar study in 2012 found that less than 10% of Nepali physicians practicing in country's capital of Kathmandu reported that they felt comfortable recognizing a child with autism, and 65% of these physicians were found to have insufficient knowledge of autism spectrum disorder.[22] Many refugee children with ASD are therefore unlikely to be identified prior to entry into the US. Thus, it is important that pediatricians in the US caring for this growing population have a validated tool to screen young Nepali refugee children for ASD. Additionally, this tool will allow pediatric providers in the US to comply with Medicaid requirements for universal ASD screening for all 18 and 24 month well-child visits [23], identify children with ASD at younger ages and connect those children with appropriate educational and behavioral services, and facilitate epidemiologic and clinical research on ASD in the refugee population in the US.

## Culturally Competent Translation Protocols

There is no universal protocol available to guide the translation of culturally competent instruments. However, the World Health Organization (WHO) has produced a standard protocol used in the translation process of any WHO materials.[24] This is a three-step process, consisting of 1) a forward translation of materials into the target language 2) a bilingual Expert Panel discussion, in which inadequate and inappropriate words and phrases are identified and resolved and 2) a back translation, in which a native English speaker with no knowledge of the instrument translates the materials back into English. Following the first three steps, the instrument is piloted, or pre-tested, among the target population. In this phase, cognitive interviews are conducted to ensure that intent of the original questionnaire has been preserved throughout the translation process. Many other variations of translation protocols are endorsed throughout the international medical community. Some techniques include two forward-translations (and no back-translation)[25], which are later reconciled by translator reviewers. Regardless of the exact method proposed, nearly all experts in translation protocol stress the need for committee/panel review of the translated material, as bilingual professionals often produce translations that are too literal or too formal.

## Project Purpose

The purpose of this project is to appropriately adapt an existing widely-used ASD screening tool (M-CHAT-R/F) into Nepali for use in the Nepalese refugee community.

Specific objectives include:

1. Culturally appropriate modification and translation of the M-CHAT-R/F into Nepali to be used at the DeKalb County Refugee Pediatric Clinic.
2. 10 qualitative interviews of Nepali caregivers of infants ages 16 – 30 months using the Nepali M-CHAT-R/F.
3. Dissemination of the adapted Nepali M-CHAT-R/F to other clinics serving similar patient populations.

# CHAPTER 2: COMPREHENSIVE REVIEW OF THE LITERATURE

## Autism Spectrum Disorder

### Brief Description & History

Autism Spectrum Disorder (ASD) refers to neurodevelopmental conditions, characterized by a deficit in a child's ability to communicate or interact socially with others. ASD encompasses a wide spectrum of severities, with symptom manifestations ranging from mild to debilitating.

Autism was first described in 1943 by a psychiatrist, Dr. Leo Kanner, at Johns Hopkins University.[4] Kanner described a small group of children with complete indifference to others and extreme aloofness.[4] Nearly forty years later, the term "Infantile Autism" appeared in the third edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-III), the standard classification of mental health disorders; however, official diagnostic criteria did not occur until the fourth edition's publication in 1994.

### Epidemiology

As awareness, knowledge, and screening have increased regarding ASD, so have estimates of ASD's prevalence. The earliest epidemiologic studies of ASD took place in the 1960's and 1970's [26]; estimates of ASD prevalence from this research – 1 in 2500 children [26] – are shockingly low when compared to more recent estimates. Beginning in 2000, for example, researchers estimated that prevalence of ASD was approximately 6 per 1000 children.[3] Since that time, the Centers for Disease Control and Prevention (CDC) has organized the Autism and Developmental Disabilities Monitoring Network (ADDM), which comprises a multi-site ASD surveillance program. In 2004, the ADDM estimated that the prevalence of ASD ranged from 1 in 94 to 1 in 303 children among 8-year-old children, with an overall prevalence of 6.6 per 1,000 children (or, 1 in 150 children).[4, 27] CDC recently published estimates of the prevalence of ASD to be 1 in 68 children in 2010, ranging from 1 in 45 in areas of New Jersey to 1 in 175 in areas of Alabama.[3, 28] Geographic differences likely represent variation in community identification of children with ASD. ASD prevalence also varies across gender and race. For example, males are consistently found to have higher rates of ASD than females: in the most recent AADM publication from CDC, boys were nearly five-times more likely than girls to receive a diagnosis of ASD.[3, 28] The same report describes differing prevalence between racial groups: based upon documentation from community-health providers, white children were nearly 30% more likely to be diagnosed with ASD than black children and almost 50% more likely to receive a diagnosis of ASD than Hispanic children.[3, 28]

### Etiology

ASDs are highly heritable neurodevelopmental disorders.[4, 29] Although the exact causes of ASD remain elusive, the genetic underpinnings of autism have become clearer in recent years.

In fact, nearly 20% of cases are associated with molecularly defined causes.[29] Despite the impressive genetic heterogeneity associated with ASD, genetic variants have been implicated only in association with other disorders and disabilities (i.e. never in association with ASD alone).[30]

From a clinical perspective, ASD can be generally grouped into two categories: essential (idiopathic or non-syndromic) and secondary (also called syndromic, complex or 'ASD Plus').[4, 29, 30]

Essential, or idiopathic, autism accounts the vast majority of cases — approximately 75% - 80% of cases [29, 30] — and refers to children who do not have an associated condition known to cause autism.[4] These children are generally less likely to have global developmental delay or mental retardation and lack the dysmorphic features seen in children with syndromic ASD.[4] For example, children with essential autism typically have normal growth patterns and normal head circumference. Though these children are usually non-dysmorphic, they may have mild, non-specific dysmorphic features.[30] More commonly, however, children with essential autism have concurrent gastrointestinal disturbances, sleep disturbances, and in some cases, seizures.[30]

Secondary, or syndromic ASD, refers to cases in which ASD is caused by – or closely associated with – an identifiable syndrome or medical condition.[4] In approximately 5% of cases, ASD is associated with a single-gene disorder, the most common of which are Fragile X Syndrome, Rett Syndrome, Tuberous Sclerosis and mutations of the *PTEN* gene.[29, 30] Additionally, Angelman syndrome, Smith-Lemli-Opitz syndrome, Phelan-McDermid syndrome, Duchenne/Becker muscular dystrophy and phenylketonuria are neurogenetic syndromes associated with secondary ASD.[4, 29]

The flow-chart below from Carter and Scherer [30] describes the basic algorithm for genetic investigation of a child with ASD. The first step is to determine if the child has essential/idiopathic autism, or syndromic autism. This deliniation will direct further work-up. Children with 'ASD Plus' should undergo testing specific to the clinician's differential diagnosis. Children for whom essential ASD is the more likely diagnosis frequently undergo chromosomal microarray and fragile X testing.[30] *MeCP2* testing (specific for Rett syndrome) can be ordered for female patients, while *PTEN* mutation analysis should be ordered in children with macrocephaly.[30]

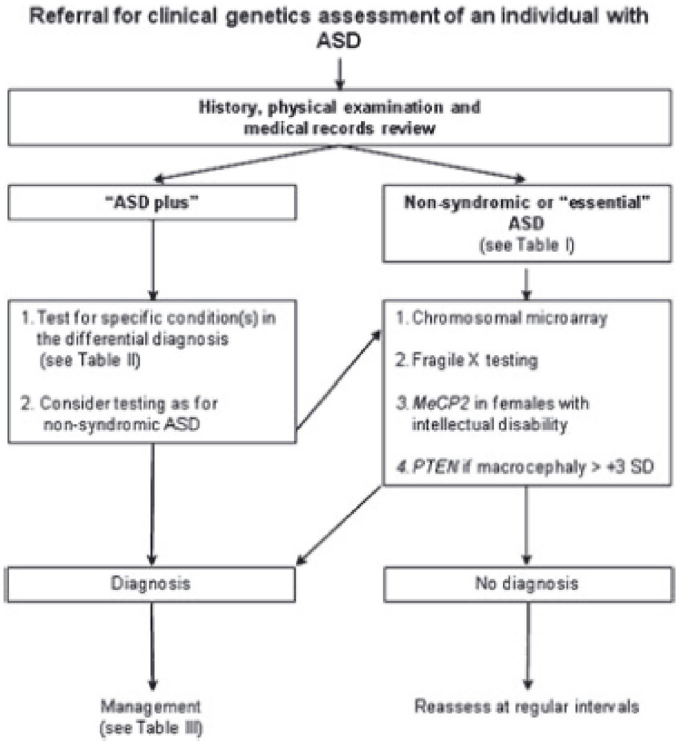


*Fig. 1.* Flow chart depicting clinical approach to genetic investigation for individuals with autism spectrum disorders (ASDs).

Figure 1. Carter, M.T. and S.W. Scherer, *Autism spectrum disorder in the genetics clinic: a review.*[30]

### Presentation & Clinical Signs

Perhaps one of the most challenging aspects of the identification of a child with ASD is the extreme heterogeneity of presenting clinical signs. ASD truly represents a spectrum of symptoms; children at the mild end of the spectrum may have dramatically different presentations than children at the severe end of the spectrum. Despite such heterogeneity, there are several features common to all children with ASDs. These features include social skills deficits, communication deficits and repetitive, restricted and/or stereotyped behaviors.[4]

Presentation & Clinical Signs: Social Deficits

Although specific to ASD, social deficits – particularly those in joint attention – can be subtle and therefore easily missed or dismissed by parents.[4] Social deficits typically manifest as a child's lack of desire to interact or connect with others. Other deficits include a consistent lack of eye-contact or the desire for the praise and attention of others.[4] As children with ASD grow older, peer relationships are noticeably absent and/or difficult to form, as these children lack the ability to appropriately discern and share emotional states with others.[4] Joint attention, as mentioned earlier, refers to an individual's ability to share and coordinate his/her attention with the attention of a social partner.[31] Joint attention begins to develop within the first year of life [32] and is displayed in behaviors such as a child smiling when her caregiver smiles or following her parent's gaze to-and-from objects.[4] Like most developmental milestones, a child's ability to receive and initiate joint attention develops in a step-wise fashion.[4, 32] For example, infants first learn to respond to joint attention by returning the gaze of a caregiver and later, by following the gaze of a caregiver. As development continues, infants and children learn to initiate joint attention by directing the attention of others to a particular object or event.[32, 33] In a child with ASD, however, both the response to and initiation of joint attention is noticeably lacking and/or absent.[4, 32] In fact, deficits in joint attention may be one of the earliest signs of ASD in a young child.[4]

Deficits in joint attention have far-reaching effects on the individual with ASD. The extent to which communicative joint attention develops predicts the extent to which language develops.[34] Research has shown that significant predictors of receptive language include gestures and non-verbal cognitive ability, while predictors of expressive language development include joint attention and imitation.[35] In fact, interventions targeting joint attention have shown remarkable improvement on speech development, supporting the assumption that joint attention is a fundamental building-block to language development.[4, 36]

### Presentation & Clinical Signs: Communication Deficits

Prelock defines communication impairment as "a delay or lack of communicative gesture use and spoken language development, challenges in the ability to initiate or maintain conversation, and unusual language use such as echolalia or idiosyncratic use of words."[33] Delayed language development (i.e. communication development), though less specific to ASD than social deficits, is the most frequently reported parental concern, prompting many caregivers to voice concerns to their child's primary care provider (PCP)**.**[4, 37] Unfortunately, such delays often go unnoticed until approximately 18 months of age, and many parents may delay discussing these concerns with the child's PCP until several months later.[4, 37, 38] Mitchell, et al., wisely points out that spoken language development is preceded by a young child's use of increasingly complex vocalizations and gestures; therefore, speech delay – as seen in ASD – may be detectable even before the expected onset of spoken words.[37] In this case, delayed gestures and vocalizations may provide one of the earliest signs on ASD.[37]

### Presentation & Clinical Signs: Restricted/Repetitive Behavior

The new DSM-V criteria for a diagnosis of ASD includes restricted, repetitive patterns of behavior which may involve and affect both language and communication**.**[39] For example, the child with ASD may demonstrate repetitive behaviors, restricted interests and/or repetitive speech patterns.

Speech, though often present to some degree in a child with ASD, may be neither functional nor fluent.[4] Unconventional speech patterns are often considered classic presentations among children with ASD. For example, speech patterns may be repetitive, restricted, or ritualized.[33] Verbal behaviors may include echolalia (repeating exactly what is said or heard) or perseverative speech, speech in which the child repeatedly produces imitated or self-generated vocalizations, or scripted speech (from favorite songs or television shows, for example).[4, 33]

Like the repetitive and restricted speech patterns mentioned above, the repetitive behaviors seen in children with ASD are nonfunctional, appearing to lack purposeful intent. These behaviors classically include hand flapping, rocking or unusual finger movements.[40, 41] It is important to note, however, that although these behaviors are classically associated with ASD, they are also seen in children with profound MR and/or severe sensory deficits and are therefore not specific to ASD.[4] Additionally, children with ASD may have restricted interests in items and topics (i.e. trains and train schedules), and the child's conversation may be dominated by that topic[4]; while the item or activity of interest may not be considered unusual for a typically developing child, the degree to which the child with ASD is fixated on the topic is often considered abnormal. Johnson gives the example of a child with ASD knowing far more about dinosaurs than other children his age, with conversation being dominated by discussion of dinosaurs.[4]

### Diagnosis & Evaluation

The first step in the diagnosis of ASD is often appropriate screening, which should occur at the 18 and 24-month well-child checks using a validated screening tool. If appropriate concern is raised through the screening process, the next step is referral to a specialist with expertise in the diagnosis of ASD. In more severe cases, a diagnosis of ASD may be fairly apparent to a general pediatrician with knowledge of ASD and the diagnostic criteria (without the use of a screening tool); in this scenario, it is appropriate for the child to receive a direct referral to a specialist with expertise in the diagnosis of ASD.

In an ideal setting, ASD is diagnosed by professionals with expertise in ASD, such as child neurologists, child psychiatrists, and developmental pediatricians. However, in communities with few – if any – pediatric specialists such as these, other healthcare providers with a sound knowledge-base of ASDs are capable of performing independent evaluations that aid in the diagnostic process; these providers include speech language pathologists, pediatric occupational therapists, child psychologists and social workers. With appropriate training, child psychologists are able to make an independent diagnosis of ASD.[4]

The fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-V) provides standardized diagnostic criteria to help diagnose ASD. The DSM-V criteria include "persistent deficits in social communication and social deficits across multiple contexts," while severity is "based on social communication impairments and restricted, repetitive patterns of behavior."[42] Although the DSM-V provides standardized diagnostic criteria for healthcare providers, certain experts caution against using such rigid diagnostic guidelines as a "gold standard." In fact, Tom Insel, current director of the National Institute for Mental Health, states that "it is critical to realize that we cannot succeed if we use DSM categories as the 'gold standard.' The diagnostic system has to be based on the emerging research data, not on the current symptom-based categories."[43] Therefore, healthcare providers with the capability of diagnosing ASD must remember to look beyond DSM-V guidelines when considering the diagnosis of ASD in a child.

### Therapy

Therapies for ASD are as diverse as the range of symptoms and should be tailored to a child's specific needs.[4] Despite the differences in individual approaches to therapy, the framework of ASD treatment rests on behavior, communication, and social interventions.[5] These interventions are often provided through Early Intervention or Early Childhood Education services; early intervention programs are subsidized public programs available to children until their third birthday, after which the child is eligible for services provided through the special education department in the local school system.[4] Most treatment teams will include speech language pathologists and occupational therapists.[4]

Among educational therapies, two of the most widely used include the applied behavior analysis (ABA) and the Early Start Denver Model (ESDM).[5] ABA is a trusted and well-studied technique that applies the principles of learning (positive reinforcement, for example) to encourage lasting changes in behavior**.**[44] Although used by a range of behavioral intervention programs, ABA has well-documented success among children with ASD with notable improvement in intelligence quotient, language, academic performance, and adaptive and social behavior**.**[44]

The ESDM is an early-intervention program that is validated for use in children with ASD, ages 12 – 48 months.[45] ESDM integrates aspects of ABA through play-based activities[5] in a variety of settings, and can be used by both treatment teams and parents. Research has shown that consistent ESDM therapy leads to greater improvement in adaptive behavior, as well as language and cognitive abilities when compared to other interventions commonly available in the community.[45] Such examples of Early Intensive Behavioral Intervention (EIBI), therapy which is delivered consistently for 20-40 hours per week, represent a well-established ASD therapy. However, the level of research evidence supporting EIBI remains limited.[46]

Alternative and creative treatment approaches for ASD abound. For example, a recent Cochrane review found that music therapy may offer multi-faceted benefits to children with ASD, including improvements in verbal communication, social interaction, initiating behavior, and social adaptation skills.[47] Hippotherapy, a type of therapeutic horseback riding, may also offer improvements in development and symptoms in children with ASD.[48] Other treatment approaches that are commonly used include diet modification and/or supplementation. Glutenfree diets are perhaps the most popular of restriction-diets, although a recent consensus states that no evidence exists to support the implementation of such diets.[49] Numerous other complementary and alternative medicine (CAM) therapies exist, including (but not limited to) mineral and vitamin supplementation, chemical chelation and hyperbaric oxygen therapy.[5]

Developmental pediatricians encourage their pediatric colleagues who practice evidenced-based medicine to remember that the absence of evidence does not necessarily equate to the absence of benefit.[5] Additionally, practitioners must be sympathetic to a caregiver's sincere desire to pursue all possible treatment options for his/her child. However, caregivers should exercise caution when pursuing CAM therapies, taking care that CAM modalities do not interfere with or preclude therapies with known effectiveness.

## Autism Spectrum Disorder Screening

Both developmental screening and ASD screening most commonly occur at a general pediatrician's office. Until recently, however, the pediatric community did not have a consensus on the best method for screening children for developmental delay and/or ASD. In fact, pediatricians often employed two distinct strategies for screening children.[50] The first proposed strategy included using a general developmental screener on all children, such as the Parents Evaluation of Developmental Status (PEDS), followed by an autism-specific screener, such as the Modified Checklist for Autism in Toddlers (M-CHAT), on children who screened positive on the initial developmental screen. The second strategy proposed using an autism-specific screener on all children, in addition to the general developmental screener. However, no published data existed comparing the efficacy of ASD-specific screening tool to its efficacy as a follow-up to a positive developmental screening tool. A 2008 study compared these two strategies, using the PEDS as a general developmental screener and the M-CHAT as an autism-specific screener.[50] Prior to this study, the reported sensitivity of the PEDS was 74% -79%, while the reported specificity was 70% – 80%.[50] In contrast, the sensitivity and specificity of the M-CHAT was found to be 88% and 38%, respectively.[51] When directly compared, researchers found notable differences between the two questionnaires. For example, many children who screened positive for ASD using the M-CHAT had corresponding normal developmental screens using the PEDS.[50] In other words, the general developmental screening tool missed many children who later screened positive for ASD using the autism-specific screening tool. These results suggest that developmental screeners and ASD-specific screeners elicit very different information regarding a child's development, thus supporting the use of both the ASD-specific screening tool, as well as a general developmental screening tool. [50]

The American Academy of Pediatrics (AAP) recommends that every child receive autism-specific screening at ages 18 and 24 months.[52] Additionally, the AAP recommends that children receive a general developmental assessment at every well-child visit, as well as developmental screening using a standardized screening tool at the 9-, 18-, and 24- or 30-month visits.[52] Table 1 below, adapted from Soares and Patel's paper on Office Screening, provides a visual display of the timeline for ASD developmental surveillance and screening.[53] Johnson and Myers describe surveillances as a "moving picture" of a child's evolving development; on the other hand, surveillance represents a "snapshot" of a specific moment in time.[4] During routine surveillance, pediatricians should ask caregivers open-ended questions regarding their child's development. Additionally, pediatricians should ask age-specific questions about whether the child has reached certain developmental milestones.[4] If concerns arise at any point during routine surveillance regarding the child's development – either from the pediatrician or from the caregiver – a formal developmental screening tool should be used.[4] Otherwise, formal developmental screening should take place at 9-, 18-, and 24 months, as shown in Table 1.[4, 53]

Despite recommendations regarding ASD screening within primary care facilities, research suggests that less than 50% of all pediatricians screen for ASD.[53] Even among children who are screened for ASD, the subsequent evaluation and diagnosis of ASD occur much later than warranted.[4] For example, a 2006 study found that the mean age of first evaluation among children with ASD was 48 months, while the mean age of diagnosis was 61 months.[54] This underscores the importance of educating general pediatricians regarding screening protocols and the identification of ASD.

While formal ASD screening should occur at 18 and 24-month well-child visits, the pediatrician should engage the caregivers regarding the child's development at every well-child visit.[4] Discussion between caregiver and pediatrician should include age-specific questions regarding developmental milestones, including verbal and nonverbal communication, social interactions and play skills.[4] Immediate referral for a thorough evaluation can – and should – be made without the use of a screening tool if the pediatrician expresses adequate concern regarding the child's development.[4]

**Table 1. Timeline for Developmental and ASD Surveillance and/or Screening [53]**

| **Age of Visit (months)** | Developmental Surveillance | Developmental Screening | ASD Screening |
|---|---|---|---|
| **9** | X | X | |
| **12** | X | | |
| **15** | X | | |
| **18** | X | X | X |
| **24** | X | X | X |

There are various ASD screening tools available for the general pediatrician. These screening tools are classified as Level 1 or Level 2.[4, 53] Level 1 screening tools are administered to all children with the intention of identifying children at risk for ASD. In contrast, Level 2 screening tools are administered to children who have been identified as "at-risk," and are used to differentiate between children at risk for ASD versus other developmental disorders; these tools are generally more time-intensive and can be used as part of a diagnostic evaluation.[4, 55] In general, Level 1 screening tools are most appropriate in a primary care setting.[4, 53]

ASD screening tools typically have different characteristics, including different target populations (low-risk vs high-risk), ages for which the tool is validated, as well as varying sensitivity and specificity. While no screening tool is perfect, it is important for a pediatrician to become familiar and comfortable with one screening tool which can be used consistently in the office setting. For the purposes of this project, the information below will focus on the M-CHAT-R/F, a Level 1 ASD screening tool that is used widely in the US, as well as internationally.

### The Revised Modified Checklist for Autism in Toddlers, with Follow-Up (M-CHAT-R/F)

The Modified Checklist for Autism in Toddlers (M-CHAT) was developed in 2001 as an extension of the previously created CHAT (Checklist for Autism in Toddlers).[56] The M-CHAT, a 23-question parent checklist, was created as a user-friendly, early identification screening tool for ASD.[56] In the original validation study, the M-CHAT was found to accurately detect children at risk for ASD when used at the 18 and 24 month health-checks.[56] Multiple other studies also validated the M-CHAT and Follow Up as a screening tool for use in toddlers ages 16 to 30 months.[10, 57, 58]

The M-CHAT is a free tool, available online and translated into many languages.[59] As discussed earlier, the M-CHAT is an easy-to-use tool with adequate sensitivity and specificity.[57] However, in an effort to maintain high sensitivity, while reducing the number of initial screen-positive cases requiring follow-up, the M-CHAT was revised in 2013.[8]

The M-CHAT, Revised with Follow-Up (M-CHAT-R/F) has been validated as an ASD screening tool among low-risk toddlers, ages 18 to 24 months. The M-CHAT-R/F is a two-stage parent-reporting screening tool designed to assess a child's risk of ASD.[10] The M-CHAT-R consists of twenty "yes/no" questions, which may be answered by the child's caregiver in a primary care setting. The Follow-Up questions (M-CHAT-R/F), or stage-2 of the screening process, is used in the event a child screens positive for ASD using the M-CHAT-R. If a child screens positive using the M-CHAT-R, the PCP should select the Follow-Up items which correspond to the M-CHAT-R items which the child failed.[60] The Follow-Up questions follow a flowchart format of "yes/no" questions, and should be administered by the PCP in an interview-like format with the child's caregivers.[60] When using the M-CHAT-R's suggested three-question cutoff score, the questionnaire's sensitivity and specificity are 91.1% and 95.5% , respectively.[10] The M-CHAT-R follow-up questions, designed to be used decreases the number of false positives by improving the specificity of the screening tool to 99.3%.[10]

## ASD across Cultures

The medical community's knowledge of ASD is driven primarily by research from Western nations. This information has flooded the medical literature and popular media of these countries in recent years, shaping the layman's view of ASD. In contrast to the constant stream of new information regarding ASD in the US and Europe, there is shockingly little known information about ASD in low and middle income countries (LMIC).[61] However, as research and surveillance of ASD increases in LMIC, it is important to remember that our western view of autism and ASD does not exist in many cultures.[62] Autistic traits represent a deviation from culturally and developmentally appropriate behavior [7]; as such, an understanding of behavior concerning for ASD is likely influenced by cultural norms and therefore may vary across cultures.[7] For example, the appropriateness of finger-pointing and making eye-contact with an adult among child differs significantly between Eastern and Western cultures. H.U. Kim points out that this may be due to the fact that "a culture defines what is abnormal and normal, and disability is socially constructed."[62] In his qualitative research on cultural understanding of autism, Kim cites wide variations between cultures' understanding of and response to autism. For example, a diagnosis of autism in Korea carries with it intense shame and guilt; in Nicaragua, on the other hand, autism is simply another term for a 'disability' of which the entire community took responsibility.[62] In other communities, the concept of autism is nearly nonexistent**.**[21]

A culture's understanding of autism, though rooted in complex social, religious and political environments, must be guided by those with a sound understanding of ASD. Unfortunately, just as stark discrepancies exist between the availability of ASD data from high-income countries and LMIC, so do medical providers' knowledge of ASD. For example, a cross-sectional study in Pakistan found that less than 45% of the country's general practitioners had heard of 'autism.'[20] Similar results have been described in Nepal: a study found that nearly 65% of surveyed pediatricians had insufficient knowledge of autism, and less than 10% of pediatricians felt comfortable recognizing a child with autism.[22]

The ability to identify ASD may be even more difficult among refugee children from non-Western cultures. Children who have been exposed to trauma, for example, are at greater risk for developing social, emotional and behavioral problems.[63] It is conceivable then, that a child's behavioral problems resulting from his/her own traumatic experiences might be difficult to distinguish between behavioral problems as a result of ASD.

Several conclusions can be drawn from this information. First, there is a clear need for sound epidemiologic data from LMIC. However, this data cannot be reliable gathered apart from the development of culturally appropriate screening tools. Lastly, if medical professionals are to contribute to ASD field surveillance and research, improvements in training regarding ASD are needed.

### Translation into other languages

As noted previously, there is a growing interest surrounding the screening and detection of ASD. Not surprisingly, the M-CHAT and M-CHAT-R/F have been translated into many languages. Direct translation of these screening tools, however, is not without complications. Without appropriate cultural adaptation, screening tools developed for use in a specific cultural context may be unreliable or invalid for use in a different context.[7] A recent cross-cultural study in Mexico determined that, although the translated version of the M-CHAT is appropriate to use, cultural differences in response items may make international comparison of test results difficult.[13] M-CHAT validation studies have recently occurred in Spain [11] and Japan.[12] Spanish authors note the necessity for cross-cultural adaptation of the M-CHAT prior to validation[11], while Japanese authors modified the testing format itself by lowering the threshold for first-stage screening.[12] These studies highlight the fact that the M-CHAT and M-CHAT-R/F, while highly useful in the international setting, often requires cross-cultural adaptation and modification prior to implementation.

### Translation Protocols

The topic of developing appropriate translations across cultures is becoming more widely discussed among health researchers; however, no standardized approach of translation and assessment of translations exist yet. There are many variations of translation protocols, and often, researchers fail to report their translation methods at all.[64]

The process of translation should achieve "conceptually equivalent" translations of the instrument or survey**.**[24] Similarly, researchers at the University of California San Francisco describe the need for translated surveys or tools to achieve "semantic equivalence across languages, conceptual equivalence across cultures, and normative equivalence to the source survey."[64]

Many translation protocols utilize the process of "back-translation," whereby the newly translated instrument is then back-translated into the original language; this helps identify any existing differences in content between the two translations. The World Health Organization (WHO) has published a document titled, the "Process of translation and adaptation of instruments." The method described by the WHO includes the following steps**:** [24]

1. Forward translation
2. Expert panel back-translation
3. Pre-testing and cognitive interviewing
4. Final version

Other groups suggest different approaches. For example, DE Beaton et al., suggest a six-stage translation process, including two independent forward translations [65]**,** while J. Harkness argues for the Translation, Review, Adjudication, Pretesting and Documentation approach using either a parallel translation (several translators complete independent translations) or a split translation (translators translate separate sections of a document) approach.[66, 67] The US Census Bureau supports the following five-step protocol for translation of survey instruments: Prepare, Translate, Pretest, Revise and Document.[25] This process should be carried out by –at minimum – a 5 person team, including two translators, a subject matter expert, a survey design expert and an translator adjudicator.[25] The guidelines for translating Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys were produced by the CAHPS II Cultural Comparability Team with the goal of standardizing the translation approach.[68] The CAHPS guidelines are similar to the protocols described above, and include the following steps:

1. Obtain forward translations
2. Conduct review of translations
3. Reconcile translations by committee consensus
4. Produce final version of translated survey

# CHAPTER 3: PROJECT CONTENT (METHODS & RESULTS)

## Participants

A total of 13 children of Nepali-speaking caregivers participated in the pilot study between June and July 2014. Seven children were recruited using the DCRPC patient database. Caregivers of eligible patients were contacted by phone and asked to bring their child to the DCRPC for a well-child check and/or ASD screening. Six additional children, known to the clinic's primary interpreter, were screened during home visits (see Figure 1). All patients were between 17 and 26 months of age during screening process.

## METHODS

---

The project proposal was submitted to the Emory University Institutional Review Board, the Georgia Department of Public Health, and the CDC Scientific Determination Process. It was determined by Emory, the Georgia Department of Public Health, and CDC to be non-research/public health practice, and thus, exempt from IRB review.

This project consisted of three steps, which occurred simultaneously: 1) M-CHAT-R/F translation and adaptation, 2) patient screening, and 3) qualitative interviews.

### 1. M-CHAT-R/F Translation and Adaptation

### Translation Methods:

Our translation methods loosely aligned with the World Health Organization's translation and adaptation protocol, with several modifications. As previously described, the WHO proposes a three-step process, consisting of a forward translation, expert panel review of the translation by bilingual participants, and back translation.[24] Our methods included these three components; however, the overall process of our project included additional phases in which modifications of the initial translation were made. Thus, our project incorporated sequential changes based upon interpreter expertise and feedback from Nepali caregivers. It is important to note that the WHO protocols state that the expert panel should be composed of bilingual speakers in the original and target language[24]; however, our expert panel did not include any bilingual physicians or researchers, only bilingual interpreters and translators.

Thus, our steps were as follows:

1. Forward Translation: an initial forward translation of the M-CHAT-R/F was completed by a certified Nepali translator.
2. Expert Panel Discussion: an expert panel convened to provide an overview of the project, ASD and ASD screening, the Atlanta refugee community, as well as discuss

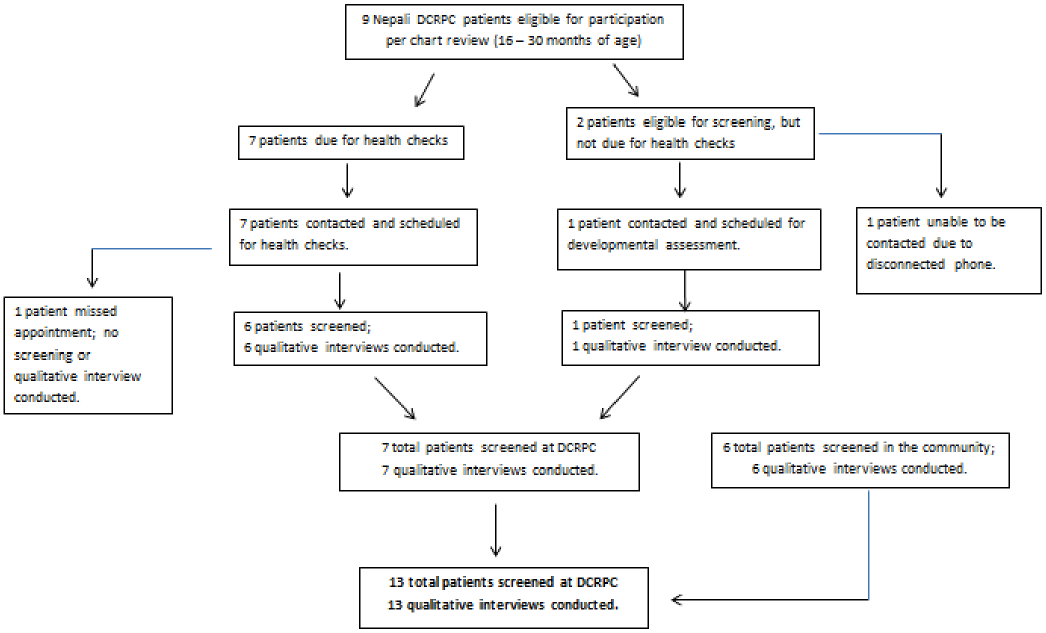
overall project methods and the initial forward translation. The panel consisted of four native Nepali speakers and certified translators, four experts in Autism Spectrum Disorders from the Centers for Disease Control and Prevention, the lead pediatrician at the DeKalb County Refugee Pediatric Clinic and the medical student-author.

3. Primary Modifications: primary modifications to the initial forward translation were provided by certified Nepali interpreter with considerable experience working at the refugee clinic. These modifications, based on her expertise in working with refugee populations in the clinical setting, primarily simplified some of the language that was found to be overly formal and/or literal.
4. Secondary Modifications: additional minor modifications were made by two experienced certified medical interpreters throughout the pilot study. These modifications occurred at the project's midpoint, and were based upon the interpreter's linguistic and cultural expertise, their experience in working in the clinical context, as well as the feedback provided by Nepali caregivers.
5. Final Back Translation: a final back translation was provided by a bilingual speaker, whose native language is Nepali.

### 2. Patient Screening & Scheduling

An initial chart review of patients at the DeKalb County Refugee Pediatric Clinic (DCRPC) identified patients eligible for M-CHAT-R/F screening. Eligibility criteria required patients to be the children of Nepali speaking caregivers and to be between the ages of 16 – 30 months during the months of June and July 2014. Ten patients were identified as eligible for M-CHAT-R/F screening. Of these patients, six were due for a 24-month health check, and one was due for an 18-month health check. These seven patients were scheduled for health checks at the DCRPC. Attempts were made to contact the remaining three patients by phone. Of these three patients, one telephone number was disconnected. (See Figure 2 below.)

Figure 2. Nepali caregiver and patient recruitment process for M-CHAT-R/F screening and adapation



DCRPC: DeKalb County Refugee Pediatric Clinic

The remaining two patients' caregivers were contacted; caregivers were asked to bring their child to the DCRPC for a free developmental assessment and participation in a translation project. Caregivers were informed that they would be given a $25.00 gift card for their time; all caregivers received a $25.00 gift card at the time of screening.

Six additional patients and caregivers were screened and interviewed, respectively, in Clarkston, Georgia. These caregivers and their children were known personally to an interpreter at the DCRPC, who contacted them regarding this project. Written or verbal consent for ASD screening and caregiver interviews was obtained with the aid of the Nepali interpreter. Caregivers were informed that they would be given a $25.00 gift card for their time. All patients were given a $25.00 gift card at the time of screening. Of these six caregivers, four were able to read through the Nepali M-CHAT-R/F questions without the assistance of an interpreter.

### 3. Qualitative Interviews

#### M-CHAT-R/F Administration

The M-CHAT-R/F was administered to Nepali caregivers in two settings: seven patients were screened in the clinical setting at the DCRPC, and six patients were screened in the community setting. A certified medical interpreter was present for all patients screened at the DCRPC. The interpreter read each question of the M-CHAT-R/F in Nepali. No clarification or explanation of the questions was given, even if requested by the caregiver; caregivers could request only that the question to be repeated. The caregiver's answer of "yes" or "no" was then recorded. For patients screened in the community, a medical interpreter was utilized if the caregiver was unable to comfortably read the Nepali M-CHAT-R/F. For caregivers who read Nepali comfortably, no interpreter was utilized for the M-CHAT-R/F administration.

For patients for whom caregiver's answered two or more questions 'positively' (i.e. concerning for ASD), the M-CHAT-R/F follow-up questionnaire was administered. After utilizing the follow-up questions, no patient continued to have responses consistent with a "positive" screening exam; and thus, no patients were referred for follow-up developmental assessment.

Following administration of the M-CHAT-R/F, qualitative questions were administered to each Nepali caregiver. These questions were designed to 1) determine the caregiver's level of understanding of each question 2) elicit information regarding Nepali words or phrases that were inappropriate and/or difficult to understand in the context of the questionnaire and 3) provide suggestions for improved wording or phrasing of the M-CHAT-R/F questions.

Prior to qualitative questioning, each caregiver received a brief explanation regarding the need for a correctly translated/adapted Nepali M-CHAT-R/F. Each interview was recorded using an iPhone® recording application.

#### Translation Adaptation

The Nepali M-CHAT-R/F adaptation process took place in two phases. In the first phase, six Nepali caregivers were interviewed according to the methods listed above. Suggestions for changes were documented, but no changes to the translation were made. After the sixth patient interview (approximately the mid-point of the screening phase of the project), changes were made to the Nepali M-CHAT-R/F version. The remaining seven patients were screened with the second version of the Nepali M-CHAT-R/F. Again, suggestions for changes were solicited from caregivers; however, no caregiver experienced any difficulty with the second version of the M-CHAT-R/F and thus had no proposed changes or suggestions.

**Table 2: Each patient's M-CHAT-R/F screening process, by location, version and administrator**

| Patient Number | Location of Screening: DCRPC or Clarkson | Nepali M-CHAT-R/F Version: Initial or Revised | Administered by: Interpreter or Caregiver |
|---|---|---|---|
| **1** | DCRPC | Initial | Interpreter |
| **2** | DCRPC | Initial | Interpreter |
| **3** | DCRPC | Initial | Interpreter |
| **4** | DCRPC | Initial | Interpreter |
| **5** | DCRPC | Initial | Interpreter |
| **6** | DCRPC | Initial | Interpreter |
| **7** | Clarkston | Revised | Interpreter |
| **8** | Clarkston | Revised | Interpreter |
| **9** | Clarkston | Revised | Caregiver |
| **10** | Clarkston | Revised | Caregiver |
| **11** | Clarkston | Revised | Caregiver |
| **12** | DCRPC | Revised | Interpreter |
| **13** | Clarkston | Revised | Caregiver |

DCRPC: DeKalb County Refugee Pediatric Clinic

## Qualitative Questions

Following administration of the M-CHAT-R/F, qualitative interviews were conducted with each Nepali caregiver. With the exception of one bilingual caregiver, these interviews were conducted with the help of a certified Nepali interpreter. These interviews were intended to gain a better understanding of 1) the caregiver's understanding of the intent of each M-CHAT-R/F item and 2) the caregiver's knowledge and awareness of child development and autism.

With minimal exceptions*, the following questions were asked following each M-CHAT-R/F item:

i. Can you explain this question in your own words? How would you explain this question to another Nepali parent?
ii. What words or phrases were difficult to understand?
iii. What suggestions do you have to make the question easier to understand?

** Questions (ii) and (iii) were reserved for M-CHAT-R/F items in which the caregiver's response to question (i) expressed vague or minimal understanding of the M-CHAT-R/F item. Additionally, questions (ii) and (iii) were asked anytime the caregiver appeared to have difficulty understanding the interpreter (asking the caregiver to repeat the question several times, asking for clarification, etc.), as well as at the end of each interview.*

Following conclusion of each interview, the following questions were asked of each caregiver:

iv. Why do doctors ask these questions about children?
v. What does the term ‘child development’ mean to you?
vi. Have you heard of the term autism? If yes, what does it mean to you?

### Interview Transcription

Qualitative interviews were transcribed immediately following qualitative interviews.

### Transcription Assessment

Transcriptions of qualitative interviews were de-identified. Using the transcription of the qualitative interviews, an expert in Autism Spectrum Disorder from CDC assessed the transcriptions for caregiver understanding of question intent. For each item of the M-CHAT-R/F, caregiver response to the question “explain the [M-CHAT-R/F] item in your own words” was assessed for adequate understanding of the question (yes, no or equivocal).

## RESULTS & ANALYSIS

**Table 3. Sociodemographic characteristics of participants**

| Patient ID | Gender | Age (mos) | No. Months in US (child) | Maternal Education Level | Paternal Education Level | Maternal Literacy Level | Paternal Literacy Level | No. Months in US (care-givers) | No. Children in Family | Other children with medical problems? |
|---|---|---|---|---|---|---|---|---|---|---|
| **1** | F | 19 | 5 | Grade 10 | Grade 10 | Poor | Fair | 5 | 1 | No |
| **2** | F | 23 | 23* | Grade 3 | Grade 10 | Fair | Fair; some English | 26 | 2 | No |
| **3** | M | 26 | 12 | Grade 10 | Grade 8 | Good | Good; some English | 12 | 1 | No |
| **4** | M | 25 | 10 | Grade 5 | Grade 10 | Good | Good; some English | 10 | 2 | No |
| **5** | F | 21 | 22 | Bachelor’s in education (Nepal) | Masters in Language (Nepal) | Excellent; some English | Excellent; some English | 11 | 1 | No |
| **6** | M | 25 | 11 | Grade 10 | Grade 10 | Good | Good | 11 | 1 | No |
| **7** | F | 19 | 19* | Grade 12 | Grade 12 | Excellent; some | Excellent; some | 4 years | 1 | No |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | English | English | | | |
| **8** | M | 17 | 17* | Grade 11 | Grade 11 | Good; some English | Good; some English | 5 years | 3 | No |
| **9** | F | 26 | 26* | Grade 12 | Grade 12 | Excellent; proficient English | Excellent; proficient English | 5 years | 2 | No |
| **10** | F | 21 | 21* | Grade 7 | Grade 10 | Excellent; some English | Excellent; some English | 3 years | 3 | No |
| **11** | M | 20 | 20* | Grade 12 | Grade 12 | Excellent; proficient English | Excellent; proficient English | 2.5 years | 1 | No |
| **12** | F | 18 | 4 | Grade 9 | Grade 8 | Good | Good | 4 | 1 | No |
| **13** | F | 25 | 25* | US Graduate Student | US Graduate Student | Bilingual | Bilingual | 5 years | 1 | No |

*US citizen

**Overview of Analysis:** Analysis of the qualitative interviews focuses on the caregivers' understanding (determined by an expert reviewer) of each M-CHAT-R/F item. Caregiver responses to M-CHAT-R/F items will be categorized as 1) concerning or non-concerning and 2) with understanding or without understanding of the question's intent (see Table 4). Caregiver responses were compiled (see Table 5) and used to determine overall acceptability of the Nepali translation.

**Terms:**

- **Concerning Response**: caregiver's response to the M-CHAT-R/F item indicates ASD risk
- **Non-Concerning Response:** caregiver's response to the M-CHAT-R/F item does not indicate ASD risk
- **With Understanding:** caregiver's response to the qualitative questions indicates understanding of the M-CHAT-R/F question's intent
- **Without Understanding:** caregiver's response to the qualitative questions indicates poor or inadequate understanding of the M-CHAT-R/F question's intent

Throughout the entirety of the screening process, a total five M-CHAT-R/F questions elicited 'concerning responses' from parents (see Table 4 below). Two of these five questions with concerning responses were later revised at the project's midway point (see Tables 5 and 6). Additionally, an ASD expert determined that, for one-half of the M-CHAT-R/F questions, at least one caregiver had poor understanding of the M-CHAT-R/F question's intent (see Table 8 below).

**Table 4. M-CHAT-R/F items with concerning response(s) for ASD**

| M-CHAT-R/F Item | No. of Times a Concerning Response Given by Caregiver |
|---|---|
| **Question 5** | 5 |
| **Question 12** | 4 |
| **Question 15** | 1 |
| **Question 17** | 2 |
| **Question 19** | 1 |

**Table 5. M-CHAT-R/F items in which caregivers had poor understanding of question's intent**

| M-CHAT-R/F Item | No. of Caregivers who did not understand question intent |
|---|---|
| **Question 1** | 3 |
| **Question 3** | 1 |
| **Question 4** | 1 |
| **Question 5** | 4 |
| **Question 9** | 1 |
| **Question 12** | 2 |
| **Question 15** | 1 |
| **Question 16** | 1 |
| **Question 17** | 2 |
| **Question 19** | 1 |

**Table 6. M-CHAT-R/F questions with both concerning responses and lack of caregiver understanding**

| M-CHAT-R/F Question | M-CHAT-R/F Question | No. of 'concerning responses' prior to M-CHAT-R/F revision | No. of caregivers with poor understanding of question's intent | Question changed by interpreter at revision point? |
|---|---|---|---|---|
| **5** | Does your child make unusual finger movements near his or her eyes? (For example, does your child wiggle his or her fingers close to his or her eyes? | 5 | 4 | Yes |
| **12** | 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?) | 4 | 2 | No |
| **15** | Does your child try to copy what you do? (For example, wave bye-bye, clap, or make a funny noise when you do?) | 1 | 1 | No |
| **17** | Does your child try to get you | 2 | 2 | |

| | | | | |
|---|---|---|---|---|
| | to watch him or her? (For example, does your child look at you for praise, or say “look” or “watch me”?) | | | Yes |
| **19** | If something new happens, does your child look at your face to see how you feel about it? (For example, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) | 1 | 1 | No |

In total, four items of the M-CHAT-R/F were changed, as seen in Table 7. These items were determined to be confusing by caregivers in conjunction with the project’s interpreter. Changes in the questionnaire’s terminology were made to ensure that caregivers of all educational backgrounds could easily understand the individual questions. It is worth noting that these changes were not made because the described behaviors within the M-CHAT-R/F were incompatible with Nepali culture. For example, the term “behavior” used in the M-CHAT-R/F’s introduction may not be easily understood by caregivers with little/no education. Therefore, the introduction of the questionnaire was changed slightly to accommodate this issue.

**Table 7: Final Revisions to Nepali M-CHAT-R/F**

| **Original** | **Reason for Change(s)** |
|---|---|
| **Introduction:**<br>**Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no.** | The term “behavior” may not be understood by caregivers with low literacy level. The word was changed so that the sentence reads: “If you have seen your child do the things below a few times, but he or she does not usually do it, then please answer no.” |
| **Question 1:**<br>**If you point to something across the room, does your child look at it?** | The Nepali word for “something” may be interpreted by those from rural regions as “cattle.” The word was changed to a more generic word for “thing” that will be more universally understood |
| **Question 5:**<br>**Does your child make unusual finger movements near his or her eyes? (For example, does your child wiggle his or her fingers close to his or her eyes?)** | The word “unusual” was found to be an unfamiliar word for many Nepali caregivers. The word was changed to mean “strange” or “odd.” |
| **Question 17:**<br>**Does your child try to get you to watch him or her? (For example, does your child look at you for praise, or say “look” or “watch me”?)** | The translation of this question (including the example) was found to be quite long, and was shortened for ease of translation. |

A large majority (91%) of M-CHAT-R/F items were understood by the child’s caregiver (Table 3). Among those M-CHAT-R/F items that were not understood by caregivers (Table 8), about one-fifth (18%) of responses were concerning for ASD. When concerning responses for ASD were given, 57% of caregivers had an appropriate understanding of the question’s intent, while 43% of caregivers had a poor understanding of the question’s intent. Importantly, after utilizing the M-CHAT-R/F follow-up questions, no responses concerning for ASD were given by caregivers.

**Table 8: Caregiver responses to M-CHAT-R/F items (concerning for ASD, non-concerning for ASD) and Caregiver understanding of M-CHAT-R/F item (n=10 caregivers, 190 item responses)**

| | % |
|---|---|
| M-CHAT-R/F Item understood by Caregiver (173) | 91% |
| Among M-CHAT-R/F Items NOT understood by Caregivers (17): | |
| Concerning responses (3) | 18% |
| Unconcerning response (14) | 82% |
| Among concerning responses (7): | |
| Caregiver understood item (4) | 57% |
| Caregiver did NOT understand (3) | 43% |
| After follow-up of concerning responses, positive M-CHAT-R/F (0) | 0% |

When asked why doctors incorporate the M-CHAT-R/F into patient visits, most caregivers believed the doctor was determining if the child was growing and maturing appropriately. When then asked to describe the term ‘child development’ in the caregiver’s own words, two issues arose. First, we learned that no comparable word exists for the phrase ‘child development’ in the Nepali language. As a result, the interpreter described the process of child development (i.e. the child growing…) to the caregiver before he/she could then answer the question. Two caregivers stated that they did not understand the questions. Other caregivers used the term ‘milestone’ or described the process of a child growing and changing as they age. Another caregiver stated that child development means that the child should be growing mentally, physically and intellectually. Most often, however, caregivers described a child’s physical growth process as an indication of overall child development.

We found that only two caregivers were familiar with the term ‘autism’ and were subsequently able to briefly describe their understanding of the disorder. These two women were employed by a local day-care facility and had completed employee training on recognizing ASD signs through their places of employment. One caregiver had heard of the term “autism,” but could not describe it. The remaining 10 caregivers had no knowledge of ASD.

## Table 9. Caregiver responses to qualitative questions regarding child development and autism

| Patient ID | Why do pediatricians ask these questions about children? | What does 'child development' mean to you? | Have you heard of the term 'autism'? If yes, what does it mean? |
|---|---|---|---|
| **1** | To understand what the child likes, what the child likes to play | Health-wise the child should be good. | No |
| **2** | It will help. It's not like 'health' like in check-up, it's like physically, something outside. [Interpreter: what he implied is 'child development'] | Does your child start walking? Does your child smile? | No |
| **3** | Maybe they want to know the child's health and state of health, and the behavior of the child. | It's a physical development, according to the age, whether the child is developing or not. Age-wise, whether the child is developing as expected or not. | No |
| **4** | What I understood, you asked me that question, whether my child could hear. If I felt my child could not hear, I could go and report to the doctor. Or if my child could speak. If I felt my child could not speak, I could go and report to the doctor. If I asked my child to do something, like throwing the trash, he is ok. It will help me to find out if my child is disabled or not. These questions will help me know if my child is normal or disabled or not.<br>You are asking whether my child is becoming better, progressing. All these things help me to know if he is good. | Now my child can walk and speak and say "mommy, daddy," things like that. He might grow also and put on weight. When my child is three years old, four years old and doesn't change, doesn't become better, then I will think something is wrong, that development is not good. If at two years he is like this, and three years he becomes better and better at speaking and follows the things we tell him, then we think he is developing. | No |
| **5** | The child should be good, there should not be anything wrong. If anything is wrong and it is pointed out, the child could be cured. For the better future of the child. | The health and development of the child. The child should develop in both physically and mentally and intellectually | I have heard about it, but can you tell me what does it mean in Nepali? I cannot define it, but I have heard it. |
| **6** | They wanted to know if the child is disabled, if the child is unable to speak or child is unable to do something, if something is happening there. Maybe they are trying to help the child. | I don't understand what that means. | I have heard it, what does it mean? |

| | | | |
|---|---|---|---|
| **7** | To rule out any disabilities, whatever the disabilities are. | It is a milestone, like at age of five, six months, baby will try to crawl. At every day or every month, what should be changing, like walking or crawling or standing up and words – one word or two words. | Yes, I heard it. I heard it at the child care facility [caregiver is job-training at a day care center]. If the child doesn't react face-to-face, and then if you try to talk to them and they don't talk straightaway. Or delay in speech or delay in development, they call Autism. |
| **8** | To learn about the child's development | Is the baby changing day-by-day and growing? | No |
| **9** | To see if the age-appropriate activities are occurring. | The natural system of development, like working, laughing and activities appropriate for the child. | Yes [through day care training]. Some children don't want to talk with eye-contact, and are not learning age-based activities. |
| **10** | To find out about disabilities, to rule-out deafness. To rule out, for example, if she doesn't talk one week, but does talk the next, is this delayed development? | The child can do anything to 1.5 years old, if the child doesn't do something by 1.5 years, something may be wrong. | No |
| **11** | In my view, whether my child will be able to be a good person according to his age, if he is a well-baby. | His activity, according to his age – like playing, eating, reading. | No |
| **12** | To see the reaction of the child in particular situations, to see how the child behaves. Maybe they want to know that. | We need to raise the child properly, and to take care, so that they will develop properly. | No. |
| **13** | Maybe any abnormalities or they want to see if the baby is growing in the normal conditions or if something should be done? | They way that the child needs to get everything in order to be growing in the right conditions. | No |

# CHAPTER 4: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

## STATEMENT OF PRINCIPLE FINDINGS / INTERPRETATION OF RESULTS

The primary purpose of this project was to produce a culturally appropriate version of the M-CHAT-R/F for use in the Nepali pediatric patients at the DeKalb County Refugee Pediatric Clinic. This was accomplished through a small pilot study which incorporated feedback from caregivers regarding their understanding of the M-CHAT-R/F items, as well as collaboration from Nepali translators. Additionally, we aimed to measure Nepali caregivers' understanding of concepts related to ASD and child development by conducting qualitative interviews.

### CAREGIVER UNDERSTANDING OF M-CHAT-R ITEMS

During the translation process, we tracked caregiver understanding of M-CHAT-R/F items as a means of determining the appropriateness of the translation. Subsequently, we found that almost all of the interviewed caregivers (80%) had poor understanding of at least one M-CHAT-R/F item. In fact, two of the most frequently poorly understood M-CHAT-R/F items (Q1 & Q5)[1] required revisions to produce a more easily understood version of the M-CHAT-R/F. This illustrates the necessity of appropriately adapting medical screening tools such as the M-CHAT-R/F. Without undergoing a thorough adaptation process, screening instruments and questionnaires are at risk of contributing to caregiver confusion and misunderstanding of the questions' intent. In the case of the M-CHAT-R/F, it is imperative that caregivers have the best opportunity to properly understand the questionnaire's items. Without proper comprehension, both physicians and caregivers may be misled when determining a child's risk of ASD. The implications of this – either a false positive or a false negative—directly affects the care of a child and the subsequent strain placed on the medical system. Given the percentage of responses in which a caregiver lacked understanding of the question, we feel that all positive responses should prompt a translated M-CHAT-R/F Follow Up questionnaire, and negative responses should be interpreted with caution in the context of the child.

### CAREGIVER UNDERSTANDING OF ASD AND CHILD DEVELOPMENT

Additionally, we found that with few exceptions, most Nepali caregivers had a limited or non-existent understanding of the terms 'autism' or 'Autism Spectrum Disorders.' Only two caregivers had pre-existing knowledge of ASD; they were employees at a daycare facility and had participated in training sessions to aid in identification of children with ASD. This lack of knowledge regarding ASD is not surprising, as there is little awareness of ASD in the caregivers'

---

[1] Question 1: If you point to something across the room, does your child look at it?
Question 5: Does your child make unusual finger movements near his or her eyes? (For example, does your child wiggle his or her fingers close to his or her eyes?)

home county of Nepal.[21, 22] More surprisingly, however, was the fact that the term 'child development' did not translate easily into Nepali. The inability to directly translate this term presented a challenge during qualitative interviews with caregivers, as the interpreter was forced to provide a basic description of child development as opposed to directly translating the term. We found that most caregivers had trouble describing the difference between 'child development' and physical development. This finding is an important one, as monitoring child development is an important part of the pediatrician's role during a child's early years. Lack of parental education regarding typical child development and/or early signs of developmental delay must be addressed by healthcare providers if caregivers are to improve their understanding of appropriate development.

Overall, we found the translation process to be time-intensive, requiring multiple revisions of the M-CHAT-R/F to ensure adequate understanding among caregivers. Each caregiver interview was approximately 60 – 80 minutes. This process, however, was necessary to produce a culturally appropriate version of the M-CHAT-R/F, and to improve the caregivers' understanding of the questions' intent (see Table 3). As discussed previously in the Literature Review section, multiple protocols exist for the translation of medical instruments. As healthcare becomes more accessible to minority/immigrant/refugee patients, the need for appropriately translated health-related material will only grow. Thus, it may be beneficial for medical associations to put forth recommendations regarding translation guidelines.

In conclusion, this project successfully completed its primary purpose, which was to appropriately adapt an existing ASD screening tool (M-CHAT-R/F) into Nepali for use in the Nepalese refugee community. Additionally, the specific objectives were met, which included the completion of 10 qualitative interviews with Nepali caregivers, as well as dissemination of the adapted Nepali M-CHAT-R/F to other clinics serving similar refugee populations.

## STRENGTHS AND WEAKNESSES

### STRENGTHS

Our project utilized many aspects of the translation protocols suggested by various groups[64] for the translation and adaptation of the M-CHAT-R/F. For example, our protocol not only implemented forward and backward translations of the English/Nepali versions of the M-CHAT-R/F, but also employed the expertise of three Nepali translators and/or interpreters. These native Nepali speakers collaborated on various aspects of the M-CHAT-R/F's adaptation, ensuring a balanced approach to the translation/adaptation process.

Additionally, our project incorporated feedback from multiple caregivers (N=13) regarding their understanding of various M-CHAT-R/F questions and their suggestions for improvement of grammar and syntax. To our knowledge, only one other group has utilized a similar approach;

however, only two caregivers were interviewed during this process. Thus, we feel that our number of caregivers provides significant strength to our project.

The M-CHAT-R/F is designed so that it may be administered directly by the caregiver, without clinician input. Therefore, it is important that the vocabulary of the questionnaire be such that caregivers of any educational level may be able to understand the questions' intent and answer appropriately. The education level among our caregivers was quite broad (range from grade 3 to graduate school), suggesting that the adapted M-CHAT-R/F is appropriate for a range of reading and comprehension levels.

Our project team included a total of three Nepali speakers throughout the process: one translator, one interpreter, and one team member who functioned as both an interpreter and translator. This small number helped ensure that our Nepali speaking team-members thoroughly understood the aim of the project and also aided in providing consistent terminology throughout the process. Each of these team members were certified medical interpreters and translators, respectively.

### WEAKNESSES

Perhaps the most obvious weakness in this project is the small sample size (n=13) used to gather information about the M-CHAT-R/F and caregivers' understanding of ASD and child development. Because of this small sample size, we were not able to validate the adapted M-CHAT-R/F. However, as stated earlier, our purpose was to appropriately adapt the M-CHAT-R/F for use in the Nepali refugee population, not to validate the M-CHAT-R/F.

Our qualitative questions regarding caregiver understanding of concepts relating to child development and ASD were brief, focusing on caregivers' basic understanding of the terms 'child development' and 'autism.' As a result, there are many themes related to these concepts that were not explored in these interviews. For example, caregivers could be asked to give examples of appropriate and/or inappropriate child development. They could also be asked about their knowledge regarding the etiology of developmental disabilities and appropriate therapy. The threshold at which caregivers feel they should alert a physician to their concern regarding a child's development could also be explored.

Standardized qualitative questions were utilized for each caregiver interview. However, these questions were standardized in English, as opposed to Nepali. Therefore, since two separate interpreters were utilized throughout the interview process, it is possible that the original English version of the questions were translated slightly differently between interpreters. To have avoided any inconsistency in interpretation of the qualitative questions, the questionnaire could have been standardized into Nepali prior to the beginning of interviews.

Lastly, our pilot study included only Nepali refugee caregivers seen at the DeKalb Pediatric Refugee Clinic. Thus, our results are specific to this population of Nepali-speakers, and may not be generalizable to the larger Nepali population or to other refugee or immigrant populations.

## PUBLIC HEALTH & POLICY IMPLICATIONS: POSSIBLE MECHANISMS AND IMPLICATIONS FOR CLINICIANS OR POLICYMAKERS

The implications of this modified ASD screening tool for clinicians who care for Nepali children are vast. As provider-awareness of the health needs specific to refugee children continues to increase, clinicians will become more skilled at providing care for refugee/immigrant children. At the present time, however, there are large disparities between the care provided for US born children and refugee/immigrant children**.[69]** These disparities may be due, in part, to poor allocation and distribution of resources. However, many of these disparities are perhaps more easily addressed, as they are related to the fact that the medical community has poor understanding of the cultural background from which these children come. For example, many of the standardized developmental screeners have yet to be translated into the languages commonly spoken by refugee children. However, as developmental screening (including screening for ASD) becomes the standard of care for children of any ethnicity, the medical community finds itself unable to appropriately screen patients of certain ethnic and language groups until screening tools have been properly adapted.

The immediate impacts of the newly adapted Nepali M-CHAT-R/F are clear: clinicians providing care for Nepali children ages 16 months – 30 months now have an appropriately adapted/translated ASD screening tool which was previously unavailable to them. The Nepali M-CHAT-R/F will help facilitate ASD screening in Nepali refugee children who are cared for in clinics across the United States similar to the DeKalb County Refugee Pediatric Clinic. The Nepali M-CHAT-R/F (follow-up) screener plays a key-role in improving specificity of the initial questionnaire.

Clinicians should also be mindful of the fact that refugee caregivers are likely to have little knowledge (if any) of autism or other developmental disabilities. In conjunction with screening children for ASD, providers caring for refugee families should educate caregivers on typical child development, as well as ASD & other developmental conditions. There is a need for ongoing education for caregivers regarding appropriate child development at primary care appointments. Unfortunately, this demands both time and resources on the part of the clinician, which may be unrealistic and impractical in a busy clinical practice. In order to provide appropriate educational materials to caregivers, medically-oriented NGO's working with the refugee population could ideally collaborate with organizations such as Autism Speaks (nationally) or the Marcus Autism Center (locally) to develop educational/awareness campaigns aimed to educate specific communities, such as the Nepali refugee community, that often have little access to mainstream advertising.

It is our hope that as similar ASD screening tools become available to the medical community, providers and researchers will have the necessary tools to collect epidemiological data on developmental delay and/or ASD in immigrant and refugee populations. However, a large-scale validation study is needed to ensure that this adapted tool is appropriate for collecting epidemiologic data.

Lastly, we believe we have provided a good guideline for those seeking to replicate the process of M-CHAT-R/F adaptation in a language that has not yet been translated. There are numerous resources to guide the translation and adaptation of medical materials. However, this wealth of information could quickly become overwhelming; therefore, a comprehensive, standardized guide for translation would be immensely useful to the medical community. Thus, we hope that our methods will serve as future guide for those hoping to adapt similar materials.

### UNANSWERED QUESTIONS AND FUTURE RESEARCH

The adaptation of the M-CHAT-R/F for use in the Nepali refugee pediatric populations provides the initial framework upon which future research can be built. The opportunity for improved knowledge and understanding of developmental disabilities and ASD in refugee/immigrant populations is enormous. However, similar tools must first be developed – and validated – if robust epidemiologic data is to be gathered.

The most obvious immediate “next step” to ensure that such data-gathering can occur involves a large-scale validation study of this tool. This study would likely necessitate multiple clinical sites that care for Nepali refugee patients to ensure adequate statistical power. The process of validation of the M-CHAT-R/F has been well-documented.[10] A similar process would be time and resource-intensive, but would provide validity to the Nepali M-CHAT-R/F. Additionally, it would make an important ethical statement that the medical community values the refugee community enough to dedicate valuable resources to their care.

Additional qualitative research is needed to further characterize Nepali caregivers’ understanding of child development and ASD. This research could take the form of in-depth interviews with caregivers, focus groups and/or Knowledge, Attitude and Practice (KAP) surveys. It has been noted that, in Nepal, children are most frequently identified as having developmental delay due to speech delay.[21] Thus, qualitative research could focus on caregivers’ understanding of appropriate child development, as well as manifestations of developmental delay that warrant medical attention.

Given the fact that there appears to be a significant knowledge gap between Nepali caregivers and healthcare professionals regarding child development and ASD, it is important for healthcare professionals to know the best approach to educate caregivers on issues relating to development and/or ASD. Additional research (in the form of qualitative interviews, etc.) regarding ASD education methodology would be immensely beneficial for clinicians caring for refugee populations.

Our research was conducted at a single-site; future research comparing caregivers' understanding based upon US residency time and geographical region may yield different results than those obtained in our qualitative interviews.

As the medical community becomes more aware of the need for culturally competent medical resources, there should be a simultaneous push for the standardization of protocols for the translation of such tools/instruments.  Currently, there is a myriad of translation processes with little consensus on the exact manner in which medical instruments/tools should be adapted to ensure cultural competence.  The medical community would benefit greatly if a standard process were adopted.

# APPENDICES

## Appendix 1. Nepali M-CHAT-R

**यी प्रश्नहरुको जवाफ तपाईंको नानीको बारेमा दिनुहोस यसो गर्दा सो नानीको दिनप्रतिदिनको आनीबानी मनमा राख्ने यहाँ सोधेको कुनै आनीबानी एक- दुइ पल्ट मात्र सो नानीले गरेको यदि देख्नु भाको हो तर सदा होइन भने त्यसको उत्तर "होइन " मा चिन्ह लगाएर दिनुहोस तलका सबै प्रश्नहरुको उत्तर "हो " या "होइन " शब्दमा गोलाकार चिन्ह लगाएर दिनु होस् सो गरे बापत हजुरलाई धेरै धन्यबाद**

| | | |
|---|---|---|
| 1. तपाइंले कोठाको पल्लो छेउमा केहि कुरालाई हातले देखाउनु भयो भने, तपाइंको नानीले त्यसलाई हेर्नु हुन्छ? (जस्तै: कुनै खेलौना या जनावरलाई देखाउनु भयो भने, तपाइंको नानीले त्यो खेलौना या जनावरलाई हेर्नु हुन्छ?) | हो | होइन |
| 2. तपाइंलाई कहिल्यै आफ्नो नानी कान पो सुन्दैनकि जस्तो लागेको छ? | हो | होइन |
| 3. तपाइंको नानीले केहि कुरा गरेको नक्कल वा नाटक गर्नु हुन्छ ? (जस्तै: खाली कप बाट पिएको जस्तो गर्ने, **फोनमा कुरा गरेको** जस्तो गर्ने, गुडिया या **नरम कपडा भरेर बनाएको जनावरलाई** खाना ख्वाए जस्तो गर्नु हुन्छ?) | हो | होइन |
| 4. तपाइंको नानी जिनिसहरु माथि चड्न मन पराउनु हुन्छ? (जस्तै: **फर्नीचर (सोफा, टेबल,** कुर्सी) खेल्ने ठाउँको खेल्ने जिनिसहरु या सिढीमा?) | हो | होइन |
| 5. तपाइंको नानीले आफ्नो आँखा अगाडि औंलाहरू अनौठो पाराले चलाउनु हुन्छ ? (जस्तै: आँखा अगाडि औंलाहरू नचाउने/हल्लाउने गर्नु हुन्छ?) | हो | होइन |
| 6. तपाइंको नानीले केहि कुरा माग्दा अथवा सहायता चाहिंदा एउटा औंलाले देखाउनु हुन्छ? (**जस्तै, भेट्न नसकिने ठाउँको खाने कुरा या खेलौनालाई औंल्याउने**) | हो | होइन |
| 7. कुनै चाखलाग्दो कुरा,तपाइंको नानीले तपाइंलाई औंलाले देखाउनु हुन्छ?(जस्तै: आकाशमा हवाई जहाज**लाई** या सडकमा ठूलो ट्रक**लाई**) | हो | होइन |
| 8. तपाइंको नानीले अरु नानीहरू**लाई** मन पराउनु हुन्छ? (जस्तै: अरु नानीहरुलाई हेर्ने, हेरेर मुसुक्क हास्ने या छेउमा जाने गर्नु हुन्छ?) | हो | होइन |
| 9. तपाइंको नानीले के के जाति ल्याएर माथि उचालेर तपाइंलाई देखाउनु हुन्छ - सहायता लिनको लागि होइन तपाइंलाई देखाउनको लागि मात्रै? (जस्तै: एउटा फूल, **नरम कपडा भरेर बनाएको जनावर** या खेलौना ट्रक?) | हो | होइन |
| 10. तपाइंको नानीले वहाँको नाम बोलाउँदा प्रतिक्रिया गर्नु हुन्छ? (जस्तै: नाम बोलाउँदा हेरने, बोलने, बड़बड़ाउने , या गरीरहेको काम छोड्ने गर्नु हुन्छ ?) | हो | होइन |
| 11. तपाइंको नानी संग तपाईं मुसुक्क हाँस्दा ,वहाँ पनि हाँस्नु हुन्छ? | हो | होइन |
| 12. तपाइंको नानी, दिनदिनै हुने आवाजहरु सुन्दा, रुने या चिच्याउने गर्नु हुन्छ? (जस्तै: धुलो सोसने मशिनको आवाज (भ्याक्युम क्लिनर).जोडले बजेको गीत/संगीत) | हो | होइन |
| 13. तपाइंको नानी हिंड्नु हुन्छ? | हो | होइन |
| 14. तपाइंको नानी संग तपाइं बोल्दा, खेल्दा अथवा लुगा **लगाइदिँदा,** नानीले तपाइंको आँखामा हेर्नु हुन्छ? | हो | होइन |
| 15. तपाइंको नानीले तपाइंले जे गर्नु हुन्छ त्यसको नक्कल गर्नु हुन्छ? (जस्तै: बाइ-बाइ गर्ने, ताली बजाउने , मुखले अनौठो आवाजहरु निकाल्दा त्यस्तै गर्नु हुन्छ?) | हो | होइन |
| 16. तपाइंले केहि कुरा हेर्नलाई टाउको घुमाउनु भयो भने, तपाइंको नानीले पनि के रहेछ भनेर त्यतै हेर्नु हुन्छ? | हो | होइन |
| 17. तपाइंको नानीले वहाँलाई याद गरुन, हेरुन भनेर त्यस्तो केहि गर्नु हुन्छ? (जस्तै: तपाइंले ‘श्याबाश/राम्रो’ भन्नु हुन्छ कि | हो | होइन |

| | | |
|---|---|---|
| भनेर तपाइंलाई हेर्ने,‘ हेर्नु होस्’ ‘मलाई हेर्नु होस् त’ भन्ने गर्नु हुन्छ ?) | | |
| 18. तपाइंको नानीले यसो - उसो गर्नु भन्दा बुझ्नु हुन्छ? (जस्तै: हातले नदेखाई कन "यो किताब कुर्सी माथि राख " या " उ त्यो ओढ्ने/कम्मल मलाइ ले ले " भन्दा बुझ्नु हुन्छ ? | हो | होइन |
| 19. केहि नौलो कुरो भयो भने, नानीले तपाइंको मुखमा हेर्नु हुन्छ, तपाइंलाई कस्तो लाग्यो भनेर?(जस्तै: अनौठो या हासउठ्दो आवाज सुन्दा या नया खेलौना देख्दा, तपाइंको मुखमा हेर्नु हुन्छ?) | हो | होइन |
| 20. तपाइंको नानीले वहाँ लाई चहलपहल गराएको मनपराउनु हुन्छ? (जस्तै पिङ्ग खेलाएको **अथवा** घुगुती खेलाएको मनपराउनु हुन्छ?) | हो | होइन |

## REFERENCES

1. *CDC Revises Estimate of Autism: 1 in 88*. [cited 2013 15 August 2013]; Available from: http://www.autismspeaks.org/science/science-news/top-ten-lists/2012/cdc-revises-estimate-autism-prevalence-1-88. .
2. *Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008*, in *MMWR Surveill Summ*2012, Centers for Disease Control and Prevention. p. 1-19.
3. *Prevalence of autism spectrum disorder among children aged 8 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2010.* MMWR Surveill Summ, 2014. **63**(2): p. 1-21.
4. Johnson, C.P. and S.M. Myers, *Identification and evaluation of children with autism spectrum disorders.* Pediatrics, 2007. **120**(5): p. 1183-215.
5. Tchaconas, A. and A. Adesman, *Autism spectrum disorders: a pediatric overview and update.* Curr Opin Pediatr, 2013. **25**(1): p. 130-44.
6. Filipek, P., et al., *The Screening and Diagnosis of Autistic Spectrum Disorders.* Journal of Autism and Developmental Disorders, 1999. **29**(6): p. 439-484.
7. Freeth, M., et al., *A cross-cultural comparison of autistic traits in the UK, India and Malaysia.* J Autism Dev Disord, 2013. **43**(11): p. 2569-83.
8. Robins, D.L., et al., *Validation of the modified checklist for Autism in toddlers, revised with follow-up (M-CHAT-R/F).* Pediatrics, 2014. **133**(1): p. 37-45.
9. Baron-Cohen, S., J. Allen, and C. Gillberg, *Can autism be detected at 18 months? The needle, the haystack, and the CHAT.* Br J Psychiatry, 1992. **161**: p. 839-43.
10. Robins, D.L., et al., *Validation of the Modified Checklist for Autism in Toddlers, Revised With Follow-up (M-CHAT-R/F).* Pediatrics, 2013.
11. Canal-Bedia, R., et al., *Modified checklist for autism in toddlers: cross-cultural adaptation and validation in Spain.* J Autism Dev Disord, 2011. **41**(10): p. 1342-51.
12. Kamio, Y., et al., *Effectiveness of using the Modified Checklist for Autism in Toddlers in two-stage screening of autism spectrum disorder at the 18-month health check-up in Japan.* J Autism Dev Disord, 2014. **44**(1): p. 194-203.
13. Albores-Gallo, L., et al., *M-CHAT Mexican Version Validity and Reliability and Some Cultural Considerations.* ISRN Neurol, 2012. **2012**: p. 408694.
14. Robins, D.L., *Screening for autism spectrum disorders in primary care settings.* Autism, 2008. **12**(5): p. 537-56.
15. *Notice of Final FY 2011 Formula Allocations for Targeted Assistance Grants to States for Services to Refugees*, 2011.
16. Martin, D., Yankay, J., *Refugees and Asylees: 2013*, in *Annual Flow Report* 2014: DHS Office of Immigration Statistics
17. Prah, P. *Which States Accepted the Most Refugees in 2012?* 2013 March 11, 2015]; Available from: http://www.governing.com/news/state/sl-refugees-in-states-2012.html.
18. *Refugees from Bhutan poised for new start*. 2008 [cited 2015 March 11, 2015]; Available from: http://www.unhcr.org/cgi-bin/texis/vtx/search?page=search&docid=47a30dc82&query=bhutan.
19. Reines, S., 2014.
20. Rahbar, M.H., K. Ibrahim, and P. Assassi, *Knowledge and attitude of general practitioners regarding autism in Karachi, Pakistan.* J Autism Dev Disord, 2011. **41**(4): p. 465-74.
21. Shrestha, M. and R. Shrestha, *Symptom Recognition to Diagnosis of Autism in Nepal.* J Autism Dev Disord, 2013.

22. Khatri, G.K., Onta, S. R., Tiwari, S., & Choulagai, B. P., *Knowledge and management practices of pediatricians about autism spectrum disorder in Kathmandu, Nepal.* Journal of Nepal Pediatric Society, 2011. **31**(2): p. 98-104.
23. *Early and Periodic Screening, Diagnostic, and Treatment*. 26 October 2013]; Available from: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html.
24. *Process of translation and adaptation of instruments*. 2014 [cited 2014 23 April 2014]; Available from: http://www.who.int/substance_abuse/research_tools/translation/en/.
25. *Census Bureau Guideline: Language Translation of Data Collection Instruments and Supporting Materials*. 2001; Available from: http://www.census.gov/cac/www/007585.html.
26. Gillberg, C. and L. Wing, *Autism: not an extremely rare disorder.* Acta Psychiatr Scand, 1999. **99**(6): p. 399-406.
27. *Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States*, 2000, 2002, Centers for Disease Control and Prevention
28. *Community Report from the Autism and Developmental Disabilities Monitoring Network*, 2014, Centers for Disease Control and Prevention.
29. Rosti, R.O., et al., *The genetic landscape of autism spectrum disorders.* Dev Med Child Neurol, 2014. **56**(1): p. 12-8.
30. Carter, M.T. and S.W. Scherer, *Autism spectrum disorder in the genetics clinic: a review.* Clin Genet, 2013. **83**(5): p. 399-407.
31. Mundy, P., M. Gwaltney, and H. Henderson, *Self-referenced processing, neurodevelopment and joint attention in autism.* Autism, 2010. **14**(5): p. 408-29.
32. Mundy, P. and L. Newell, *Attention, Joint Attention, and Social Cognition.* Curr Dir Psychol Sci, 2007. **16**(5): p. 269-274.
33. Prelock, P.J. and N.W. Nelson, *Language and communication in autism: an integrated view.* Pediatr Clin North Am, 2012. **59**(1): p. 129-45, xi.
34. Mundy, P., M. Sigman, and C. Kasari, *A longitudinal study of joint attention and language development in autistic children.* J Autism Dev Disord, 1990. **20**(1): p. 115-28.
35. Luyster, R.J., et al., *Language assessment and development in toddlers with autism spectrum disorders.* J Autism Dev Disord, 2008. **38**(8): p. 1426-38.
36. Kasari, C., et al., *Language outcome in autism: randomized comparison of joint attention and play interventions.* J Consult Clin Psychol, 2008. **76**(1): p. 125-37.
37. Mitchell, S., et al., *Early language and communication development of infants later diagnosed with autism spectrum disorder.* J Dev Behav Pediatr, 2006. **27**(2 Suppl): p. S69-78.
38. De Giacomo, A. and E. Fombonne, *Parental recognition of developmental abnormalities in autism.* Eur Child Adolesc Psychiatry, 1998. **7**(3): p. 131-6.
39. *Highlights of Changes from DSM-IV-TR to DSM-5*, 2013.
40. Wimpory, D.C., et al., *Are infants with autism socially engaged? A study of recent retrospective parental reports.* J Autism Dev Disord, 2000. **30**(6): p. 525-36.
41. Volkmar, F., K. Chawarska, and A. Klin, *Autism in infancy and early childhood.* Annu Rev Psychol, 2005. **56**: p. 315-36.
42. *DSM-5 Diagnositc Criteria* [cited 2014 21 November 2014]; Available from: http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria.
43. Insel, T., *Director's Blog: Transforming Diagnosis* 2013, National Institute of Mental Health.
44. Myers, S.M. and C.P. Johnson, *Management of children with autism spectrum disorders.* Pediatrics, 2007. **120**(5): p. 1162-82.
45. Dawson, G., et al., *Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model.* Pediatrics, 2010. **125**(1): p. e17-23.

46. Reichow, B., et al., *Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD).* Cochrane Database Syst Rev, 2012. **10**: p. CD009260.
47. Geretsegger, M., et al., *Music therapy for people with autism spectrum disorder.* Cochrane Database Syst Rev, 2014. **6**: p. CD004381.
48. Ward, S.C., et al., *The association between therapeutic horseback riding and the social communication and sensory reactions of children with autism.* J Autism Dev Disord, 2013. **43**(9): p. 2190-8.
49. Buie, T., et al., *Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.* Pediatrics, 2010. **125 Suppl 1**: p. S1-18.
50. Pinto-Martin, J.A., et al., *Screening strategies for autism spectrum disorders in pediatric primary care.* J Dev Behav Pediatr, 2008. **29**(5): p. 345-50.
51. Snow, A.V. and L. Lecavalier, *Sensitivity and specificity of the Modified Checklist for Autism in Toddlers and the Social Communication Questionnaire in preschoolers suspected of having pervasive developmental disorders.* Autism, 2008. **12**(6): p. 627-44.
52. Earls, M., Curry, E. *The AAP Autism Screening Guidelines: Integrating Screening Guidelines in Primary Care Practice*. in *Preventative Services Improvement Project*. 2011.
53. Soares, N.S. and D.R. Patel, *Office screening and early identification of children with autism.* Pediatr Clin North Am, 2012. **59**(1): p. 89-102, x-xi.
54. Wiggins, L.D., J. Baio, and C. Rice, *Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample.* J Dev Behav Pediatr, 2006. **27**(2 Suppl): p. S79-87.
55. Robins, D.L. and T.M. Dumont-Mathieu, *Early screening for autism spectrum disorders: update on the modified checklist for autism in toddlers and other measures.* J Dev Behav Pediatr, 2006. **27**(2 Suppl): p. S111-9.
56. Robins, D.L., et al., *The Modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders.* J Autism Dev Disord, 2001. **31**(2): p. 131-44.
57. Kleinman, J.M., et al., *The modified checklist for autism in toddlers: a follow-up study investigating the early detection of autism spectrum disorders.* J Autism Dev Disord, 2008. **38**(5): p. 827-39.
58. Chlebowski, C., et al., *Large-scale use of the modified checklist for autism in low-risk toddlers.* Pediatrics, 2013. **131**(4): p. e1121-7.
59. Robins, D.L. *Official M-CHAT Website*. 2013 20 November 2014]; Available from: http://www.mchatscreen.com/Official_M-CHAT_Website.html.
60. Robins, D., Fein, D., Barton, M., *Modified Checklist for Autsim in Toddlers, Revised, with Follow-Up*, 2009.
61. Samms-Vaughan, M.E., *The status of early identification and early intervention in autism spectrum disorders in lower- and middle-income countries.* Int J Speech Lang Pathol, 2014. **16**(1): p. 30-5.
62. Kim, H.U., *Autism across cultures: rethinking autism.* Disability and Society, 2012. **27**(4): p. 535-545.
63. Familiar, I., et al., *Post-traumatic stress symptoms and structure among orphan and vulnerable children and adolescents in Zambia.* Child Adolesc Ment Health, 2014. **19**(4): p. 235-242.
64. *Guidelines for Translating Surveys in Cross-Cultural Research: Annotated Bibliography*. [cited 2014 19 April 2014]; Available from: http://dgim.ucsf.edu/cadc/mm/translationguide.pdf.
65. Beaton DE., B.C., Guillemin F., Ferraz MB, *Recommendations for the Cross-Cultural Adaptation of Health Status Measures*, A.A.o.O. Surgeons, Editor 2002: Rosemont (IL).

66. Harkness J., P.B., Schoua-Glusberg A., *Survey Questionnaire Translation and Assessment*, in *Methods for Testing and Evaluating Survey Questionnaires*. 2004, John Wiley & Sons, Inc.: Hoboken, N.J. p. 453-473.
67. Harkness J, V.d.V.F., and Moher P., *Questionnaire Translation*, in *Cross-Cultural Survey Methods*. 2003, John Wiley & Sons, Inc.: Hoboken N.J. p. 35-56.
68. Weidmer, B., Murtado, M., Weech-Maldanado, R., Ngo-Metzger, Q., Bogen, K. *Guidelines for Translating CAHPS Surveys*. 2006 [cited 2014 20 April 2014]; Available from: https://www.cahps.ahrq.gov/surveys-guidance/helpful-resources/resources/cahpsGuidelines_Translation.html.
69. *Improving Children's Health: Understanding Children's Health Disparities and Promising Approaches to Address Them*, 2006, Children's Defense Fund: Washington, D.C.