

**Identifying Young Children with Autism Spectrum Disorder in Nepal:
Implementing and Evaluating Social Attention and Communication Surveillance**

Submitted By

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2016

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ABBREVIATIONS

ABC	Autism Behaviour Checklist
ACNS	AutismCare Nepal Society
ADOS-2	Autism Diagnostic Observation Scale- Second Edition
ADOS-G	Autism Diagnostic Observation-Generic
AE	Age Equivalent
AoD	Age of Diagnosis
ASD	Autism Spectrum Disorder
AQ-C	Autism Spectrum Quotient-Child Version
CABS	Clancy Autism Behaviour Scale
CARS	Childhood Autism Rating Scales
CF	Consent Form
CHAT	Checklist for Autism in Toddlers
CP	Cerebral Palsy
DD	Developmental Disorders
DIAGINT	Diagnosis and Intervention
DS	Down Syndrome
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition,
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revised
DQ	Developmental Quotient
EI	Early Intervention
EL	Expressive Language of Mullen Scale of Early Learning
ELB	Early Language Behaviours
EPI	Epidemiology
FCHVs	Female Community Health Volunteers

FM	Fine Motor of Mullen Scale of Early Learning
GDD	Global Developmental Delay
HEAT	Health Education and Training
HEW	Health Extension Worker
HICs	High-Income Countries
HPs	Health Posts
HR	High-risk
ICD-10	International Classification of Diseases, Tenth Revision
ISAA	Indian Scale of Assessment of Autism
LMICs	Low- and Middle-Income Countries
LR	Low-risk
MCH	Maternal and Child Health
M-CHAT	Modified Checklist for Autism in Toddlers
MON	Monitoring
MSEL	Mullen Scale of Early Learning
NVDQ	Non-Verbal Developmental Quotient
REF	Referring
PDD	Pervasive Developmental Disorder
PHC	Primary Health Centre
PIS	Participant Information Statement
PPV	Positive Predictive Value
PRPB	Peer Relations and Play Behaviours
RL	Receptive Language of Mullen Scale of Early Learning
RRBI	Restricted, Repetitive Behaviour, Interests, or Activities
SACB	Social Attention and Communication Behaviours
SACS	Social Attention and Communication Study

SACS-N	Social Attention and Communication Surveillance-Nepal
SCDC	Social Communication Disorder Checklist
SCIB	Social Communication and Interaction Behaviour
SCQ	Social Communication Questionnaire
SHPs	Sub-Health Posts
TD	Typically Developing
TQ	Ten Questions
23Q	23-Question Screener
VDC	Village Development Committee
VDQ	Verbal Developmental Quotient
VR	Visual Reception of Mullen Scale of Early Learning
WHO	World Health Organisation

THESIS SUMMARY

The overall aim in the research presented in the current thesis was to implement and evaluate a Nepali version of Social Attention and Communication Surveillance (SACS-N) to identify children between 11-30 months at “high likelihood” of autism in a local community in Kathmandu (Kirtipur). The aim was achieved by training 60 Female Community Health Volunteers (FCHVs) to identify and monitor the early signs of autism.

The age of diagnosis (AoD) of Autism Spectrum Disorder (ASD) was first examined to establish a baseline diagnostic age prior to the implementation of SACS-N. The mean AoD of ASD was determined by a record review at AutismCare Nepal Society, which was found to be 58 months, much later than the age at which a reliable autism diagnosis is possible.

The FCHVs monitored 1926 children using the SACS-N, with only 11 children (0.57%) referred for further assessments. Seven children attended these assessments, with three diagnosed with autism (43%), and four diagnosed with global developmental delay (57%). The estimated prevalence of ASD in the current study ranged between 0.16 % to 0.26%.

The FCHVs’ knowledge of autism before, immediately after, and at 12-months following training was examined next along with knowledge about autism amongst the parents/caregivers who were monitored by the FCHVs. Following training, the FCHVs showed significant improvement in knowledge about autism and reported greater confidence in monitoring and referring young children who are at “high likelihood” of autism. Most FCHVs reported a positive impact of training on their work. The survey among 1895 caregivers revealed a significant lack of knowledge about autism including symptoms, causes, epidemiology, diagnosis and intervention.

The findings provide evidence of the feasibility of community-based developmental monitoring of autism and other developmental delays by FCHVs, and this

is a cost-effective and sustainable approach to raise awareness and promote early identification in Nepal. Further training of FCHV's and increased awareness of autism is needed in the community to raise the low referral rates and uptake of assessments. Regular supervision of FCHVs is also required to increase the accuracy of referral for autism using the SACS-N.

STATEMENT OF AUTHORSHIP

This thesis includes work by the author that has been published or accepted for publication as described in the text. Except where reference is made in the text of the thesis, this thesis contains no other material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

Several people contributed to the studies, journal article and other materials presented in this thesis. My principal supervisor, Professor Cheryl Dissanayake, and co-supervisor, Dr Josephine Barbaro, have made a number of contributions, including assistance with the development of the study and research design, data analysis, interpretation of findings, manuscript drafting and editing. The AutismCare Nepal Society (ACNS) provided the data for analysis that was utilised in Chapter 4. Ajita Deuja and Shruti Rana assisted with the assessments of the children at ACNS and the administrative work involved in the studies outlined in Chapter 5, 6 and 7. Predominantly, however, I carried out the empirical research presented here, analysed the data, and produced all the written materials.

All research procedures reported in this thesis were approved by the Nepal Health Research Council (NHRC Approval Number: 112/2016) and the La Trobe University Human Ethics Committee (HEC Approval Number: 16-073).



Rena Shrestha

10 July, 2019

FORMAT AND STRUCTURE OF THESIS

The La Trobe Graduate Research School states that a thesis may include one or more articles or chapters published, accepted or submitted for publication. The studies presented in this thesis follow a logical sequence, describing a cohesive research program.

This thesis consists of eight chapters. The introductory section (Chapters 1, 2 and 3) provides a general introduction to Autism Spectrum Disorder, review of the relevant literature and general methodology; building the rationale for the following empirical studies (Chapters 4 to 7). The final section (Chapter 8) provides a general discussion summarising and integrating the study findings and addressing limitations and future directions for research. Appendices relating to a specific study are presented within the relevant chapter, while general appendices are presented at the end of the thesis.

This thesis has been formatted in accordance with the guidelines of the American Psychological Association (APA, 2010) irrespective of the format and style of the international peer-reviewed journals to which manuscripts were submitted/accepted. However, figures and tables for each study are presented in the body of the manuscript, rather than being attached at the end.

References

American Psychological Association. (2010). *Publication manual of the American*

Psychological Association. (6th ed.). Washington, DC: American Psychological Association.

THESIS OUTLINE

A brief outline of the thesis is presented here, including a published paper and unpublished papers submitted for publications.

Chapter 1. General Introduction

This chapter presents an overview of Autism Spectrum Disorder (ASD), the importance of early identification, a brief overview of early markers, current global epidemiological findings focused on Low- to Middle-Income Countries (LMICs), and an introduction to the Social Attention and Communication Surveillance framework. The context of Nepal and the health care system is also presented, followed by the rationale for the current study and the research objectives.

Chapter 2. Early Identification of Autism Spectrum Disorder in Low- and Middle-Income Countries: A Literature Review Focusing on Nepal

This chapter provides a comprehensive review of the current status of early identification of ASD in LMICs focusing on Nepal, including early screening/surveillance tools for ASD, prevalence estimates and age of diagnosis (AoD) of ASD, and factors affecting AoD. This chapter also highlights the applicability of community-based primary health care systems and the developmental surveillance approach to raising awareness and promoting early detection of ASD in Nepal, addressed in this thesis.

Chapter 3. General Methodology

This chapter outlines the research methodology adopted in this thesis. It briefly presents the study settings, research designs, participant recruitment and related details, measures used, procedures applied, ethical considerations, and data analysis techniques.

Chapter 4. Age of Diagnosis of Autism Spectrum Disorder in Nepal

The first empirical study, published in 2019, is presented in Chapter 4, which examines the AoD in Nepal using deidentified data of children provided by the AutismCare Nepal

Society. Changes in AoD over six years and the presence of autism severity in the sample are explored in this study. Differences in AoD across gender, ethnicity, and geographic locations are also investigated.

Chapter 5. Implementing and Evaluating Social Attention and Communication

Surveillance (SACS) to Prospectively Identify Autism in Very Young Children in Nepal

The second empirical study presented in Chapter 5 details the outcomes of developmental surveillance of infants and toddlers between 11-30 months undertaken at Kirtipur Municipality using the Nepali version of Social Attention and Communication Surveillance (SACS-N). This was achieved by training Female Community Health Volunteers (FCHVs) to identify children at “high likelihood” of ASD. The study presents the referral rate of children identifies at “high likelihood” of ASD, the Positive Predictive Value of the SACS-N, the developmental profiles of children and the estimated prevalence of autism in the SACS-N cohort.

Chapter 6. Changes in Knowledge on the Early Signs of Autism among Female Community Health Volunteers in Nepal

The third empirical study presented in Chapter 6 examines the changes in FCHVs’ knowledge of social attention and communication development, and early signs of autism prior to and following training on the developmental surveillance of autism, based on the SACS-N approach. Change in FCHVs’ confidence in monitoring and referring children at “high likelihood” of autism, as well as their evaluation of training, are described in this study.

Chapter 7. Caregivers’ Knowledge of Autism in a Local Peri-urban Community of Nepal: A Cross-sectional Study in Kirtipur, Kathmandu

The fourth empirical study presented in Chapter 7 examines knowledge of autism among caregivers of children monitored by FCHVs in Kirtipur municipality. Differences in

knowledge of autism as a function of caregivers' age, education level, and caste are also examined.

Chapter 8. General Discussion

The general discussion summarises the main findings from each study presented in this thesis. The methodological limitations are discussed, and directions for future research proposed, followed by the implications of the current findings for other LMICs, prior to the conclusions.

CHAPTER 1

GENERAL INTRODUCTION

Chapter Overview

This chapter provides a brief overview of Autism Spectrum Disorder (ASD), including the associated characteristic features, the importance of early identification, the early markers, and current global epidemiology with a focus on low- and middle-income countries (LMICs). As this thesis focuses on a community-based developmental surveillance approach to identifying children at “high likelihood of ASD”, a brief overview of the Social Attention and Communication Surveillance framework is presented. The Nepalese context and the health care system therein are also discussed. The chapter concludes with the study rationale, and research objectives addressed in this thesis. In this thesis, the terms ‘ASD’ and ‘autism’ are used interchangeably.

Characteristics and Diagnostic Criteria

Autism Spectrum Disorder is a neurodevelopmental disorder that significantly impairs functioning due to difficulties in social communication and interaction accompanied by restricted and repetitive pattern of behaviours and interests (American Psychiatric Association [APA], 2013). Although the Diagnostic Statistical Manual of Mental Disorder (DSM-5; APA, 2013) defines ASD as a single diagnostic category, it comprises a group of heterogeneous conditions wherein individuals may demonstrate a range of behaviours across the symptom domains and with differing severity.

The social communication and interaction domain consists of deficits in social-emotional reciprocity, nonverbal communicative behaviours, and developing, maintaining, and understanding relationships (APA, 2013). Young children with ASD with difficulties in social-emotional reciprocity (compared to typically developing children) may present with a range of characteristics including failure of typical back-and-forth conversation, reduced sharing of interests or emotions, and difficulties in initiating or responding to social interactions. Deficits in nonverbal communication skills make it hard for children with ASD to communicate due to difficulties in making eye

contact and communicating through body language, including using gestures and facial expressions. Because of deficits in developing, maintaining and understanding relationships, children may have difficulties in adjusting their behaviours according to different social contexts, sharing imaginative play, making friends and may show an apparent lack of interest in peers (APA, 2013).

In order to meet diagnostic criteria for ASD, individuals are required to also present with two out of four restricted and repetitive behaviour patterns (APA, 2013): 1) repetitive motor movements (hand flapping), use of objects (lining toys) or speech (echolalia); 2) insistence on sameness (extreme distress in small changes), rigid adherence to routines (need to take same route) or ritualized patterns of verbal or nonverbal behaviour (greeting rituals); 3) highly restricted or fixated interests (strong attachments or preoccupations with objects or activities); and 4) seeking or avoiding sensory inputs (excessive smelling/touching of objects, aversive reaction to loud noises) (APA, 2013).

Epidemiology and Global Efforts

Once considered rare, the rising prevalence of ASD is of widespread concern. Epidemiological studies suggest that approximately 1-2% of the global population is affected by ASD irrespective of country or region, socioeconomic condition or cultural factors (Elsabbagh et al., 2012; Wallace et al., 2012). The prevalence estimates reported by the Centers for Disease Control and Prevention (CDC) in the United States, showed that children who met diagnostic criteria for ASD increased from 1 in 150 in 2002 (Kuehn, 2007) to 1 in 59 children in 2014 (Baio et al., 2018). While the causes of this increased prevalence are widely debated, research suggests that broadening of diagnostic criteria, the accuracy of case identification, awareness among relevant professionals, and an increase in actual incidence may all have contributed to the increase in prevalence (Elsabbagh et al., 2012; Fombonne, 2009)

Autism Spectrum Disorder and other developmental disorders contribute to the global burden of disease in children under ten years of age (Murray et al., 2012; Patel, Kieling, Maulik, & Divan, 2013) leading to an extensive focus in research on ASD over the last few decades (Charman & Gotham, 2013). However, research on ASD is mostly conducted in high- income countries (HICs)¹, where 10% of the world's children live (Durkin et al., 2015; Elsabbagh et al., 2012). The majority of children in the world reside in LMICs and have received little attention in regard to childhood disabilities, including ASD (Maulik & Darmstadt, 2007; Patel, Flisher, Nikapota, & Malhotra, 2008).

Unlike HICs, LMICs have limited awareness of ASD, service provision and research (Durkin et al., 2015; Wallace et al., 2012). Although the prevalence of ASD across HICs is well established, knowledge and prevalence in LMICs is limited (Brennan, Fein, Como, Rathwell, & Chen, 2016). An estimated 70 million people worldwide live with ASD (Elsabbagh et al., 2012). Both the United Nations (2007) and the World Health Organization (2013) have acknowledged this as an urgent public health concern that needs more global research with strategies for early identification, diagnosis and interventions of ASD in LMICs. Evidence- and competency-based training, task sharing and feasible models of primary health services have been suggested to enhance knowledge and build capacity to promote early identification of ASD (Durkin et al., 2015; Elsabbagh et al., 2012; Khan et al., 2012; World Health Organization, 2013).

¹The World Bank (The World Bank, 2019b) has classified global economies to four income groups based on gross national income per capita — low income (\$995 or less), middle-income (upper-middle: \$996-\$3895 and lower-middle: \$3896-\$12,055), and high-income (HICs, \$12,056 or more) countries. Current US dollars are units for this measure and thresholds. The terminology low- and middle-income countries (LMICs) has been used in this thesis.

Importance of Early Identification

Early detection of young children at risk of ASD facilitates early referral and diagnosis (Barbaro, Ridgway, & Dissanayake, 2011; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014; Perry et al., 2008) enabling timely intervention when young brains are malleable (Dawson, 2008). Early intervention can prevent the loss of language and social skills found in young children with ASD (Dawson, 2008), as well as secondary manifestations including aggressive and self-harming behaviour patterns (Dawson & Bernier, 2013; Koegel et al., 2014). It also reduces parental/family stress and anxiety that result from delayed diagnosis (Barbaro & Dissanayake, 2009). Importantly, early detection and intervention can also lower the significant economic impact on families (Peters-Scheffer, Didden, Korzilius, & Matson, 2012). Thus, early identification leading to diagnosis and intervention can help improve individuals' lives and reduce long term economic cost (Knapp, Romeo, & Beecham, 2009; Peters-Scheffer et al., 2012; Xiong et al., 2011).

Early Markers of ASD

Previous studies on early symptoms of ASD from retrospective home videos (Clifford & Dissanayake, 2008; Werner, Dawson, Osterling, & Dinno, 2000), parental interviews (Watson et al., 2007; Young, Brewer, & Pattison, 2003), prospective studies of 'high risk' siblings (Ozonoff et al., 2010; Ozonoff et al., 2014; Zwaigenbaum, Bryson, & Garon, 2013) and prospective community-based studies (Barbaro & Dissanayake, 2010, 2013) have all identified early markers present within the first years of life. Although atypical eye gaze and neural connectivity are also considered important biomarkers, with eye-tracking technology and electroencephalography available as promising screening measures for ASD, there remains limited evidence on the success of these biomarkers in ASD detection (Dasgupta et al., 2016).

In the absence of reliable biological markers, developmental history and early behavioural presentations are key to early identification of ASD (Charman & Gotham, 2013). Despite many children with ASD showing early symptoms within the first 12 months, some children demonstrate typical development in the first year with appropriate language and social skills but gradually decrease in these skills between first and second year (Landa, Holman, & Garrett-Mayer, 2007; Ozonoff et al., 2010). Atypical social attention and communication behaviours between 12 and 24 months are deemed reliable early markers of ASD (Barbaro & Dissanayake, 2010; Wetherby, Watt, Morgan, & Shumway, 2007; Zwaigenbaum et al., 2013).

Early signs include reduced social smiling, eye contact, responding to name call, joint attention skills such as showing and requesting, gestures, vocalisations, and little interest in social and imaginative play (Barbaro & Dissanayake, 2009). While some sensory, motor, repetitive and stereotyped behaviours have been identified in infants with ASD, the most reliable early markers are primarily a lack of or inconsistent social attention and communication behaviours (Barbaro & Dissanayake, 2009; Zwaigenbaum et al., 2009). Hence, early identification of ASD is possible within the first years of life with regular and repeated monitoring of social attention and communication behaviours.

Social Attention and Communication Surveillance Framework

Using early social attention and communication surveillance markers, Barbaro and Dissanayake (2010) undertook a prospective community-based study to identify children before 24 months who may be at “high likelihood” of ASD. They trained community Maternal and Child Health (MCH) nurses to monitor babies during their routine developmental checks between 12 and 24 months. Developmental surveillance involves routine and repeated monitoring of children over time to promote healthy development and identify children who may have developmental problems.

A total of 184 MCH nurses in 17 local government areas in metropolitan Melbourne were trained in Social Attention and Communication Surveillance (SACS; Barbaro & Dissanayake, 2010; Barbaro et al., 2011) to monitor social attention and communication behaviours in children aged between 12 to 24 months, based on those behaviours found to be the most predictive of ASD. Children were considered at “high likelihood” for ASD if they show a pattern of failure on three of the five key items (see Appendices 3, 4 and 5; Chapter 5). The SACS was the first large-scale community-based study in the world to reliably identify ASD between 12-24 months with excellent estimated sensitivity (84%) and specificity (99.8%) and high positive predictive value (PPV; 81%). The current study adopted this approach by training community-based Female Community Health Volunteers (FCHVs) in a local community in Nepal.

The Nepalese Context

Nepal is a low-income country with a gross national income capita of \$800 (The World Bank, 2019a). It lies in South Asia, located in between India and China. Eighty-two per cent of Nepal’s population of 26.5 million lives in rural areas (Central Bureau of Statistics, 2014). Nepal’s multidimensional poverty index (MPI; National Planning Commission, 2018) encompassing the three dimensions of health, education and living standards shows that 29% of Nepalese are living in poverty with significant urban (7%) and rural (33%) disparity. Thirty-seven per cent of children under the age of five are stunted, and 30% are underweight (National Planning Commission, 2016). Like many LMICs, malnutrition, infectious diseases and acute respiratory diseases are the most prevalent causes of infant and child mortality in Nepal (Ministry of Health and Population, New ERA , & ICF International, 2012). Thus child health program in Nepal is focused on interventions for child survival (Department of Health Services & Ministry of Health and Population, 2015).

Nepal has recently achieved significant progress in reducing the under-five mortality rate from 162 per 1,000 births in 1990 to 38 per 1,000 births in 2014. Remarkably, Nepal is ahead in reducing the under-5 child mortality rate compared to other South Asian countries: India (55/1,000), Bangladesh (41/1,000), and Bhutan (45/1,000) (National Planning Commission, 2016). This substantial decline in child mortality has recently resulted in a shift toward improving the quality of life of all children in Nepal, led to an increased focus on identifying and managing children with developmental problems, including ASD (Heys et al., 2016).

Health Care System in Nepal

Like other LMICs, Nepal's health system is centred on primary health care principles, which include community to tertiary level services (Department of Health Services & Ministry of Health and Population, 2015). While tertiary level health care in Nepal is undertaken in central and regional hospitals, primary health services are decentralised to the Village Development Committee (VDC) level with services delivered through primary health care centres (PHCs), health posts (HPs) and sub-health posts (SHPs) (Department of Health Services & Ministry of Health and Population, 2017). PHC services further consist of outreach health clinics, immunisation programs and the FCHVs network.

The FCHVs are local women who are primarily trained to deliver MCH services in their community (Ministry of Health and Population, New ERA, & ICF International, 2008). They have made a significant contribution in promoting maternal and newborn care, managing community-based integrated childhood disease treatment programs, participating in immunisation campaigns and implementing Vitamin A programs. They also refer mothers and children to tertiary centres as required (Glenton et al., 2010; Ministry of Health and Population et al., 2008).

Rationale of the Current Study

Despite evidence that early markers of ASD are present within the first two years of life and children can be reliably diagnosed by 24-months-of-age (Barbaro & Dissanayake, 2010), with good diagnostic stability (Barbaro & Dissanayake, 2017), children in LMICs are typically diagnosed later, missing opportunities for better outcomes. Previous studies in LMICs (Bravo Oro et al., 2012; Daley, 2004; Kommu et al., 2017; Lagunju, Bella-Awusah, & Omigbodun, 2014; Preeti, Srinath, Seshadri, Girimaji, & Kommu, 2017; Talero-Gutiérrez, Rodríguez, De La Rosa, Morales, & Vélez-Van-Meerbeke, 2012) reported a mean age of diagnosis between 45-72 months.

A small sample study in Nepal comprising 50 parents found that the average age of diagnosis was 56 months (Shrestha & Shrestha, 2014). Little knowledge, a shortage of trained professionals, and lack of early screening/surveillance tools are significant barriers in the early identification and diagnosis of ASD in Nepal (Heys et al., 2017; Heys et al., 2018; Khatri, Onta, Tiwari, & Choulagai, 2011; Shrestha & Santangelo, 2014; Shrestha & Shrestha, 2014) similar to other LMICs (Bakare et al., 2009; Daley & Sigman, 2002; Daley, 2004; Esegbe et al., 2015; Imran et al., 2011; Rahbar, Ibrahim, & Assassi, 2011).

Raising awareness in local communities via cost-effective training and task sharing with community health workers has been advocated (Ruparelia et al., 2016; World Health Organization, 2013). Task sharing refers to the decentralisation of health programs by training non-professional health workers to deliver health services to overcome the shortages of health workers in low-resource settings (Dawson, Buchan, Duffield, Homer, & Wijewardena, 2013; Lehmann, Van Damme, Barten, & Sanders, 2009). Non-professional healthcare workers such as mothers and women's groups, female community workers, and community-based health workers have been significant contributors in rural and remote communities in LMICs to improving maternal and infant

health (Bang et al., 1990). Moreover, research (Ertem, 2012; Ruparelia et al., 2016) suggests that such community-based PHC systems in LMICs, which have access to young children and their families, can play a crucial role in promoting child development and in preventing, detecting and managing developmental difficulties. Based on this background, FCHVs in Nepal has the potential to contribute to the early identification of autism.

The impact of ASD is growing globally, and there are encouraging prospects of early identification and intervention: a locally translated and validated tool is urgently needed. To date, there is only one epidemiological study on ASD which was conducted in Nepal (Heys et al., 2018) comprising children of age 9-13 years using the Nepali translation of the short Autism Spectrum Quotient (AQ-10; Allison, Auyeung, & Baron-Cohen, 2012). No epidemiological studies on ASD focused on younger children in Nepal. Therefore, it was decided that the translation, adaptation and the implementation of a Nepali version of the SACS be undertaken. This was achieved by training FCHVs on the early features of ASD to enable identification of ASD at the community level to facilitate earlier diagnoses. Since FCHVs live in the communities they serve (Ministry of Health and Population et al., 2008), it is likely that training FCHVs at a local community level is both a sustainable and feasible way to monitor children at risk of ASD. It was expected that the research findings would contribute to the limited information available regarding early identification of ASD in Nepal (and others LMICs).

Research Aims

The overall aim in the research presented in the current thesis was to implement and evaluate a Nepali version of Social Attention and Communication Surveillance (SACS-N) to identify children between 11-30 months at “high likelihood” of autism in a local community in Kathmandu, Nepal. The next chapter comprises a literature review on the current status of early identification of autism in LMICs, with a focus on Nepal,

followed by an outline of the general methodology used across the studies reported in this thesis.

The research aim addressed in the first empirical paper (Chapter 4) was to examine the age of diagnosis (AoD) of ASD in Nepal to establish a baseline diagnostic age prior to SACS-N implementation. Change in AoD over six years of sampling was examined along with autism severity in the sample. Differences in AoD across gender, ethnicity, and geographic locations were also investigated. The aims were achieved by accessing data on children with a diagnosis of ASD registered at AutismCare Nepal Society.

The research aim in the second empirical paper (Chapter 5) was to evaluate the implementation of SACS-N by examining referral rates of children identified with a high likelihood of ASD following monitoring at 12-, 18- and 24- months. This allowed calculation of the PPV (the proportion of children identified at risk on the SACS-N who received an ASD diagnosis) and the prevalence estimates of ASD in 11-30-month-olds in Kirtipur Municipality. The aims were achieved by monitoring 1926 infants and toddlers by trained FCHVs using the SACS-N and by examining the diagnostic and developmental outcomes of those children who attended the assessments at ACNS.

The research aim addressed in the third empirical paper (Chapter 6) was evaluating changes in FCHVs knowledge of early social attention and communication development, and early signs of autism in infants and toddlers following training on the developmental surveillance of autism, based on the SACS-N. Change in FCHVs' confidence in monitoring and referring children at "high likelihood" of autism was also examined. Evaluation of training was undertaken immediately after training, and after 6- and 12-months of SACS-N implementation.

The research aim addressed in the fourth study was examining knowledge about autism amongst the parents/caregivers of children monitored by FCHVs in Kirtipur

municipality. Differences in caregivers' knowledge of autism by caste, ethnicity, and education level were also examined. A population-based cross-sectional survey of 1895 caregivers was conducted to achieve this aim.

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CHAPTER 2

EARLY IDENTIFICATION OF AUTISM SPECTRUM DISORDER IN LOW- AND MIDDLE-INCOME COUNTRIES: A LITERATURE REVIEW FOCUSING ON NEPAL

Chapter Overview

Remarkable progress has been made in the mortality rate of children under 5-years-old living in low- and middle-income countries (LMICs) in the last 25 years, with a 60% reduction in child death in Asia and 54% in Africa (You et al., 2015). As more children are surviving, the global disease burden has moved away from communicable to non-communicable diseases and premature death to years lived with disability (Murray et al., 2012). It is estimated that 200 million children under five years in LMICs have developmental disabilities (Grantham-McGregor et al., 2007). Consequently, there is a shift from improving child survival programs to promoting child development (Liu et al., 2015; Yousafzai, Lynch, & Gladstone, 2014). This change has led to a greater interest in LMICs in the early identification of developmental problems, including Autism Spectrum Disorder (ASD) (Grantham-McGregor et al., 2007; Khan et al., 2013; Scherzer, Chhagan, Kauchali, & Susser, 2012)

Current evidence shows that ASD can be identified from as early as 12-months-of-age, and reliably diagnosed by 24 months, with diagnosis remaining stable over time (Barbaro & Dissanayake, 2010, 2017; Guthrie, Swineford, Nottke, & Wetherby, 2013; Lord et al., 2006). Early detection and subsequent diagnosis of ASD with access to early intervention (EI) can maximise developmental outcomes in young children (Dawson, 2013), increase parental well-being (Barbaro & Halder, 2016) and reduce lifetime costs associated with ASD (Peters-Scheffer, Didden, Korzilius, & Matson, 2012). It is therefore vital to identify the early markers of ASD to facilitate timely referral, provide diagnosis and access to EI.

However, many children in LMICs are identified and diagnosed at a later age (Durkin et al., 2015a; Elsabbagh et al., 2012) and are therefore missing the opportunity of EI and its long-term benefits. The purpose of this review is to explore the current status of early identification of ASD in LMICs with a focus on Nepal. The review will include (a)

a summary of the importance of early identification and the early markers of ASD as identified in previous studies; (b) early screening tools for ASD available in LMICs; (c) prevalence of ASD in LMICs (d) age of diagnosis (AoD) of ASD in LMICs, and factors affecting AoD; (e) status of ASD in Nepal; and (f) examination of future directions to promote early identification of ASD in Nepal and other LMICs.

Importance of Early Identification and Diagnosis of ASD

Early identification and diagnosis of ASD, leading to EI provide young children with the best learning experiences when their brains are highly malleable (Dawson, 2008). Children who commenced EI at a younger age demonstrated better verbal and cognitive development and improved social skills than children who were diagnosed at a later age (Clark, Vinen, Barbaro, & Dissanayake, 2017; Flanagan, Perry, & Freeman, 2012; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014). Besides, EI focusing on early social communication behaviours can reduce or prevent secondary behaviours such as aggression, tantrums and self-harm (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). Current research suggests that identifying and diagnosing children with ASD at the earliest age can enhance parental well-being by addressing their initial concerns, reducing stress, and providing genetic counselling given the increased risk of recurrence of ASD in siblings of children with ASD (Barbaro & Halder, 2016).

Autism places a financial strain on families regarding their children's long-term health care needs. For example, more than 88% of urban and rural families of children with ASD in China spent a higher proportion of funds on behavioural therapies, outpatient care, prescription medicines, transportation and accommodation, compared to provincial household expenditure (Xiong et al., 2011). Likewise, it costs approximately US\$2.4 million in the United States and US\$2.2 million in the United Kingdom to take care of individuals with ASD with comorbid intellectual disability throughout their lifetime (Buescher, Cidav, Knapp, & Mandell, 2014).

Raising an individual with ASD requires considerable parental time and care. As a result, parents often participate less in the workforce, resulting in lower earnings. Mothers of children with ASD in the United Kingdom earn 35% less than mothers of children with other lifelong health conditions, and 56% less than mothers of children with no health issues and have 28% lower family earnings (Cidav, Marcus, & Mandell, 2012). Peters-Scheffer et al. (2012) therefore emphasised the implications of investing in early intensive behavioural interventions, with an estimated saving of over US\$1.23 billion per individual with ASD between three- to 65-year of age in the Netherlands. Given the impact of ASD on individual care and parental employment, early diagnosis coupled with EI can contribute to improving the quality of life of people with ASD, which can ultimately reduce the substantial economic impact on families and societies as a whole (Koegel et al., 2014; Peters-Scheffer et al., 2012).

Early Signs of ASD

As there are no known biological markers for ASD, diagnosis is based on behavioural presentations and developmental history (Charman & Gotham, 2013; Zwaigenbaum et al., 2015). Previous studies using retrospective home videos (Clifford & Dissanayake, 2008; Werner, Dawson, Osterling, & Dinno, 2000), parental interviews (Watson et al., 2007; Young, Brewer, & Pattison, 2003), prospective studies with high-risk (HR) siblings of children with ASD (Ozonoff et al., 2010; Ozonoff et al., 2014; Zwaigenbaum, Bryson, & Garon, 2013) and prospective community samples (Barbaro & Dissanayake, 2010, 2013) have indicated that early markers of ASD comprise deficits in social attention and communication during infancy and toddlerhood. For example, a longitudinal study on HR infants later diagnosed with ASD described a presence of atypical eye contact, visual tracking, orienting to name, imitation, social smiling, affect, social interest, sensory-oriented behaviours, disengagement of visual attention and language delay at 12-months (Zwaigenbaum et al., 2005). Reduced visual attention

disengagement was also evident by 14- months-of-age in infants later diagnosed with ASD (Elsabbagh et al., 2013).

In a prospective community-based sample, Baron-Cohen et al. (1996) identified proto-declarative pointing (pointing to share interest), gaze monitoring and pretend play as deficits at 18 months. Wetherby, Watt, Morgan, and Shumway (2007) demonstrated that deficits in gaze shifts, gaze/point follow, joint attention, communication and gestures were prevalent in 18- to 24-months-old children who developed ASD differentiating them from developmentally delayed and typically developing (TD) children. Likewise, in examining social communication behaviours in 25 HR infants matched with 25 low-risk (LR) children between 6- and 18- months of age, Ozonoff et al. (2010) found significantly diminished gaze to the face and social smiling at 12 months in HR infants. They also found that behaviours such as gaze to face, gaze to objects, smiles, nonverbal vocalisations, single word and phrase verbalisation had decreased by 18 months. Together, these studies indicate that ASD symptoms emerge during the second half of the first year of life and continue over the period of early development.

Other studies have indicated that the onset of ASD is variable over the first two years, with some infants showing typical early development, with later symptom onset between 18-24 months. Landa, Holman, and Garrett-Mayer (2007) reported that children who were diagnosed with ASD by 14 months showed early social communication deficits lasting through 24 months of age. However, other toddlers, indistinguishable at 14 months from the non-ASD group, showed atypical social and communication behaviours at 24 months which were similar to the early onset group. This loss of skills is reported to occur in a significant subset of children in the second year of development (Hansen et al., 2008).

Based on the early signs of ASD and the positive impact of the EI, researchers have developed autism screening tools for infants and toddlers (Boyd, Odom,

Humphreys, & Sam, 2010) with many utilising screening tools at one point in time. However, given its variable onset, Barbaro and Dissanayake (2009) have argued for developmental surveillance throughout infancy and toddlerhood to identify ASD rather than using a single screening at a given age. In their prospective Social Attention and Communication Study (SACS; Barbaro & Dissanayake, 2010; Barbaro & Dissanayake, 2013), the key behavioural markers were monitored at 12- (including deficits in eye contact, pointing, use of gestures, imitation and responses to name), 18- and 24-months of age (eye contact, pointing, use of gestures showing and pretend play) to identify children developing ASD. A total of 22,168 children between 12- and 24- months of age were monitored by 174 Maternal and Child Health (MCH) nurses at 17 local government areas within the MCH system in Victoria, Australia. The MCH nurses were trained to monitor the early social attention and communication behaviours during their routine checks of children at 12-, 18-, and 24-months. The SACS reliably identified children at risk of ASD between 12- and 24-months of age with excellent estimated sensitivity (84%) and specificity (99.8%), and a positive predictive value 81%. Hence, repeated developmental monitoring of key markers of early social attention and communication, during the second year of development, was found to be the most accurate and sensitive method for the early identification of ASD in infants and toddlers (Barbaro & Dissanayake, 2010, 2013).

The SACS approach has been proven to be better than other approaches utilising screening at one point in time such as the Checklist for Autism in Toddlers (CHAT; Baron-Cohen et al., 1996), the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001) and the First Year Inventory (FYI; Reznick, Baranek, Reavis, Watson, & Crais, 2007). Like the SACS, all these tools have been developed and tested in HICs.

Screening for ASD in LMICs

Regardless of considerable ASD-specific early screening instruments in developed countries, limited screening tools have been developed or validated in LMICs.

Furthermore, study designs, screening administration methods, and the cut-off scores in existing early screening studies varied extensively in LMICs across Africa, the Eastern Mediterranean Region and Asia (Stewart & Lee, 2017).

Africa

Kakooza-Mwesige et al. (2014) adapted the parent report Ten Questions (TQ) checklist into a 23-item screener (23Q) for use in Uganda. The original TQ, which uses a yes/no response format, and validated in Bangladesh (Zaman et al., 1990), Pakistan (Durkin, Hasan, & Hasan, 1995) and Jamaica (Thornburn et al., 1992), was designed to screen cognitive, motor, visual/hearing abilities, and seizures in children aged 2-9 years. Despite its broad application as a screening tool for childhood disabilities in low-resource settings, the TQ is more accurate in identifying severe forms of disabilities than milder problems (Maulik & Darmstadt, 2007). The 23Q retained the original questions with additional 10 ASD-related (5 for children aged 2-9 years and 5 for children <5 years) and three visual, hearing and seizure-related questions.

The locally translated and tested 23Q was administered to 1,169 Ugandan children in a community-based household screening. Failure on one or more items on the 23Q were considered screen positive. Following administration, 603 children (320 children who screened positive and 283 children comprising every third child who screened negative) were invited for a comprehensive medical examination at a local hospital. However, only 379 (63%; 216 children who screened positive and 163 who screened negative) children participated, with the remainder lost to follow-up. Half of these 379 ($n = 189$) children were referred to a child psychiatrist for diagnostic evaluations. Finally, 141 (91 children who screened positive and 50 who screened negative) children

participated in diagnostic assessments with eight children diagnosed with ASD. The psychometric properties of the 23Q were based on two assumptions: 1. children who screened negative but were lost to follow-up after screening had no disabilities; and 2. all children lost to follow-up after screening had the same rate of disability as children who participated in the clinical assessments. The sensitivity of the ASD items on the 23Q ranged between 52-57%, specificity was 92%, and PPV was 8%. However, the sensitivity increased to 68-80% when ASD and TQ items were combined. Failure of one or more ASD items in combination with failure of one or more TQ items was more sensitive than either set of items alone in identifying a subgroup of children at notably high risk of ASD.

The Eastern Mediterranean Region

The Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001) is a free, widely used parent questionnaire. To determine the utility of the Arabic version of the M-CHAT, Seif Eldin et al. (2008) administered it to parents of 122 children with ASD and 106 children with (TD) and aged between 18- to 124-months across nine Arab speaking countries including Kuwait, Oman, Qatar, Saudi Arabia, Jordan, Lebanon, Syria, Egypt and Tunisia. Based on two different scoring systems - either total scoring (failing ≥ 3 items out of the total 23 items) or critical scoring (failing ≥ 2 of the critical items) - the Arabic version of the M-CHAT revealed a sensitivity of 86% (78-92%), specificity of 80% (70-92%) and PPV of 88% (82-94%). However, the limited sample size and the use of children with ASD as well as the wide age range makes it difficult to generalise the findings to use in a LR sample.

Kara et al. (2014) adapted the M-CHAT (Robins et al., 2001) into Turkish and administered it to 191 parents of children aged between 18- and 36-months of age at a hospital-based, well-child clinic in Istanbul. Although ninety-four children screened positive, only 48 children were followed-up. Of these, only six children screened positive in the follow-up phone call, yielding a high false positives rate. As a result, the team

replaced the parent-filled M-CHAT with an interview format – to be administered by a health-care professional (nurse/psychologist). In the next study, a healthcare staff member interviewed parents of 80 HR children with social-communication problems and 538 LR children who had not participated in the previous study. All available HR participants ($n = 60$) and a random sample of LR children ($n = 120$) participated in a diagnostic evaluation using the Diagnostic and Statistical Manual of Mental Disorders, Fourth edition, text revised (DSM-IV-TR; APA, 2000) and the Turkish version of the Childhood Autism Rating Scales (CARS; Schopler, Reichler, DeVellis, & Daly, 1980). Of these, 45 from the HR (75%) and two from the LR group (1.6%) received an ASD diagnosis. Thus, the PPV of the tool increased when the format was changed, but it should be noted that the sample was already a high risk one.

Asia

Srisinghasongkram, Pruksananonda, and Chonchaiya (2016) also used the M-CHAT (Robins et al., 2001) to screen 109 HR child with language delay and 732 LR (visiting regular health check-ups or attending child health promotion events) children aged 18- to 48-months in Thailand. Of the 109 HR children, 41 children screened positive, whereas 68 children screened negative on the M-CHAT. Among HR children, 40 from the screened-positive and five from the screened-negative group eventually received a diagnosis of ASD. Although parental reports in the LR group showed 207 children scored positive on the M-CHAT, only ten children were screened positive after the follow-up interview. The remaining 197 children were false positives. Using two different scoring methods (as mentioned in the Arabic version of M-CHAT), the sensitivity ranged from 76-91%; specificity was 99.7%, and PPV ranged from 95-96%. Here, the total scoring criteria gave the highest sensitivity and PPV, unlike critical scoring method in the Arabic-Version. However, these results should be interpreted cautiously as these are based on HR samples together with the use of the M-CHAT follow-up interview.

Perera, Wijewardena, and Aluthwelage (2009) carried out a community-based screening in Sri Lanka using 'Red Flag' criteria in children aged 12- to 24- months. A total of 374 children participated in the screening. Twenty-eight children screened positive with one or more of the 'Red Flag' signs, and their parents completed the Sinhala version of the M-CHAT (Robins et al., 2001) and participated in clinical assessments. Eight children screened positive in the M-CHAT. However, only one child among four who received a diagnosis of ASD screened positive in the M-CHAT; the remaining seven children who screened positive on the M-CHAT were not diagnosed with ASD, revealing a sensitivity of 25% with a specificity of 70% and PPV of 13%. If the 'Red Flags' signs were not used, all these children with ASD might have been missed.

To study the utility of the Social Communication Disorder Checklist (SCDC; Skuse, Mandy, & Scourfield, 2005) and the Autism Spectrum Quotient-Child Version (AQ-C; Auyeung, Baron-Cohen, Wheelwright, & Allison, 2008) in the Indian context, Rudra et al. (2014) administered the Bengali and Hindi translations of SCDC and AQ-C to Bengali speaking parents ($n = 188$, 77 with an ASD and 111 TD children) and Hindi speaking parents ($n = 172$, 92 with an ASD and 81 TD children); all children were aged between 4- to 7-years. A significant difference in the mean cut-off scores of ASD and TD children was found, with a recommendation made of the applicability of these tools in identifying children with ASD in South Asia. However, the researchers did not report the psychometric properties of the tools. Moreover, these tools were designed for children aged 5-17 years (SCDC) and 4-11 years (AQ-C), which is older than the targeted age, and the findings are based on children who already had a diagnosis of ASD; thus, these tools are not applicable to younger children, and the findings not relevant for population-based samples.

There are number of other ASD screening tools validated in LMICs including the Autism Behaviour Checklist (ABC; Krug, Arick, & Almond, 1980) in Zimbabwe (Khan

& Hombarume, 1996) and India (Juneja, Sharma, & Mukherjee, 2010), the Gilliam Autism Rating Scale (GARS; Gilliam, 1995) in Iran (Samadi & McConkey, 2014), and the Social Communication Questionnaire (Rutter, LeCouteur, & Lord, 2003) in Iran (Samadi, Mahmoodizadeh, & McConkey, 2012). However, once again, all these studies focused on older children (beyond the early years of life) and comprised HR samples. Limited validation studies are available on the use of community-based early screening tools and no developmental surveillance approach has been studied in the context of LMICs which is a critical gap, given the importance of repeated monitoring of early behaviours in young children.

All studies reviewed here were cross-sectional in design with each using a screening tool at a single point in time, followed by a diagnostic evaluation. Although the M-CHAT has been designed as a level-one screening tool to screen toddlers between 16 and 30 months, it has been used as both a level-one (Srisinghasongkram et al., 2016) and level-two (Perera et al., 2009) tool, and with children as old as 5 years (Samadi & McConkey, 2015; Seif Eldin et al., 2008).

Many researchers (Kakooza-Mwesige et al., 2014; Kara et al., 2014; Perera et al., 2009) have raised concerns regarding the psychometric properties of current screening instruments for ASD. For instance, the researchers have reported on the low PPV of the 23Q (Kakooza-Mwesige et al., 2014) and have suggested improving the sensitivity and PPV of the screener to identify children with ASD by developing culturally specific questions. Likewise, the PPV of the M-CHAT (Srilanka; Perera et al., 2009) was also very low (13%) when used in Srilanka, consistent with the low PPV (1.5-11%) observed in previous studies (Chlebowsky, Robins, Barton, & Fein, 2013; Kleinman et al., 2008; Robins et al., 2014; Stenberg et al., 2014), in particular when used without a follow-up interview in a LR general population sample.

The M-CHAT studies have resulted in both false positive (Kara et al., 2014; Srisinghasongkram et al., 2016) and negatives (Perera et al., 2009) when parents filled the checklist without any follow-up clarification on their responses. Research suggests that false positives impact resources by taking more professional time as well as creating unnecessary anxieties in the family (Robertson, Hatton, Emerson, & Yasamy, 2012) whereas false negatives result in children at risk of ASD being missed (Perera et al., 2009). This is especially challenging in LMICs, which already have limited resources to provide diagnostic evaluations.

The majority of epidemiological studies used the screening tools at hospitals or special centres where many children may not have access, particularly in LMICs. Hence, the psychometric properties of the screening tools are affected by the selective samples that visit hospital clinics for specific concerns and are thus not applicable to the wider population (Barbaro & Halder, 2016; Stewart & Lee, 2017). Although screening instruments have identified ASD at times, the significant disparity in psychometric properties along with the variability in study designs, population characteristics, screening methodology and cut-off used for screen positives has prevented identification of optimal screening tools. Consequently, many children are identified at later ages or misdiagnosed, or even remain unidentified through their lifespan possibly contributing to the lower prevalence rates of ASD in LMICs compared to HICs (Barbaro & Halder, 2016; Elsabbagh et al., 2012).

Prevalence of ASD in LMICs

Systematic reviews report that the global prevalence of ASD varies between 1-2% (Elsabbagh et al., 2012). However, the majority of these studies were carried out in HICs. Current studies within and between countries in LMICs show marked variability in the prevalence estimates which is most likely due to diversity in study designs as well as the screening and diagnostic tools used (Elsabbagh et al., 2012; Sun & Allison, 2010).

The systematic review and meta-analysis of 25 studies (1997-2011) in China, Hong Kong and Taiwan reported a pooled prevalence of 0.11% for ASD (Sun et al., 2013). Case counting from hospital and health records, sample selecting from local kindergartens and primary schools, and general population screening were used for case identification. The Chinese versions of Clancy Autism Behaviour Scale (CABS; Clancy, Dugdalei, & Rendle-Shortt, 1969), the M-CHAT (Robins et al., 2001), the Autism Behaviour Checklist (ABC; Krug et al., 1980) and the Autism Spectrum Disorder in Adults Screening Questionnaire (ASDASQ; Nylander & Gillberg, 2001) was used during screening, with the choice of screening instrument being associated with the prevalence estimates. For instance, the use of the M-CHAT showed higher prevalence (0.17%) than using the CABS (0.12 %) or the ABC (0.02%). Different diagnostic criteria (APA, 1987, 1994, 1993; World Health Organization, 1993) and tools, including the CARS (Schopler et al., 1980) and the Autism Diagnostic Interview-Revised (ADI-R; Le Couteur, Lord, & Rutter, 2003) were used for diagnosis (see Sun et al., 2013).

Of seven epidemiological studies in South Asia, prevalence estimates varied widely across India: 0.07-0.8%, (Poovathinal et al., 2016; Raina, Kashyap, Bhardwaj, Kumar, & Chander, 2015; Rudra et al., 2017), Bangladesh: 0.15-0.8% (Mullick & Goodman, 2005; Non Communicable Diseases Control Programme, 2013; Rabbani et al., 2009), and Sri Lanka: 1.07% (Perera et al., 2009). Nine screening instruments have been used for seven prevalence studies. Three Indian studies used four different screening instruments such as the Hindi and Bengali translated versions (Rudra et al., 2017) of the SCDC (Skuse et al., 2005) and the Social Communication Questionnaire (SCQ; Rutter et al., 2003), the questionnaire-based survey on chronic diseases including developmental disabilities (Poovathinal et al., 2016), the Hindi version of Indian Scale of Assessment of Autism (ISAA; Raina et al., 2015); three studies in Bangladesh used the Strengths and Difficulties Questionnaire, and the Development and Well-Being Assessment (SDQ and

DAWBA; Mullick & Goodman, 2005), the Reporting Questionnaire for Children (RQC; Rabbani et al., 2009), the Developmental Screening Questionnaire and the Ten Questions Plus, the Rapid Neurodevelopmental Assessment (DSQ and TQP; Non Communicable Diseases Control Programme, 2013); and the Srilankan study used the Sinhala translation of the M-CHAT (Perera et al., 2009). For diagnosis (Rudra et al., 2017) used the Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord et al., 2000) whereas two other studies used the DSM-IV-TR (Poovathinal et al., 2016) and the CARS (Raina et al., 2015). All screening tools, except the SCDC, SCQ and the ISAA, are not autism-specific screening instruments. Instead, these are screening tools, for childhood disabilities including ASD. As reported previously, methodological differences make it difficult to compare the outcomes from these studies

In Africa, population-based prevalence studies are absent (Elsabbagh et al., 2012) with available studies limited due to use of clinic-based samples. For instance, Lagunju, Bella-Awusah, and Omigbodun (2014) reported a prevalence of 2% of children attending a pediatric neurology and child psychiatry clinic at the university hospital in Nigeria. Bakare, Bello-Mojeed, Munir, Ogun, and Eaton (2016) reported a prevalence of 0.9% for neurodevelopmental disorders (with 15% of these having an ASD) with the study undertaken while participants visited immunisation clinics in South West Nigeria. A 0.3% prevalence was reported in a study at a neurodevelopmental clinic of Al-Khadra Hospital in Tripoli, Libya (Zeglam & Maouna, 2012). The Infant Development Inventory (IDI; Ireton, 1992, age:0-18 months), the Child Development Review (CDR; Ireton, 1996, age:>18 months), Centers for Disease Control Milestone Moments (CDCMM; Centers for Disease Control and Prevention, 2016), the ICD-10 (Bakare et al., 2016), and the DSM-IV (Lagunju et al., 2014; Zeglam & Maouna, 2012) were used for screening and diagnosis.

Prevalence estimates using clinic samples were also reported in the Middle-east. Al-Farsi et al. (2011) reported a prevalence of 0.01% in the hospital-based, retrospective studies in the Sultanate of Oman among children aged zero- to 14-years, using the DSM-IV-TR and the CARS for diagnosis. In a nation-wide Iranian special education screening program, Samadi et al. (2012) used the Iranian translation of the SCQ (Rutter et al., 2003), and reported a prevalence of 0.06% among six- to 13-years-old children. It is, therefore, difficult to confirm the exact prevalence of ASD as well as generalise these results to other settings.

Prevalence studies in LMICs, most of which followed a hospital-based convenience sampling method, have reported marked variations in prevalence estimates. These disparities reflect a lack of consistency in access to professionals, services, and knowledge about ASD in LMICs (Barbaro & Halder, 2016; Durkin et al., 2015b). Moreover, methodological differences in study designs including case identification, and use of a mix of screening and diagnostic tools hinder the comparability of the prevalence of ASD across LMICs (Baxter et al., 2015; Hossain et al., 2017). With the exception of the LR community-based Sri Lankan study (Perera et al., 2009), the prevalence estimates obtained in the majority of LMICs is much lower than those reported in HICs, indicating a potential under-detection and under-diagnosis of ASD across LMICs (Sun et al., 2013).

Age of ASD Diagnosis in LMICs

Despite the importance of the recognition of early signs of ASD and diagnosis of children as young as 24 months, there is a substantial delay (as noted earlier) in the AoD of children with ASD in LMICs (Daniels & Mandell, 2014; Fountain, King, & Bearman, 2011) in comparison to HICs. Seven published studies in five LMICs (Colombia, India, Jamaica, Jordan and Mexico) reported the delay of 2- to 3-years with mean AoD ranging between 45- to 57-months (Samms-Vaughan, 2014). In other studies, the diagnosis was delayed up to 5-years from the point of initial parental concerns (Kishore & Basu, 2011).

Researchers have identified potential factors that contribute to delayed diagnosis of ASD in LMICs.

Families' Early Concerns and Help-Seeking Behaviours

Studies suggest that different child-rearing practices influence parental perception regarding the early signs of ASD (Hussein, Taha, & Almanasef, 2011; Mandell & Novak, 2005) and their response to those behaviours (Taha & Hussein, 2014) which, subsequently influence their help-seeking behaviours (Daley, 2002; Kleinman, 1980; Mandell & Novak, 2005). For instance, supernatural beliefs of ancestral spirits and sinful wrongdoing were predominant explanations in the understanding of ASD among African mothers, who took their children to traditional faith healers in preference to seeking medical consultation (Ruparelia et al., 2016). Similarly, supernatural beliefs were found to be dominant in Taiwanese parents regardless of their level of education, affecting their choice of treatment strategies (Lotus Shyu, Tsai, & Tsai, 2010). In another study, Daley (2004) found that parents followed several alternative treatment approaches like Ayurveda, homeopathy, acupressure, vitamin therapy, pranic healing, and reflexology. Hence, families' early concerns and responses, as shaped by their cultural experiences, can hinder appropriate help-seeking behaviours.

Stigma of Diagnosis

Studies in LMICs have shown that caregivers of children with autism often do not seek help due to stigma, discrimination, feelings of guilt, and fear of exclusion. In a study carried out in Ethiopia, 45% of parents of children with developmental disorders, including ASD, were ashamed of their child's condition; 27% kept their condition undisclosed and 39% were concerned to take them out (Tilahun et al., 2016). Similarly, in a study in Iran, parents underreported their children's difficulties even when they were aware of the situation due to fear of being referred to special schools and the possible

stigma associated with this (Samadi et al., 2012). The stigma associated with a diagnosis of ASD can, thus, contribute to delayed diagnosis.

Knowledge of Early Signs of ASD among Health Professionals

A significant limitation to early diagnosis is the lack of knowledge of broader autism spectrum conditions among health professionals (Daley, 2004). An increasing number of studies in LMICs have found consistency in diagnosing severely affected children, overlooking cases with milder behavioural presentations. Fifty to 80% of children diagnosed with ASD in Africa were non-verbal (Belhadj, Mrad, & Halayem, 2006; Lagunju et al., 2014; Mankoski et al., 2006; Springer, van Toorn, Laughton, & Kidd, 2013). Likewise, 96% of children diagnosed with ASD at a child development clinic of a tertiary hospital in India had a developmental delay (Juneja, Mukherjee, & Sharma, 2005) and more than 81% displayed severe autism symptoms in a retrospective study of clinical samples in Iran (Shooshtari, Sadeghiyeh, Mohammadi, Ghanizadeh, & Akhondzadeh, 2009). Thus, the findings from these studies show that mildly affected children, including those without an associated cognitive disability, may be missed during diagnosis.

In contrast to their contemporaries in HICs where the most common basis of referral for a diagnosis of ASD is language delay (Barbaro & Dissanayake, 2009), most of the paediatricians, psychologists, and psychiatrists in India placed less emphasis on language delays (Daley & Sigman, 2002), with the widespread misconception in South Asia that male children speak late (Daley, 2004). A similar tendency was widespread among psychiatrists, pediatricians, neurologists, psychologists and speech therapists in Pakistan who regarded speech delay as typical in 2- to 3- year old children (Imran et al., 2011). Thus, both clinical training of health professionals as well as their cultural background influences their recognition and acknowledgment of early behavioural markers of ASD (Amr et al., 2012; Daley & Sigman, 2002; Hussein et al., 2011).

Diagnostic overshadowing was found to be another limitation in timely diagnosis. Daley (2004) found children with common autism symptoms received their diagnosis before those with co-morbid medical problems (seizure, gastrointestinal or respiratory) despite the latter group being taken to the doctors earlier than children with typical autism symptoms. Hence, insufficient knowledge amongst health professionals regarding early autism symptoms results in either incorrect diagnosis or the failure to diagnose ASD in the early years.

Inequity in Accessibility to Early Identification Services

In addition to the lack of qualified professionals available to recognise early signs of ASD, inequity in access to early identification services is yet another barrier. In their study in Goa, India, Divan, Vajaratkar, Desai, Strik-Lievers, and Patel (2012) reported that parents consulted multiple professionals regarding their children's diagnosis and treatment. Since nobody could provide them with adequate information, parents travel from Goa to other major cities to get their children diagnosed. Similarly, Daley (2004) found that families in their study visited several national medical centres and the renowned hospitals in India for their children's diagnosis. Parents sometimes travelled 2000 miles from North to South India (the location of the National Institute of Mental Health and Neurosciences) for a consultation.

Furthermore, studies indicate that the majority of families with children with a diagnosis of ASD in India reside in urban areas (Jain, Juneja, & Sairam, 2013) and belong to the middle or upper classes (Daley, 2004). It is likely that children from lower socioeconomic backgrounds in LMICs may have limited access to diagnostic facilities. Hence, the inequity in services for ASD identification and diagnosis in LMICs further impacts on the AoD of ASD (Ruparelia et al., 2016).

Status of ASD in Nepal

Autism Spectrum Disorder is a recent phenomenon in Nepal, with relatively few reported medical cases before 2004 (Shrestha & Santangelo, 2014). Moreover, developmental disabilities, including ASD, was not recognised in national policies and planning priorities of the Government of Nepal (Shrestha & Santangelo, 2014). While the Disability Act Nepal (2006) identifies ASD as a mental disability (Ministry of Women Children and Social Welfare & Government of Nepal, 2006), it had no existence in the Education Act until the Seventh amendment. However, the recent Education (Act 2015) made significant changes in recognising ASD as a separate condition in its Eighth Amendment Bill, endorsed unanimously in the Parliament on June 4, 2017 (Ministry of Women Children Social Welfare & Government of Nepal, 2017).

Since there is an absence of child developmental surveillance programs or data registry systems, the exact prevalence of ASD in Nepal remains unknown. Moreover, the population census conducted by the Central Bureau of Statistics every five years includes intellectual disability, but not ASD. According to the Central Bureau of Statistics (2011), 2% of the total population has a disability, with 2% prevalence in rural areas compared to 1.2% in urbanised regions. Among them, physical disability is the most common form of disability (33%); followed by blind/low vision (20%), deafness/ hearing problems (16%), speech problems (11%), intellectual disability (9%), and deaf-blind (2%).

A cross-sectional census study in Makwanpur district in the east-central part of Nepal consisting of 28,376 households ($N = 169,776 > 20$ years) reported a prevalence of 0.95% for childhood and adolescent disabilities. Moreover, 89 % of those identified had motor problems; 22 % had communication difficulties; and 6% had learning difficulties (Sauvey, Osrin, Manandhar, Costello, & Wirz, 2005).

Studies have attempted to identify the frequency of ASD using hospital-based samples in Nepal. For instance, 539 participants ranging from 4-months to 21- years at

the child and adolescent guidance clinic (Chapagai, Dangol, & Tulachan, 2013) reported a frequency of 4% ($n = 20$) ASD cases at the tertiary hospital in Kathmandu. Likewise, 9 out of 85 (11%) children with developmental problems attending the developmental and behavioural paediatric clinic in the Eastern region had ASD (Rimal et al., 2014). Another child and adolescent psychiatric centre at the tertiary hospital in Eastern Nepal found 1% prevalence of ASD in individuals up to 28 years of age (Shakya, 2010). Variations in setting, methods of assessment and age of participants, making it difficult to estimate the real prevalence of ASD in Nepal. Population-based studies are required to generate valid prevalence estimates (Hossain et al., 2017).

Diagnosis of ASD

A study conducted at AutismCare Nepal Society (ACNS) with 50 children found that they were diagnosed at around 56 months, ranging from 12 to 180 months (Shrestha & Shrestha, 2014). As expected, the most common parental concern was speech delay, confirming the findings from other LMICs such as Sri Lanka (Perera, Jeewandara, Guruge, & Seneviratne, 2013) and Egypt (Hussein et al., 2011). Although parents were concerned when their children were around 28-months-of-age, the diagnosis was significantly delayed by another 29 months, on average (Shrestha & Shrestha, 2014).

A variety of factors similar to those discussed previously in other LMICs might explain the higher AoD of ASD in Nepal. Research shows that 65% of paediatricians with 10- to 45-years of experience in Kathmandu have inadequate knowledge of ASD, and 91% of them reported having difficulties in making a diagnosis (Khatri, Onta, Tiwari, & Choulagai, 2011). They most likely miss the subtle behavioural presentations or atypical behaviours of presenting children, especially when coupled together with co-morbidities such as epilepsy and intellectual disability, due to a general lack of awareness of autism symptoms (Shrestha & Santangelo, 2014).

In another study comprising both urban and rural settings, Heys et al. (2016) found a substantial lack of knowledge on ASD among 106 participants, including parents of autistic and non-autistic children, paediatricians, community health workers and primary school teachers. The majority of them, except paediatricians, attributed atypical behaviours in children to an outcome of poor parenting, maternal malnutrition, and prenatal medication and birth complications. Similarly, spiritual beliefs regarding ASD were also predominant in parents and community workers (Heys et al., 2016).

As noted earlier, the perceived stigma and discrimination associated with atypical child development, including ASD, is another obstacle to the timely help-seeking behaviours and looking for support within their communities (Heys et al., 2016). As most of the healthcare services are centralised in Kathmandu, the capital of Nepal, people in rural areas rarely have access to such facilities (Heys et al., 2016). Hence, a large number of children with ASD in Nepal go undetected because of limited services for diagnosis and intervention (Shrestha & Santangelo, 2014). There is a need for community awareness and training health professionals in Nepal to identify, diagnose and intervene children with ASD across the population (Heys et al., 2016; Khatri et al., 2011; Shrestha & Shrestha, 2014).

Building Capacity and Raising Awareness in Nepal

The shortage of specialised health professionals in remote and rural areas is a major concern (Ministry of Health and Population, 2012) in Nepal. Only 62% of Nepalese have access to health facilities within 30 minutes, with a significant urban (86%) and rural (59%) gap (Ministry of Health and Population, 2012). However, the primary health centres (PHC) in Nepal consists of at least one health post/sub-health post within a village with Female Community Health Volunteers (FCHVs) actively working throughout Nepal (Ministry of Health and Population, 2012). Around 51,470 FCHVs are Nepal's backbone

of rural health and point of referral to PHCs and other secondary and tertiary health care services (Ministry of Health and Population, New ERA , & ICF International, 2012).

The FCHVs Program was initiated by the Government of Nepal in 1988 to strengthen primary health care through the voluntary participation of local women in the community. These volunteers receive an 18-day initial training, and follow-up refresher training primarily focused on maternal and child health (Ministry of Health and Population, New ERA , & ICF International, 2008). The FCHVs have been a significant resource in promoting maternal and newborn care, creating awareness in family planning, managing community based integrated treatment programs for childhood illness, and referring on to other health care facilities when needed (Khanal et al., 2011). They also participate in immunisation campaigns (Glenton et al., 2010; Ministry of Health and Population et al., 2008) and implementing Vitamin-A supplementation programs (Fiedler, 2000) at an interval of every six months.

Primary health setting is the best starting point to promote community awareness and deliver early identification services to the maximum number of under-served populations across LMICs including Nepal. Community health workers or women health volunteers visiting home to home, teachers in preschools or day-care centres, and nurses at immunisation clinics can all be appropriate service providers of early identification of ASD within any existing health care system in LMICs (Ruparelia et al., 2016). Given that the majority of people live in resource-limited settings with a disparity in health access including significant lack of trained manpower at all levels, FCHVs in Nepal can be further supported to identify developmental problems, including ASD. Since FCHVs live in the communities they serve, it is likely that training them to monitor children at risk of ASD within the first two years of life can be achieved by integrating early detection services within the existing primary health programs they participate in. This includes programs such as childhood immunisation or Vitamin A/nutritional supplementation

mentioned above, campaigns which can ensure sustainability and cost-effectiveness of early autism detection (Divan et al., 2012).

Significantly, the World Health Organization (2008) has advocated task-shifting (or task sharing) to enhance the capacity building of local non-specialist health workers in overcoming the dearth of trained health professionals and disparities in health care services in resource-limited countries. Moreover, research in LMICs has demonstrated the effect and applicability of task-shifting in improving other primary health care programs. For example, training non-specialist health workers including mother's groups, female community workers, women's groups, traditional birth attendants and lady health workers were instrumental in improving maternal and child health in rural and remote communities in Sub-Saharan Africa and South Asia (Bang et al., 1990). Likewise, the cluster randomised controlled trials across low-resource settings in Pakistan, Uganda and India showed improved recovery rates of depression among participants by implementing psychological treatment (cognitive behaviour therapy-based or interpersonal psychotherapy) using community health workers or laypersons without any prior training on mental health (Patel, Chowdhary, Rahman, & Verdelli, 2011). Research thus suggests that such community resources could be replicated in more primary health programs with training, monitoring, supervision, support and monetary compensation (Dawson et al., 2008; Fiedler, 2000).

Research studies (Ruparelia et al., 2016; Samms-Vaughan, 2014) suggest that raising awareness and capacity building in a community should couple with early identification tools to facilitate detection of ASD in LMICs as early as possible. Although early identification measures are developed and validated in HICs, limited early screening tools, the majority of which are based in a clinical setting, have been adapted and validated in LMICs. To date, there is no single early identification tool translated or validated for young children in the context of Nepal. There is a need for adaptation,

development and validation of culturally-relevant, cost-effective, early identification tools for ASD in Nepal and other LMICs.

Soto et al. (2015), in a review on cultural adaptation of tools, recommends that any translation of early identification tools to local languages should consider adding culturally relevant markers of autism to avoid pathologising culturally relevant practices. Moreover, words should be carefully chosen to minimise misinterpretation, including examples to remove any confusion, and using a suitable response format to align with the local response style. In addition, it has been noted that tools should be reliable, brief and easy to learn, simple to administer and of low cost (Ertem et al., 2008).

A number of reviews (Barbaro & Halder, 2016; Samms-Vaughan, 2014; Stewart & Lee, 2017) on early detection of ASD have suggested the usefulness of a collaboration of researchers and community stakeholders in LMICs with scholars and clinicians from developed countries who have extensive knowledge on the early detection of ASD. The sharing of knowledge within and between countries is thus essential to develop a context-suitable, cost-effective and sustainable approach to the early detection of ASD in LMICs (Pijl, Buitelaar, Korte, Rommelse, & Oosterling).

Summary and Future Directions

Early markers of ASD are present in the first two years of life. These include deficits in key social attention and communication behaviours such as social smile, eye contact, responding to name call, use of vocalisation, following finger points, and reduced social and imaginative play. Research suggests that early detection of ASD is possible within the first years of life. Moreover, EI research supports the positive impact of early detection and diagnosis of ASD on developmental outcomes of young children. However, children across LMICs are diagnosed much later, missing the opportunities for early referral, timely diagnosis and EI is known to improve social, behavioural and cognitive outcomes.

Lack of knowledge about ASD amongst families and health professionals, cultural impact on understanding behavioural presentations, the stigma associated with ASD, lack of well-validated early identification tools and inequity in access to healthcare services remain significant barriers to timely diagnosis of ASD in LMICs, including Nepal. However, research suggests these factors associated with the delayed diagnosis are modifiable (Daniels & Mandell, 2014). There is a great need to advance knowledge of ASD among public and health professionals in LMICs, including Nepal.

Growing evidence shows that task shifting to non-specialist health workers can be a feasible and practical method given the scarcity of trained health professionals in LMICs and the inequities between and within nations in the availability and distribution of resources. Future research should focus on developing human resource capacity by training local community health workers, teachers and nurses in primary level as well as developing, adapting and validating cost-effective and easily accessible early identification tools for under-served communities. In the case of Nepal, FCHVs can be the appropriate service providers in raising community awareness, promoting stigma-reduction campaigns and identifying children at risk of ASD following training on early identification. For this, there is a need for community-based studies and translation, adaptation and validation of existing early identification tools for ASD for use across different cultures in LMICs, including Nepal.

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CHAPTER 3

GENERAL METHODOLOGY

Chapter Overview

Each empirical study undertaken as part of this research program consists of individual manuscripts, either published (Study 1, Chapter 4) or submitted to scientific journals (Studies 2-4, Chapters 5-7). Study 1 was conducted using the deidentified administrative data of children registered at AutismCare Nepal Society (ACNS) with a diagnosis of ASD from 2010 to 2015. This chapter provides the methodology used in the remaining studies (Chapters 5-7) in detail, including study setting, research design, participant details, measures used, as well as information on the ethical considerations and data analysis.

Study Setting

The study was conducted in Kirtipur Municipality, located about 7 km south-west of Kathmandu in Province Three (see Figure 1). According to the Central Bureau of Statistics (2012), the total population of Kirtipur is ~65,607. Predominantly comprising of Newar ethnic people whose lives are based on agriculture, and practising Hinduism or Buddhism (Central Bureau of Statistics, 2012), the community has grown increasingly multi-ethnic with people taking different occupations after migration (Maharjan, Maharjan, & Dangol, 2019). There has also been significant urbanisation of people from different parts of Nepal (Maharjan et al., 2019).

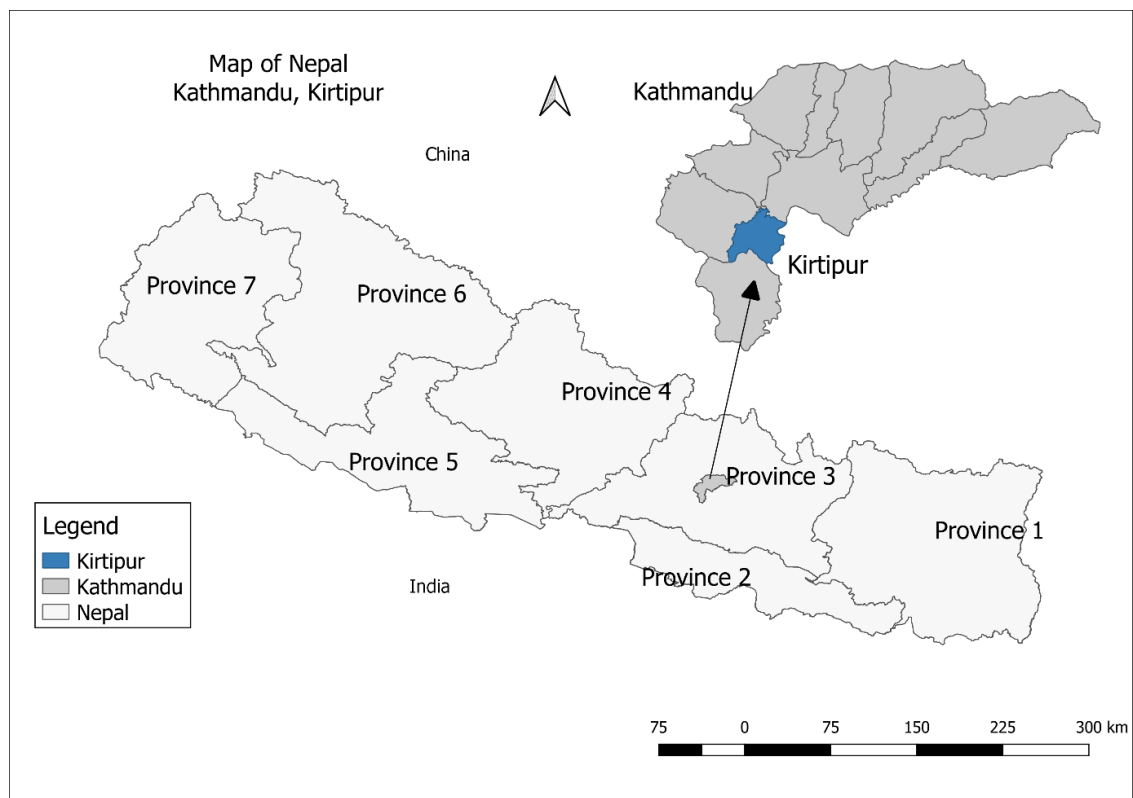


Figure 1. Location map of Kirtipur Municipality

The study site consisted of 19 wards (local units in Nepal) in eight village development committees at the time of the commencement of the study (November 6, 2016), which, after the restructuring by the local government, were merged into 10 wards on March 10, 2017 (see Figure 2; Ministry of Federal Affairs and General Administration, 2017). The primary health programs in Kirtipur Municipality are implemented through eight primary health services, including one primary health care (PHC), one health post (HP) and six sub-health posts (SHPs). These are Bishnudevi PHC, Champadevi HP, Bahirigaun SHP, Palifal SHP, Layaku SHP, Chithubihar SHP, Paanga Balkumari SHP and Chovar SHP (see Figure 2).

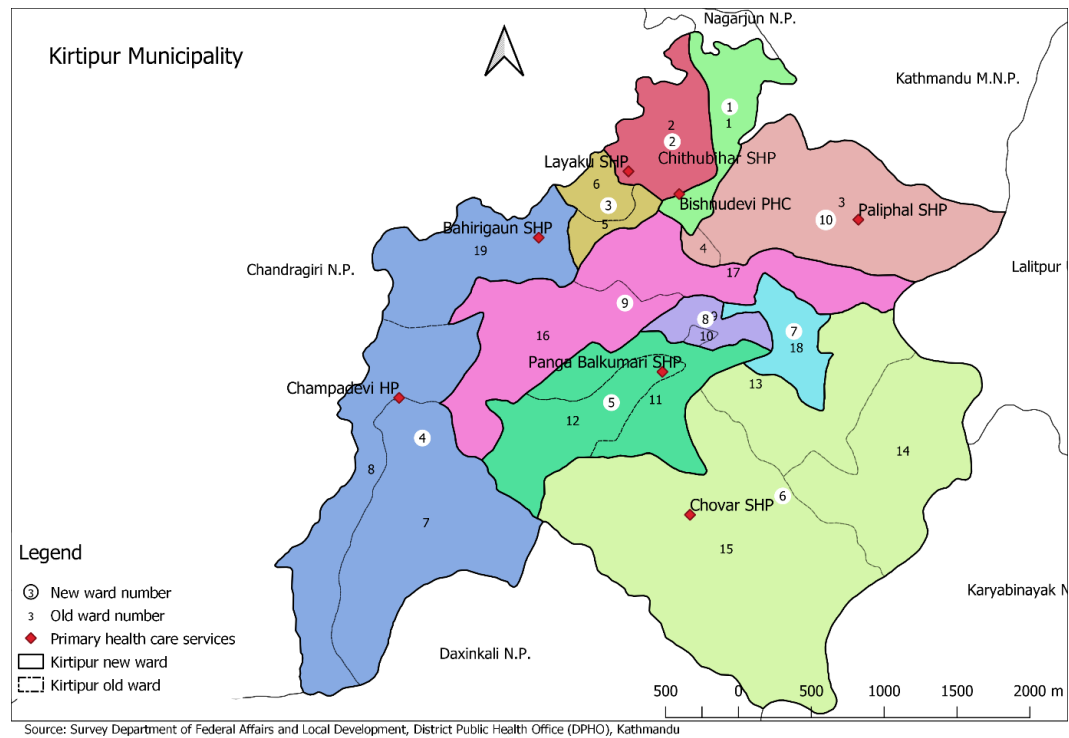


Figure 2. Map showing wards and primary health care services within Kirtipur Municipality

The municipality was selected for two main reasons: firstly, being the peri-urban community; and secondly, to facilitate referrals to ACNS, which is within 12 kilometres and is where the developmental and diagnostic assessments were conducted. ACNS is a parent-run organisation based in Kathmandu, and it is the only active organisation for children with ASD in Nepal (AutismCare Nepal Society, 2018). It provides services including assessment and diagnosis, interventions (occupational, speech, music, physical, and art therapy), educational and vocational training programs, training for parents/caregivers and teachers and awareness, advocacy and outreach programs in different districts of Nepal (AutismCare Nepal Society, 2018).

Study Designs

Study 2 was a prospective, longitudinal, community-based, cohort study designed to monitor early social attention and communication behaviours in children aged between 11-30 months using the Nepali version of Social Attention and Communication Surveillance (SACS-N). A prospective, cohort study design is ideal for monitoring the

presence and absence of the behaviours of interest at given ages over a period of time (Barbaro & Dissanayake, 2009; Salkind, 2010). In addition to informing about the early signs of autism in infancy, prospective, longitudinal, studies also have the advantage of identifying previously unrecognised cases of autism (Barbaro & Dissanayake, 2009).

A pre-test post-test follow-up survey design was used in Study 3 to examine FCHVs' knowledge of social attention and communication behaviours in young children and the early signs of autism prior to, immediately after, and following one year of the delivered training. Evaluation of training was also conducted immediately following the training, and after 6-, and 12-months of implementation of SACS-N. Finally, a population-based, cross-sectional, once-off survey was used to assess caregivers' knowledge of autism in Study 4.

Participants

Participants Recruitment

Sixty FCHVs who received SACS-N training were recruited through their respective PHC services. The trained FCHVs in Kirtipur Municipality were involved in recruiting children between 11 to 30 months of age using the records from the Vitamin A Distribution Program, which occurs at 6-month intervals and includes information of all children under five years of age within each FCHVs' catchment areas. The record files available at each PHC, HP and SHPs were approved to use in this study (see Appendix V). All PHC services in Kirtipur Municipality involved in the study also displayed a poster describing the municipality's involvement in the SACS-N, which outlined the study details (See Appendix A). Child recruitment began on November 7, 2016, and ended on July 16, 2018.

All FCHVs and children's caregivers were provided with the Participant Information Statements (PIS) (see Appendix B and Appendix D) and Consent Forms (CFs) (see Appendix C and Appendix E), in Nepali. They were provided with information

about the aims of the study and their right to withdraw their consent at any time. During SACS-N implementation, trained FCHVs visited each house and requested consent for participation for the caregivers. If provided, participation in the study was undertaken at this time. Caregivers who were literate signed the CFs while, for the parents who were illiterate, FCHVs read the PIS and CFs, after which they provided verbal consent marked by X. In the case of children identified at “high likelihood” of ASD and who were referred to ACNS and attended diagnostic/developmental assessments, caregivers were provided another PIS (see Appendix F) about the assessments to be undertaken at ACNS prior to giving consent (see Appendix G) for the assessments to be used in research.

Participant Details

Study 2. In total, 60 FCHVs administered SACS-N to 1977 children aged 11-30 months over 18 months. A total of 51 children were excluded from the study for the following reasons: chronological age below 11 months ($n = 3$) and older than 30 months ($n = 13$); missing child's age ($n = 6$); missing SACS-N data ($n = 9$); and incorrect SACS-N checklist used for the child's age ($n = 20$). Overall, 1926 infants/toddlers (56% male) aged 11 to 30 months, with a mean age of 20 months ($SD = 5.96$) participated in the study. The number of children monitored at each group was 590 at 12- months, 449 at 18- months, and 887 at 24- months.

Children belonged to major three caste groups: Newar (31%), Chhetri (39%) and Brahmin (20%). Hinduism was the predominant religion (81%). The mean age of mothers was 29 years ($SD = 5.24$) and 32 years for fathers ($SD = 5.56$). In comparison to fathers (1%), four per cent of mothers did not know how to read or write. About half the parents had more than 12 years of education

Study 3. The sixty FCHVs who participated has a mean age of 44.6 years (range 29.0-61.5) with 82% having at least 6-years education, 73% had >10 years of work

experience. All 60 FCHVs completed the survey forms at T1 and T2, and 58 FCHVs completed these at T3.

Study 4. A total of 1895 caregivers completed the survey comprising mostly mothers (93%) with 40% of them being housewives. Most mothers were married, and 38% were between 26-30 years (Mean age = 28.82 years, $SD = 5.26$) with about half (46%) having more than ten years of education. Forty per cent of them were housewives. Around one-third of the respondents (31%) were Newar, followed by Chettri (21%) and Brahmin (19%).

Measures

Demographic Measure

Demographic information obtained included child's age, gender, parents' age, education, occupation, caste, and religion based on the national population census 2011 (see Appendix L) (Central Bureau of Statistics, 2012, 2014). The FCHVs' survey included information on their age, education and work experience (see Appendix M).

Developmental Surveillance Measure

Social Attention and Communication Surveillance-Nepal (SACS-N). The SACS-N is a Nepali version of the SACS tool developed by Barbaro and Dissanayake (2010, 2013). The SACS was used to monitor social attention and communication behaviours in children aged between 12 to 24 months. Children are considered to be at "high likelihood" of ASD if they show atypical presentations in three of five "key" items at 12-, 18- or 24-months (see Appendices I-K). The measure was chosen because of its adaptability to the Nepalese context, and its excellent psychometric properties: sensitivity (84%); specificity (99.8%); and positive predictive value (81%).

Translation and Adaption of SACS into Nepali. The PhD candidate, a Nepalese-English bilingual with a decade of clinical and research experience in ASD translated SACS into Nepali (SACS-N). Nepalese professionals (paediatrician, psychologists and

specialist teachers) with expertise in the assessment, diagnosis and intervention of ASD reviewed the SACS-N to ensure its applicability to the Nepalese context. Instead of the English noun-structure (pointing, eye contact, waving, imitation) used in the original SACS, a verb-structure "points," "makes eye contact," "waves bye-bye," "imitates" was adopted. Simple Nepali sentences were used for all statements while retaining the original meaning.

A professional translator then carried out a back translation. The original SACS developer and registered psychologist co-supervisor (JB), twice examined the back translation and made necessary changes. The Nepali version (SACS-N) was finalised after review of the primary supervisor CD and consensus between the original authors of the SACS (JB & CD) and Nepali professionals.

The original SACS for its use in Nepal was adapted in two ways: (a) the toys used (for example, use of a doll instead of a teddy bear and a ball when there was no block available), and (b) additional examples to explain the meaning of the item "loss of skill".

Knowledge Survey

The knowledge survey consisted of three sections: knowledge on early social attention and communication development; knowledge on autism; and confidence in monitoring and referring children at "high likelihood" of autism. All knowledge items had three response choices: "agree", "disagree", and "do not know".

Knowledge on early social attention and communication development. This section included 17 survey statements, adapted from SACS items (Barbaro & Dissanayake, 2010, 2013), which were related to eye contact, pointing, response to name, showing, imitation, gestures, pretend play, social smiling, joint attention, use/understanding of language, parallel play, and interest in peers (see Appendices N). The items were grouped based on the similarity of items to form three subscales (see

Table 1): 1) social attention and communication behaviours (SACB), 2) early language behaviours (ELB), and 3) peer relations and play behaviours (PRPB).

Knowledge on autism. This section included 23 items (see Appendices O). adapted and grouped into five subscales following a literature search: 1) social communication and interaction behaviour (SCIB), 2) restricted, repetitive behaviour, interests, or activities (RRBI), 3) epidemiology (EPI), 4) diagnosis and intervention (DIAGINT), and 5) causes (causal factors).

Confidence in monitoring and referring children at “high likelihood” of autism. This section comprised ten items with five each to assess the FCHVs' confidence to identify and monitor the signs of autism (MON) and to refer the child at “high likelihood” of autism for developmental and diagnostic evaluations (REF). The statements (see Appendices P) were based on the survey measure following SACS training in Australia (Barbaro, Ridgway, & Dissanayake, 2011).

Evaluation form. Adapted from the SACS training of MCH nurses (Barbaro et al., 2011), this measure had five items related to the impact of training on the FCHV's work, ease of implementation of SACS-N into their current practice, timely advice on any of their queries, parents comfort in the SACS-N being undertaken at their homes, and the perceived benefit of being part of the SACS-N. Items were rated “strongly agree” to “strongly disagree” on a 4-point scale (See Appendix Q). Two open-ended questions were also provided for comments on SACS-N and feedback to improve their community's use of SACS-N.

Table 1

Subscales and Items

Subscales	Items
Knowledge of social attention and communication behaviours	
SACB (Barbaro et al., 2011)	Eye contact, response to name, gestures, showing, follow pointing, social smile, imitation, points to facial features
ELB (Barbaro et al., 2011)	Speaks 1-3-word, 5-10 words, 20-50 words, 2-phrase words, understands and follows simple commands
PRPB (Barbaro et al., 2011)	Interest in other children, pretend play, parallel play
Knowledge of autism	
SCIB (APA; 2013)	Communication, eye contact, gestures, friendships, pretend play
RRBI (APA; 2013)	Repetitive speech, movements, use of objects, sameness, unusual interest hyper/hypo-sensitivities
EPI (Rahbar, Ibrahim, & Assassi, 2011; Stone & Rosenbaum, 1988)	Boys vs girls, higher socioeconomic status, higher education, presence in less than 12 years
DIAGINT (Bakare et al., 2009; Barbaro & Dissanayake, 2009; Barton, Dumont-mathieu, & Fein, 2012; Campbell, Reichle, & Van Bourgondien, 1996; Dawson, 2008; Dawson & Bernier, 2013; Guthrie, Swineford, Nottke, & Wetherby, 2013; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014; Stone & Rosenbaum, 1988)	Neurodevelopmental condition, intellectual disability, early identification, diagnosis, treatment, early intervention
Causal Factors (Heys et al., 2017)	Multiple choice items
Confidence	
MON & REF (Barbaro et al., 2011)	Ten items
Evaluation Form (Barbaro et al., 2011)	Five items

Note. SACB=Social attention and communication behaviours; ELB=Early language behaviours; PRPB=Peer relationship and play behaviours; SCIB= Social communication and interaction behaviours; RRBI= Restricted, repetitive behaviour or interests; EPI= Epidemiology; DIAGINT=Diagnosis and intervention; MON=Monitoring children at risk of autism; REF=Referring children at risk of autism.

Development, translation and adaptation of the knowledge survey. Following an extensive literature review, the survey items were developed and adapted to suit the Nepali context. Discussions were also held with Nepalese psychologists, special educators, and a public health officer, all with expertise with autism. The survey forms were first developed in English using both positive and negative wording and then

translated by the PhD Candidate (RS) into Nepali. An expert translator with bilingual language skills and experience (English & Nepali) back-translated the survey into English.

Pre-testing of the Nepali-version was then conducted to determine comprehension of the items as well as to assess the time required to conduct the survey. Pre-testing included ten participants in Kathmandu between 29-66 years of age, ranging from having no formal education (but can read and write) to those with more than higher secondary education. The survey was revised and finalised based on feedback from these participants

Diagnostic Assessment

Autism Diagnostic Observation Scale-Second Edition - Toddler. The ADOS-2 (ADOS-2 Lord et al., 2012) toddler module is designed for very young children who are pre-verbal or uses single words and are between the ages of 12 and 30 months. The ADOS-2 is often referred to as the "gold standard" measure for ASD. The administration time is about 45 minutes in which the assessor focuses on the child's response to loosely structured activities, including how s/he initiates or maintains the social interaction. Information regarding child's communication, reciprocal social behaviours and repetitive behaviours or interests is observed during administration of 11 primary activities and four secondary tasks. Forty-one items related to Social Affect (SA) and Restricted and Repetitive Behaviour (RRB) are coded. There are two scoring algorithms: "All Younger/Older" with "Few to No Words", and "Older with Some Words, and three levels of concern: 'Little-to-No Concern'; 'Mild to Moderate Concern'; and "Moderate to severe concern".

The psychologists at ACNS used the ADOS-2 when conducting their diagnostic assessments of children (AutismCare Nepal Society, 2018; Shrestha & Santangelo, 2014). The English version of the ADOS-2 Toddler module was used with subsequent

translation in the Nepali language as the module requires less language ability to diagnose ASD children. Importantly, the available resources and current ongoing practices at ACNS was utilised to conduct a detailed diagnostic assessment of the referred child. The PhD candidate was trained to research reliability on this measure, with co-supervisor (JB), a research-reliable ADOS administrator, observing and providing feedback to the psychologists at ACNS on their ADOS administrations, alongside the PhD candidate.

Developmental Assessment

Mullen Scales of Early Learning. The MSEL (MSEL; Mullen, 1995) was used to assess early development, yielding Age Equivalent (AE) scores in five subscales: Gross Motor (GM), Visual Reception (VR), Fine Motor (FM), Receptive Language (RL), and Expressive Language (EL). The AE of subscales FM and VR were used to evaluate non-verbal skills while the AE of the subscales RL and EL were used to assess verbal skills. Developmental Quotients (DQs) for each of the four domains were calculated. The Non-Verbal Developmental Quotient (NVDQ) and Verbal Developmental Quotient (VDQ) was calculated by dividing the non-verbal and verbal skill scores by the chronological age and multiplying by 100 (Messinger et al., 2013). The MSEL was chosen given its relative language-free administration, which is ideal for very young children, particularly in the absence of standardised and validated developmental assessment tools in Nepal. The MSEL has also been used in other LMICs in Asia, (Fernandez-Rao et al., 2014), Africa (Koura et al., 2013), Latin America (Miller, Chan, Comfort, & Tirella, 2005), and also in low-resource communities in HICs (Kasari et al., 2014).

Procedures

Ethical Clearances

The research project obtained approvals from the La Trobe University Human Ethics Committee (see Appendices R) and the Nepal Health Research Council (see Appendices S). NHRC is the Ministry of Health's (Government of Nepal) research

department and principal health research authority. Permissions were also obtained from ACNS (see Appendix T) to conduct developmental/diagnostic assessments. We also consulted with the local community leaders, municipality officials, and PHC personnel regarding the study. Permissions were granted by Kirtipur Municipality (see Appendix U), and PHC (see Appendix V). FCHVs received an allowance 400 Nepalese Rupees ~AUD\$5.21 under PHC's daily training allowance rule and were provided lunch during the training. During SACS-N implementation, FCHVs received 50-100 Nepalese Rupees (AUD\$0.65- \$1.30) for each child they visited in their catchment area. Eight FCHV leaders selected from each group were provided 50 Nepalese Rupees monthly to recharge their mobile phones to organise and notify of monthly meetings and to send messages to the research team at ACNS.

All diagnostic and developmental assessments were provided free of charge for children assessed at ACNS. All children who met criteria for ASD were referred for ACNS interventions and support service. Children who did not meet criteria for ASD, but had Global Developmental Delay, were referred to local tertiary health care services or related organisations in Kathmandu for further evaluations.

Training of FCHVs

Sixty FCHVs received a five-hour SACS training workshop (See Figure 3) on November 5, 2016, which focused on typical and atypical social-communicative development, the importance of early identification and diagnosis of autism, the early signs of autism, and the monitoring of behaviours relevant to the identification of autism in infants/toddlers using SACS-N. Co-supervisor (JB) delivered the training, which was simultaneously translated into Nepali by the PhD candidate (RS). The details training is presented in Study 2 and Study 3. The FCHVs completed the survey immediately before the training (T1), immediately after the training (T2) and after one year of implementation

of the SACS-N (T3). They also evaluated the implementation of the SACS immediately after the training (T2a), after 6- (T2b), and 12-months (T3) of implementation.



Figure 3. FCHVs participating in SACS-N training in Kirtipur Municipality.

Implementation of SACS-N and Administration of Caregivers' Survey

Following training, the FCHVs began to administer SACS-N to monitor social attention and communication behaviours of children between 11 and 30 months in their homes (see Figures 4 and 5). They also administered the caregivers' survey assessing their knowledge on autism (Study 4). Children identified at "high likelihood" of autism by FCHVs were referred to ACNS for a comprehensive developmental/diagnostic assessment. All remaining children in Kirtipur Municipality, who were not at "high likelihood" of autism, continued to be monitored at 6-monthly intervals by FCHVs until they were 22-30 months, with any children subsequently identified at "high likelihood" being referred to ACNS. The FCHVs were provided with regular monthly meetings by research assistants at ACNS and feedback on their queries by the PhD Candidate after consultation with the supervisors, as required.



Figure 4. FCHV administering SACS-N in Kirtipur Municipality.



Figure 5. FCHV administering SACS-N in Kirtipur Municipality.

Assessments Procedures at ACNS

All assessments were performed in a standardised format with children sitting on the floor, or on a child-sized chair at a table. One psychologist evaluated the child while the other carried out a developmental interview with the parents. An ACNS volunteer operated a video camera while sitting in the same room. Except for two parents, all agreed to a video recording of the assessments.

The ADOS-2 scores and parental responses in the developmental interview, together with the clinical judgements of the two psychologists, were used to determine the diagnostic status of children. The PhD candidate reviewed all ADOS assessment videotapes and re-checked the forms to assist with the diagnostic decision. Parents were provided with verbal feedback regarding their child's assessment, and provided with written report summarising the outcomes of the developmental assessment.

Data Preparation**Data Storage and Security**

All files, including the consent forms and survey forms, were securely stored in a locked cabinet in a lockable room at ACNS. All data entered electronically was password-protected, in a computer according to La Trobe University's policy, and stored at La Trobe University. These data will be destroyed after seven years post-publication, according to the La Trobe University data storage and security policy. Personal identifications such as name, family name, addresses, and phone numbers were removed before data analysis.

Data Cleaning

Data were entered into Microsoft Excel spreadsheet. Double entry of 10% of data in Study 3 and Study 4 ensured data entry reliability was $\geq 90\%$. Missing data were inspected and Little's MCAR test revealed that data were missing randomly (see Study 3

and Study 4). The missing values were replaced using mean substitution for minimal, randomly missing items (Tabachnick & Fidell, 2013).

Data Analysis

All analyses were carried out using Statistical Package for Social Sciences version 25.0 for analysis (SPSS; IBM Corp, 2017). Means and Standard Deviations were calculated for continuous data, while frequency counts and percentages were presented for categorical data. Details of inferential analysis relevant to each study are presented below.

Study 2. For the evaluation of SACS-N implementation, Positive Predictive Value (PPV) was calculated using the following formula: $TP/TP+FP$, where TP = True Positive (TP) and FP = False Positive (FP). The estimated prevalence was calculated using the following formula: (Total children identified with ASD/total children monitored for ASD) *100.

Study 3. Change in FCHV knowledge was presented through a descriptive analytic approach using percentage correct response. A Shapiro-Wilk test ($p < .05$) suggested a non-normal data distribution. However, data transformation attempts were unsuccessful. One-way repeated measures analysis of variance (ANOVA) was conducted before and after transformation, revealing similar results. Untransformed data analysis was reported with Bonferroni adjustment for multiple comparisons. A conservative .017 p-value was accepted for all analyses. The ANOVA effect sizes were interpreted to indicate small, medium and large effect for a partial η^2 (ηp^2) of 0.02, 0.13, and 0.26 respectively (Pierce, Block, & Aguinis, 2004). Paired-sample t-tests were used to examine 6- and 12-month follow-up responses on evaluation of SACS-N implementation. Two open-ended questions were reviewed for common themes and summarised with quotes.

Study 4. For this study examining caregiver knowledge, a Shapiro-Wilk test ($p < .05$) and visual inspection of the histograms showed that data were non-normally

distributed. Hence, Kruskal-Wallis H tests were used to compare caregivers' knowledge regarding socio-demographic factors, including survey respondents, caregivers' age, education, and caste. A series of pairwise comparisons were run using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. Statistical significance was adopted at $p = .005$ for caregivers' age, $p = .016$ for education, and $p = .003$ for caste.

Summary of Methodology

Table 2 presents a summary of the three studies, including study designs, participants, measures, and data analysis.

Table 2

Summary of Methodology Used in Studies 2, 3 and 4

Study	Study Design	Participants	Measures	Data Analysis
2	Prospective, longitudinal, community-based, cohort study design	<i>Developmental surveillance</i> : 1926 infants/toddlers aged 11-30 months	Demographic survey	Frequency, percentage
			SACS-N	Mean, standard deviation
				T-test and chi-square tests
				Positive Predictive Value
3	Pre-test post-test follow-up survey design	60 FCHVs in Kirtipur Municipality	Developmental interview	Prevalence rate
			<i>Diagnostic/Developmental Assessments</i> : 7 children attended assessments at ACNS	
			MSEL	
			ADOS-2	
4	Population-based cross-sectional survey	1895 caregivers of children aged 11-30 months	Demographic survey	Frequency, percentage
			FCHVs' knowledge survey	Mean, standard deviation
			Evaluation survey	One-way repeated measure analysis of variance (ANOVA)
				Paired-sample t-test
4	Population-based cross-sectional survey	1895 caregivers of children aged 11-30 months	Demographic survey	Frequency, percentage
			Caregivers' knowledge survey	Mean, standard deviation
				Kruskal-Wallis H tests

Note. ACNS, AutismCare Nepal Society; SACS-N, Social Attention and Communication Developmental Surveillance-Nepal; MSEL, Mullen Scale of Early Learning; ADOS-2, Autism Diagnostic Observation Scale-Second Edition

Fieldwork Challenges

Two devastating earthquakes on 25 April (7.8 rector scale) and 12 May 2015 (7.3 rector scale) followed by numerous aftershocks in Nepal lead to almost 9000 deaths, over 22,000 injuries and massive destruction and damages of health infrastructure (Maharjan et al., 2019). The focus of the Nation was shifted to rescue works and emergency health care services and significantly impacted our consultations and meetings with local stakeholders and community health workers in Kirtipur Municipality. As a result, our fieldwork began later than planned.

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CHAPTER 4

STUDY 1: AGE OF DIAGNOSIS OF AUTISM SPECTRUM DISORDER IN NEPAL

This paper has been published in the *Journal of Autism and Developmental Disorders*.
The published manuscript version is included in Appendix W.

References:

Shrestha, R., Dissanayake, C. & Barbaro, J. (2019). Age of diagnosis of autism spectrum disorder in Nepal. *Journal of Autism and Developmental Disorders* 49(6), 2258-2267. doi.org/10.1007/s10803-019-03884-7

Abstract

The current study investigated the age of diagnosis (AoD) of Autism Spectrum Disorder (ASD) in Nepal by using de-identified data on 246 children with a diagnosis of ASD registered at AutismCare Nepal Society from 2010 to 2015. The mean AoD in children was 58 months (range 14-187 months). The majority of children were male (76%), lived in the Kathmandu valley (75%), and were from upper caste groups (62%). The mean diagnostic age of ASD in Nepal is much later than the age at which a reliable diagnosis is possible, indicating the need to reduce the gap between the age at which it is possible to diagnose ASD, and the average age at which ASD is currently diagnosed.

Keywords: Autism spectrum disorder, Age of diagnosis, Low- and middle-income Countries, Nepal

Age of Diagnosis of Autism Spectrum Disorder in Nepal

Early markers of Autism Spectrum Disorder (ASD) are present within the first two years of life making diagnoses possible by 24 months (Barbaro & Dissanayake, 2013). Timely diagnosis enables access to early intervention programs, known to promote better developmental outcomes in young children due to early brain plasticity (Dawson, 2008). The age of entry to early intervention is associated with better cognitive, language and adaptive improvements in children with ASD (Clark, Vinen, Barbaro, & Dissanayake, 2017; Flanagan, Perry, & Freeman, 2012). These gains in child functioning eventually reduce the significant individual, family and societal costs associated with ASD across the lifespan (Barbaro & Halder, 2016; Peters-Scheffer, Didden, Korzilius, & Matson, 2012). Therefore, early diagnosis of ASD which enables earlier access to early intervention is critical to maximise children's developmental outcomes and reduce lifetime costs associated with these conditions.

Although ASD can be diagnosed as early as 24 months, children in low- and middle-income countries (LMICs) are typically diagnosed at a later age, missing the opportunities for better outcomes. Previous studies in LMICs including Nigeria (Lagunju, Bella-Awusah, & Omigbodun, 2014), India (Daley, 2004; Kommu et al., 2017; Preeti, Srinath, Seshadri, Girimaji, & Kommu, 2017), Colombia (Talero-Gutiérrez, Rodríguez, De La Rosa, Morales, & Vélez-Van-Meerbeke, 2012) and Mexico (Bravo Oro et al., 2012) reported mean age of diagnosis (AoD) of children with ASD that varied between 45- to 72-months. Similar to LMICs, several studies across High-Income Countries (HICs) such as the United States (Baio et al., 2018), Canada (Coo, Ouellette-Kuntz, Lam, Yu, & et al., 2012), Australia (Bent, Dissanayake, & Barbaro, 2015), and the UK (Brett, Warnell, McConachie, & Parr, 2016; Petrou, Parr, & McConachie, 2018) have also found substantial delay in the AoD of children with ASD, with mean AoD ranging from 50- to 60-months.

Although the AoD reported in LMICs appear similar to that in HICs, these data must be interpreted with caution. Unlike population-based studies in HICs (Idring et al., 2012; Randall et al., 2016; Williams, Thomas, Sidebotham, & Emond, 2008), where the AoD of children is examined across the spectrum of ASD, nearly all studies in LMICs are either hospital-based or specialist centre-based (Bravo Oro et al., 2012; Kommu et al., 2017; Lagunju et al., 2014; Montiel-Nava, Chacín, & González-Ávila, 2017; Preeti et al., 2017; Talero-Gutiérrez et al., 2012). Thus most of these studies include children with severe autism symptoms (Bravo Oro et al., 2012; Lagunju et al., 2014; Montiel-Nava et al., 2017) and intellectual delay (Kommu et al., 2017), possibly missing children with milder behavioural presentations. Research suggests that children with severe autism features have more learning impairments including intellectual disability (Vivanti, Barbaro, Hudry, Dissanayake, & Prior, 2013), possibly leading to earlier concerns amongst parents and professionals. In addition to greater symptom severity, other child factors such as developmental regression (Daniels & Mandell, 2014; Rosenberg, Landa, Law, Stuart, & Law, 2011) and having a sibling with ASD (Bickel, Bridgemohan, Sideridis, & Huntington, 2015; Coo et al., 2012) are associated with an earlier age at diagnosis, while comorbid neurological and psychiatric conditions have been linked to delayed diagnosis (Brett et al., 2016; Kommu et al., 2017; Mandell, Novak, & Zubritsky, 2005).

A number of sociodemographic and geographic factors also have been associated with AoD of ASD (Daniels & Mandell, 2014). For example, studies in HICs (Brett et al., 2016; Coo et al., 2012; Giarelli et al., 2010; Mandell et al., 2010) and LMICs (Kommu et al., 2017; Lagunju et al., 2014; Preeti et al., 2017; Talero-Gutiérrez et al., 2012) have consistently reported a male to female ratio of about 4-5:1, with no gender difference in AoD despite a growing recognition that there may be under-diagnosis of females with ASD (Petrou et al., 2018). Studies regarding the association of AoD and ethnicity across

HICs have shown mixed findings reporting either no difference in AoD between ethnicities (Mandell et al., 2005) or the later diagnosis of children from an ethnic minority background (Montiel-Nava et al., 2017; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). Likewise, other factors such as socio-economic status, parental education, their knowledge on early signs of ASD, their concerns about child development (Daniels & Mandell, 2014; Fountain, King, & Bearman, 2011) and stigma associated with a diagnosis of ASD (Tilahun et al., 2016) have been found to contribute to delayed diagnosis of ASD.

With respect to geographic factors, children living in semi-urban or rural settings are likely to receive a diagnosis at a later age compared to children living in urban areas due to inadequate access to early identification and diagnostic services (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017; Bello-Mojeed, Bakare, & Munir, 2014; Chen, Liu, Su, Huang, & Lin, 2008). Previous research in a HIC has similarly reported that children in metropolitan regions were diagnosed earlier than children living in non-metropolitan and rural areas (Bent et al., 2015). Although these studies provide important information regarding factors that are associated with the AoD of ASD, they are from HICs, and the studies in LMICs have rarely examined the association between ethnicity and geographic factors with AoD of children with ASD.

Research suggests that many of the factors associated with diagnostic age are modifiable, and it is vital to plan and deliver ASD-specific early identification services (Daniels & Mandell, 2014; Rosenberg et al., 2011) to lower the age at which children with ASD are diagnosed. However, limited research exists regarding the AoD and the factors affecting the AoD among ethnically and geographically diverse populations in LMICs, including Nepal. Previous studies in Nepal (Pandey, Dhakal, Karki, Poudel, & Pradhan, 2013) have also revealed gender, ethnic and geographic disparities in access to health services. For example, girls in Nepal have reduced opportunities for healthcare

facilities compared to boys due to a high preference for male children (Bhandari, Shrestha, & Ghimire, 2007). Ethnically, the children with a disadvantaged (lower castes) and other minority ethnic backgrounds have less access to health facilities compared to upper caste groups who are at the top of the social hierarchy (Bhandari et al., 2007; Pandey et al., 2013). Geographically, the mountain region, due to its rugged terrain and poor health infrastructure poses a significant barrier to healthcare facilities (Goli, Bhandari, Atla, & Chattopadhyay, 2017; Ministry of Health and Population, New ERA, & ICF International, 2012; Pandey et al., 2013). Likewise, geopolitically, the Kathmandu valley - the capital city - has always received significant attention from the government in terms of transportation, communication and healthcare facilities (Goli et al., 2017; Ministry of Health and Population et al., 2012; Pandey et al., 2013). Given this background, an understanding of gender, ethnic and geographic disparities in AoD of ASD is necessary to increase and strengthen early identification services at the local level in Nepal.

To date, there has been only one study in Nepal that has examined AoD comprising 50 children derived from the AutismCare Nepal Society (ACNS) registry (Shrestha & Shrestha, 2014), where the mean AoD of ASD was 56 months. The age of the sample ranged from 12- to 180-months, and the male to female ratio was 3.5:1. The current study addressed this gap in the literature by examining the AoD of children with ASD in an extended sample by accessing the ACNS registry from 2010 to 2015. The change in AoD across the six years of sampling was also examined to ascertain change over time, as well as autism severity in the sample. The frequency of children diagnosed with ASD was also studied with regard to gender, ethnicity and geographical location (ecological regions and districts) to facilitate a deeper understanding of the epidemiology of those being diagnosed with ASD in this LMIC.

Methods

Ethics approval was obtained from the Nepal Health Research Council (112/2016) and the La Trobe University Human Ethics Committee (HEC16-073). A written request to use the organisation's data registry was approved by the ACNS.

Sample

The study included de-identified data of 246 children registered at the ACNS from January 2010 to December 2015 and diagnosed with ASD. The ACNS, established in 2008 in Kathmandu, is the only active autism society in Nepal and is run by a group of parents of children with ASD (AutismCare Nepal Society, 2018; Shrestha & Santangelo, 2014). The ACNS serves as a major ASD resource centre for referrals for ASD evaluation from health professionals, educators, teachers and other therapists. The organisation provides assessment and diagnostic services, intervention programs, parent training and counselling, day care facilities, vocational training for adults with ASD, and capacity building for health, educational and other paraprofessionals (AutismCare Nepal Society, 2018). It also engages in awareness raising regarding ASD. The ACNS has a data registry, with a record of each child visiting the centre, including documentation of diagnosis as confirmed by pediatricians, child or adult psychiatrists, and psychologists.

Diagnosis of ASD in Nepal is generally conducted at the pediatric unit, the child guidance clinic or the psychiatric outpatient department at government hospitals or private clinics. These clinical diagnoses are based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth edition (DSM-V; American Psychiatric Association, 2013), the Diagnostic and Statistical Manual of Mental Disorders, Fourth edition, text revised (DSM-IV-TR; American Psychiatric Association, 2000) or International Classification of Diseases, tenth revision (ICD-10; Shakya, 2010; Tulachan, Chapagain, Kunwar, & Sharma, 2014; World Health Organization, 1993). It is rare that autism-specific diagnostic tools are used in these contexts. The ACNS also undertakes some

diagnostic assessments. Here, a part-time pediatrician and a psychologist trained on the Autism Diagnosis Observation Scale (ADOS-G; Lord et al., 2000) provide diagnoses for children (Shrestha & Santangelo, 2014). The diagnostic category of ASD is used here which comprises the individual categories under the Pervasive Developmental Disorder (PDD) heading in DSM-IV-TR (American Psychiatric Association, 2000; Autistic Disorder, Asperger's Disorder and PDD-Not Otherwise Specified).

Measures and Procedures

The age of an ASD diagnosis (in months) of children, their gender, ethnicity, postcode of residence and the ADOS-G scores (where available) were extracted from the registry. Other information, such as birth order, intellectual level, and co-morbidities, are not included in the registry. Children's AoD was calculated by subtracting their date of birth from the date that diagnosis was confirmed and rounded to the closest month. The postcodes of residences were categorized into districts and ecological regions (Central Bureau of Statistics, 2012).

Ecological regions and Districts. Geographically, Nepal is divided into three ecological regions: the Terai, the hills, and the mountains (Central Bureau of Statistics, 2012). The mountains in the north constitute the Himalayan region, elevates from 4877 to 8848 meters in altitude and covers 35% of the land (Ministry of Health and Population et al., 2012). The mountain region is the most deprived region in terms of resources, infrastructure and access to health services compared to the hills and the Terai (Bhandari et al., 2007; Goli et al., 2017). Only seven per cent of the total population lives here, and therefore represents a remote region. The hills in the central region range between 610 to 4877 meters above sea levels and cover 42% of the land. Around 43% of people live in the hill region (Ministry of Health and Population et al., 2012). Due to variations in landscape and the concentration of population, significant rural-urban disparities exist within the hills regarding infrastructure development and healthcare access (Bhandari et

al., 2007). The Terai in the south is the open terrain below 610 meters, covers 23% of Nepal and has the most fertile land which is home to 50% of the total population of Nepal (Ministry of Health and Population et al., 2012). Ecologically, this region is privileged compared to the hills and the mountains regarding transport, communication facilities and other infrastructure (Ministry of Health and Population et al., 2012).

Administratively, Nepal is divided into 75 districts (Central Bureau of Statistics, 2012). The Kathmandu valley comprises three districts of Kathmandu (the capital city of Nepal) and the surrounding two districts, Lalitpur and Bhaktapur. The Kathmandu valley represents the most urbanised area in the hill region and has received significant government priority (Ministry of Health and Population et al., 2012). The majority of the children registered at ACNS were from the Kathmandu valley, and there were only a few children (range 1-6) from other districts. Based on the small sample sizes in these other districts, they were collapsed into a single group resulting in two groups: those within Kathmandu Valley and the remainder of the districts (Others).

Ethnicity. Ethnicity in Nepal constitutes a hierarchy-based caste system with shared social and cultural practices (Pandey et al., 2013). The 2011 Census identified 125 castes/ethnic groups in Nepal (Central Bureau of Statistics, 2012). The current study utilised the six ethnic codes developed by the Health Management Information System, Department of Health Services, Nepal (Bhandari, Angdembe, Dhimal, Neupane, & Bhusal, 2014; Pandey et al., 2013). The six classifications were grouped into three: ‘Disadvantaged Groups,’ ‘Relatively Advantaged Janajatis,’ and ‘Upper Caste Groups.’ The first category ‘Disadvantaged Groups’ combined the most underprivileged caste groups including ‘Dalits,’ ‘Disadvantaged Janajatis,’ ‘Disadvantaged Non-Dalit Terai Caste Groups,’ and ‘Religious Minorities’ (see Table 1) given the low prevalence of these groups in the sample.

Table 1

Ethnic Codes as Defined by the Health Management Information System

Ethnic Codes	Classification of ethnicity	Regrouping of ethnicity
1	Dalits: Hills of Kami, Damai, Sharki, Gaine, Badi	Disadvantaged Groups
2	Disadvantaged Janajatis: Hills of Magar, Tamang, Rai, Limbu, Sherpa, Bhote, Walung, Sunuwar, Kumal, Jirel, Danuwar, Thami, Raji	
3	Disadvantaged Non-Dalit Terai Caste Groups: Yadav Teli	
4	Religious Minorities: Muslims, Chureto	
5	Relatively Advantaged Janajatis: Newar, Thakali, Gurung	Relatively Advantaged Janajatis
6	Upper Caste Groups: Brahmin, Chhetri, Thakuri, Sanyashi, Raajput, Kaayastha, Baniya, Marwadi, Jaire, Nurang, Bengali	Upper Caste Groups

Note. In the current study, the six classifications were grouped into three: 'Disadvantaged Groups,' 'Relatively Advantaged Janajatis,' and 'Upper Caste Groups'. The first category 'Disadvantaged' Groups combined the most underprivileged caste groups including 'Dalits,' 'Disadvantaged Janajatis,' 'Disadvantaged Non-Dalit Terai Caste Groups', and 'Religious Minorities' given the low prevalence of these groups in the sample.

Autism Severity. Data on ASD severity were derived from the ADOS-G (Lord et al., 2000) which is a semi-structured, standardised assessment of communication, social interaction, play and imaginative use of materials for assessing individuals with possible ASD. The ADOS-G comprises different modules based on the expressive language skills of the child. The total cut-off scores from the three modules of ADOS-G were used in this study. Module 1 is administered to children who are preverbal and do not use spontaneous phrase speech. Module 2 is used for children who use phrase speech. Module 3 is

intended for children with fluent speech for whom playing with toys is age appropriate. The ADOS-G calibrated scores ranging from 1-10 is derived from the sum of the communication and social interaction scores which were used to determine the severity of their symptoms following the revised algorithm procedure (Gotham, Pickles, & Lord, 2009). The children are classified into one of three classification ranges on the basis of the ADOS-G calibrated score: ‘non-spectrum’ (1-3), ‘ASD’ (4-5) or ‘Autism’ (6-10). The ADOS-G calibrated scores were available for only 52 (21%) of the 246 cases. The subset of children with ADOS-G scores were those who had received a diagnosis at ACNS.

Statistical Analysis

The AoD was non-normal in distribution, as assessed by Shapiro-Wilk’s test ($p < .05$). Further, inspection of the boxplot revealed outliers in the data. Given the importance of wide variability in the AoD and limited data from low-resource settings, the outliers were included in the analysis. Attempts at transforming the data were unsuccessful. Thus, both parametric (Independent t-test and One-way ANOVA) and non-parametric (Mann-Whitney U-Test and Kruskal-Wallis test) tests were run before and after transformation, revealing similar results. As Tabachnick and Fidell (2013) suggest that parametric tests, including independent t-tests and One-way ANOVA, are considered “robust” to a violation of normality, the parametric statistics on untransformed data are presented here. A p -value < 0.05 was considered statistically significant. Data analysis was conducted using the Statistical Package for Social Sciences version 25.0 (SPSS; IBM Corp, 2017).

Results

Age and Frequency of Diagnosis of ASD

The average AoD in children registered at ACNS between 2010 and 2015 in Nepal was 58 months ($SD = 34.38$) ranging from 14- to 187- months (see Figure 1). A total of 65% of the children registered at ACNS were diagnosed after 36 months of age

(Table 2). An overall increase in the number of children registered at ACNS is apparent from 2010 to 2015, with slight decreases seen in 2013 and 2015 (Figure 2). Significant differences in AoD were evident across six years of sampling, $F(5, 90.85) = 3.09$, $p = .013$, $d = 0.04$ (Figure 3). Games-Howell post hoc analysis indicated mean AoD for 2015 ($M = 43.13$, $SD = 25.28$) was significantly different from 2013 (22.59, 95% [.31, 44.87], $p = .04$) and 2014 (18.22, 95% [.30, 36.14], $p = .04$).

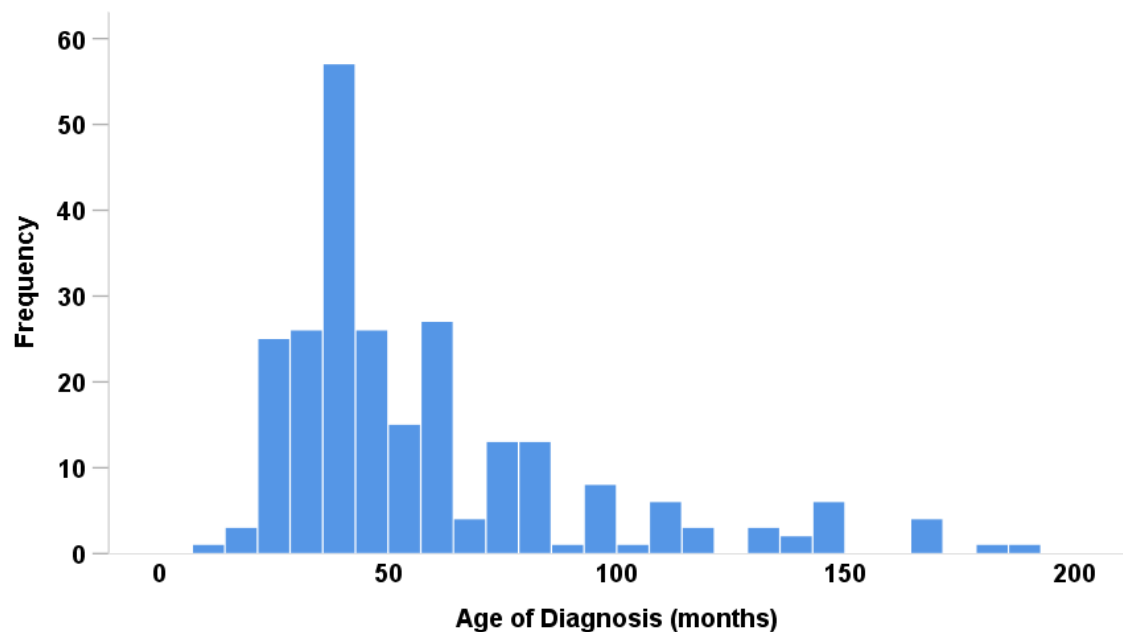


Figure 1. Distribution of age at diagnosis of ASD in children registered at AutismCare Nepal Society

Table 2

Frequency and Proportion of Children Diagnosed with ASD Across Age Groups ($N = 246$)

Age group	n	% [95% CI]
≤ 36 months	87	35.4% [29.03, 40.96]
>36 months	159	64.6% [59.03, 70.96]

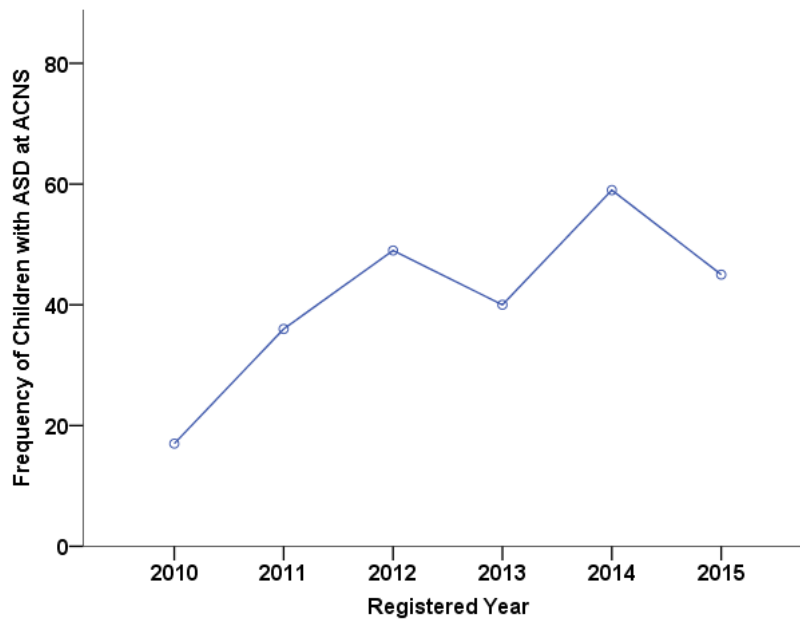


Figure 2. Frequency of children with an ASD diagnosis registered at AutismCare Nepal Society from 2010 to 2015

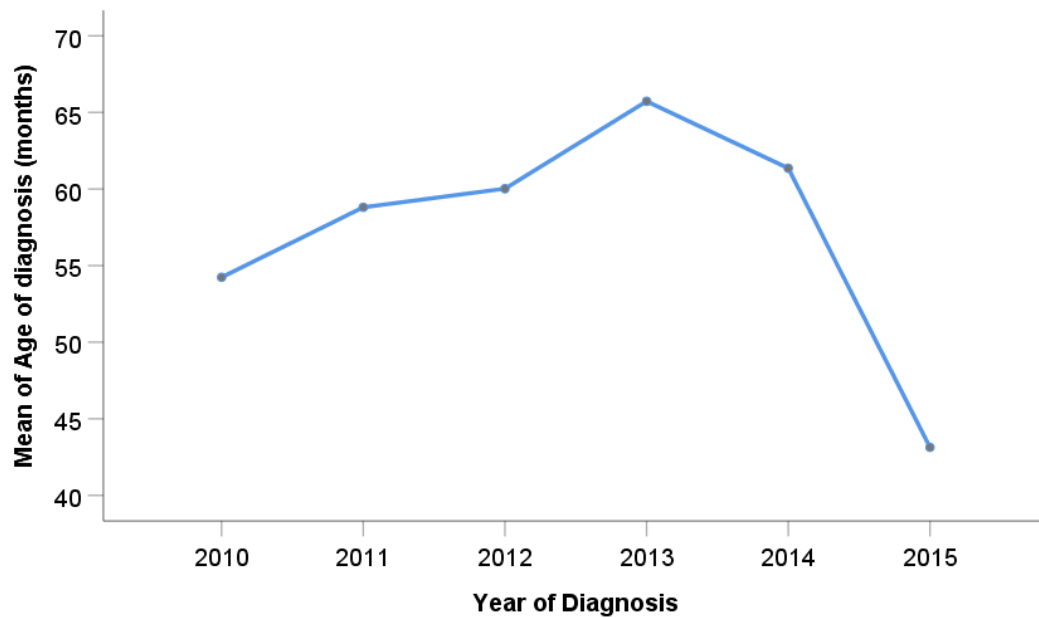


Figure 3. Change in the mean age of diagnosis of children with ASD from 2010 to 2015. Significant differences in AoD were found across six-years of sampling.

Age of Diagnosis by Gender and Ethnicity

Boys constituted 76 % of the sample (Table 3), with the male-to-female ratio for the sample being 3:1. There were no gender differences on AoD, $t(244) = 0.15$, $p = .88$, $d = 0.02$; males: $M = 57.79$, $SD = 34.71$; females: $M = 57.02$, $SD = 33.61$. The majority of the children (62%, $n = 152$) were from the upper caste group, with 63 children (26%) from relatively advantaged groups, and 31 (13%) from disadvantaged groups. Although the AoD was 7 months lower among the upper caste group ($M = 53.97$, $SD = 30.43$) compared to the relatively advantaged group ($M = 60.24$, $SD = 37.04$), and 16 months lower than the disadvantaged group ($M = 70.03$, $SD = 57.60$), the difference in AoD between these ethnic groups was not statistically significant, $F(2, 67.54) = 2.30$, $p = .10$, $d = 0.02$.

Table 3

Frequency of Diagnoses and Comparison of AoD of ASD ($N=246$)

Categorisations	<i>n</i> (% of total)	Mean age [95 % CI]	Group differences
Gender			
Male	187 (76 %)	57.79 [52.78, 62.79]	t (244) = 0.15, p = .88, d = 0.02
Female	59 (24 %)	57.02 [48.26, 65.78]	
Ethnicity			
Upper Caste Groups	152 (61.8%)	53.97 [49.10, 58.85]	F (2, 67.54) = 2.30, p = .10, d = 0.02
Relatively Advantaged Groups	63 (25.6%)	60.24 [50.91, 69.57]	
Disadvantaged Groups	31 (12.6 %)	70.03 [53.98, 86.08]	
Ecological regions			
Hills	211 (85.8 %)	57.66 [52.82,62.50]	t (242) = 0.48, p = .63, d = 0.10
Terai	33 (13.4 %)	54.58 [46.84,62.31]	
Districts			
Kathmandu valley	185 (75.2 %)	56.96 [51.77,62.15]	t (244) = 0.51, p = .60 d = 0 .07
Other districts	61 (24.8%)	59.56 [51.89,67.22]	

Note. CI=confidence interval. There were no significant differences in the AoD between gender, ecological regions or districts and ethnicity.

Age of Diagnosis by Ecological Zones and Districts

The hill region had the highest number of diagnosed children ($n = 211$, 86%) in contrast to the Terai ($n = 33$, 13%) and the Mountain regions ($n = 2$, 1%). However, there was no difference in mean AoD between the hills ($M = 57.66$, $SD = 35.65$) and the Terai ($M = 54.58$, $SD = 21.81$) $t(242) = 0.48$, $p = .63$, $d = 0.10$. In particular, 75 % of the children from the hill region lived in the metropolitan Kathmandu valley including Kathmandu, Bhaktapur and Lalitpur districts (see Table 3). Although, ASD was diagnosed 3 months earlier in the Kathmandu Valley ($M = 56.96$, $SD = 35.78$) compared to the Other districts ($M = 59.56$, $SD = 29.92$, the difference in mean AoD between the two groups were not significant; $t(244) = 0.51$, $p = .60$, $d = 0.07$.

Autism Severity

Table 4 presents the available data on the ADOS-G. Of the 52 ADOS-G administrations, 46 children (88%) scored between 6 and 10 indicating the classification of autism, with that large majority of children administered module 1. Moreover, the majority of ADOS administrations (79%) were conducted during the years 2014-2015.

Table 4

ADOS Administration and ADOS Calibrated Scores (N = 52)

Age group	n (%)
Modules	
Module 1	45 (86.5%)
Module 2	5 (9.6%)
Module 3	2 (3.9%)
ADOS Administration Year	
2010-2013	11(21.2%)
2014-2015	41(78.8%)
ADOS Calibrated Score	
ASD (4-5)	6 (11.5%)
AUT (6-10)	46 (88.5%)

Note. ADOS = Autism Diagnostic Observation Schedule; ASD = Autism Spectrum Disorder classification on the ADOS; AUT = Autism classification on the ADOS

Discussion

The study revealed that the mean AoD of ASD among 246 children registered at ACNS from 2010 to 2015 was 58 months, confirming that for most children with ASD in Nepal, diagnosis occurs much later than what research suggests is possible. This finding is consistent with the previous small study undertaken in Nepal (Shrestha & Shrestha, 2014), and other LMICs which have reported the mean AoD of children with ASD at between 45- to 57-months. Further, the findings show wide variability in the AoD of children with ASD ranging from as young as 14- to 187-months of age.

Overall, the majority of the children (65%) were diagnosed after they reached 36-months-of-age, missing the critical period of early development when the malleability of the brain is at its greatest. Encouragingly, despite the increasing frequency of children with ASD diagnosed over the study period, there was an apparent decrease in the diagnostic age over time, potentially attributable to an increasing awareness of ASD. Indeed, the awareness programs on ASD among health professionals and the public in recent years (Shrestha & Santangelo, 2014) has possibly resulted in the recent drop in AoD over the six-year period of this dataset.

The majority of children (88%) had more severe symptom presentations as indicated by their ADOS-G severity scores. However, it is important to note that only 21% of children had been administered the ADOS-G, representing only one-fifth of the sample. The diagnosis of severely affected children as demonstrated by ADOS-G is comparable with other studies across LMICs that have also reported the diagnosis of a higher number of children with severe autistic symptoms (Juneja, Mukherjee, & Sharma, 2005; Shooshtari, Sadeghiyeh, Mohammadi, Ghanizadeh, & Akhondzadeh, 2009; Springer, van Toorn, Laughton, & Kidd, 2013). These studies indicate that children with milder symptom presentations may miss out on being diagnosed. Despite increasing awareness of ASD, there remains a need for more knowledge on the broader autism

spectrum including the more subtle behavioural markers of ASD amongst clinicians and other health professionals, including the general population (Daley, 2004).

The majority of children diagnosed with ASD were males, with the data comparable to previous gender ratios (Elsabbagh et al., 2012; Van Wijngaarden-Cremers et al., 2014), and there were no differences in the AoD between males and females. Given the growing concern that the female children might have been underdiagnosed, it is likely that Nepalese girls are also at more risk of being underdiagnosed compared to boys, particularly as they have less access to healthcare facilities due to the high value attached to male children (Bhandari et al., 2007). Research suggests that fewer girls with disabilities compared to boys in Nepal are brought to specialised centres for diagnosis, treatment and rehabilitation (Thapa, 2016).

The current findings indicate that a significant proportion of the children diagnosed were from the upper caste groups compared to the disadvantaged group, which may be explained by the fact that high caste groups in Nepal are the most privileged people with regard to their sociocultural position and economic status; it is established that they have better access to educational and healthcare services compared to other disadvantaged ethnic groups (Bhandari et al., 2007; Pandey et al., 2013). Although the differences in AoD were not significant among ethnic groups comparable to previous findings (Bent et al., 2015; Mandell et al., 2005), it is important to note that the higher caste group had an earlier AoD than the disadvantaged groups; this trend, despite not being significant has clinical and public health relevance indicating the need to target ethnically marginalised populations in terms of early identification and diagnostic services. It seems reasonable to speculate that their access to support services would also be limited.

Similarly, regional disparities were apparent in the number of children diagnosed with ASD across the three ecological zones, although there was no significant difference

in their mean AoD. The majority of children who received a diagnosis were from the hill region, primarily from the Kathmandu valley - a metropolitan region which is a political, economic and administrative centre (Central Bureau of Statistics, 2014). This finding is consistent with other child health research in Nepal which identified far fewer children from the remote mountain regions, probably because of limited access to services which are generally being more prevalent in Kathmandu, which is also where ACNS is based (Bhandari et al., 2007; Ministry of Health and Population et al., 2012). As evidence of this, rural parts of both the hill and the Terai regions were less represented in the ACNS registry. These differences are likely to be the outcome of limited access to transportation, communication and health services for those living away from the Kathmandu valley. Moreover, a larger number of children from the upper caste group and diagnosed with ASD were living in Kathmandu within the urban area of the hill region which may have given them added benefit for better access to educational and health care services. Research also suggests that the rural and remote areas characterised by geographic challenges, poorer socioeconomic status, lower educational level and lack of ASD awareness further contribute to delayed or missed diagnosis of ASD (Antezana et al., 2017).

Strength and Limitations

The strength of the study includes the relatively large sample size compared to an earlier study. However, there are also some limitations, including a strong potential for selection bias as it only investigated the AoD of those children registered at ACNS. It appears that our sample included those children with a severe presentation of ASD and who had access to the centre. Thus, other children who were diagnosed but not recorded on the ACNS registry, or were diagnosed very late and thus not registered, were not able to be included in this study. Because of this potential selection bias, the AoD reported here may be an underestimation of true AoD in Nepal. As most of the cases had been

clinically diagnosed, the reliability of their diagnoses could not be examined by confirmation with the administration of an ADOS-G. In order to address these issues, it is important to undertake population-based surveillance for ASD to ascertain the true prevalence of ASD in Nepal and the AoD of ASD.

Furthermore, the study is limited by the lack of information on child characteristics such as birth order, intellectual level, developmental regression, and co-morbid conditions. Further, as already noted, only 52 children had ADOS-G scores, indicating a need for further professional training in the use of diagnostic measures for diagnosis of ASD in Nepal. Finally, family factors including their concerns, education, and socioeconomic status were not evaluated, which could also have affected the AoD of children with ASD.

Conclusion

The current study provides important information on the mean AoD of ASD in Nepal, an LMIC where autism resources and studies are scarce. The findings demonstrate a delay in AoD of ASD to what is possible, with wide variability in diagnostic age. However, the increase in the number of children with ASD diagnoses with a decreasing diagnostic age over six years of sampling is promising and indicates a growing awareness of ASD. Nonetheless, the diagnosis of children with severe symptoms indicates the lack of knowledge on less severe presentations of ASD among the public and professionals alike, calling for greater and widespread community education on the many manifestations of ASD during the early years of life. Further, the higher proportion of children with a diagnosis of ASD from the Kathmandu valley and the upper caste ethnic groups illustrate a significant geographical disparity and ethnic inequality in accessing identification and diagnostic services. Although not a focus of the current study this would also be reflective of access to support services for children and their families,

indicating the need to build capacity, perhaps using task shifting/task sharing, to serve all communities.

Given the importance of early identification of ASD leading to subsequent diagnosis and early intervention, there is a great need to advance the knowledge of ASD, and efforts are needed to reduce the disparity in available services to identify and diagnose ASD across the population in Nepal. The findings highlight the need to develop cost-effective, reliable and easily-accessible early identification services in local communities in Nepal to lower the diagnostic age of ASD and to ensure that all children despite their gender, ethnicity, and place of residence have the opportunity to access and benefit from the positive impacts of early diagnosis and intervention.

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CHAPTER 5

STUDY 2: IMPLEMENTING AND EVALUATING SOCIAL ATTENTION AND COMMUNICATION SURVEILLANCE (SACS) TO PROSPECTIVELY IDENTIFY AUTISM IN VERY YOUNG CHILDREN IN NEPAL

This paper has been submitted for publication.

Abstract

Early identification of Autism Spectrum Disorder (ASD) is the crucial first step in beginning early intervention. Although children can be identified as early as 12 months and diagnosed reliably by 24 months, the mean age of diagnosis of ASD in Nepal is ~58 months, with children missing the opportunity to access early intervention. The study aim was to implement and evaluate a Nepali version of the Social Attention and Communication Surveillance (SACS) tool, to identify children between 11-30 months who are at “high likelihood” of ASD in a local community in Nepal. Sixty Female Community Health Volunteers (FCHVs) were trained to monitor and identify the early signs of ASD using SACS. A total of 1926 children were monitored, with 11 children (0.57%) referred for further assessments. Seven children attended these assessments, with three diagnosed with ASD (43%), and four diagnosed with global developmental delay (57%). The estimated prevalence of ASD ranged between 0.16 % to 0.26. Community-based developmental monitoring of autism and other developmental delays by FCHVs is a promising and sustainable approach to promoting early identification of ASD in Nepal. Further training and awareness of autism is needed for more accurate and increased referral rates using the SACS-N, including regular supervision of FCHVs.

Keywords: Autism Spectrum Disorder, developmental surveillance, screening, early identification, Nepal, Social Attention and Communication Surveillance

Implementing and evaluating Social Attention and Communication Surveillance (SACS)
to prospectively identify autism in very young children in Nepal

Over the past 25 years, significant progress has been made in mortality rates for children under the age of five living in low- and middle-income countries (LMICs) (You et al., 2015). With more children surviving in LMICs, the global burden of disease has shifted from improving child survival programs to promoting child development (Liu et al., 2015; Yousafzai, Lynch, & Gladstone, 2014). Nepal, a low-income country, has made remarkable progress in reducing the under-five child mortality rate from 162 per 1,000 births in 1990 to 38 per 1,000 births in 2014 (National Planning Commission, 2016). With improved survival rates, the identification and management of an emerging population of children with developmental disorders, including Autism Spectrum Disorder (ASD) (Scherzer, Chhagan, Kauchali, & Susser, 2012), is of increasing importance (Heys et al., 2017). Given the benefits of early detection and intervention, which is associated with improved developmental outcomes as well as reduced family stress and lower societal costs (Peters-Scheffer, Didden, Korzilius, & Matson, 2012), early identification of children with developmental disorder is essential (Maulik & Darmstadt, 2007).

Epidemiological research (Elsabbagh et al., 2012) suggests that ASD affects 1-2% of children globally. While prevalence rates in high-income countries (HICs) such as North America and the UK are well established, the prevalence in LMICs vary significantly (Elsabbagh et al., 2012), and are typically lower than in HICs. For example, with the exception of Sri Lanka (Perera, Wijewardena, & Aluthwelage, 2009), prevalence in India varies from 0.09% (age: 1-10 years; Raina, Kashyap, Bhardwaj, Kumar, & Chander, 2015) to 0.23% (age: 1-30 years; Poovathinal et al., 2016) and is 0.15% in Bangladesh (age: 0-9 years; Non Communicable Diseases Control Programme, 2013). A comprehensive meta-analysis of the 44 studies in China found the pooled prevalence of ASD to be 0.39% (age: 1.6-8 years; Wang et al., 2018). The only population-based ASD

screening in Nepal (age: 9-13 years; using the Nepali translation of the short Autism Spectrum Quotient (AQ-10; Allison, Auyeung, & Baron-Cohen, 2012) reported an estimated prevalence of 0.3% (Heys et al., 2018). These variations are likely due to diversity in study designs as well as limited resources, including limited access to reliable, valid, and culturally suitable screening/developmental surveillance tools in LMICs (Elsabbagh et al., 2012; Soto et al., 2015).

Evidence shows that early markers of ASD emerge between 12 and 24 months (Barbaro & Dissanayake, 2009) and include social attention and communication difficulties with reduced eye contact, social smiling, use of gestures, imitation, response to name, and joint attention skills such as pointing to share interest (Barbaro & Dissanayake, 2013; Elsabbagh et al., 2013; Zwaigenbaum et al., 2005). Research across LMICs (Perera, Jeewandara, Seneviratne, & Guruge, 2017; Rudra et al., 2014) suggests that core autism traits are universal. However, the socio-cultural context including literacy level, ethnicity, and religion can influence health care providers' and families' understanding of these traits (Daley & Sigman, 2002; Daley, 2004; Hussein, Taha, & Almanasef, 2011; Mandell & Novak, 2005). Moreover, different perceptions of these behaviours and differences in help-seeking behaviours (Daley, 2002; Mandell & Novak, 2005; Taha & Hussein, 2014) can lead to a gap between the identification and management of autism behaviours. For example, a child who has little eye contact or pointing may not raise concerns for health care providers if such behaviours are not encouraged in some cultures (Albores-Gallo et al., 2012).

A study in Sri Lanka found that mothers did not consider their children's social and communication delays as problematic (Perera et al., 2009), although these are considered to be key markers of autism. Families may also refrain from follow-up evaluations due to the stigma associated with developmental disorders like ASD, which has been well documented LMIC studies (Samadi, Mahmoodizadeh, & McConkey, 2012;

Tilahun et al., 2016). Such findings in LMICs (Ruparelia et al., 2016; Samms-Vaughan, 2014; World Health Organization, 2013) suggests that awareness-raising and capacity building within a community should be combined with early identification tools in local languages that can bridge the gap from identification to diagnosis and management.

Although the mean diagnostic age of ASD in Nepal is around 58 months, there are significant geographical disparities and ethnic inequalities in access to identification and diagnostic services (Shrestha, Dissanayake, & Barbaro, 2019), with 65% of children diagnosed after three years of age. Like other LMICs (Kakooza-Mwesige et al., 2014; Ruparelia et al., 2016; Tilahun et al., 2017), limited knowledge of the early signs of ASD, shortage of trained professionals, and lack of early screening or developmental surveillance tools remain significant barriers to early detection and diagnosis of ASD in Nepal (Heys et al., 2018; Shrestha & Santangelo, 2014; Shrestha et al., 2019). There is an urgent need for low-cost, easily accessible, culturally appropriate early identification tools in Nepal, including the promotion of community awareness about ASD and training of health care workers.

Given that most of the world's population live in resource-limited environments with disparities in access to health facilities, including a significant lack of trained personnel at all levels, the World Health Organization (WHO) has recommended that mobilising frontline-health care providers in LMICs can be a sustainable solution for the early detection and management developmental disorders, including ASD (Ertem, 2012; World Health Organization, 2008). For instance, developmental monitoring during immunisations and/or micronutrient interventions provide an excellent opportunity to identify conditions like ASD (Ertem, 2012; Ruparelia et al., 2016).

The primary health system in Nepal (Ministry of Health and Population, New ERA, & ICF International, 2012) consists of at least one primary health centre (PHC), health post (HP) or sub-health post (SHP) at the village level, which utilises community-

based volunteers known as Female Community Health Volunteers (FCHVs). Around 51,470 FCHVs are Nepal's backbone of rural health and point of referral between communities and health services (Ministry of Health and Population, New ERA, & ICF International, 2014). This system was launched in 1988 by the Nepalese Government to strengthen PHC through the voluntary participation of local women (Ministry of Health and Population et al., 2012). These volunteers receive an initial 18-day training program and refresher training, primarily focused on maternal and child health, following selection by their local communities (Ministry of Health and Population, New ERA, & ICF International, 2008; Ministry of Health and Population et al., 2014).

The FCHVs' contribution at the grassroots level has been well recognised as promoting maternal and newborn care, raising awareness in family planning, managing integrated treatment programs for childhood disease and, where necessary, referring to other health facilities (Ministry of Health and Population et al., 2014). They also participate in vaccination campaigns and the implementation of vitamin A supplementation programs at 6-month intervals (Ministry of Health and Population et al., 2014). Since FCHVs live in the communities they serve (Ministry of Health and Population et al., 2014), it is possible to train them to monitor children for the early signs of autism during their first two years of life, and to integrate this monitoring into existing primary health programs such as the vitamin A / nutritional supplementation campaigns.

In their prospective Social Attention and Communication Study (SACS; Barbaro & Dissanayake, 2010; Barbaro & Dissanayake, 2013), Barbaro and Dissanayake trained Maternal and Child Health (MCH) nurses in 17 local government areas in Victoria, Australia on the early behavioural markers of autism, which were then monitored within this free universal service at 12- 18- and 24-months of age. The SACS reliably identified children developing ASD with excellent Positive Predictive value (PPV; 81%), and estimated sensitivity (84%) and specificity (99.8%).

Given the excellent psychometric properties of the SACS (Barbaro & Dissanayake, 2010, 2013; Barbaro, Ridgway, & Dissanayake, 2011), a community-based study was conducted by translating and adapting the SACS for implementation in Nepal (SACS-N) followed by training of 60 FCHVs in Kirtipur, Nepal to monitor the early signs of ASD using the SACS framework.

The Current Study

The aim in the current study was to evaluate the SACS-N in identifying children between 11-30 months who were developing ASD in Kirtipur, Nepal. The study evaluated the implementation of SACS-N through: 1) referral rates of children identified at ‘high likelihood’ of ASD when monitored at 12, 18 and 24 months, and 2) the PPV (the proportion of children identified at risk on the SACS-N who received an ASD diagnosis. A further aim was to 3) chart the developmental characteristics of children identified as developing ASD, and 3) to examine the prevalence estimates of ASD in 11-30-month-olds in Kirtipur Municipality. It was expected that the implementation of SACS-N would enable identification of ASD at the community level and facilitate earlier diagnoses.

Method

Study Setting

A prospective, community-based, cohort study was conducted in Kirtipur Municipality from November 2016 to July 2018. Kirtipur lies about 7 km south-west of Kathmandu in Province three, with a population of ~65,607 (Central Bureau of Statistics, 2012), comprising predominantly individuals from Newars caste practising Hinduism or Buddhism (Central Bureau of Statistics, 2012). However, due to migration from outside the Kathmandu valley, the composition of residents is becoming increasingly multi-ethnic (Maharjan, Maharjan, & Dangol, 2019).

The study site consisted of 10 wards in eight village development committees (VDCs). Village Development Committees and wards are the lowest administrative units in Nepal. The municipality was selected given its peri-urban community and to facilitate ease of referral to AutismCare Nepal (ACNS) which is within 12-km, and where the developmental and diagnostic assessments were carried out. AutismCare Nepal is the only active autism organisation in Nepal, which was established by parents of children with ASD (AutismCare Nepal Society, 2018). It is a non-for-profit organisation based in Kathmandu, providing a wide-range of services including assessment and diagnosis, interventions (occupational, speech, music, physical, and art therapy), educational and vocational training programs (Arambha Pre-primary School, Aakar Vocational Unit), parental/caregiver and teacher trainings, and awareness, advocacy and outreach programs provided in different districts of Nepal (AutismCare Nepal Society, 2018).

Participants

A total of 1977 children were administered SACS-N over a period of 18 months by 60 FCHVs. A total of 51 children were excluded from the study for the following reasons: chronological age less than 11 months ($n = 3$) and greater than 30 months ($n = 13$); child's age missing ($n = 6$); SACS-N data missing ($n = 9$); and incorrect SACS-N checklist used based on age ($n = 20$). The final sample comprised 1926 infants/toddlers (56% male) aged 11 to 30 months, with a mean age of 20 months ($SD = 5.96$) at the first assessment.

The number of children monitored at each age group was 590 at 12 months (range: 11-15 months), 449 at 18 months (range: 16-21 months), and 887 at 24 months (22-30 months). Figure 1 presents the number of children monitored during SACS-N implementation. Of the 590 initially monitored at 12- months, 356 were monitored at all ages (12-, 18- and 24- months), 43 children were only monitored at their initial assessment, 109 were monitored at 12- and 18-months, and 82 were monitored at 12- and

24-months. Of 449 children initially monitored at 18-months, 389 were monitored at both 18- and 24- months while 60 children were only monitored at one time. Altogether, 92.71% children initially monitored at 12-months and 86.63% children initially monitored at 18-months were followed-up at one or more checks after their initial check.

Children were predominantly from Newars (31%) caste followed by Chhetris (39%) and Brahmins (20%), with 81% of the group being Hindu (see Table 1). The mean age of mothers and fathers was 29 years ($SD = 5.24$) and 32 years ($SD = 5.56$), respectively. More mothers (4%) were illiterate (could not read or write) compared to fathers (1%). However, 45% of mothers and 50 % of fathers had more than 12 years of education.

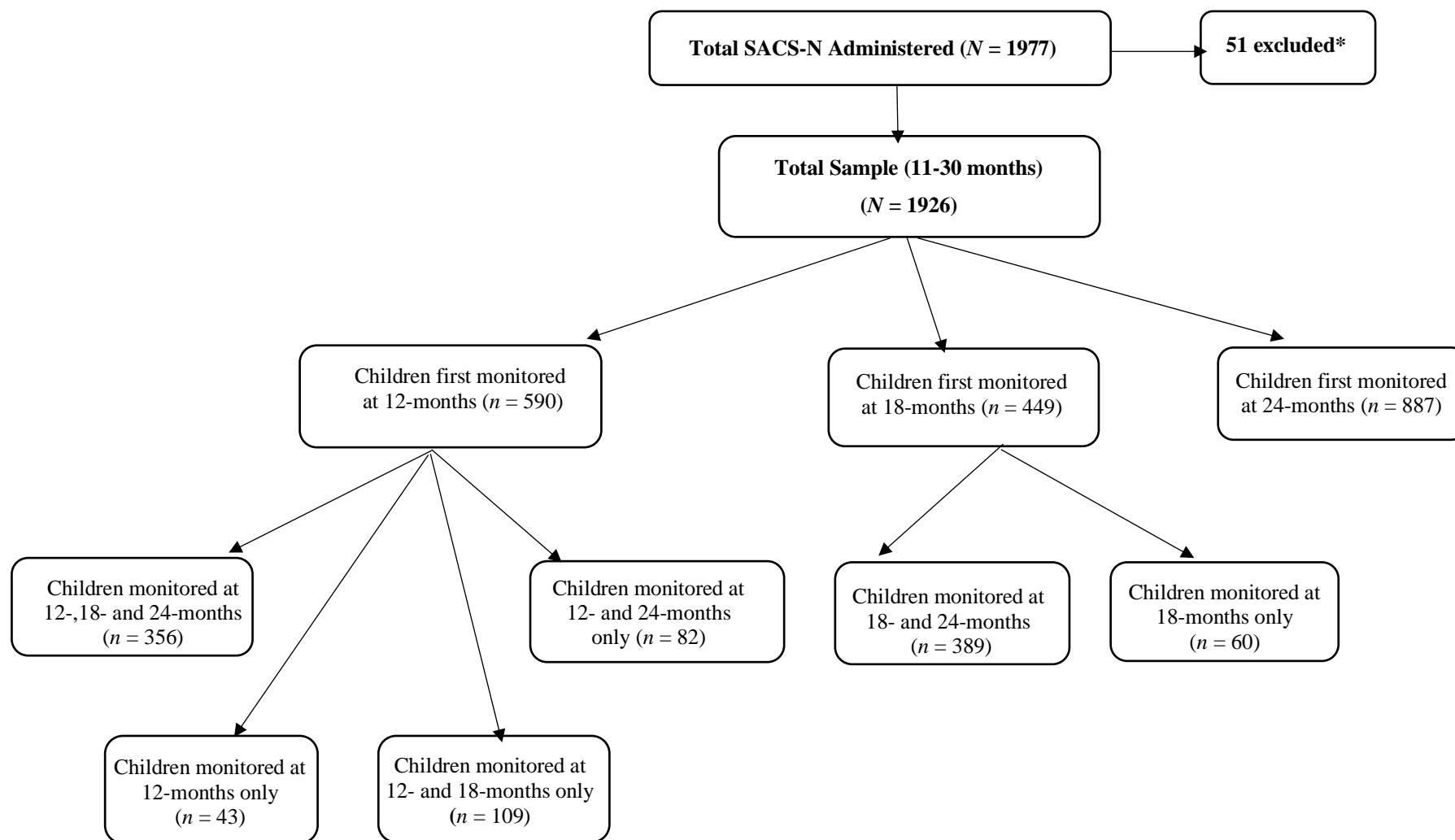


Figure 1. Total children monitored in SACS-N Implementation.

Note. *Children ($n=51$) out of total SACS-N administration ($N=1977$) were excluded from the study for: chronological age <11 months ($n=3$) and >30 months ($n=13$); missing child's age ($n=6$); missing SACS-N ($n=9$) and incorrect SACS-N checklist used based on age ($n=20$).

Table 1

Demographic Characteristics of the Sample ($N = 1926$)

Variables	n (%)
Child	
Mean age in months (SD)	19.99 (SD = 5.96).
Sex	
Male	1084 (56%)
Female	855 (44%)
Caste	
Newar	610 (31.4%)
Brahmin	363 (18.7%)
Chhetri	398 (20.5%)
Tamang	248 (12.8%)
Magar	85 (4.4%)
Others	239 (12.3%)
Religion	
Hinduism	1580 (81.3%)
Buddhism	272 (14%)
Kirant	17 (0.9%)
Islam	12 (0.6%)
Christianity	54 (2.8%)
Mother's Mean age in months (SD)	28.65 (SD = 5.09)
Mother's education	
Illiterate	84 (4.3%)
Can read and write	184 (9.5%)
Primary education (1-5 years)	191(9.8%)
Lower secondary education (6-8 years)	200 (10.3%)
Secondary education (9-10 years)	406(20.9%)
> Secondary education	878 (45.2%)
Father's Mean age in months (SD)	32.19 (SD = 5.39)
Father's education	
Illiterate	24 (1.2%)
Can read and write	139 (7.2%)
Primary education (1-5 years)	166 (8.5%)
Lower secondary education (6-8 years)	271 (13.9%)
Secondary education (9-10 years)	375 (19.3%)
> Secondary education	968 (49.8%)

Measures

Demographic measures. Demographic information on child age, gender, parents' age, education, caste, and religion (based on the national population census, 2011) (Central Bureau of Statistics, 2012, 2014) was obtained.

Social Attention and Communication Surveillance-Nepal (SACS-N). The SACS-N is a Nepali version of the SACS tool developed by (Barbaro & Dissanayake, 2010); Barbaro and Dissanayake (2013). Children are considered to be at "high likelihood" of autism if they show atypical presentations in three of the five "key" items at 12-, 18- and/or 24-months (see Appendices 3, 4 and 5). The SACS was chosen because of its adaptability to the Nepalese context, and its excellent psychometric properties.

Informed by the literature (World Health Organisation, 2009), the current translation process comprised five steps: (1) instrument translation from the source language (English) into the target language (Nepali); (2) synthesis of the translated versions; (3) analysis by the technical team of the synthesised version; (4) back translation, and (5) analysis of the back translation by the original SACS developer (JB & CD). Translation of SACS into Nepali (SACS-N) was undertaken by the first author (RS), a Nepali-English bilingual with a decade of clinical and research expertise in ASD. A Nepalese team of professionals (pediatricians, psychologists, and special educators) with experience in assessment, diagnosis and management of children with ASD then reviewed the Nepalese translation to ensure its relevance within the Nepalese context. For e.g., the verb-structure "points", "makes eye contact", "waves by-bye", "imitates" was adopted rather than the original noun-structure of English (pointing, eye contact, waving, imitation) used in the original SACS. For all statements, simple sentences in Nepali were used while maintaining the sense of the original as closely as possible.

Two modifications were made to the original SACS for use in Nepal: (a) adaptation of the toys used (for e.g., a doll was used instead of a teddy bear, and if no

blocks were available, a ball was used instead); and (b) addition of examples to clarify meaning of the item "loss of skills." A professional translator then undertook a back translation into English. The last author (JB), the developer of the original SACS and a Registered Psychologist, then reviewed the back-translation twice-over, and made appropriate amendments where necessary. Following review by author CD, and consensus between the original SACS authors (JB & CD) and Nepali professionals, the Nepali version (SACS-N) was finalised.

Autism Diagnostic Observation Scale-Second Edition. The ADOS-2 (ADOS-2 Lord et al., 2012) toddler module was administered, which is suited for 11-30 month-olds who are pre-verbal or use single words. The psychologists at ACNS use the ADOS when conducting their diagnostic assessments of children (AutismCare Nepal Society, 2018; Shrestha & Santangelo, 2014). The first author (RS) had been trained to research reliability on this measure, and the last author (JB), a research reliable ADOS administrator, observed and provided feedback to the psychologists at ACNS on their ADOS administrations ($n = 4$), alongside RS.

Mullen Scales of Early Learning. The Mullen Scales of Early Learning (MSEL; Mullen, 1995) was used to assess non-verbal skills using Age Equivalent (AE) scores on the Fine Motor (FM) and Visual Reception (VR) subscales while verbal skills were assessed using AE on the Receptive Language (RL) and Expressive Language (EL) subscales. Developmental Quotients (DQs) were calculated by dividing the non-verbal and verbal age equivalent scores by the chronological age and multiplying by 100 (Messinger et al., 2013). Since there is no standardised and validated developmental assessment tool in Nepal, the MSEL was chosen as it is relatively language-free in its administration with very young children, and has been used in LMICs in Asia, (Fernandez-Rao et al., 2014), Africa (Koura et al., 2013) and Latin America (Miller,

Chan, Comfort, & Tirella, 2005), as well as in low-resource communities in HICs (Kasari et al., 2014).

Procedure

The study was approved by the Nepal Health Research Council (112/2016), the La Trobe University Ethics Committee (HEC16-073), the ACNS, the Kathmandu District Public Health Office, Kirtipur Municipality and PHC services. To inform the adaptation of the SACS training for FCHVs, the candidate undertook systematic planning (Dasgupta et al., 2016; Semrau et al., 2018) which included (1) review of previous community-based frameworks used in other low- and middle-income countries, (2) an assessment of community-level needs, (3) meeting with stakeholders, and (4) ongoing dialogue and discussion with the local FCHVs and PHC officials. Every meeting with FCHVs involved a representative from AutismCare Nepal Society, and the PHC in-charge to assist in building the collaboration adapting the SACS training.

Sixty FCHVs were trained on the SACS-N in a five-hour workshop by the last author (JB), which was simultaneously translated by the first author (RS) into Nepali. The workshop educated FCHVs to monitor the social-communication development of children using the SACS-N checklists for 12-month-olds (range: 11-15 months), 18-month-olds (16-21 months), and 24-month-olds (22-30 months). The workshop focused on typical and atypical development of social attention and communication, the importance of early identification and diagnosis of ASD, the early signs of ASD, and the monitoring of the “key” markers in infants and toddlers (Barbaro & Dissanayake, 2013; Barbaro, Ridgway, & Dissanayake, 2011).

The FCHVs were trained to identify children at “high likelihood” of autism if three of the five “key” behavioural items on any of the 12-, 18- or 24-months checklists were deemed atypical. The FCHVs were advised to re-administer items not demonstrated up to a maximum of (only) three times (e.g., calling the child’s name), and were trained to

recognise “atypical” behaviour rather than the presence or absence of a given behaviour. Video clips of behaviours that distinguish children with and without ASD at different ages were presented to the FCHVs, alongside commentary by the last author (JB) on the differences between the two groups. The FCHVs were also trained on how to discuss the importance of social-communication milestones with parents/caregivers, and how to raise concerns with them when children were identified as having a “high likelihood” of ASD on the SACS-N. All FCHVs were advised to refer these families to ACNS for further assessment and diagnosis (see Figure A1; Appendix 1).

A second workshop of four hours followed the next day, conducted by the first author (RS), which focused on regional specific issues relating to the use and implementation of the SACS-N in their local community, addressing any questions, queries, or concerns the FCHVs had. The use of the participant information (see Appendix 6), consent (see Appendix 7), and withdrawal forms (see Appendix 8) was also covered. The consent forms were translated into simple sentences to be easily understood, and do not reflect a literal translation of the English version.

Following both training workshops, the FCHVs implemented the SACS-N during their home visits. Children who were not found to be at high likelihood of ASD continued to be monitored by FCHVs at 6- monthly intervals until they are 22-30 months old, with any children subsequently identified as “high likelihood” of ASD being referred for an assessment at ACNS (see Figure A1; Appendix 1 for details).

Internal Consistency of SACS-N checklist and Reliability of SACS-N Administration

Cronbach’s alphas on the SACS-N ranged between .77-.83 indicating good reliability. The 12-month checklist showed a Cronbach’s alpha of .77. Although Cronbach alphas on the 18- and 24-month checklists were initially .59 and .66, these increased to .79 and .83 respectively when the item “loss of skill” was deleted (which was not one of the “key markers” of ASD used for referral).

The reliability of the SACS-N administration by FCHVs was determined by the first author (RS) co-monitoring children during FCHVs home-visits. A total of 20% of the FCHVs ($n = 12$) were randomly selected to co-monitor one child from each age group (11-15; 16-21; 22-30 months). The interclass correlation coefficients (ICC) ranged between .78 and .97.

During the study period, research assistants in Kathmandu co-ordinated monthly meetings that took place with the group of FCHVs of each PHC/HP/SHP to discuss any challenges they faced during the implementation of SACS-N. Online meetings were also held every fortnight with the first author (RS).

Assessments protocols for referred children

Upon arrival at ACNS, the parents/caregivers were given another participant information statement about the assessments (see Appendices 9 & 10) to be undertaken, which comprised a brief developmental interview with the parent and administration of the ADOS-2 and MSEL to the child. All assessments were conducted in a standardised format with children sitting on the floor or in a child sized chair at a table. One psychologist assessed the child while the other conducted the developmental interview with the parent/s. An ACNS volunteer operated a video camera while seated behind the child in the same room. All except two parents consented to video recording of the assessments.

The diagnostic status of children was determined using a combination of the ADOS-2 and the developmental interview, as well as the clinical judgment of the two psychologists. The first author (RS) reviewed the videotapes of the ADOS assessments and re-checked the evaluation forms to assist with the diagnostic decision. Parents were counselled about their child's progress on the assessments and were provided with written reports on the results of the developmental assessment. All children who met criteria for ASD were provided with interventions and support at the ACNS. Those children who did

not meet criteria for ASD, but had Global Developmental Delay (GDD), were referred for further evaluations to local tertiary health care services or related organisations in Kathmandu.

Statistical Analysis

Missing data on demographic variables were as follows: sex (0.2%), caste (0.1%), mother's age (4.7%) and their education (5.5%), father's age (5.6%) and their education (3.0%), ethnicity (0.5%), and religion (1.6%). As Little's MCAR test revealed that data were missing at random, $\chi^2 8.05$, $df = 5$, $p = .15$, these were replaced using the mean substitution method (Tabachnick & Fidell, 2013).

Demographic characteristics of the children were summarised using Means and Standard Deviations (SD) for continuous data and Frequency Counts and Percentages for categorical data. Positive Predictive Value (PPV) was calculated by using the following formula: $TP/TP+FP$, where TP = True Positive (TP) and FP = False Positive (FP). The estimated prevalence was calculated by using the following formula: (Total children correctly identified with ASD/total children monitored for ASD) *100.

Results

Characteristics of children who were evaluated at ACNS

Of the 1926 children monitored by FCHVs using the SACS-N), 11 (0.57%) children were identified with a "high likelihood" of ASD with four ($n = 4$) identified between 11-15 months, four identified between 16-21 months ($n = 4$), and three identified between 22-30 months ($n = 3$). All were referred for further assessment to the ACNS (8 male; 3 female – ratio 3:1). Of these 11 children, only seven ($n = 7$) attended the developmental/diagnostic evaluations at ACNS. Table 2 presents the characteristics of each of these seven children. Six children were assessed at only one time point (two at 12-months, one at 18-months and three at 24-months) and one child was assessed at two time points (18- and 24- months). In total, 8 assessments were conducted at ACNS.

Table 2

Characteristics of Each Child Evaluated at ACNS (N=7)

Child	CA	Gender	DQ		ADOS-2 Score			Diagnosis
			VDQ	NVDQ	SA	RRB	Total	
1	27	Male	51.85	51.85	19	6	25	ASD
2	22	Male	59.09	61.36	12	2	14	ASD
3	25	Female	81.25	94.00	10	1	11	ASD
4	20	Male	60.00	80.00	NA	NA	NA	CP/GDD
5	13	Male	46.15	30.76	NA	NA	NA	GDD
6	12	Male	33.33	41.66	NA	NA	NA	GDD
7*	18	Male	55.55	66.66				DS/GDD
7*	29		65.51	58.62	3	1	4	DS/GDD

Note. ACNS = AutismCare Nepal Society; CA = chronological age; DQ= developmental quotient; GM = gross motor; ADOS-2 = Autism Diagnosis Observation Scale- 2nd Edition; VDQ = verbal developmental quotient ; NVDQ = verbal developmental quotient; MA = mental age; VR = visual reception; FM = fine motor; RL= receptive language; EL = expressive language; severity score; SA = social affect; RRB = restricted and repetitive behaviours; NA, = not administered; ASD = autism spectrum disorder; CP = cerebral palsy; GDD = global developmental delay; DS = down syndrome. 7* = same child followed-up at 29 months.

Table 3 presents the summary of diagnostic/developmental assessments undertaken at ACNS collapsed into three groups: 1) ASD (24-months); 2) DS with GDD (24- months); 3) CP with GDD (18-months); and 4) GDD (12-months). Of the seven children who were assessed at ACNS, three were diagnosed with ASD. A further two children, who attended their evaluations at 12-months, could not be administered the ADOS due to their low mental ages; thus, only the MSEL was administered. They did not attend any further follow-up assessments. However, their MSEL scores show that these two children had GDD. Of the remaining two children attending at 18-months (one attended follow-up at 24-assessments), one child had Cerebral Palsy (CP) with GDD and the other had Down Syndrome (DS) with GDD.

A total of four children were administered a diagnostic assessment for ASD. Of these, three met the criteria for ASD, and one met the criteria of non-ASD (see Table 3). The mean total score of the three children with ASD on the “Social Affect” ($M = 13.67$,

$SD = 4.7$) and “Restricted and Repetitive Behaviour” ($M = 3.0$, $SD = 2.64$) domains of the ADOS was higher than the scores for the child without ASD.

The three children diagnosed with ASD (see Table 3) showed a lower VDQ ($M = 64.06$, $SD = 15.30$) compared to NVDQ ($M = 69.07$, $SD = 22.10$), with the lowest mean AE score on RL ($M = 13.33$, $SD = 5.03$). While the ASD group had a lower mean score on RL than the GDD 18- and 24-months group, the GDD group had a lower score on EL. Comparisons between groups were not performed due to the small sample sizes. Although not measured, the ASD group did not have any gross motor problems, unlike those presenting with GDD.

Table 3

Summary Characteristics (Mean, Standard deviations) of assessments at ACNS (N = 7)

Variables	ASD	DS with GDD	CP with GDD	GDD*
Assessment age group	24-months (n =3)	24-months (n = 1)	18-months (n = 1)	12-months (n =2)
Age in months				
Chronological age	24.67 (2.51)	29. (-)	20.00 (-)	12.50 (0.70)
Overall mental age	16.08 (3.39)	18.00 (-)	14.00 (-)	4.75 (0.35)
Verbal DQ	64.06 (15.3)	65.51(-)	60.00 (-)	39.7 (9.06)
Nonverbal DQ	69.07 (22.10)	58.62(-)	80.00 (-)	36.21(7.07)
Age equivalent in months				
Visual reception	17.00 (5.29)	18 (-)	15.00(-)	3.5 (-)
Fine motor	18.00 (3.78)	16 (-)	17.00 (-)	3.5 (2.12)
Receptive language	13.33 (5.03)	25 (-)	15.00(-)	4.5 (-)
Expressive language	16.00 (7.76)	20 (-)	9.00 (-)	4.00 (-)
ADOS Score				
Social affect	13.67 (4.7)	3	NA	NA
Restricted repetitive behaviours	3 (2.64)	1	NA	NA
Gender	2 Male, 1 Female	1 Male, 0 Female	1 Male, 0 Female	2 Male, 0 Female

Note. ACNS = AutismCare Nepal Society; ASD = autism spectrum disorder; DS = down syndrome; CP = cerebral palsy; GDD = global developmental delay. CP child was not administered ADOS-2.

*Two children with GDD did not attend the follow-up assessments and were not administered ADOS due to significant delay in mental age; these results were based on their MSEL administration; NA = Not administered

Characteristics of children who were not evaluated at ACNS

Four children who had been referred to the ACNS could not be assessed as the parents of three children did not attend their scheduled assessments, and one family migrated from the municipality.

No information is available on the child who migrated. Of the remaining children ($n = 3$) who did not attend their scheduled assessments, two children are likely candidates for an ASD diagnosis as they each presented with failure on the SACS-N key items and did not have any accompanying physical problems. The fourth child also demonstrated failure on the key SACS-items but also presented with physical problems, which made it

difficult to estimate the likelihood of an ASD. These clinical judgements were based on the observations of the first author (RS) during home visits with FCHVs to schedule diagnostic/developmental assessments at ACNS.

Positive Predictive Value of SACS-N

As noted, of the 11 children referred to ACNS, no information is available about one child ($n = 1$) who migrated. Of the remaining children ($n = 10$), based on observation, all presented with developmental disorders, including ASD and GDD, indicating that the overall PPV of SACS-N for all developmental disorders is likely to be 100%. Only taking into account children who attended diagnostic/development assessment at ACNS ($n = 7$), three had ASD; thus, the PPV of SACS-N for ASD is 43%. However, if all children who are “likely” to have ASD who were not assessed are included, the PPV of SACS-N is 50% for ASD (5 out of 10), including two children who were likely to meet the criteria of ASD based on clinical judgement during observation at home visit, but who did not attend the diagnostic/developmental assessment at ACNS (See Figure 2). Since the whole cohort of children initially monitored could not be followed up, and only a small number of children were referred, the Negative Predictive Value (NPV), specificity, and sensitivity of the SACS-N cannot be calculated.

Prevalence of ASD in the SACS-N cohort

Figure 2 presents the estimated prevalence rate of ASD in the SACS-N sample. The rate of ASD in this sample, using only children evaluated and classified as ASD (i.e., three of 1926), is 1.6 (0.16%). The estimated prevalence rate of ASD is 2.6 (0.26 %) when the children who attended the developmental/diagnostic assessments with an ASD were combined with two of those referred as “high likelihood”, but did not attend a developmental/diagnostic assessment, assuming a likely diagnosis of ASD for these children based on clinical judgement (see Figure 2).

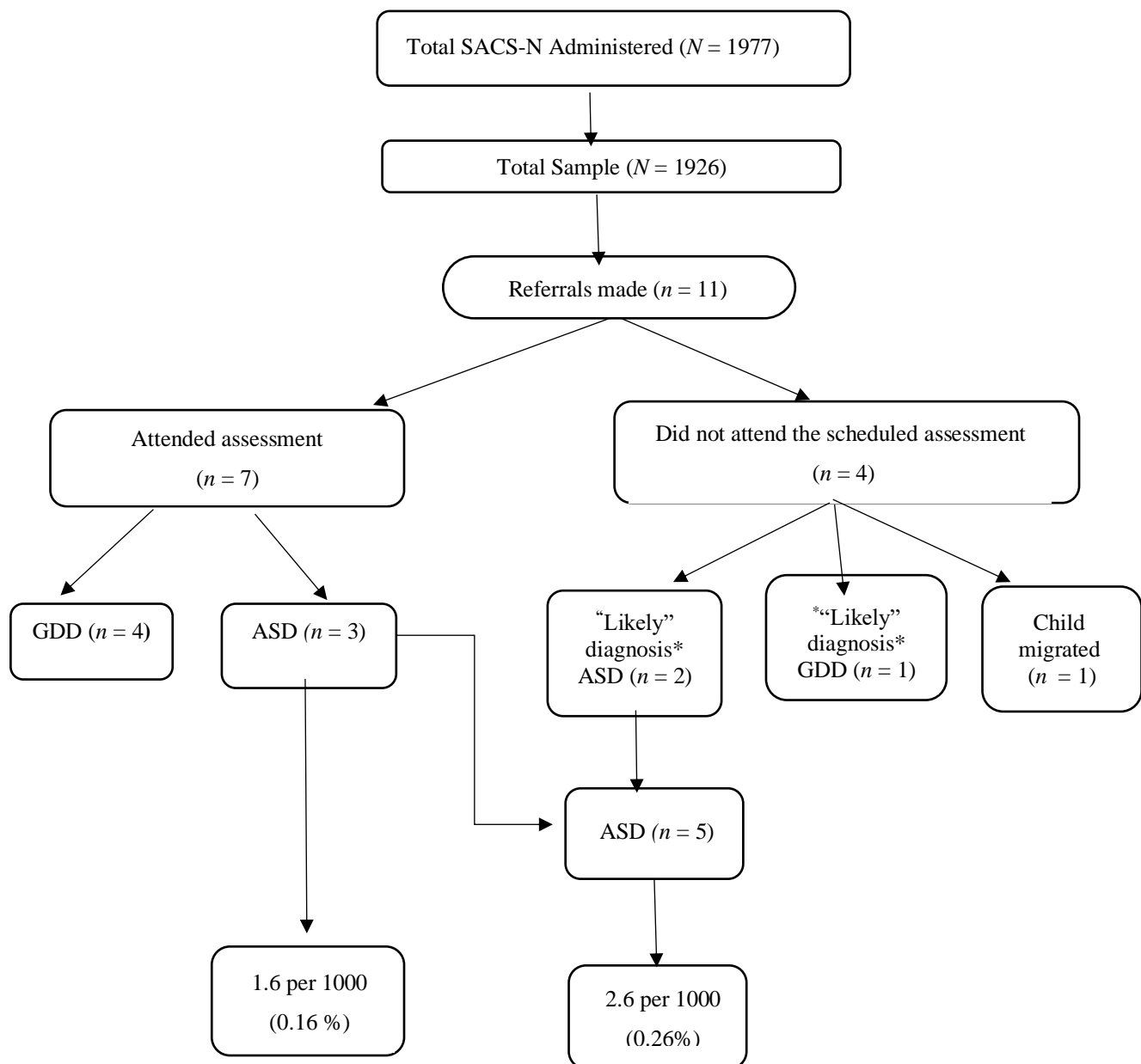


Figure 2. Calculation of the prevalence of ASD in the SACS-N sample

Note. SACS-N, Social Attention and Communication Surveillance-Nepal; ASD, autism spectrum disorder; GDD, global developmental delay.

*These were based on first author's observations during home visits with Female Community Health Volunteers to schedule diagnostic/developmental assessments at ACNS. However, these children did not attend their scheduled assessments at ACNS.

Discussion

To the best of our knowledge, this is the first prospective, community-based study of early identification of ASD in Nepal, which implemented and evaluated the SACS-N using a developmental surveillance framework by training local FCHVs to identify children with ASD between 11-30 months of age. The FCHVs followed-up 87-93% of children who were initially monitored at 12- and 18-months. Good to excellent inter-rater agreement was found between the first author (RS) and the FCHVs, consistent with implementation of the Australian SACS (Barbaro & Dissanayake, 2010). This translated and adapted Nepali version also demonstrated good internal consistency.

Unlike the referral rate with the original SACS (0.90%; (Barbaro & Dissanayake, 2010), SACS-N implemented by FCHV's resulted in a lower referral rate of children (0.57%) identified at "high likelihood" of ASD. There are several possible explanations for this lower referral rate in the current study. Indeed, the last census (Central Bureau of Statistics, 2012) also noted a lower prevalence of disability in Kirtipur Municipality, with the reported prevalence for speech problems, mental disability, and intellectual disability being 0.13%, 0.08%, and 0.02% respectively (Central Bureau of Statistics, 2012). Although ASD was identified as a mental disability during the census (Ministry of Women Children and Social Welfare & Government of Nepal, 2006), it is unclear whether cases of ASD were included in this report.

It is possible that in the current study, FCHVs were hesitant about raising concerns with parents given the low level of autism awareness amongst the caregivers (Heys et al., 2017) and the associated stigma with ASD (Tilahun et al., 2016). The referral rate may also be low due to cultural differences in understanding of early autism symptoms (Daley, 2004; Heys et al., 2017; Imran et al., 2011; Perera, Wijewardena, & Aluthwelage, 2009), despite the training received by FCHVs. Together, these possible explanations may also account for the low estimated PPV of 50% for ASD obtained in the

current study, compared to 81% in Australia (Barbaro & Dissanayake, 2010). However, the overall PPV for identifying developmental disorders in general was 100% – this is a positive finding given that children with other developmental disorders also require referral for supports and early intervention. This finding is consistent with the SACS implementation in Australia, whereby children who did not meet criteria for ASD had another developmental delay/disorder (Barbaro & Dissanayake, 2010). Research suggests that high-false positives impact on resources, as children who are falsely identified as ‘at risk’ must go through the diagnostic process, as do children correctly identified as ‘at risk’ for ASD (Soto et al., 2015; Toh, Tan, Lau, & Kiyu, 2018). This finding has important implications for Nepal and other LMICs where resources are limited to assess children in need of a diagnosis.

Four of the 11 children referred to ACNS did not attend their scheduled developmental assessment. Although efforts were made by the FCHVs and the first author (RS) to refer families, by meeting with them directly regarding developmental concerns following the SACS-N administration, it is likely that these parents choose not to attend the assessments due to a lack of knowledge on early signs of autism and/or the stigma associated with a possible diagnosis (Samadi, Mahmoodizadeh, & McConkey, 2012; Tilahun et al., 2016). Studies in LMICs have shown that caregivers of children with ASD often do not seek help due to a lack of awareness as well as stigma, discrimination, feelings of guilt, and fear of exclusion ((Tilahun et al., 2016), as well as their belief in supernatural forces (Kakooza-Mwesige et al., 2014). Research in Nepal (Shrestha & Shrestha, 2014) and other LMICs (Ruparelia et al., 2016; Tilahun et al., 2017) found that parent often seek help from traditional healers rather than professional help, delaying the timely identification of ASD.

The nonverbal and verbal mental DQs (and AE scores) on the MSEL of those children assessed at ACNS indicated that each child demonstrated significant delay. The

results are consistent with previous studies in LMICs, which reported that diagnoses of children with ASD was accompanied with developmental delays (Brennan, Fein, Como, Rathwell, & Chen, 2016).

The prevalence of ASD in the sample monitored in Kirtipur with the SACS-N was 0.16% and the estimated prevalence based on all children referred was 0.26%, significantly lower than the estimated prevalence in the Australian study (0.84%), conducted between 2006-2008. The current international estimates are much higher, being 1 to 2% (Hahler & Elsabbagh, 2015). However, the estimated prevalence (0.26%) in the current study is similar to recent prevalence estimates of 0.3% in Nepal (Heys et al., 2018), and is higher than those from other LMICs, including India (0.09-0.23%; Poovathinal et al., 2016; Raina, Kashyap, Bhardwaj, Kumar, & Chander, 2015) and Bangladesh (0.15%; Non Communicable Diseases Control Programme, 2013). These lower prevalence rates (compared to the global prevalence rates of ASD) can be attributed to the low referral rates of children, and a high likelihood of missing a group of children with milder behavioural presentations, including those without associated cognitive delays, who tend to have delayed diagnosis (Daniels & Mandell, 2014). It is thus noteworthy that all children who attended the ACNS for a developmental/diagnostic assessment in the current study had marked developmental delays, indicating that those children with milder ASD presentations were not identified.

The current findings need to be considered within the context of LMICs and Nepal in particular, where diagnoses of ASD prior to 2004 were rare (Shrestha & Santangelo, 2014). Knowledge of ASD and service provision then and now remain limited to non-existent (Heys et al., 2017; Shrestha & Santangelo, 2014; Shrestha, Dissanayake, & Barbaro, 2019). As noted previously, research in LMICs (Perera, Jeewandara, Seneviratne, & Guruge, 2017; Rudra et al., 2014) suggest that although the emergence of ASD symptoms are universal, cultural differences exist in how ASD behavioural

presentations are perceived (Daley & Sigman, 2002; Perera et al., 2017; Perera et al., 2009). It is possible, therefore, that these cultural differences may lead to inconsistencies in response to items, regardless of the instrument used (Pinto-Martin et al., 2008).

The current study represents the first step towards implementing and evaluating the utility of SACS-N by training FCHVs in Nepal. With good internal consistency, inter-rater agreement, the high percentage of children being monitored at one or more checks and no false positive cases for developmental disorders in general, the findings suggest that SACS-N can be a promising tool for developmental surveillance of social attention and communication behaviours amongst Nepalese infants and toddlers. The findings also indicate that there is a need for further training on ASD and, where necessary, further explanations and examples of the early signs of autism are needed to embed this knowledge. Adding visual aids such as pictures (Inada, Koyama, Inokuchi, Kuroda, & Kamio, 2011) or photographs (Perera et al., 2017) to checklist items could enhance comprehensibility of each item (Albores-Gallo et al., 2012; Brennan et al., 2016). Furthermore, raising community awareness more generally will also be important, so that parents are confident in seeking professional guidance regarding their child's development.

Strengths and Limitations

The SACS-N was able to be used by local women with limited education following brief training prior to its implementation. Following Soto et al. (2015), the Nepali version of the SACS was suited to the local context and language by ensuring correct Nepali sentence structure and adapting the items used (toys) as needed.

Co-monitoring of children was conducted to ensure that the FCHVs' were reliable in their developmental surveillance of children using SACS-N. Given the broad range of participants from different castes and ethnic groups, the findings are representative of the population in the Kirtipur Municipality. Moreover, the current study included

developmental and diagnostic assessments using standardised tools comparable with the original SACS (Barbaro & Dissanayake, 2010), and other international studies (Messinger et al., 2013; Ventola et al., 2007). There were no false positives in the current study preventing unnecessary evaluations as well as unnecessary parental stress. Despite these strengths, there were some limitations that should be acknowledged.

Three major limitations are apparent in the current study. Firstly, assessors were aware that all referred children had a high likelihood of autism as determined by SACS-N. It was not possible to calculate the sensitivity, specificity, and NPV of the tool due to the small size of the referred sample. Furthermore, the entire sample could not be monitored for a number of reasons, including seasonal migration of parents working in a brick factory in Kirtipur Municipality, which operates mostly in the dry season (winter). Local families are busy in their fields during monsoon seasons for planting paddy samplings, and some of these children may have been missed during this time.

Four of the 11 children (36%) identified as “high likelihood” of ASD and referred to ACNS did not participate in a diagnostic/developmental evaluation. Nonetheless, the PPV of the tool was calculated combining the children assessed at ACNS and based on clinical judgement of the three children who were briefly observed during home visits but did not attend their scheduled assessments at ACNS. Likewise, the prevalence of ASD in the SACS-N sample was estimated based on all referrals, rather than just those evaluated at the ACNS. It is therefore necessary to treat the prevalence rate estimated here with caution. Finally, there is a high possibility that children with milder symptoms and without associated cognitive delay, as reflected in the developmental profiles of children assessed at ACNS, have been missed.

Conclusion

In conclusion, the findings provide preliminary evidence of the implementation of SACS-N by trained FCHVs in a local community in Nepal, which served to identify not

only children with ASD, but also children with GDD. Given the scarcity of resources in Nepal, community-based developmental surveillance for ASD can be integrated into PHC services through frontline-health workers such as FCHVs, which is possibly a cost-effective as well as being a sustainable solution. However, more work is needed to raise awareness of ASD and its early signs, and to circumvent possible stigma and cultural interpretations of behaviours of concern, indicating the need for further training combined with regular supervision. This will hopefully not only increase the numbers of children correctly identified with developmental conditions and disorders but will also increase those correctly identified and diagnosed with ASD, so that there is early access to much needed services and support for the children and their families.

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Appendix 1

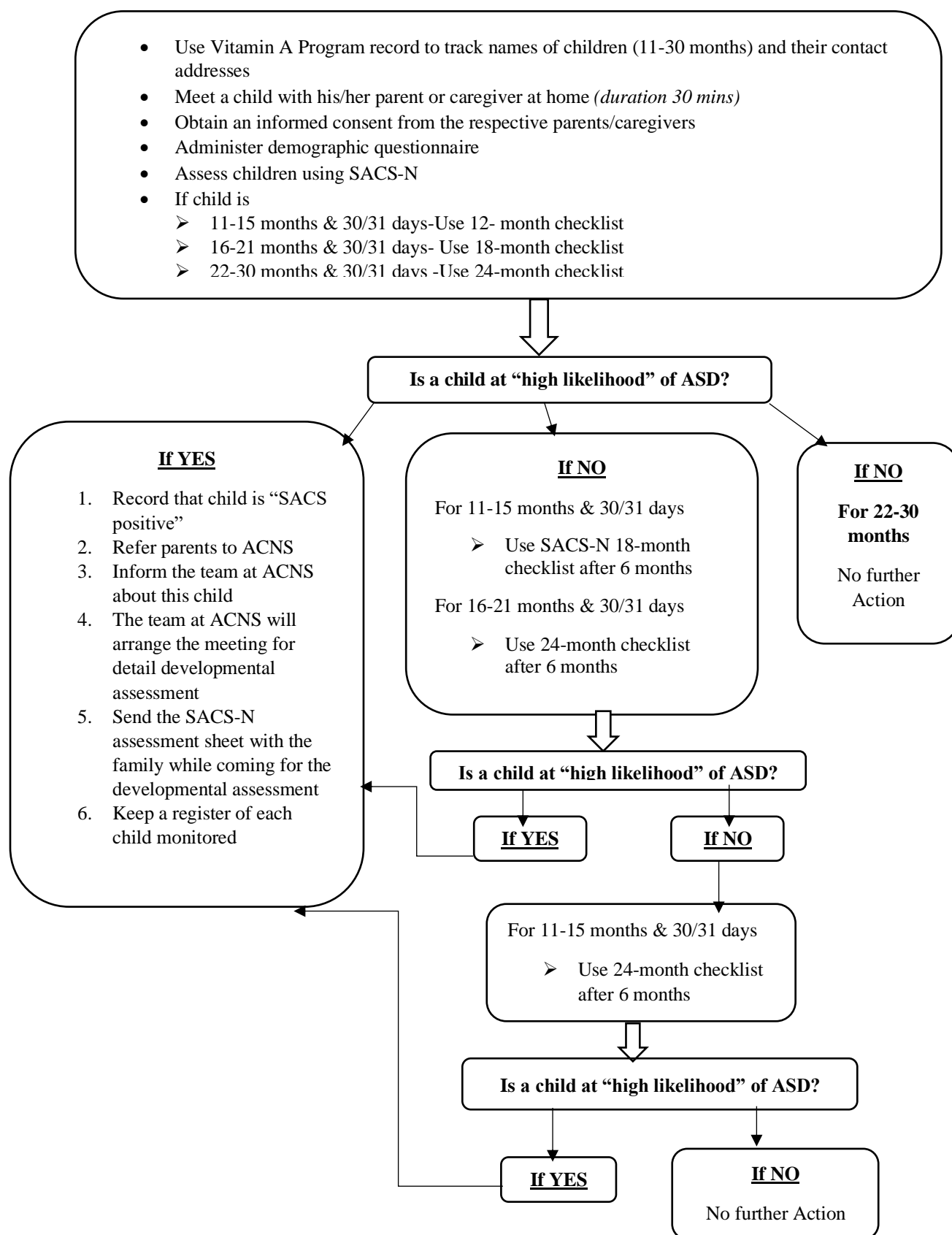


Figure A1. Pathway for Female Community Health Volunteers (FCHVs) to refer a child to the AutismCare Nepal Society (ACNS)

Appendix 2

PART I: GENERAL AND DEMOGRAPHIC INFORMATION

Please answer the following questions.

Child Details	
Child ID Number:	
Child's Name:	<div> <div></div> <div>First Name</div> <div>Last Name</div> </div>
Date of Birth:	<div> <div>____/____/____ (YYYY/MM/DD)</div> <div>Age in months: _____</div> </div>
Parental Details	
Mother's Name:	<div> <div></div> <div>First Name</div> <div>Last Name</div> </div>
Date of Birth:	____/____/____ (YYYY/MM/DD)
Please tick (✓) on suitable option that you think is the most relevant.	
Level of Education:	<input type="checkbox"/> Can read and write <input type="checkbox"/> Primary education (1-5), please specify: _____ <input type="checkbox"/> Lower secondary education (6-8), please specify: _____ <input type="checkbox"/> Secondary education (9-10), please specify: _____ <input type="checkbox"/> More than secondary education, please specify: _____
Usual Occupation:	<input type="checkbox"/> Agriculture, please specify: _____ <input type="checkbox"/> Government Job, please specify: _____ <input type="checkbox"/> Government Job, please specify: _____ <input type="checkbox"/> Non-Government Job please specify: _____ <input type="checkbox"/> Business, please specify: _____ <input type="checkbox"/> Daily wage labour, please specify: _____ <input type="checkbox"/> Foreign employment, please specify: _____ <input type="checkbox"/> Others, please specify: _____
Monthly Income (In Nepalese Rupees):	<input type="checkbox"/> ≥ 45,751 <input type="checkbox"/> 22,851-45,750 <input type="checkbox"/> 17,151-22,850 <input type="checkbox"/> 11,451-17,150 <input type="checkbox"/> 6,851-11,450 <input type="checkbox"/> 2,301-6,850 <input type="checkbox"/> ≤2,300
Country of Birth:	<input type="checkbox"/> Nepal <input type="checkbox"/> Other (please specify): _____
Caste/Ethnicity:	<input type="checkbox"/> Newar <input type="checkbox"/> Brahmin <input type="checkbox"/> Chhetri <input type="checkbox"/> Tamang <input type="checkbox"/> Magar

	<input type="checkbox"/> Other (<i>please specify</i>): _____
Religion:	<input type="checkbox"/> Hinduism <input type="checkbox"/> Buddhism <input type="checkbox"/> Kirant <input type="checkbox"/> Islam <input type="checkbox"/> Christianity <input type="checkbox"/> Other (<i>please specify</i>): _____
Father's Name:	<div style="border-bottom: 1px solid black; width: 100%;"></div> <div style="display: flex; justify-content: space-between;"> First Name Last Name </div>
Date of Birth:	____/____/____ (YYYY/MM/DD)
Please tick (✓) on suitable option that you think is the most relevant.	
Level of Education	<input type="checkbox"/> Can read and write <input type="checkbox"/> Primary education (1-5), <i>please specify</i> : _____ <input type="checkbox"/> Lower secondary education (6-8), <i>please specify</i> : _____ <input type="checkbox"/> Secondary education (9-10), <i>please specify</i> : _____ <input type="checkbox"/> More than secondary education, <i>please specify</i> : _____
Usual Occupation:	<input type="checkbox"/> Agriculture, <i>please specify</i> : _____ <input type="checkbox"/> Government Job, <i>please specify</i> : _____ <input type="checkbox"/> Government Job, <i>please specify</i> : _____ <input type="checkbox"/> Non-Government Job <i>please specify</i> : _____ <input type="checkbox"/> Business, <i>please specify</i> : _____ <input type="checkbox"/> Daily wage labour, <i>please specify</i> : _____ <input type="checkbox"/> Foreign employment, <i>please specify</i> : _____ <input type="checkbox"/> Others, <i>please specify</i> : _____
Monthly Income (In Nepalese Rupees):	<input type="checkbox"/> ≥ 45,751 <input type="checkbox"/> 22,851-45,750 <input type="checkbox"/> 17,151-22,850 <input type="checkbox"/> 11,451-17,150 <input type="checkbox"/> 6,851-11,450 <input type="checkbox"/> 2,301-6,850 <input type="checkbox"/> ≤ 2,300
Country of Birth:	<input type="checkbox"/> Nepal <input type="checkbox"/> Other (<i>please specify</i>): _____
Caste/Ethnicity:	<input type="checkbox"/> Newar <input type="checkbox"/> Brahmin <input type="checkbox"/> Chhetri <input type="checkbox"/> Tamang <input type="checkbox"/> Magar <input type="checkbox"/> Other (<i>please specify</i>): _____
Religion:	<input type="checkbox"/> Hinduism <input type="checkbox"/> Buddhism <input type="checkbox"/> Kirant <input type="checkbox"/> Islam <input type="checkbox"/> Christian <input type="checkbox"/> Other (<i>please specify</i>): _____

Family Type:	<input type="checkbox"/> Nuclear <input type="checkbox"/> Joint <input type="checkbox"/> Extended
The Parents are:	<input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Other (<i>please specify</i>): _____
The Primary Caregiver of the Child:	<input type="checkbox"/> Both parents <input type="checkbox"/> Mother only <input type="checkbox"/> Father only <input type="checkbox"/> Grandparents <input type="checkbox"/> Other (<i>please specify</i>): _____
Contact Address:	District _____ Municipality/VDC _____ Town/Village _____ House no. _____ Ward no. _____ Telephone (Home, if applicable): _____ Mobile (Mother/Father): _____ Email (Mother/Father): _____

Appendix 3**SACS 12-month Checklist****Pointing (Key Item)**

Get a doll, show it to the child and say 'This is doll'. Then put the doll across the room (where the child can see it) and say, 'Where's doll?' Does the child point to the doll and look at your face?

YES/NO

Eye Contact (Key Item)

Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does he/she make eye contact with you? **YES/NO**

Waving 'bye-bye' (Key Item)

Elicit the social routine of waving bye-bye (e.g. pretend to leave room and wave bye-bye to the child). Does he/she wave back? **YES/NO**

Imitation (Key Item)

Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'. Does he/she imitate you? **YES/NO**

Response to name (Key Item)

Call the child's name. Does he/she turn to look at you? (Make sure child is not already looking at you) **YES/NO**

Follows point

Get the child's attention and then point to an object across the room and say 'WOW, look at that!' Does he/she look at where you are pointing at (as opposed to just looking at your hand/arm)?

YES/NO

Social smiles

Has the child smiled while making eye contact with you? If not, smile at the child. Does he/ she smile back? (Do not use physical contact to elicit a smile) **YES/NO**

Conversational babble

Does the child babble (e.g. saying agaga, adaba, mama, dada) in a conversational like manner?

YES/NO

Speaks 1–3 words

Does the child speak 1–3 recognisable words? **YES/NO**

Understands simple instructions

Show the child a block and place it beside him/her. Then ask, 'Give me the block'. Does he/she give you the block? **YES/NO**

Attending to sounds

Has the child been attending to/seem interested in sounds during the session? **YES/NO**

If answered NO to 3 of the 5 KEY ITEMS, child is at “HIGH LIKELIHOOD” of ASD

Appendix 4

SACS 18-month Checklist

Pointing (Key Item)

Get a doll, show it to the child and say 'This is doll'. Then put the doll across the room (where the child can see it) and say, 'Where's doll?' Does the child point to the doll and look at your face?

YES/NO

Eye Contact (Key Item)

Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does he/she make eye contact with you? **YES/NO**

Waving 'bye-bye' (Key Item)

Elicit the social routine of waving bye-bye (e.g. pretend to leave room and wave bye-bye to the child). Does he/she wave back? **YES/NO**

Showing (Key Item)

Does the child try to communicate with you or the parent in a SOCIAL manner? (That is, has s/he held up a toy/object and "showed" it to you, WITH eye contact? **YES/NO**

Pretend play (Key Item)

Give the child a toy cup and pot. Say 'Can you pour a drink and drink it?' Does the child pretend to pour a drink and/or drink it? (Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy) **YES/NO**

Imitation

Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'. Does he/she imitate you? **YES/NO**

Response to name

Call the child's name. Does he/she turn to look at you? (Make sure child is not already looking at you) **YES/NO**

Follows point

Get the child's attention and then point to an object across the room and say 'WOW, look at that!' Does he/she look at where you are pointing at (as opposed to just looking at your hand/arm)? **YES/NO**

Social smile

Has the child smiled while making eye contact with you? If not, smile at the child. Does he/she smile back? (Do not use physical contact to elicit a smile) **YES/NO**

Uses 5–10 words

Does the child use 5–10 words? **YES/NO**

Understands words

Does the child understand many more words? **YES/NO**

Obeys simple instructions

Show the child a block and place it beside him/her. Then ask, ‘Give me the block’. Does he/she give you the block? **YES/NO**

Points to facial features

Get the child’s attention. Say ‘point to your eyes/nose/mouth’. Does he/she point to his/her eyes/nose/mouth? **YES/NO**

Loss of skills

Ask the parent if the child has lost ANY language or social skills at ANY age. Has the child lost any skills? **YES/NO**

If answered NO to 3 of the 5 KEY ITEMS, child is “HIGH LIKELIHOOD” of ASD

Appendix 5

SACS 24-month Checklist

Pointing (Key Item)

Get a doll, show it to the child and say 'This is doll'. Then put the doll across the room (where the child can see it) and say, 'Where's doll?' Does the child point to the doll and look at your face?

YES/NO

Eye Contact (Key Item)

Has the child spontaneously made eye contact with you during the session? If not, interact with the child to elicit eye contact. Does he/she make eye contact with you? **YES/NO**

Waving 'bye-bye' (Key Item)

Elicit the social routine of waving bye-bye (e.g. pretend to leave room and wave bye-bye to the child). Does he/she wave back? **YES/NO**

Showing (Key Item)

Does the child try to communicate with you or the parent in a SOCIAL manner? (That is, has s/he held up a toy/object and "showed" it to you, WITH eye contact? **YES/NO**

Pretend play (Key Item)

Give the child a toy cup and pot. Say 'Can you pour a drink and drink it?' Does the child pretend to pour a drink and/or drink it? (Other examples include feeding the teddy with a spoon, or using a pretend phone to call teddy) **YES/NO**

Imitation Get the child's attention. Use a brush/comb on your hair. Give it to the child and say 'your turn'. Does he/she imitate you? **YES/NO**

Response to name

Call the child's name. Does he/she turn to look at you? (Make sure child is not already looking at you) **YES/NO**

Follows point Get the child's attention and then point to an object across the room and say 'WOW, look at that! Does he/she look at where you are pointing at (as opposed to just looking at your hand/arm)? **YES/NO**

Social smile

Has the child smiled while making eye contact with you? If not, smile at the child. Does he/she smile back? (Do not use physical contact to elicit a smile) **YES/NO**

Uses 20–50 words

Does the child use 20–50 words? **YES/NO**

2-Word Utterances

Does the child use some two-word phrases (e.g. want drink)? **YES/NO**

Follows simple commands

Show child a teddy bear and place it beside him/her. Then ask “Give me teddy”. Does h/she give you the teddy? **YES/NO**

Loss of skills

Ask the parent if the child has lost ANY language or social skills at ANY age. Has the child lost any skills? **YES/NO**

Parallel Plays

Does the child play near (not necessarily with) other children? (ask parent) **YES/NO**

Interest in other children

Does the child seem interested in other children of their own age? (ask parent) **YES/NO**

If answered NO to 3 of the 5 KEY ITEMS, child is at “HIGH LIKELIHOOD” of ASD

Appendix 6

Name of the Study: Social Attention and Communication Surveillance -NEPAL (SACS-N)

Researchers: Prof. Cheryl Dissanayake
Dr. Josephine Barbaro
Ms. Rena Shrestha

Introduction

I am

female health community volunteer (FCHV), in your ward and I am working with a research team from AutismCare Nepal Society, Nepal and the School of Psychology and Public Health at La Trobe University, Australia.

This information statement tells you about this research which we would like to invite you and your child to participate in. If there is anything you do not understand, please ask me and I will explain it to you.

About the Study:

The purpose of this study is to promote the early identification of problems in social attention and communication behaviours in infants and toddlers between 11-30 months in the Kirtipur Municipality, which represent important developmental milestones. This study is being funded by a La Trobe University Faculty of Science, Technology and Engineering.

Social attention and communication skills include making regular eye contact with people, showing interest in other people, smiling at others, sharing an interest in an object or event with others, and producing communicative vocalisations. The frequent occurrence of these behaviours during infancy and toddlerhood indicates healthy development.

Participation Type

This research will involve:

- your participation in a survey about “Knowledge of Early Child Development among Parents/Caregivers in Kirtipur Municipality” that will take about 10 mins.
- assessment of your child’s social attention and communication behaviours by FCHV which will take about 15-20 mins.

Participant Selection

You are being invited to take part in this research because you have a child between 11 – 30 months of age. We want to determine parent’s knowledge about developmental milestones in young children, which can lead to developing different awareness programs about developmental difficulties common in early childhood.

Your child’s participation in this study can contribute to better understanding of early social and communication development in Nepalese infants and toddlers. This participation can contribute to developing a reliable tool to identify children with social attention and communication problems early in life so that the families can access the necessary supports in a timely manner, which are known to promote better developmental outcomes for children.

Procedure

Your child’s behaviour will be monitored by the FCHV at 6-monthly intervals until s/he is 24 months. If the FCHV finds that your child is showing any difficulty in his/her social attention and communication skills, you will be invited to have a thorough developmental assessment of your child at the child development unit at AutismCare Nepal Society (ACNS), Gairidhara, Kathmandu. ACNS is supporting this research study by helping is to conduct developmental assessments of children referred by FCHVs in Kirtipur Municipality. It will provide you the

opportunity to have a free comprehensive developmental assessment of your child to check his/her development to make sure that s/he is developing normally.

Benefit of Participation:

We will be able to detect if your child is presenting with any problems in his/her social attention and communication development and, if this is the case, your child can receive a comprehensive developmental assessments free-of-charge.

By signing the Consent Form, you give permission to participate in the study to complete the parental knowledge survey and allow us to assess your child at 12-, 18- and 24- months depending on his/her age during the first assessment. It also allows us to refer your child for a developmental assessment at ACNS.

Confidentiality

The information gathered for the study will be used for research. The results will be published in scholarly journals and presented at conferences, but no information that discloses your own or your child's identity will be used so that all personal details will remain confidential. Any information about you or your child will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information at the AutismCare Nepal Society Office and the Child Development Unit at La Trobe University in a secure database in an unidentifiable form. The information gathered may be used in other related research projects, aimed at understanding social attention and communication in infants and toddlers, undertaken by Professor Dissanayake, Dr Barbaro, Ms. Shrestha and other student researchers working under their supervision.

Withdrawal

You have the right to withdraw from active participation in this project at any time. You may also request that data arising from your participation are not used in the research project provided that this right is exercised within four weeks of the completion of your participation in the project. You are asked to complete the "Withdrawal of Consent Form" or to notify the researcher by email or telephone that you wish to withdraw your consent for your data to be used in this research study."

Questions regarding this study can be directed to Ms. Rena Shrestha (Tel; +977-9841484162/+61 450 392 010; email: shrestha.r@latrobe.edu.au) at the School of Psychological Science, La Trobe University, Bundoora, Victoria, 3083, Australia.

If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Member Secretary, Nepal Health Research Council, Kathmandu Nepal (P: 977-1-4254220, 4227260, E: nhrc@nhrc.org.np) or the Senior Human Ethics Officer, Ethics and Integrity, Research Office, La Trobe University, Victoria, 3086, Australia (P:+61 3 9479 1443, E: humanethics@latrobe.edu.au).

Appendix 7

Social Attention and Communication Surveillance-Nepal (SACS-N)

Please complete the following:

I, _____, have read /have had read to me and understood **the Participant Information Statement and Consent Form**, and any questions I have asked have been answered to my satisfaction. I agree to participate in the project with my child, realising that I may withdraw at any time

I agree that research data provided by me or with my permission during the project may be included in a thesis, presented at conferences and published in journals on the condition that neither my name nor any other identifying information is used.

☐ **Written Consent**

☐ **Verbal Consent**

_____ **Date of Birth:** ____ / ____ / ____

(Name of Child) (Block Letters)

Name of Parent/Caregiver (Block Letters)

Date: ____ / ____ / ____

Signature of Parent/Caregiver (if applicable)

Contact Details

District: _____ Municipality/VDC: _____

Town/Village: _____ House no: _____ Ward no: _____

Telephone (Home): _____ (Mobile): _____

Email: _____

Office Use Only

Name of Female Health Community Volunteer (Block Letters)

Date: ____ / ____ / ____**Signature of Female Health Community Volunteer**

Name of Investigator (Block Letters)

Signature of Investigator

Name of Student Supervisors (Block Letters)

Appendix 8**La Trobe University
University Human Ethics Committee****Withdrawal of Consent for Use of Data Form****Social Attention and Communication Surveillance-Nepal (SACS-N)**

I, _____, wish to WITHDRAW my consent to the use of data arising from my participation. Data arising from my participation must NOT be used in this study as described in the Information and Consent Form. I understand that data arising from my participation will be destroyed provided this request is received within four weeks of the completion of my participation in this project. I understand that this notification will be retained together with my consent form as evidence of the withdrawal of my consent to use the data I have provided specifically for this study.

☐ **Written Withdrawal of Consent**
Consent

☐ **Verbal Withdrawal of**

Participant's name:

.....

Signature (if applicable):

.....

Date:

.....

Appendix 9

Name of the Study: Social Attention and Communication Surveillance-Nepal (SACS-N)

Researchers: Prof. Cheryl Dissanayake
Dr Josephine Barbaro
Ms. Rena Shrestha

Your female community health volunteer (FCHV) has identified that your child may be experiencing some difficulty in his/her social attention and communication as indicated during social attention and communication surveillance. As a result we would like to undertake a thorough developmental assessment of your child's social attention and communication abilities. It will involve:

1) Direct observation of your child at the AutismCare Nepal Society (ACNS) during administration of a developmental and behavioural assessment which will take about 2 hours to complete.

2) Parental/caregiver interview and completion of questionnaires about your child.

The number of sessions you and your child are required to attend will depend on the age of your child at your first visit to the ACNS. We would like to see your child at 6-monthly intervals until s/he is 24 months of age.

Each session will be videotaped for later analysis, and the consultation will be free-of-charge.

Benefit of Participation:

We will be able to detect if your child is having any problems with his/her development, and if this is the case, we will refer your child for further assessments and/or early intervention. The early detection of any developmental problems in your child is important for maximising his/her positive developmental outcomes.

The results of all developmental assessments of your child will be available to you on request (also free-of-charge). A summary of the results of this study will also be available on request at the conclusion of the study.

Withdrawal:

You have the right to withdraw from active participation in this project at any time. You may also request that data arising from your participation are not used in the research project provided that this right is exercised within four weeks of the completion of your participation in the project. You are asked to complete the "Withdrawal of Consent Form" or to notify the researcher by email or telephone that you wish to withdraw your consent for your data to be used in this research study.

How the Data will be used:

The information gathered for the study will be used for research. The results will be published in scholarly journals and presented at conferences, but no information that discloses your own or your child's identity will be used so that all personal details will remain confidential. Participant results will be stored in locked files in the Autism Care Nepal Society Office and Child Development Unit, La Trobe University in a secure database in an unidentifiable form. The information gathered may be used in other related research projects, aimed at understanding social attention and communication in infants and toddlers, undertaken by Professor Dissanayake, Dr Barbaro, Ms. Shrestha and other student researchers working under their supervision.

Questions regarding this study can be directed to Ms. Rena Shrestha (Tel; +977-9841484162/+61 450 392 010; email: shrestha.r@latrobe.edu.au) at the School of Psychological Science, La Trobe University, Bundoora, Victoria, 3083, Australia.

If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Member Secretary, Nepal Health Research Council, Kathmandu Nepal (P: 977-1-4254220, 4227260, E: nhrc@nhrc.org.np) or the Senior Human Ethics Officer, Ethics and Integrity, Research Office, La Trobe University, Victoria, 3086 (P: +61 3 9479 1443, E: humanethics@latrobe.edu.au).

Appendix 10**Social Attention and Communication Surveillance-Nepal (SACS-N)**

Please complete the following:

I, _____, have read /have had read to me and understood **the Participant Information Statement and Consent Form**, and any questions I have asked have been answered to my satisfaction. I agree to participate in the project with my child, realising that I may withdraw at any time. I agree to allow the video recording of the sessions and am aware that I can request a copy of this recording.

I agree that research data provided by me or with my permission during the project may be included in a thesis, presented at conferences and published in journals on the condition that neither my name nor any other identifying information is used.

☐ **Written Consent**

☐ **Verbal Consent**

(Name of Child) (Block Letters) **Date of Birth:** ____ / ____ / ____

Name of Parent/Caregiver (Block Letters)

Signature of Parent/Caregiver (if applicable) **Date:** ____ / ____ / ____

Office Use Only

Name of Investigator /Psychologist at ACNS (Block Letters)

Date: ____ / ____ / ____

Signature of Investigator /Psychologist at ACNS

Name of Investigator (Block Letters)

Signature of Investigator

Name of Student Supervisors (Block Letters)

CHAPTER 6

STUDY 3: CHANGES IN KNOWLEDGE ON THE EARLY SIGNS OF AUTISM AMONG FEMALE COMMUNITY HEALTH VOLUNTEERS IN NEPAL

This paper has been submitted for publication.

Abstract

Inadequate knowledge, shortage of trained professionals, and lack of early screening/surveillance tools remain significant barriers in the early identification (and diagnosis) of autism in low- and middle-income countries (LMICs). Raising awareness in local communities through cost-effective training and task sharing to community health workers have been advocated. The study evaluated Nepalese Female Community Health Volunteers' (FCHVs) knowledge regarding social attention and communication development and the early signs of autism before, immediately after, and at 12-months following training. Sixty FCHVs attended a workshop on Social Attention and Communication Surveillance, which included typical and atypical social attention and communication development in infants, the early signs of autism, and how to monitor key behaviours relevant to the identification of autism in infants/toddlers. Following training, the FCHVs showed significant improvement in knowledge about autism and reported greater confidence in monitoring and referring young children at risk of autism, which was sustained one year later. Most FCHVs reported a positive impact of training on their work. The findings indicate the effectiveness of training in improving FCHVs' knowledge and confidence to monitor and refer young children at "high likelihood" of autism.

Keywords: autism, early identification, screening, developmental surveillance, training, knowledge, low- and middle-income countries, Nepal

Changes in Knowledge on the Early Signs of Autism among Female Community Health Volunteers in Nepal

Autism is an early-onset neurodevelopmental condition associated with a lifelong impact and disability. According to the 'Global Burden of Disease Study' 2010, autism contributes to 10% of global disability-adjusted life years (Murray et al., 2012). The reported prevalence rates of autism have been increasing steadily over the past 30 years (Magán-Maganto et al., 2017) affecting all racial, ethnic and socioeconomic groups Centers for Disease Control and Prevention (2014). However, the prevalence of autism is still unknown in many low- and middle - income countries (LMICs) (World Health Organization, 2013). While 90% of the world's children live here (Elsabbagh et al., 2012), there is little awareness, limited services and scarce research undertaken in LMICs (Durkin et al., 2015; Wallace et al., 2012). Inequalities in service provision to people with autism in LMICs, including identification, support and intervention programs after diagnosis, are increasingly recognised as global concerns (Durkin et al., 2015; Elsabbagh et al., 2012).

International efforts include: the United Nation's recognition of autism as an emerging public health issue, and declaration of April 2nd as world autism awareness day (United Nations, 2007); the World Health Organisation's (WHO) endorsement of the Mental Health Gap Action Program (World Health Organization, 2008); and the Sixty-Sixth World Health Assembly's adoption of the Comprehensive Mental Health Action Plan (2013-2020) (World Health Organization, 2013); all have emphasised the need to scale up services in LMICs. Following this call for action, the WHO consultation meeting (Hahler & Elsabbagh, 2015; World Health Organization, 2013) brought together experts, government representatives, UN agencies and civil societies across High Income Countries (HICs) and LMICs calling for the urgent need to strengthen health services for people with autism and other developmental disorders (DDs). This WHO-led meeting

(World Health Organization, 2013) and a number of other researchers (Durkin et al., 2015; Elsabbagh et al., 2012; Khan et al., 2012) recommended strategies aimed at improving knowledge, building capacities with evidence- and competency-based training, promoting task sharing and developing sustainable, cost-effective models of care within primary health services.

It is now well acknowledged that early identification and diagnosis of autism provide pathways to early intervention when the brain is highly malleable (Dawson, 2008), enhancing cognitive, language and adaptive skills (Clark, Vinen, Barbaro, & Dissanayake, 2017; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014). Despite evidence that children can be reliably diagnosed with autism by 24-months-of-age (Barbaro & Dissanayake, 2010), this is rarely achieved in LMICs. A study conducted at AutismCare Nepal Society (ACNS) found the mean age of diagnosis of autism to be 56 months in a sample of 50 children (Shrestha & Shrestha, 2014). The mean age of diagnosis was recently re-examined using de-identified data of 246 children with autism registered at ACNS from 2010 to 2015 (Shrestha, Dissanayake, & Barbaro, 2019), with the age of diagnosis being 58 months, indicating that most children miss the critical window for early intervention.

Limited knowledge of autism amongst health professionals remains a significant barrier for early identification and diagnosis of autism in Nepal. Sixty-five per cent of paediatricians with 10- to 45-years of experience in Kathmandu had inadequate knowledge of autism, and 91% of them reported having difficulties in making a diagnosis (Khatri, Onta, Tiwari, & Choulagai, 2011). These findings are consistent with previous studies in LMICs including Nigeria (Bakare et al., 2009; Esegbe et al., 2015), India (Daley & Sigman, 2002), and Pakistan (Imran et al., 2011; Rahbar, Ibrahim, & Assassi, 2011). For example, health care professionals in Pakistan were unaware of early autism symptoms before 36 months of age with the majority of them believing that language

delay is typical for 2-3-year-old toddlers (Imran et al., 2011). Likewise, when Daley and Sigman (2002) asked Indian health professionals to rate 18 diagnostic characteristics of autism, they were less likely to rate language delay as a concern, despite being a common marker for diagnosing autism in toddlerhood (Zwaigenbaum, Bryson, & Garon, 2013).

Heys et al. (2017) found a substantial lack of knowledge regarding typical and atypical child development, including autism, in Nepal. Parents, community workers, primary school and early childhood teachers characterised atypical behaviours in autism as "stubborn". They also used the term "slow-mindedness" ("susthadimaag" in Nepali, often used to describe intellectual disability) to label the child with possible autism indicating the lack of knowledge between these two conditions. Consistent with previous studies (Gona, 2015; Minhas et al., 2015; Tilahun et al., 2016) in LMICs, many participants attributed autism to poor parenting, the maternal and child's diet, maternal behaviour, and spiritual or supernatural reasons including fate, karma and curse of God. Consequently, many children in LMICs remain unidentified or misdiagnosed in their early years, highlighting the necessity to reduce misconceptions about autism.

A recent study among 4098 rural Nepali children (9-13 years) reported an estimated prevalence of 3 cases per 1000 (Heys et al., 2018), which is lower than the reported global prevalence of 6.2 per 1000 (Elsabbagh et al., 2012). The finding indicates a potential under-detection and under-diagnosis of autism that is likely to reflect a lack of knowledge about autism, coupled with a lack of early screening/surveillance programs and tools, and an inadequate number of trained health professionals (Heys et al., 2017; Shrestha & Santangelo, 2014). Raising awareness in local communities through cost-effective training, and task sharing to community health workers has been advocated to promote early identification of autism and other developmental problems in LMICs (Ruparelia et al., 2016; World Health Organization, 2013).

Task sharing involves decentralisation of health programs that enable a cost-effective, equitable and sustainable healthcare system by training non-professional primary health workers (Lehmann, Van Damme, Barten, & Sanders, 2009). Specialists participate in building non-specialist health workers' capacity, ensuring the availability and quality of services (Divan et al., 2015). Studies in Ethiopia, India, Nepal, South Africa, and Uganda demonstrated that it is feasible and effective to use other non-specialist workers such as teachers and community-level workers to deliver child and adult mental health interventions (Mendenhall et al., 2014). A comprehensive review (Reichow, Servili, Yasamy, Barbui, & Saxena, 2013) also highlighted the ability of non-specialist workers including teachers, parents, and aides to deliver applied behaviour analysis, cognitive rehabilitation, and training and support to children with intellectual disabilities and autism, with potential for expansion in LMICs. In the past, non-specialist health workers including mother's and women's groups, female community workers, traditional birth attendants and "lady health" workers have contributed significantly to improving maternal and child health (MCH) in rural and remote communities in Sub-Saharan Africa and South Asia (Bang et al., 1990).

Task sharing was used in rural Ethiopia to increase access to services for children with autism as an extension to their ongoing community-based MCH programmes (Tilahun et al., 2017). The training included three groups of community-based health extension workers (HEWs): (1) basic mental health module (HEAT group), (2) HEAT and DD module including autism (HEAT+ group) and (3) untrained in any mental health module (Untrained Group). Compared to untrained HEWs, the HEAT and HEAT+ trained groups showed improved positive beliefs about autism and decreased negative attitude toward children with autism, with a reduced preferred social distance toward these children and their families, highlighting the relevance of task sharing for scaling up of autism services in LMICs.

Based on the above literature, the Female Community Health Volunteers (FCHVs) in Nepal have the potential to contribute to the early identification of autism. The Government of Nepal initiated the FCHVs Program in 1988 to strengthen primary health care through the voluntary participation of local women in the community. These volunteers receive an 18-day training on MCH, including birth preparedness, family planning, management of childhood illness, immunisation campaigns, and nutrition supplementation programs. A nationwide survey showed that 83% of FCHVs are literate and their median age is 41 years, with 2% being 60 years of age or older (Ministry of Health and Population, New ERA , & ICF International, 2014). FCHVs work an average of eight hours per week with an annual turnover rate of around 4% (Ministry of Health and Population, New ERA , & ICF International, 2008).

Evaluation studies (Ministry of Health and Population et al., 2008, 2014) show that 99% of FCHVs have access to children aged between 6-59 months in their communities during the Vitamin A supplementation program, which occurs at 6-monthly intervals. This program provides a unique opportunity to train FCHVs to monitor children for developmental conditions such as autism, through developmental surveillance during the first two years of life in an effort to ensure feasibility, sustainability and cost-effectiveness.

The Current Study

The aim in the current study was to train FCHVs on developmental surveillance of autism, based on Social Attention and Communication Surveillance (SACS; Barbaro & Dissanayake, 2010), and to evaluate changes in their knowledge of early social attention and communication development, and early signs of autism in infants and toddlers. This was achieved by examining their knowledge before and immediately following the training (knowledge change), and after 12-months (knowledge retention). Change in FCHVs' confidence in monitoring and referring children at "high likelihood" of autism

was also examined. Finally, an evaluation of the training on FCHVs' day-to-day practice with families within homes immediately after training, and after 6- and 12-months of implementation of the Social Attention and Communication Surveillance - Nepal (SACS-N) was conducted.

Studies have been conducted globally to examine knowledge of autism in community, clinical and educational settings (Arif, Niazy, Hassan, & Ahmed, 2013; Atun-Einy & Ben-Sasson, 2018; Bakare et al., 2009; Heys et al., 2017; Imran et al., 2011; Rahbar et al., 2011; Stone & Rosenbaum, 1988; Tilahun et al., 2017). Despite the wide range of studies examining the autism knowledge using a variety of assessment approaches (e.g. responses to autism vignettes and true/false or Likert-style response options for factual questions), there is little consensus on the most effective method of ascertaining this knowledge (Harrison, Slane, Hoang, & Campbell, 2016). The systematic review of 44 tools for assessing autism knowledge (Harrison et al., 2016) found few measures that have validated psychometric properties and included knowledge items on the very early signs of autism. The knowledge assessment tool utilised in the current study was designed specifically to measure baseline knowledge and change in knowledge following training, as well as knowledge retention, considering Nepal's context and participant's low level of literacy. To this end, an extensive literature search was conducted to develop this tool by adapting items from various sources (see Table 3).

Social Attention and Communication Surveillance (SACS-N) is a Nepali version of the Social and Communication Surveillance tool developed by Barbaro and Dissanayake (SACS; Barbaro & Dissanayake, 2010, 2013) to monitor social attention and communication behaviours in children aged 12 to 24 months. The SACS monitors 12-15 behavioural markers with the five key items at each age found to be the most predictive of a diagnosis of autism at 24 months (see Table 1; Barbaro & Dissanayake, 2010, 2013). SACS was first used in a large-scale, longitudinal community-based study in Australia

between September 2006 and June 2007 in which MCH nurses were trained to monitor early behavioural markers of autism between 12-24 months during their routine child health checks.

Table 1

Key markers of autism between 12-24 months

12 Months	18 Months	24 Months
Pointing	Pointing	Pointing
Eye contact	Eye Contact	Eye Contact
Response to name		
	Showing	Showing
Gestures	Gestures	Gestures
Imitation		
	Pretend Play	Pretend Play

Note. Adapted from “Early markers of autism spectrum disorders in infants and toddlers prospectively identified in the Social Attention and Communication Study”, by Barbaro, J., & Dissanayake, C., (2013), *Autism: International Journal of Research and Practice*, 17(1), 78.

The MCH nurses reported improved knowledge and greater confidence in identifying, monitoring and referring children at “high likelihood” of autism; they also found that the training positively impacted their practice and reported ease of implementation of the SACS into their daily work (Barbaro, Ridgway, & Dissanayake, 2011). The SACS also had an excellent positive predictive value of 81%, and excellent estimated sensitivity (84%), and specificity (99.8%)(Barbaro & Dissanayake, 2010). Hence, the SACS was chosen for implementation in Nepal. It was predicted that the FCHVs would report increased knowledge about social attention and communication behaviours and the early signs of autism following training (based on Barbaro et al., 2011), and increased confidence in monitoring and referring children based on their use of SACS-N. It was also expected that FCHVs would report improved day- to- day practice following training and over the course of one year.

Method

Study Design

A pretest-posttest-follow-up survey design was used between November 5, 2016, and January 30, 2018 to assess FCHVs' knowledge regarding social attention and communication development and the early signs of autism: prior to (T1), immediately after (T2) and following one year (T3) of the SACS-N training (n.b. the derivation and implementation of this tool is the subject of a separate manuscript). The FCHVs also evaluated the implementation of the SACS-N immediately after the training (T2a) and after 6- (T2b) and 12- (T3) months of implementation. The study reported here was conducted as a part of a larger study to implement and evaluate the effectiveness of SACS-N in identifying children at "high likelihood" of autism between 11 to 30 months of age in Kirtipur Municipality following training of FCHVs.

Study Setting

The Kirtipur Municipality is situated 7 km south-west of Kathmandu, the capital city of Nepal, with a population of 65607 (Central Bureau of Statistics, 2012). The municipality is divided into ten wards (the smallest administrative unit), with 111 FCHVs (Kathmandu District Public Health Office, 2016) volunteering in eight primary health care services (Ministry of Federal Affairs and General Administration, 2017) delivered through one primary health care centre (PHC), one health post (HP), and six sub-health posts (SHPs). To date, no community-based training on autism has been conducted in Kirtipur with this municipality selected for its peri-urban setting and to facilitate ease of referral to the ACNS 12-km away, where developmental and diagnostic assessments were carried out.

Participants

Sixty FCHVs (Mean age: 44.6 years; range 29.0-61.5) were randomly selected from eight primary health services. Eighty-two per cent of FCHVs had at least 6-years

education, and 73% had >10 years of work experience (see Table 2). All 60 FCHVs completed the survey forms at T1 and T2, and 58 FCHVs completed these at T3.

Table 2

Sample Characteristics of FCHVs (N=60)

Variable	% (n)
Age group (years)	
29-39	28.3% (17)
40-50	55% (33)
51-61	16.7% (10)
Education	
Adult education (Can read and write)	3.3% (2)
Primary (1-5)	13.3% (8)
Lower secondary (6-8)	16.7% (10)
Secondary (9-10)	38.3% (23)
More than secondary	28.3% (17)
Work Experience (years)	
1-5	10% (6)
6-10	16.7% (10)
>10	77.3% (44)

Note. FCHVs= Female Community Health Volunteers.

Measures

The knowledge survey consisted of four sections: demographic information; knowledge on early social attention and communication development; knowledge on autism and; confidence in monitoring and referring children at “high likelihood” of autism (see Appendix 2). All knowledge items had three response choices: “agree”, “disagree” and “don’t know”.

Knowledge on early social attention and communication development: This section included 17 survey statements, adapted from SACS items (Barbaro & Dissanayake, 2010, 2013) which were related to eye contact, pointing, response to name, showing, imitation, gestures, pretend play, social smiling, joint attention, use/understanding of language, parallel play and interest in peers (see Appendix 3). The items were grouped based on the similarity of items to form three subscales (see Table 3) namely social attention and communication behaviours (SACB), early language behaviours (ELB), peer relations and play behaviours (PRPB).

Knowledge on autism: This section included 23 items (see Appendix 4). which were adapted and grouped into subscales from a literature search (see Table 3) namely social communication and interaction behaviour (SCIB), restricted, repetitive behaviour, interests, or activities (RRBI), epidemiology (EPI), diagnosis and intervention (DIAGINT) and causes.

Confidence in monitoring and referring children at “high likelihood” of autism: Five items assessed the FCHVs' confidence in identifying and monitoring the signs of autism (MON) and five items assessed their confidence in referring the child at “high likelihood” of autism for developmental and diagnostic evaluations (REF). The statements were based on the survey used (Barbaro et al., 2011) following SACS training in Australia (see Appendix 5)..

Evaluation form: This five-item measure, also based on SACS training for MCH nurses (Barbaro et al., 2011) were related to the impact of training on the FCHV's work, ease of implementation of SACS-N into their current practice, timely advice on any of their queries, parents comfort in the SACS-N being undertaken at their homes, and the perceived benefit of being part of the SACS-N. Items were rated on a 4-point scale from “strongly agree” to “strongly disagree” (See Appendix 6). The form also included two

open-ended questions for FCHVs' comments on SACS-N and their suggestions to improve the use of the SACS-N in their community.

The Cronbach alpha coefficient of the full survey was .96; the Cronbach alphas for the sub-scales, SACB, ELB, PRPB were .69, and .66 and .41 respectively. Cronbach alphas for the sub-scales SCIB was .95, RRBI was .93, EPI was .94 and DIAGINT was .94. The Cronbach alphas were .98 for each of the sub-scales MON and REF. The Cronbach alphas for the SACS-N evaluation survey was .61.

Translation and Adaptation of Survey Items

The survey items were developed following consultation with Nepalese psychologists, special educators, and public health officer working in the field of autism to ensure suitability for the context. The survey forms had both positively and negatively worded items. They were first developed in English and translated into Nepali by the first author. The back translation to English was done by a professional translator with bilingual (English and Nepali) skills and experience in translation from English to Nepali and vice versa.

The Nepali-version of the survey was then piloted with ten participants in Kathmandu within a broad age range (29-66 years) and educational qualifications (literate to more than higher secondary education) to confirm the comprehensibility of the items, and to assess the time taken to conduct the survey. The survey was revised and finalised based on feedback.

Table 3

Subscales and Item Distribution

Subscales	Items
Knowledge on social attention and communication behaviours	
SACB (Barbaro et al., 2011)	Eye contact, response to name, gestures, showing, follows pointing, social smile, imitation, points to facial features
ELB (Barbaro et al., 2011)	Speaks 1-3-word, 5-10 words, 20-50 words, 2-phrase words, understands and follows simple commands
PRPB (Barbaro et al., 2011)	Interest in other children, pretend play, parallel play
Knowledge on autism	
SCIB (APA; 2013)	Communication, eye contact, gestures, friendships, pretend play
RRBI (APA; 2013)	Repetitive speech, movements, use of objects, sameness, unusual interest hyper/hypo-sensitivities
EPI (Rahbar et al., 2011; Stone & Rosenbaum, 1988)	Boys Vs girls, higher socio-economic status, higher education, presence in less than 12 years
DIAGINT (Bakare et al., 2009; Barbaro & Dissanayake, 2009; Barton, Dumont-mathieu, & Fein, 2012; Campbell, Reichle, & Van Bourgondien, 1996; Dawson, 2008; Dawson & Bernier, 2013; Guthrie, Swineford, Nottke, & Wetherby, 2013; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014; Stone & Rosenbaum, 1988)	Neurodevelopmental condition, intellectual disability, early identification, diagnosis, treatment, early intervention
Causal Factors (Heys et al., 2017)	Multiple choice items
Confidence	
MON & REF (Barbaro et al., 2011)	Ten items
Evaluation Form (Barbaro et al., 2011)	Five items

Note. SACB=Social attention and communication behaviours; ELB=Early language behaviours; PRPB=Peer relationship and play behaviours; SCIB= Social communication and interaction behaviours; RRBI=Restricted, repetitive behaviour or interests; EPI= Epidemiology; DIAGINT=Diagnosis and intervention; MON=Monitoring children at risk of autism; REF=Referring children at risk of autism.

Procedure

Informed consent (see Appendices 7 and 8) was obtained from 60 FCHVs before the SACS-N training. The study was approved by the Nepal Health Research Council (112/2016) and the La Trobe University Ethics Committee (HEC16-073). Permission was obtained from the Kathmandu District Public Health Office and the Kirtipur Municipality. In-charges at PHC, HP and SHP were informed about the study.

FCHVs completed a survey on three occasions: before the training (T1), immediately after the training (T2) and after one year of implementation of the SACS-N (T3). Each FCHV filled the survey form. The researcher was present before the T1 and research assistants distributed the survey at T2 when each FCHV independently completed the form, alongside the other FCHVs. At T3, the research assistants once again distributed the survey and each of the FCHVs completed the survey form independently. The FCHVs also evaluated the implementation of the SACS immediately after the training (T2a), after 6- (T2b), and 12-months (T3) of implementation.

Training.

Day one. Sixty FCHVs attended a five-hour SACS workshop on November 5, 2016, delivered by the second author and simultaneously translated by the first author in Nepali. The training focused on typical and atypical social attention and communication development in young children, the importance of early identification and diagnosis of autism, the early signs of autism, and the monitoring of "key" behaviours relevant to the identification of autism in infants/toddlers using SACS-N.

The SACS-N contains three checklists, designed for 12-month-olds (11-15 months) ; 18-month-olds (16-21 months) ; and 24-month-olds (22-30 months). Children are considered at "high likelihood" for autism if they fail three of the five key items (Barbaro & Dissanayake, 2010, 2013) on SACS-N at any age. The FCHVs were advised to re-administer failed items a maximum of three times and were trained to recognise

atypical behaviour rather than simply presence or absence of the behaviour. Video clips of behaviours differentiating children with and without autism were presented during training. The workshop also trained the FCHVs on how to raise concerns with parents/caregivers of children identified at “high likelihood” of autism and refer to the ACNS for further assessment/diagnosis.

Day two. The second day of the workshop was conducted by the first author. The first half of the training focused on the discussion of SACS-N checklists. The FCHVs were provided with the opportunity to ask any questions regarding the use of SACS-N checklists. The second half of the workshop focused on the SACS-N implementation in Kirtipur Municipality which included using participant information, consent and withdrawal forms, and completing the caregivers' survey forms and SACS-N checklists.

SACS-N implementation. Following training, the FCHVs began administering SACS-N to all children between 11- to 30-months within the homes they visited to monitor their social-communication skills. Children identified at “high likelihood” of autism by FCHVs were referred to ACNS for a comprehensive diagnostic assessment. All remaining children in Kirtipur Municipality who were not at “high likelihood” of autism continued to be monitored at 6-monthly intervals by FCHVs until they were 22-30 months, with children subsequently identified as at “high likelihood” being referred to the ACNS. The FCHVs were provided with regular monthly meetings and feedback on their queries.

Data Analysis

Data was entered into Microsoft Excel spreadsheet and imported into the Statistical Package for Social Sciences version 25.0 for analysis (SPSS; IBM Corp, 2017). Each scale item received a score of 1 if answered correctly, and a score of 0 if not responded correctly. A score of 0 was also given if they responded "don't know" on the assumption that a "don't know" response implies a lack of knowledge of the item. For

each item, the mean scores for T1, T2 and T3 were calculated, reflecting the proportion of each group that responded to the item correctly. Total scores of each subscale were calculated by summing the number of correct answers within each subscale for each of the three time points. A total confidence score, representing the FCHVs agreement on ten confidence items, were compared across time. For the evaluation data, “strongly agree” and “agree” responses were combined to yield a total agreement score which was compared at each point. Open-ended responses were reviewed and noted for common themes and are illustrated with quotes.

Demographic characteristics of the FCHVs were summarised using frequency and percentages. A descriptive analytic approach was undertaken with the frequency of correct responses on FCHVs' knowledge regarding social attention and communication development and autism across T1, T2 and T3. One-way repeated measure analysis of variance (ANOVA) was conducted on each of the sub-scale scores to determine whether there were significant differences in change in knowledge from pre-training to immediately after training and at the 12-month follow-up. A paired-sample t-test was conducted to compare mean difference between the agreement responses on evaluation survey at 6- and 12-month follow-up.

The Shapiro-Wilk test ($p < .05$) suggested a non-normal distribution of data. Attempts at transforming the data were unsuccessful. One-way repeated measures ANOVA was run before and after transformation, revealing similar results. Data analysis on the untransformed data were reported. Bonferroni adjustments controlled for multiple comparisons. A conservative p -value of .017 was adopted for all analyses. The ANOVA effect sizes were interpreted to indicate small, medium and large effect for a partial η^2 (η_p^2) of 0.02, 0.13, and 0.26 respectively (Pierce, Block, & Aguinis, 2004).

Results

Social Attention and Communication Behaviours (SACB)

Figure 1 illustrates the percentage of correct responses by FCHVs regarding early social attention and communication behaviours in children prior to training (T1), immediately after the training (T2) and 12-months after training (T3). The FCHVs showed good knowledge of: response to name, follows pointing, social smile and points to facial features across all three time points. By contrast, their knowledge on eye contact, gestures, showing and imitation at T1 was lower. However, marked improvement is apparent following training for gestures (T1= 63%, T2=90%, T3=86%), showing (T1= 72%, T2=92%, T3=86%), and imitation (T1= 67%, T2=92%, T3=93%), with the percentage of correct responses remaining high at the 12-month evaluation. Interestingly, in the case of eye-contact (T1= 75%), there is an increase in the percentage who had a correct response immediately after the training (T2=95%), but a decrease in knowledge is evident at the final assessment (T3=78%) returning to the pre-training level. When the analysis was undertaken on the subscale created from these items, a significant change was found in SCAB as indicated in Table A1 (see Appendix 1), $F(1.58, 90.16) = 10.73$, $p < .001$, $\eta_p^2 = 0.17$, with knowledge increasing over time. Post hoc analysis revealed that knowledge increased significantly from T1 to T2 (-.94, 95% [-1.61, -.28, $p < .001$), and from T1 to T3 (-.86, 95% [-1.63, -.08, $p = .007$); moreover, knowledge on SCAB was retained from T2 to T3 (.08, 95% [-.39, .56, $p = 1.00$).

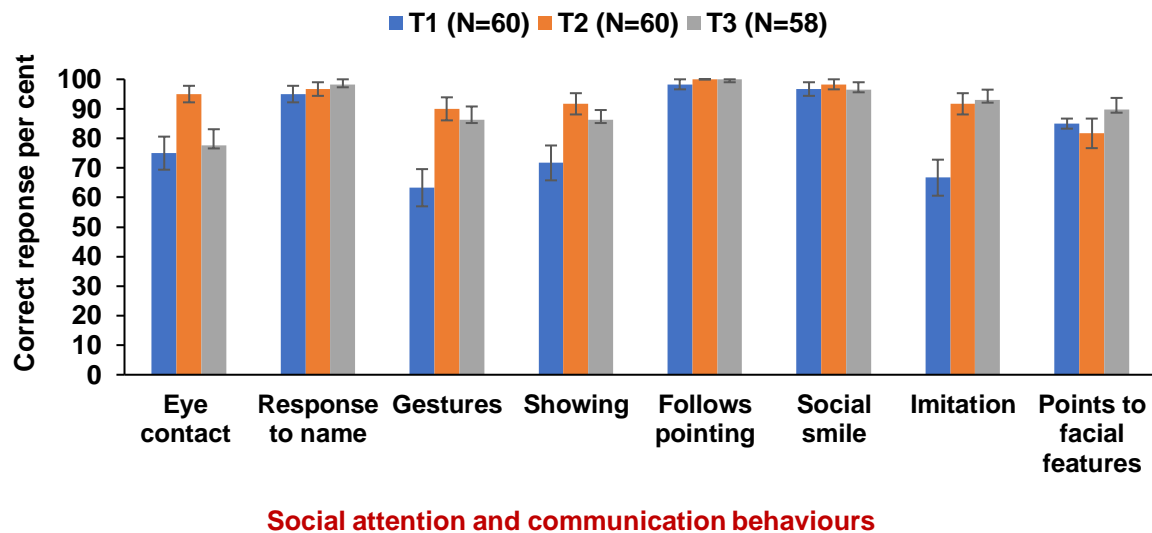


Figure 1. Knowledge on social attention and communication behaviours in typical development. Error bars represent standard errors.

Early Language Behaviours in Typical Development (ELB)

Figure 2 illustrates the changes in FCHVs' knowledge on children's use and understanding of language between 12 and 24 months of age, with increases in the percent of nurses understanding using 1-3 words (T1=87 %, T2=100%, T3=98%), 5-10 words (T1= 85%, T2=95%, T3=95%), 20-50 words (T1= 62%, T2=93%, T3=90%), and using two-word phrases (T1=75%, T2=87%, T3=88%). The FCHVs already had good knowledge in understanding simple instructions (T1=95 %, T2=98%, T3= 98%) and following simple commands (T1= 85%, T2=82%, T3=88 %). Table A1 (see Appendix 1) presents the changes in FCHVs' knowledge on the subscale of children's use and understanding of language between 12-24 months of age. The ANOVA revealed a significant increase in knowledge, $F(1.59, 91.01) = 10.97, p = .001, \eta^2 = 0.13$, over time with a medium effect size. Post hoc analysis revealed that knowledge increased significantly from T1 to T2 (-.65, 95% [-1.21, -.09, $p = .004$), and from T1 to T3 (-.69, 95% [-1.33, -.04, $p = .004$); knowledge remained stable from T2 to T3 (-.03, 95% [-.43, .36, $p = 1.00$).

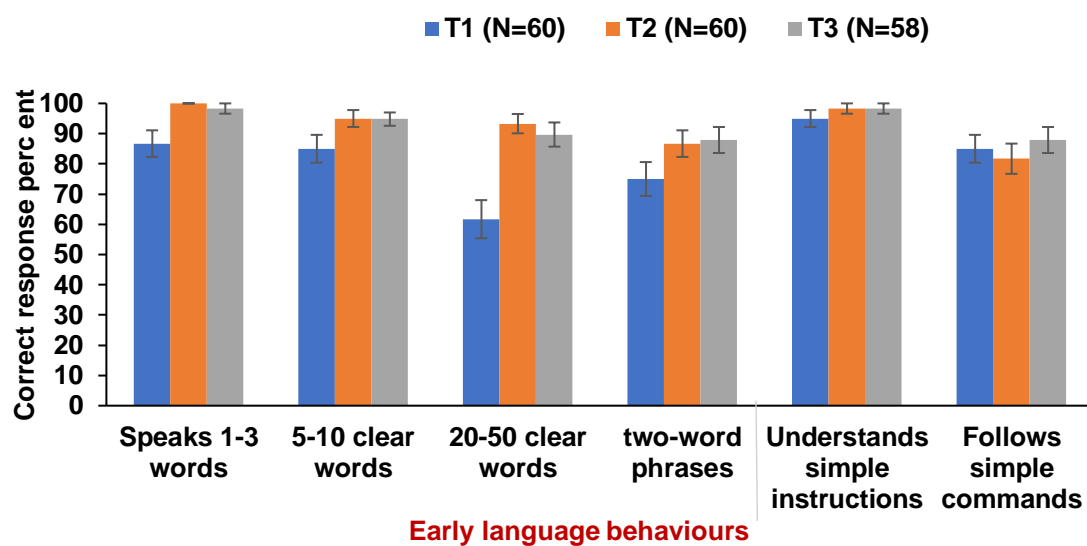


Figure 2. Knowledge on early language behaviours in typical development. Error bars represent standard errors.

Peer Relations and Play Behaviours in Typical Development (PRPB)

Figure 3 summarises the impact of training on FCHVs' knowledge regarding early peer relations and play, with only half of the FCHVs (47%) responding correctly about their knowledge of pretend play at T1, which increased to 90% immediately after training at T2 and remained high (98%) over time at T3. As the Cronbach alpha on this subscale was low, no further analysis was undertaken here.

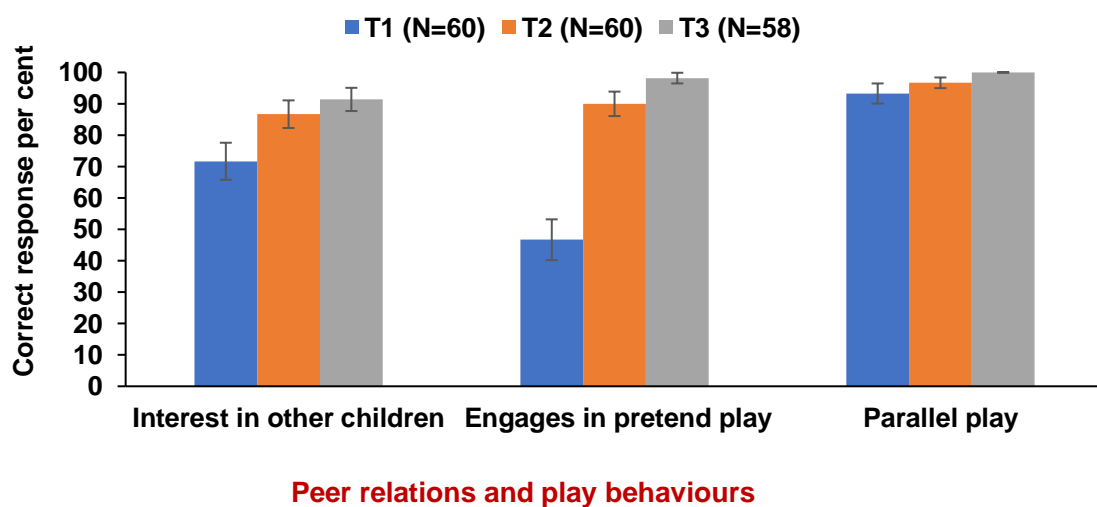


Figure 3. Knowledge on peer relations and play in typical development. Error bars represent standard errors.

Social Communication and Interaction Behaviours in Autism (SCIB)

Only one fourth (37%; $n=22$) of the FCHVs reported knowing the word autism prior to training. Even those who had heard about autism had very little knowledge about the condition. As apparent in Figure 4, most FCHVs had little knowledge about difficulties in social communication and interaction in autism including items related to communication, eye contact, gestures, friendships and pretend play. The FCHVs' knowledge increased substantially $F(1.36, 77.72) = 107.33, p < .001, \eta_p^2 = 0.65$, with large effect size over time (see Table A2; Appendix 1). Post hoc analysis revealed that knowledge significantly increased from T1 to T2 ($-2.98, 95\% [-3.72, -2.23, p < .001]$), and from T1 to T3 ($-2.79, 95\% [-3.56, -2.01, p < .001]$); knowledge on SCIB was retained from T2 to T3 ($.19, 95\% [1.18, .56, p = .44]$).

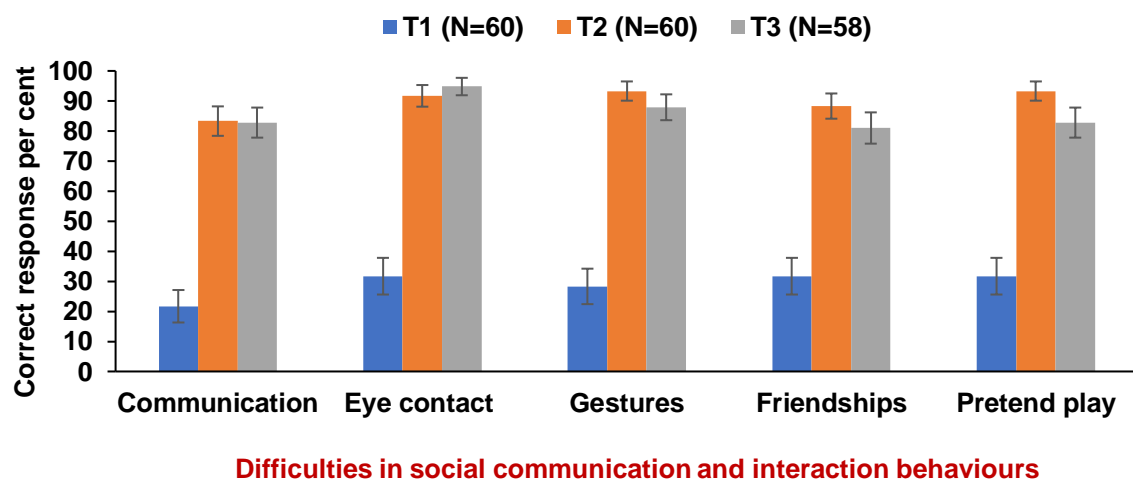


Figure 4. Knowledge on difficulties in social communication and interaction behaviours in autism. Error bars represent standard errors.

Restricted, Repetitive Behaviours and Interests in Autism (RRBI)

Only up to 20% of FCHVs knew about restricted, repetitive behaviours and interests characteristics of autism at T1. Correct responses increased at T2, which was largely sustained T3 (see Figure 5). The ANOVA showed significant increase in

knowledge $F(1.74, 99.64) = 111.78, p < .001, \eta_p^2 = 0.66$ (see Table A2; Appendix 1)..

Although post hoc analysis revealed that knowledge increased significantly from T1 to T2 ($-3.58, 95\% [-4.40, -2.76, p < .001]$), and from T1 to T3 ($-3.6, 95\% [-4.59, -2.74, p < .001]$) with retention of knowledge from T2 to T3 ($-.08, 95\% [-.73, .56, p = 1.00]$), the FCHVs showed lesser knowledge about the presence of unusual interests in autism (T1=8%, T2=25%, T3=15%) at all time-points. Despite training, most lacked knowledge on repetitive speech and stereotyped movements and hyper- and hyposensitivities which remained at only around 60% being correct following training.

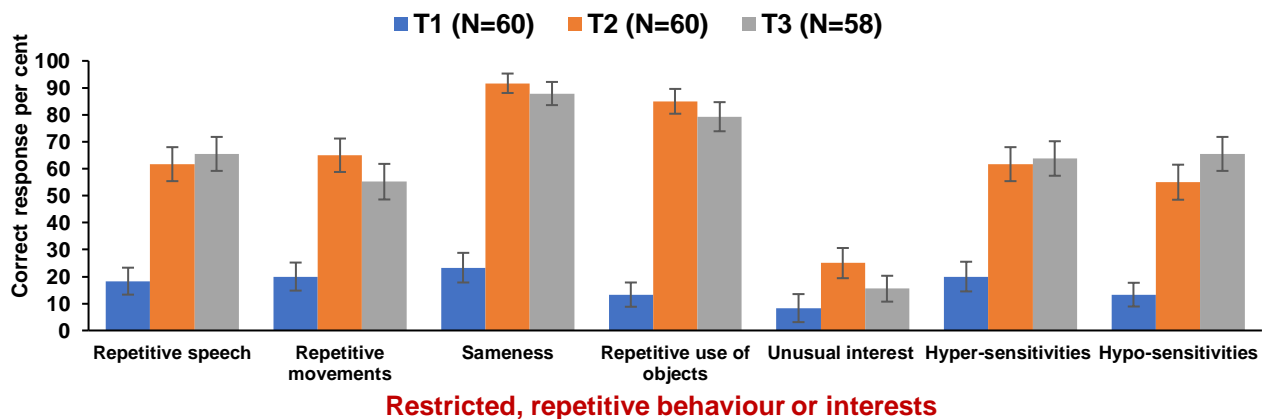


Figure 5. Knowledge on restricted, repetitive behaviours in autism. Error bars represent standard errors.

Epidemiology of Autism (EPI)

All FCHVs showed lesser knowledge initially regarding epidemiology, with a substantial increase following training, at T2 (see Figure 6). Despite an increase in numbers responding correctly regarding the “presence of autism in children less than 12 years” following training (T1=15%, T2=52%), the majority of FCHVs had lesser knowledge on this item, with the percentage who gave correct responses remaining low over time. The change in EPI knowledge following training was significant, $F(1.80, 101.23) = 82.40, p < .001, \eta_p^2 = 0.59$, with a large effect size (see Table A2; Appendix

1). While post hoc analysis indicated a significant improvement in knowledge from T1 to T2 (-2.33 95%[-2.86, -1.80, $p < .001$), and from T1 to T3 (-1.77, 95%[-2.39, -1.14, $p < .001$), little retention was observed from T2 to T3 (.56, 95%[.08, 1.03], $p = .004$). The observed decrease in knowledge could be attributed to the knowledge on gender ratios in autism and the “presence of autism in children less than 12 years” which lost some ground at T3 (see Figure 6).

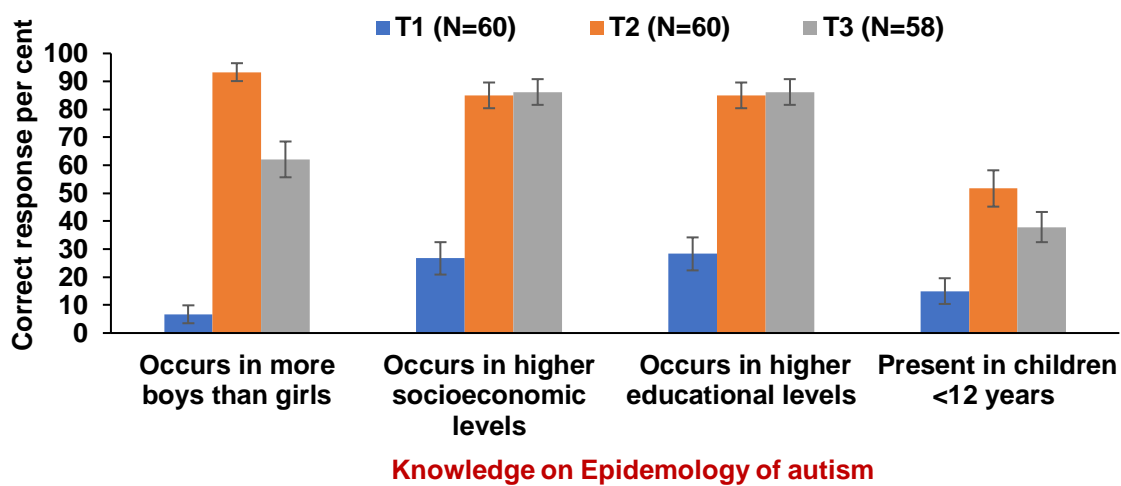


Figure 6. Knowledge on epidemiology of autism. Error bars represent standard errors.

Diagnosis and Intervention of Autism (DIAGINT)

Only a few FCHVs had knowledge regarding diagnosis and intervention for autism at T1, with improved awareness on most of these items following training, $F(1.33, 76.11) = 99.39, p < .001, \eta_p^2 = 0.63$ ((see Table A2; Appendix 1; Figure 7). Post hoc analysis showed most respondents' increased understanding on knowledge about diagnosis and intervention from T1 to T2 (-3.13, 95% [-3.97, -2.30, $p < .001$), and from T1 to T3 (-2.91, 95% [-3.73, -2.08, $p < .001$), with retention of knowledge from T2 to T3 (.22, 95% [-.16, .61], $p = .30$). Although, change in knowledge was evident on the item “autism is just an intellectual disability” with an increased percentage disagreeing with this item at T2, there was a decrease in number with correct responses at T3; nonetheless, the percentage remained above than at pre-training (T1).

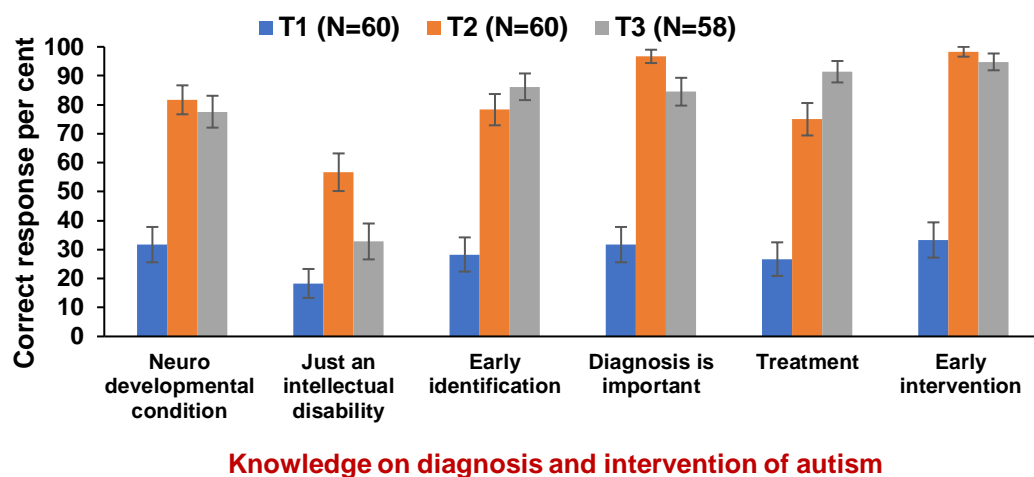


Figure 7. Knowledge on diagnosis and intervention of autism. Error bars represent standard errors.

Confidence in Monitoring and Referring Children at “high likelihood” of Autism

Figures 8 illustrates the FCHVs confidence in monitoring the signs of autism from 12 to >60 months, and in referring children for a developmental assessment. Confidence increased markedly following training and was largely maintained at the 12 months follow up. FCHVs reported higher confidence in monitoring and referring younger children (between 12-30 months) than children aged between 31 to >60 months. The summary data in Table A2 (see Appendix 1) indicates that confidence in monitoring increased markedly following training and was largely maintained at the 12 months follow up, $F(1.83, 104.66) = 103.17, p < .001, \eta_p^2 = 0.64$. Post hoc analysis revealed that confidence significantly increased from T1 to T2 (-3.10, 95% [-3.87, -2.33, $p < .001$), and from T1 to T3 (-3.19, 95% [-3.97, -2.4, $p < .001$), with this confidence retained to T3 (-.08, 95% [-.69, .52, $p = 1.00$).

Similarly, confidence in referring children at “high likelihood” of autism also increased substantially, $F(1.58, 90.45) = 106.79, p < .001, \eta_p^2 = 0.65$. Post hoc analysis indicated that confidence significantly increased from T1 to T2 (-3.00, 95% [-3.83, -2.16, $p < .001$), and

from T1 to T3 (-3.31.50, 95% [-4.07, -2.54, $p < .001$), with this confidence retained to T3 (-.31, 95% [-.82, .20, $p = .25$).

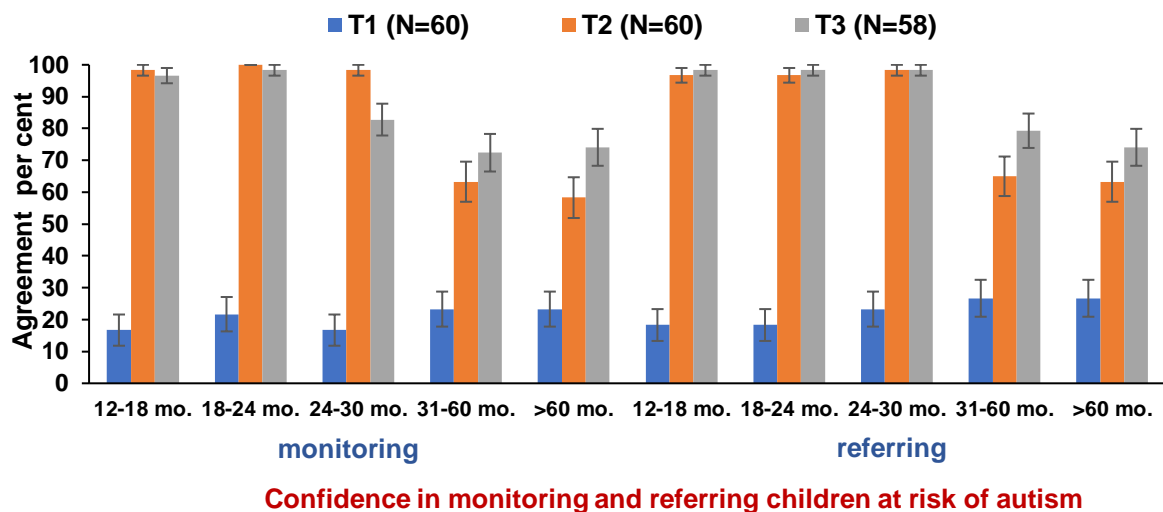


Figure 8. Confidence in monitoring and referring children at risk of autism. Error bars represent standard errors.

Causes of Autism

Table 6 presents the percentage of FCHVs who reported about the causes of autism at each time point. Heredity and abnormal brain development were the most frequent causes of autism reported by FCHVs at T2 and T3 compared to T1. Following training, increased awareness was evident with a reduced number of FCHVs reporting vaccines, diet and poor parenting cause autism. A few of them (2-6%) reported that autism is due to past karma, fate or curse of God. However, 15-23 % FCHVs following training reported that the exact cause of autism is unknown.

Table 4

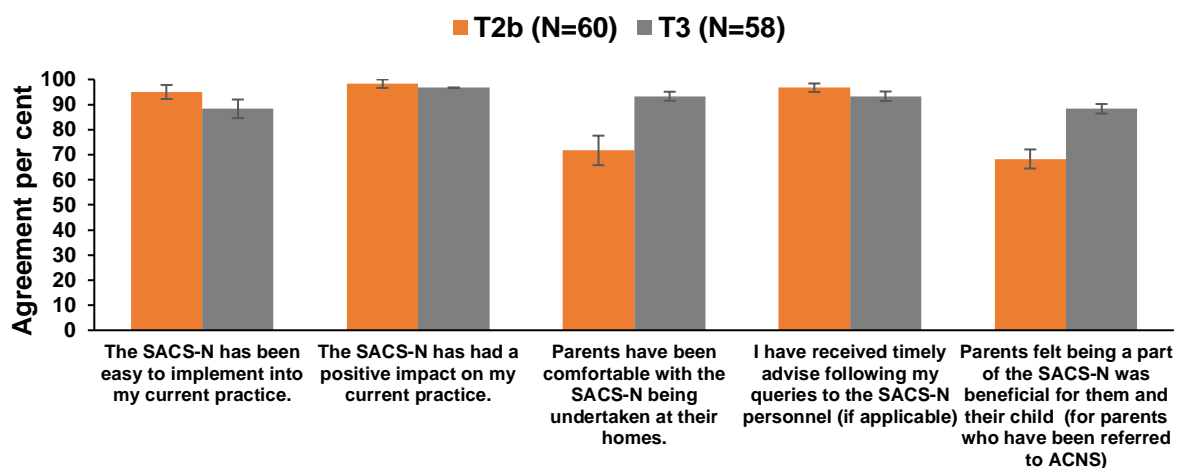
FCHVs' Knowledge on the Causes of Autism at Three Time Points

Causes	T1 (N = 60)	T2 (N = 60)	T3 (N = 58)
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Heredity	19 (31.7)	59 (98.3)	39 (67.2)
Abnormal brain development	26 (43.3)	29 (48.3)	40 (69)
Environmental Influence (toxins)	13 (21.7)	5 (8.3)	10 (17.2)
Vaccines	16 (26.7)	4 (6.7)	0 (0)
Brain trauma	26 (43.3)	10 (16.7)	20 (34.5)
Childhood illness	18 (30)	4 (6.7)	7 (12.1)
Diet	13 (21.7)	3 (5)	4 (6.9)
Poor parenting	18 (30)	5 (8.3)	12 (20.7)
Past Karma	0 (0)	1 (1.7)	2 (3.4)
Fate	0 (0)	0 (0)	4 (6.9)
God's Curse	1 (1.7)	1 (1.7)	1 (1.7)
Factors related to mother	21 (35)	8 (13.3)	12 (22.4)
Factors related to father	9 (15)	7 (11.7)	10 (17.2)
The exact cause is unknown	4 (6.7)	14 (23.3)	9 (15.5)

Evaluation of Social Attention and Communication Surveillance-Nepal

Figure 9 presents data on the per cent of FCHVs who responded positively to the implementation of the SACS-N at 6- (T2b) and 12-months (T3) following training (T2a).

FCHVs reported a positive impact of training on their work found it easy to implement SACS-N into their current practice and reported receiving timely advice on any queries they had. They also reported that parents were comfortable with the SACS-N being undertaken at their homes. For those FCHVs who referred children to the ACNS, most reported parents felt being part of the SACS-N was beneficial. Data analysis indicated that the change from 6-months ($M = 4.28$, $SD = 0.83$) to 12-months post training ($M = 4.76$, $SD = 0.54$) was significant, $t(57) = -4.72$, $p < .001$, $d = 0.62$, with a large effect size.



Social Attention and Communication Surveillance-Nepal Evaluation Statements

Figure 9. Evaluation of Social Attention and Communication Surveillance-Nepal (SACS-N). Error bars represent standard errors.

Discussion

To the best of our knowledge, this is the first study assessing Nepalese FCHVs' knowledge on social attention and communication development, early signs of autism, and their confidence in monitoring and referring children at "high likelihood" of autism following training on the SACS-N. The findings demonstrated significant improvements in FCHVs' knowledge and confidence after training which, importantly, was mostly retained at the 12-month follow-up. They also reported that training had a positive impact on their day-to-day practice. The findings indicate the feasibility and sustainability of training community-based FCHVs about the early signs of autism and their confidence about these signs to make a referral as needed within a primary healthcare system in Nepal. Previous studies have shown that improved knowledge and confidence can promote the early detection of autism (Barbaro et al., 2011; Ben-Sasson, Atun-Einy, Yahav-Jonas, Lev-On, & Gev, 2018).

Our findings indicated a significant change in knowledge of SCAB amongst FCHVs, with the exception of one behaviour – eye contact. Research suggests that these

social attention and communication behaviours are critical markers for identifying children who are at “high likelihood” of developing autism (Barbaro & Dissanayake, 2010, 2013; Zwaigenbaum et al., 2013) (Barbaro & Dissanayake, 2010, 2013; et al., 2013). As a predominantly Hindu society (81%) (Central Bureau of Statistics, 2012) and a collectivist culture (Watkins et al., 2011), social interaction and communication in Nepal promotes harmony with others and obedience and respect for elders (Triandis, 2001). Direct eye contact, however, with elders and those with authority is generally considered disrespectful and impolite (Videbeck, 2010), which is also common in other Asian countries (Daley, 2004; Freeth, Sheppard, Ramachandran, & Milne, 2013; Senju et al., 2013). It is likely that these cultural practices may have influenced FCHVs' responses to the eye-contact item. This finding indicates that eye contact during early social interaction between young children and caregivers as perceived in the Nepalese context should be a topic of discussion when training on the SACS-N. Unfortunately, there is no research on dyadic social interactions between young Nepalese children and their caregivers to add more context to this discussion. It may be important to focus on the wording of the eye contact item within SACS-N to reflect more qualitative aspects of looking, rather than it being a dichotomous (present/absent) construct (Atun-Einy & Ben-Sasson, 2018).

A knowledge gap was also evident in the FCHVs' awareness of the use of language (speaking 20-50 words and using two-word phrases), reflecting the common belief in South Asia that male children speak late (Daley & Sigman, 2002). The current finding is comparable to earlier studies in India (Daley & Sigman, 2002) and Pakistan (Imran et al., 2011) which indicated fewer concerns regarding early language delays among health professionals. Nevertheless, after training, the FCHVs showed marked improvement in their knowledge about the use of language, at T2 and T3.

Although 77% of FCHVs had more than a decade of work experience, only a quarter of them had heard about autism, and thus had poor knowledge of autism features, causal factors, epidemiology, diagnosis, and intervention, which is consistent with previous studies across LMICs (Bakare et al., 2009; Esegbe et al., 2015; Heys et al., 2018; Imran et al., 2011; Khatri et al., 2011; Rahbar et al., 2011). However, these FCHVs showed substantial improvement in their knowledge of autism across all relevant behavioural items from T1 to T2, which was retained at the 12-month follow (T3). The few available studies to date (Atun-Einy & Ben-Sasson, 2018; Ben-Sasson et al., 2018; Schwartz & Drager, 2008; Tilahun et al., 2017) have also demonstrated a change in autism knowledge among health professionals following training.

Although there was a significant gain in FCHVs' knowledge on RRBI from T1 to T2 and T3, the overall correct response per cent was relatively low about these behaviours. For example, only 60% of FCHVs showed an understanding of sensory hyper- and hyposensitivities; only 40% FCHVs demonstrated knowledge of repetitive movements and speech, and 20% showed knowledge on unusual interests. A possible explanation for these results may be that the workshop focused on those early social attention and communication behaviours that are useful in identifying young children at “high likelihood” of autism. Only a brief overview on the RBIs was provided, as these behaviours are less predictive of an early autism diagnosis, and present in more subtle ways in very young children (Barbaro & Dissanayake, 2009), indicating the need for more education on these items.

The impact of training was also evident with regards to autism aetiology. Most FCHVs correctly reported heredity and abnormal brain development as the most frequent causes of autism following training, with fewer FCHVs attributing the causes to vaccines, diet and poor parenting. Indeed, Heys et al. (2017) found community health workers, early childhood teachers and parents in Nepal frequently attributed the causes of atypical

child development, including autism, to diet and nutrition as well as poor parenting. Hence, the current findings suggest that the training was effective in reducing these misconceptions. However, a few FCHVs still endorsed supernatural reasons (past karma, fate or curse of God) as the causes of autism post-training and beyond. Previous studies exploring knowledge on the aetiology of autism in Nepal and other LMICs have described similar misconceptions. Since health workers in LMICs play an essential role in providing information to parents, their beliefs on the aetiology of autism profoundly influence the help-seeking behaviours of families/caregivers. Thus, the findings suggest the need for culture-specific awareness programs to reduce the superstitious beliefs regarding the causes of autism.

There remained some variability in knowledge about autism epidemiology following training. Before training, the majority of FCHVs had little knowledge regarding the prevalence of autism and socioeconomic and educational factors, similar to a previous study (Imran et al., 2011). However, following training, most FCHVs rejected the outdated view that “autism occurs more commonly among higher socioeconomic or educational levels”. Understanding of the gender ratios in autism and “the presence of autism in children less than 12 years of age” remained low even following the training, indicating the need for further training on some of these items.

Most FCHVs exhibited understanding on the importance of early identification, diagnosis, early intervention, and treatment following training. This is encouraging within an LMIC where, generally, children are identified at older ages despite having severe speech and intellectual delays along with additional behavioural problems (Tilahun et al., 2017). Although more FCHVs negated “autism is just an intellectual disability” at T2 and T3 compared to T1, the correct response rate was lower on this item compared to other items regarding autism. The majority of children identified with autism in Nepal (Shrestha et al., 2019) and other LMICs (Juneja, Mukherjee, & Sharma, 2005; Lagunju,

Bella-Awusah, & Omigbodun, 2014; Springer, van Toorn, Laughton, & Kidd, 2013) have severe autism symptoms with comorbid intellectual disabilities and limited or no verbal abilities, which may be responsible for a general understanding of autism as an intellectual disability. The findings thus indicate the need for training on the cognitive profile and broad behavioural presentation of children with autism.

Research suggests that the principal outcome of any training is not only enhancing knowledge and skills but also developing confidence in the ability to translate that knowledge into practice (Atun-Einy & Ben-Sasson, 2018; Ben-Sasson et al., 2018). The FCHVs showed increased confidence in monitoring and referring child at “high likelihood” of autism, reporting the positive impact of training on their work at both T2 and T3. The current findings are also consistent with those of Barbaro et al. (2011) who reported the positive effect of training on raising the confidence of MCH nurses in Australia to identify and monitor early signs of autism and referring children developing autism for further assessments. Other studies on training physical therapists (Ben-Sasson et al., 2018), speech therapists (Schwartz & Drager, 2008), and paediatric allied healthcare professionals (Atun-Einy & Ben-Sasson, 2018) also reported greater confidence amongst these professionals in identifying children with autism after training. The confidence of frontline health workers is vital to translate their knowledge into practice so that the general population have access to primary level autism-specific identification services within their community. Needless to say, knowledge of early identification goes in hand with access to diagnosis and, importantly, to relevant interventions and supports. In the current study, ACNS was the referral point, with an agreement to provide the necessary diagnostic and intervention supports for affected children and their families.

Immediately following the SACS-N workshop, the FCHVs reported that the training would have a positive impact on their work. Recurrent themes in their comments

revealed they were happy to be the part of the training which helped them to understand the presentation of autism and hopeful that it would help in their work as illustrated by the following qualitative evidence from the evaluations: *"This is our first training on autism. We were pleased to participate in the programme and wish to get more opportunity of such type of training"; "I am pleased to receive this training to understand about autism, and I feel that this knowledge will help me in my work"; "The training helped me to understand that autism is not a disease. I also learnt to recognise children with autism."* Similar positive responses were also reported by Barbaro et al. (2011) following training MCH nurses on the SACS in Australia

At the 6- and 12-months follow-up regarding the implementation of the SACS-N, most FCHVs reported ease of implementation of the tool into their current practice as evident in their comments: *"The SACS-N program has been very effective for children. It has facilitated to identify children with/without autism, and the parents are also curious to know their child's development. This technique is crucial in the Nepalese context"; "This is a simple technique. This approach can identify our children at "high likelihood" of autism. The training is valuable learning for FCHVs. It should be available in every municipalities and village for its effectiveness."*

At the 12-month follow-up, more FCHVs reported that parents felt comfortable with the SACS-N being undertaken at their homes, compared to the 6-month interim period. This finding may reflect the FCHVs apprehension about the SACS-N implementation at the beginning, where with more practice and confidence, they were increasingly comfortable with the SACS-N, and consequently, parents also became comfortable with the SACS-N. Most FCHVs reported that parents felt being part of the SACS-N was beneficial. One FCHV stated: *"Now I feel pleased that I can also educate people about autism in my community. I am also capable of identifying autism in children by playing with them and observing them"*. Another said: *"I feel this is an effective*

programme in the community which helped me to understand the symptoms of autism in children. Especially, mothers are highly benefited by this programme."

This study demonstrated the ease of administration and acceptability of the implementation of the SACS-N, stating: *"This program is very beneficial. We never heard about autism before. We want to participate in such programs again and again in future. Such programs should be conducted regularly. It would be more effective if we can see children up to 5 years of age."* *"This type of training should be continued among FCHVs' monthly seminars."* *"It is very beneficial if autism education could be included in the school curriculum."*

Most FCHVs recommended continuity and promotion of training to improve the applicability of SACS-N in their communities. Besides, they also recommended the contact office for parents of children with autism in all municipalities. They provided feedback that, *"The health posts and schools should run awareness programs about autism at a local level. Training on autism should be provided regularly to FCHVs."* *"Information about SACS-N training should be disseminated through television, radio, newspapers, posters, pamphlets to be accessible and effective."* *"It would be more effective if parents of children with autism have a contact point at all municipalities."*

Strengths and Limitations

The study included a representative sample of FCHVs from all wards within eight primary health facilities in Kirtipur Municipality. The training incorporated the use of a low-cost autism-specific developmental surveillance tool to monitor and identify the early signs of autism in young children within a local community. We also examined the impact of training by re-evaluating FCHVs' knowledge and confidence after 12-months. Only two of the 60 FCHVs did not complete the knowledge survey and evaluation form at the 12-month follow-up, indicating the representativeness of the data reported here.

Several limitations in the current study need to be acknowledged. Firstly, the results may not be representative of all FCHVs nationwide. However, it is likely that the findings will be relevant to other districts of Nepal, similar to Kiritipur Municipality, and possibly to other areas within LMICs, considering the lack of knowledge on early signs of autism, including misconceptions and outdated beliefs. Future studies should investigate the impact of training on knowledge and confidence among other frontline service providers including other community workers, nurses and early childhood educators.

Change in FCHVs' knowledge regarding children's behaviours and autism was examined using the structured self-reports survey using a simple pre-post-follow-up design, rather than through direct observation and ratings from actual cases. The straightforward approach was chosen as little if any work has been undertaken to date in Nepal; the approach taken was based that of Barbaro et al. (2011). However, self-reports can be subject to socially desirable response biases, indicating the need to independently validate the findings reported here. Although the items in the survey were derived through an extensive literature review, the survey tool itself has not been validated. Given the of FCHV's knowledge on eye contact item, it needs to be based on further detailed research and pre-testing. Moreover, except for a few items (4, 6, 9, 18, 19) in the 'knowledge of autism' part of the survey, most items were positively worded with "agree" as the correct response, which may have led to response bias. Further, the majority of statements in the 'evaluation survey' were worded positively and could be further enhanced by adding some negatively-worded items.

It is also important to acknowledge that training regarding knowledge about autism and use of the SACS-N to identify children with autism in early life is only one step in a larger process toward diagnosis and provision of supports. Thus, our focus in this study was narrow, with our aim being to establish the feasibility and acceptability of early

identification of autism by FCHVs as a means towards diagnosis and intervention for children with autism in Nepal.

Conclusion

The findings indicate the effectiveness of training in improving FCHVs' knowledge on early social attention and communication behaviours in children and the early manifestations of autism. Following training, FCHVs expressed a greater sense of confidence in identifying and monitoring early signs of autism and referring young children at "high likelihood" of autism for developmental assessment. They also reported the positive impact of training, and the benefit of implementing the SACS-N into their current practice.

The evidence from this study indicates the feasibility of developing potentially cost-effective services through task sharing to monitor, identify and refer children developing autism at an early age within the community, as part of standard practice with families. Future research should focus on training more FCHVs and other community health workers, nurses, and early childhood educators to increase their knowledge regarding the early markers of autism in young children to reach a wider population of children at the community level.

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Appendix 1

Table A1

Changes in Knowledge on Social Attention and Communication Behaviour at Three Time Points

Variables	T1	T2	T3	Difference
SACB	6.48 (1.66)	7.43 (1.07)	7.34 (1.22)	$F(1.58, 90.16) = 10.73, p < .001, \eta_p^2 = 0.17$
ELB	4.88 (1.40)	5.53 (0.68)	5.57(1.04)	$F(1.59, 91.01) = 10.97, p = .001, \eta_p^2 = 0.13$

Note. SACB=Social attention and communication behaviours; ELB=Early language behaviours

Table A2

Changes in Knowledge of Autism and Confidence and Monitoring of Children at Three Time Points

Variables	T1	T2	T3	Difference
SCIB	1.50 (1.90)	4.48 (0.73)	4.29 (.95)	$F(1.36, 77.72) = 107.33, p < .001, \eta_p^2 = 0.65$
RRB	1.34 (2.05)	4.93 (1.25)	5.02 (1.53)	$F(1.74, 99.64) = 111.78, p < .001, \eta_p^2 = 0.66$
EPI	0.79 (1.2)	3.12 (.92)	2.56 (0.82)	$F(1.80, 101.23) = 82.40, p < .001, \eta_p^2 = 0.59$
DIAGINT	1.76 (2.13)	4.90 (0.87)	4.67 (0.80)	$F(1.33, 76.11) = 99.39, p < .001, \eta_p^2 = 0.63$
MON	1.05 (1.85)	4.16 (1.00)	4.24 (1.11)	$F(1.83, 104.66) = 103.17, p < .001, \eta_p^2 = 0.64$
REF	1.17 (1.99)	4.17 (1.11)	4.48 (0.84)	$F(1.58, 90.45) = 106.79, p < .001, \eta_p^2 = 0.65$

Note. SCIB= Social communication and interaction behaviours; RRBI= Restricted, repetitive behaviour or interests; EPI= Epidemiology; DIAINT=Diagnosis and intervention; MON=Monitoring children at risk of autism; REF=Rereferring children at risk of autism.

Appendix 2

PART I: GENERAL AND DEMOGRAPHIC INFORMATION

Female Community Health Volunteers (FCHV) Details

Survey ID Number:	
FCHV's Name:	<div style="display: flex; justify-content: space-between;"> First Name _____ Last Name _____ </div>
Date of Birth:	_____/_____/_____ (YYYY/MM/DD)
Address:	District _____ Municipality/VDC _____ Town/Village _____ House no. _____ Ward no. _____ Telephone/Mobile no. _____ Email: _____
Please tick (✓) the box which best describes your view.	
Level of Education:	<input type="checkbox"/> Can read and write <input type="checkbox"/> Primary education (1-5), <i>please specify:</i> _____ <input type="checkbox"/> Lower secondary education (6-8), <i>please specify:</i> _____ <input type="checkbox"/> Secondary education (9-10), <i>please specify:</i> _____ <input type="checkbox"/> More than secondary education, <i>please specify:</i> _____
Work Experience:	<input type="checkbox"/> 1-5 years <input type="checkbox"/> 6-10 years <input type="checkbox"/> More than 10 years
Marital Status:	<input type="checkbox"/> Married <input type="checkbox"/> Unmarried <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widow
Caste/Ethnicity:	<input type="checkbox"/> Newar <input type="checkbox"/> Brahmin-Hills <input type="checkbox"/> Chhetri <input type="checkbox"/> Tamang <input type="checkbox"/> Magar <input type="checkbox"/> Other (<i>please specify</i>): _____
Religion:	<input type="checkbox"/> Hinduism <input type="checkbox"/> Buddhism <input type="checkbox"/> Kirant <input type="checkbox"/> Islam <input type="checkbox"/> Christianity <input type="checkbox"/> Other (<i>please specify</i>): _____
Monthly Family Income (In Nepalese Rupees):	<input type="checkbox"/> ≥ 45,751 <input type="checkbox"/> 22,851-45,750 <input type="checkbox"/> 17,151-22,850 <input type="checkbox"/> 11,451-17,150 <input type="checkbox"/> 6,851-11,450 <input type="checkbox"/> 2,301-6,850 <input type="checkbox"/> ≤ 2,300

Appendix 3

Knowledge on early social attention and communication development in children

Here are some statements about social attention and communication development in children between 12 to 24 months. Please tick (✓) the box which best describes your view.

SN	Statements	Agree	Disagree	Do not know
1.	A 12 month child speaks 1-3 words.			
2.	A 12 month child understands simple instructions.			
3.	A 12-24 month old child does not make regular eye contact with others.			
4.	A 12-24 month old child responds when someone calls his/her name.			
5.	A 12-24 month old child does not use gestures.			
6.	A 12-24 month child does not show toys or objects to parents.			
7.	A 12-24 month old child smiles when someone smiles at him/her.			
8.	A 12-24 month old child is not interested in other children of similar age.			
9.	A 12-24 month old child does not imitate other's actions.			
10	A 12-24 month old child follows someone's finger point by looking at the object where s/he is pointing.			
11	A 18-month old child speaks 5-10 clear words			
12	A 18-month old child does not point his/her facial features.			
13	A 18-24 month old child engages in pretend play.			
14	A 18-24-month old child does not follow simple commands.			
15	A 24-month old child does not use two-word phrases.			
16	A 24-month old child play near or next to, other children.			
17	A 24-month old child speaks 20-50 clear words.			

Scoring: Correct responses are summed to yield a total correct response per cent. Correct response to items 1, 2, 4,7,10,11,13,16, and 17 is Agree; correct response to items 3, 5, 6,8,9,12,14, and 15 is Disagree.

Appendix 4

Knowledge on autism

Here are some statements about autism. Please tick (✓) the box which best describes your view.

SN	Statements	Agree	Disagree	Do not know
1.	I have heard the word 'autism'.			
	If agree, how did you first hear about autism? (Please tick (✓) all that apply)			
	<input type="checkbox"/> Radio <input type="checkbox"/> Television			
	<input type="checkbox"/> Newspaper <input type="checkbox"/> Other community workers			
	<input type="checkbox"/> Awareness programs <input type="checkbox"/> Training			
	<input type="checkbox"/> Brochure, pamphlets, flyers <input type="checkbox"/> Others (please <i>specify</i>):			
2.	Autism is a neurodevelopmental condition.			
3.	Autism is just an intellectual disability.			
4.	A child with autism makes regular eye contact with others.			
5.	A child with autism shows deficits in communicating with others.			
6.	A child with autism understands and uses gestures.			
7.	A child with autism has difficulties in making friends.			
8.	A child with autism shows repetitive patterns of speech such as repeating words and phrases they hear in the exact tone of the original message.			
9.	A child with autism has imaginative play appropriate to his/her developmental level.			
10.	A child with autism does not show the repetitive movements such as body rocking, flapping hands.			
11.	A child with autism prefers sameness in his/her routine such as eating the same food or taking the same route to go to school.			
12.	A child with autism shows the repetitive use of an object such as lining up toys or spinning objects.			

13. A child with autism shows hyper-sensitivities to the environment around them such as avoiding loud noises and getting upset in the crowd.
14. A child with autism does not display an unusual interest or a strong attachment to an object.
15. A child with autism shows hypo-sensitivities to the environment around him/her such as excessive smelling or touching of objects.
16. A child with autism can be identified by the age of 24 months.
17. Autism occurs more in boys than girls.
18. Autism occurs more commonly among higher socioeconomic levels.
19. Autism occurs in more commonly higher educational levels.
20. If a child has autism, getting a diagnosis is important.
21. A child with autism can be treated.
22. Early intervention is important for a child with autism.
23. Autism is present in children less than 15 years.
24. What do you think may be the cause of autism? **(Please tick (✓) all that apply)**
 - ☐ Heredity
 - ☐ Abnormal development of brain
 - ☐ Environmental influences/toxins
 - ☐ Vaccines
 - ☐ Birth Trauma
 - ☐ Childhood illness
 - ☐ Diet
 - ☐ Poor parenting
 - ☐ Past karma
 - ☐ Fate
 - ☐ Curse of God
 - ☐ Factors to do with mother (e.g., age, illness, smoking, medication)
 - ☐ Factors to do with father (e.g., age, illness, smoking, medication)
 - ☐ The exact cause is not known.
 - ☐ Others, *please specify*: _____

Scoring: Correct responses are summed to yield a total correct response per cent. Correct response to items 2, 5, 7, 8, 11, 12, 13, 14, 15, 16, 17, 20, 21, and 22 is Agree; correct response to items 3, 4, 6, 9, 10, 18, 19 and 23 is Disagree.

Appendix 5

Confidence in monitoring and referring children at risk of autism

Here are some statements on your confidence in monitoring autism and referring child at risk of autism for further developmental assessment. Please tick (✓) the box which best describes your view.

SN	Survey Statements	Agree	Disagree	Do not Know
1.	I feel confident in monitoring the signs of autism at 12-18 months of age.			
2.	I feel confident in monitoring the signs of autism at 18-24 months of age.			
3.	I feel confident in monitoring the signs of autism at 24-30 months of age.			
4.	I feel confident in monitoring the signs of autism at 31-60 months of age.			
5.	I feel confident in monitoring the signs of autism at more than 60 months of age.			
6.	I feel confident in referring children between 12-18 months at risk of autism for a further developmental assessment.			
7.	I feel confident in referring children between 18-24 months at risk of autism for a further developmental assessment.			
8.	I feel confident in referring children between 24-30 months at risk of autism for a further developmental assessment.			
9.	I feel confident in referring children between 31-60 months at risk of autism for a further developmental assessment.			
10.	I feel confident in referring children more than 60 months at risk of autism for a further developmental assessment.			

Scoring: Agree responses are summed to yield a total agreement response per cent.

Appendix 7

Name of the Study: Social Attention and Communication Surveillance-Nepal (SACS-N)

Researchers: Prof. Cheryl Dissanayake
Dr. Josephine Barbaro
Ms. Rena Shrestha

About the Study

The survey we would like you to complete is designed to investigate knowledge of social attention and communication development in children between 12-24 months of age among female community health volunteers (FCHVs) in Kirtipur Municipality. We also aim to assess knowledge on autism and your confidence in monitoring the early signs of autism in children and referring them when they are found to be at risk of autism. The survey will be administered three times. Before you receive SACS-N training (at present), immediately following training and following 12 months after monitoring children on the SACS-N.

The information from completing the survey will help us in developing awareness programs on early social attention and communication development milestones in young children. Likewise, your participation in this survey will contribute to developing capacity building programs at a community level to identify, to monitor and to refer children at risk of autism early so that the families can access the necessary supports for their child in a timely manner, which is known to promote better developmental outcomes for children. This study is being funded by a La Trobe University Faculty of Science, Technology and Engineering.

Confidentiality and Withdrawal

The information gathered for the study will be used for research. The results will be published in scholarly journals and presented at conferences, but no information that discloses your identity will be used so that all personal details will remain confidential. Participant results will be stored in locked files in the Child Development Unit at La Trobe University in a secure database in an unidentifiable form. The information gathered may be used in other related research projects, aimed at understanding social attention and communication in infants and toddlers, undertaken by Professor Dissanayake, Dr Barbaro, Ms. Shrestha and other student researchers working under their supervision.

Your participation in this survey is voluntary, and you have the right to withdraw from completing the survey at any time. You may also request that data arising from your participation are not used in the research project provided that this right is exercised within four weeks of the completion of your participation in the survey. You are asked to complete the "Withdrawal of Consent Form" or to notify the researcher by email or telephone that you wish to withdraw your consent for your data to be used in this research study."

Questions regarding this study can be directed to Ms. Rena Shrestha (Tel; +977-9841484162/+61 450 392 010; email: shrestha.r@latrobe.edu.au) at the School of Psychological Science, La Trobe University, Bundoora, Victoria, 3083, Australia.

If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Member Secretary, Nepal Health Research Council, Kathmandu Nepal (P: 977-1-4254220, 4227260, E: nhrc@nhrc.org.np) or the Senior Human Ethics Officer, Ethics and Integrity, Research Office, La Trobe University, Victoria, 3086, Australia (P:+61 3 9479 1443, E: humanethics@latrobe.edu.au).

Appendix 8**Social Attention and Communication Surveillance-Nepal (SACS-N)**

I, _____, have read and understood **the participant information statement and consent form**, and any questions I have asked have been answered to my satisfaction. I agree to participate in the survey, realizing that I may withdraw at any time.

I agree that research data provided by me or with my permission during the survey may be included in a thesis, presented at conferences and published in journals on the condition that neither my name nor any other identifying information is used.

(Name of Female Health Community Volunteer) (Block Letters)

Signature of Female Health Community Volunteer

Date: ____ / ____ / ____

Name of Investigator (Block Letters)

Signature of Investigator

Name of Student Supervisors (Block Letters)

CHAPTER 7

STUDY 4: CAREGIVERS' KNOWLEDGE OF AUTISM IN A LOCAL PERI-URBAN
COMMUNITY OF NEPAL: A CROSS-SECTIONAL STUDY IN KIRTIPUR,
KATHMANDU

This paper has been submitted for publication.

Abstract

Early markers of autism emerge during the first two years of life with a reliable diagnosis possible by 24 months of age. Caregivers' knowledge about autism is crucial to facilitate the early identification of autism. However, research on caregivers' knowledge of autism in low- and middle-income countries (LMICs) is scarce. The current study examined Nepalese caregivers' knowledge about autism and potential differences in knowledge as a consequence of demographic characteristics. A population-based cross-sectional survey was conducted with 1895 caregivers (Mean age = 28 years, $SD = 5.2$) with children between 11-30 months of age in Kirtipur Municipality in Kathmandu, Nepal. Although Nepalese caregivers showed strong knowledge on early social attention and communication behaviours in infants/toddlers, only one-fourth reported any knowledge about autism. Moreover, knowledge on autism differed significantly by caregivers' age, education and caste. Caregivers over 25 years of age, with more than secondary education and belonging to the upper caste, had more knowledge about autism. The significant lack of knowledge regarding autism amongst Nepalese caregivers indicates the need to raise awareness, targeting caregivers from all ages, educational levels and caste groups, to facilitate early recognition of autism.

Keywords: autism, knowledge, caregivers, Nepal

Caregivers' knowledge of autism in a local peri-urban community of Nepal: A cross-sectional study in Kirtipur, Kathmandu

The rising prevalence of autism and its significant impact on individual functioning is a major public health concern (Baxter et al., 2015; Hahler & Elsabbagh, 2015). Research suggests that early markers of autism emerge during the first two years of life and include deficits in social attention, interaction and communication (Barbaro & Dissanayake, 2010; Wetherby, Watt, Morgan, & Shumway, 2007; Zwaigenbaum, Bryson, & Garon, 2013). Early identification of autism with subsequent diagnosis and intervention, results in better developmental outcomes, improved parental well-being and reduced long-term economic costs (Barbaro & Dissanayake, 2009). However, the time from parents' first concerns to a definitive diagnosis of Autism Spectrum Disorder (ASD) is relatively long, particularly in low- to middle-income countries (LMICs). Daley (2004) found that parents in India first noticed something different in their children's development at around 26 months, much later than parents who first noticed abnormalities at 14 months in the United States (Chawarska et al., 2007). Most parents passively waited for behavioural concerns to resolve, with some waiting an additional 32 months before seeking professional help (Daley, 2004). Comparable to this finding, Nepalese parents first noticed their children's autistic symptoms at around 28 months, and the time lag to a diagnosis was a further 29 months, with children receiving a diagnosis of ASD at around 56 months of age (Shrestha & Shrestha, 2014). A recent re-examination of the mean age of an ASD diagnosis in Nepal indicated it to be 58 months (Shrestha, Dissanayake, & Barbaro, 2019a), revealing little change over time. Given the importance of early intervention, there is an urgent need to enhance earlier identification and diagnosis of ASD.

Early recognition and diagnosis of developmental disability is influenced by caregivers' knowledge and help-seeking behaviours. Heys et al. (2017) showed that

Nepalese parents, community workers, and primary and early childhood teachers all have a substantial lack of knowledge about atypical child development, including autism. Furthermore, studies in LMICs (Daley, 2004; Huang, Jia, & Wheeler, 2013), including Nepal (Heys et al., 2017; Shrestha & Shrestha, 2014), have revealed common misinterpretations of children's behaviours related to autism. For example, behavioural difficulties were considered as the child 'being naughty,' having an 'uncommon personality' (Huang et al., 2013), or attributed to 'stubbornness' and/or 'aggression' (Shrestha & Shrestha, 2014). Children with limited social interaction were perceived as being 'good' and 'trouble-free' (Daley, 2004). Parents considered incomprehensible speech and echolalia as either normal or as the child having unique language use, rather than being indicative of a developmental disability (Perera, Jeewandara, Guruge, & Seneviratne, 2013).

In the absence of known causes of autism, it is not uncommon for parents/caregivers in LMICs to ascribe autism to supernatural causes such as fate, karma or the curse of God (Heys et al., 2017; Ruparelia et al., 2016; Tilahun et al., 2016). Comparable to other LMICs (Ruparelia et al., 2016), Nepalese parents take their children to temples and traditional healers before seeking medical assistance (Shrestha & Shrestha, 2014). This potential delay in seeking professional help contributes to later diagnosis, further compromising children's developmental outcomes (Ruparelia et al., 2016). Therefore, it is vital that parents/caregivers have adequate knowledge about autism and the services and supports available for affected children.

Studies have shown that various socio-demographic variables are associated with knowledge about autism. For example, caregivers' lower age and education have been linked with lower knowledge about autism (Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013; Wang et al., 2012). Higher education may provide greater access to resources, thus enhancing caregivers' knowledge (Prickett & Augustine, 2016; Radey &

Randolph, 2009). Being from an ethnic minority background has also been found to be associated with lower knowledge about autism and access to services (Dillenburger et al., 2013; Magaña, Lopez, Aguinaga, & Morton, 2013).

In Nepal, the caste /ethnic group is a key determinant of social identity (Pandey, Dhakal, Karki, Poudel, & Pradhan, 2013). Previous studies (Bhandari, Shrestha, & Ghimire, 2007; Pandey et al., 2013) have well documented that social exclusion based on caste / ethnic identities contributes to significant social, economic and educational disparities. For example, upper caste ethnic groups (Brahmin, Chettri) have sociocultural, economic and political privilege compared to disadvantaged caste/ethnic groups (Magar, Tamang), with better access to education, information and health services (Bhandari et al., 2007). Although, studies in Nepal have highlighted the association between upper caste/advantaged group and increased knowledge and access to services (Bhandari et al., 2007; Pandey et al., 2013), research on caregivers' knowledge on autism with regard to caste/ethnicity is scarce (Heys et al., 2017).

The aim in the current study was to examine Nepalese caregivers' knowledge of early social attention and communication development in young children, given its relevance in the early identification of autism, and their knowledge regarding autism. Differences in caregivers' knowledge of autism by caregivers' age, education level and caste were also examined. The study was undertaken in the hope that the findings would inform the development of health promotion programs to raise community-level awareness of autism in Nepal.

Method

Study Design and Setting

A population-based cross-sectional survey was conducted among caregivers of children aged between 11 to 30 months (from November 2016 to July 2019) in Kirtipur Municipality. The study was part of a larger study (Shrestha, Dissanayake, & Barbaro,

2019c) which implemented and evaluated the Nepali version of Social Attention and Communication Surveillance (SACS; Barbaro & Dissanayake, 2010, 2013) in Kirtipur to facilitate early recognition of autism.

The Kirtipur municipality is an ancient city 7 kilometres from Kathmandu – the capital city of Nepal. According to the last census (Central Bureau of Statistics, 2012), the municipality's population was 65,607 (male: 56% and female: 44%), with total households numbering 19,441. The population is predominantly Newars, with most people practising Hinduism or Buddhism; work participation is primarily based on agriculture (Central Bureau of Statistics, 2014). However, the municipality is becoming increasingly diverse due to rapid migration and urbanisation. (Maharjan, Maharjan, & Dangol, 2019). The study site included all ten wards (the lowest administrative units) of the municipality within eight village development committees which have eight primary health services (namely Paaliphal, Layaku, Bahirigaun, Chithubihar, Champa Devi, Bishnudevi, Panga Balkumari and Chovar).

Participants

A total of 1895 caregivers completed the survey, whose demographic characteristics are presented in Table 1. Most caregivers were married mothers (93%), with over one third (38%) aged between 26-30 years (Mean age = 28.82 years, $SD = 5.26$). Around half of the caregivers (46%) had more than secondary education (> 10 years of education), were housewives (40%), with around one-third (31%) being Newar, followed by Chettri (21%) and Brahmin (19%). The mean age of their children was 20 months ($SD = 5.95$) at the time of completing the survey, and 56% of children were male.

Table 1

Demographic Characteristics of Participants (N = 1895)

Variables	<i>n</i> (%)
Child variables	
Mean age in months (SD)	19.92 (SD = 5.95)
Sex	
Male	1069 (56.4%)
Female	826 (43.6%)
Caregivers' variables	
Survey respondents	
Mothers	1769 (93.4%)
Fathers	104 (5.5%)
Others (Grandparents, aunts, uncles)	22 (1.2%)
Caregivers' Mean age in months (SD)	28.82 (5.26)
Caregivers' age group	
16- 20 years	91 (4.8%)
21-25 years	441 (23.3%)
26-30 years	727 (38.4%)
31-35 years	424 (22.4%)
>35 years	212 (11.2%)
Parental relationship	
Married	1889 (99.7%)
Separated	4 (0.2%)
Divorced	0 (0))
Other	2 (0.1)
Education	
Primary (1-5 years) or less	176 (9.3%)
Lower secondary education (6-8 years)	195 (10.3%)
Secondary education (9-10 years)	343 (18.1%)
More than secondary education	881 (46.5%)
Occupation	
Unemployed/Housewife	753 (39.7%)
Agriculture	170 (9.0 %)
Government Job	177 (9.3%)
Non-Government Job	166 (8.8%)
Business	178 (9.4%)
Daily wage labour	181 (9.6%)
Foreign employment	28 (1.5%)
Others	242 (12.8%)
Caste	
Newar	589 (31.1%)
Brahmin	353 (18.6%)
Chhetri	392 (20.7%)
Tamang	239 (12.6%)
Magar	82 (4.3%)
Others	240 (12.7%)

Measures

A caregiver questionnaire was developed to incorporate a range of information, as outlined below.

Demographic Information. Participants were asked to provide information on their child's age and gender, and their own age, education, caste, occupation and relationship status. Information on caste, occupation and relationship status was adapted from the last census report (Central Bureau of Statistics, 2012).

Knowledge of early social attention and communication development. This section of the questionnaire comprised 17-items related to children's eye contact, pointing, response to name, showing, imitation, gestures, pretend play, social smiling, joint attention, use and understanding of language, parallel play and interest in peers (see Appendix 1). The survey statements were modified from items derived from the Social Attention and Communication Study (Barbaro & Dissanayake, 2010, 2013). Based on the similarities of items, three subscales were formed including social attention and communication behaviours (SACB), early language behaviours (ELB), and peer relations and play behaviours (PRPB).

Knowledge of autism. This section included 23 items (see Appendix 2) which were adapted and grouped into four subscales following a literature search: social communication and interaction behaviour (SCIB); restricted, repetitive behaviour, interests, or activities (RRBI); epidemiology (EPI); diagnosis and intervention (DIAGINT). All items had three response choices: "agree", "disagree" and "do not know," except for the item on "causes", which had multiple choice options. On the latter, participants could endorse as many choices as needed; they also had an opportunity to provide additional information on causal factors.

Each scale item received a score of 1 if answered correctly, and a score of 0 if not responded to correctly. A score of 0 was also given for a response of "do not know" on the assumption that this response implies a lack of knowledge of the item. For each item, the mean scores were calculated, reflecting the proportion of participants that responded

to the item correctly. Total scores for each subscale were calculated by summing the number of correct answers on items within each subscale.

Development of Survey Items

The survey items were developed based on a review of the literature and in consultation with autism professionals in Australia. These were then finalised following consultation with professionals (psychologists, special educators, and public health officer) working in the field of autism in Nepal, to ensure cultural suitability. The survey was first developed in English, which was subsequently translated into the Nepali language by the first author (RS), which was back-translated to English by a professional translator who was bilingual (English and Nepali). The Nepali-version of the survey was piloted prior to use in the study. The survey was then revised and finalised based on feedback from the pilot study.

The Cronbach alpha coefficient of the full survey was .93; the Cronbach alphas for the sub-scales SACB, ELB, and PRPB were .82, .75, and .53 respectively. Cronbach alphas for the sub-scales SCIB, RRBI, EPI, and DIAGINT was .92, .91, .79, and .92, respectively.

Procedures

Ethical approval was obtained from the Nepal Health Research Council (112/2016) and the La Trobe University Human Ethics Committee (HEC16-073). The Kathmandu District Public Health Office and the Kirtipur Municipality also approved the conduct of the study. Participants were asked to complete the survey statements by Female Community Health Volunteers (FCHVs) who visited their homes, following provision of informed consent to participate in the larger study (Shrestha et al., 2019c).

Data Analysis

Data analyses were carried out using Statistical Package for Social Sciences version 25.0 (SPSS; IBM Corp, 2017). Double entry of 10% of data ensured the reliability

of data entry at $\geq 90\%$. Missing data on demographic variables were as follows: sex of child (0.2%), parental relationship (2.3%), caregivers' age (4.9%), education (2.2%), and occupation (5.4%). Little's MCAR test revealed that data were missing at random, $\chi^2 .607$, $df = 1$, $p = .43$; thus, missing data were replaced using mean substitution (Tabachnick & Fidell, 2013). Descriptive statistics were calculated for all variables of interest. Kruskal-Wallis H tests were conducted to compare caregivers' knowledge with regard to relevant demographic variables. Pairwise comparisons were performed using Dunn's (1964) procedure with a Bonferroni correction for multiple comparisons. Statistical significance was accepted at $p = .005$ for caregivers' age, $p = .016$ for education, and $p = .003$ for caste. Data analysis was not conducted on the PRBR scale, given its low Cronbach alpha coefficient.

Results

Knowledge of Social Attention and Communication Behaviours

Table 2 presents the proportion of caregivers' correct responses to social attention and communication behaviours in 11-30-month-old typically developing children. The average correct response was 90% (range: 81-97%), indicating a high level of knowledge about these behaviours. When examining knowledge differences based on caregivers who completed the survey (mother, father, other) and demographic variables (see Table 3), no significant differences were found for knowledge on the SCAB subscale based on respondent, $H(2) = 1.012$, $p = .60$; age, $H(4) = 5.916$, $p = .20$; education, $H(2) = 2.929$, $p = .23$; or caste, $H(5) = 9.275$, $p = .099$.

No differences were found on the ELB subscale based on the respondent, $H(2) = .740$, $p = .69$, or caregivers' age, $H(5) = 6.117$, $p = .19$ (Table 3). However, a significant difference was found in knowledge of ELB as a function of caregiver's educational level, $H(2) = 9.758$, $p = .008$, and caste group, $H(5) = 16.848$, $p = .005$. Post hoc analysis revealed that caregivers with "more than secondary education" had higher knowledge

compared to those with “primary education or less” ($p = .008$), and caregivers with “secondary education” had more knowledge compared to those with primary education or less ($p = .032$). No difference in knowledge was found between caregivers with “secondary” and “more than secondary education”. Regarding caste, the “Magar” caste group had less knowledge compared to “Newar” ($p = .003$), “Tamang” ($p = .009$), “Chhetri” ($p = .003$) and “Others” ($p = .004$).

Table 2

Caregivers' Correct Responses on Social Attention and Communication Behaviours (N = 1895)

Subscale/Items	Correct response n (%)
Social attention and communication behaviours (SACB)	
Eye contact	1607 (84.8%)
Response to name	1836 (96.9%)
Gestures	1659 (87.5%)
Showing	1649 (86.6%)
Follows Pointing	1819 (96.0%)
Social smile	1835(93.8%)
Imitation	1675 (88.4%)
Points to facial features	1698 (89.6%)
Early language behaviours (ELB)	
Speaks 1-3 words	1759 (92.8%)
5-10 clear words	1680 (88.7%)
20-50 clear words	1538 (81.2%)
two-word phrases	1630 (86.0%)
Understands simple instructions	1825 (96.3%)
Follows simple commands	1693 (89.3%)
Peer relations and play (PRPB)	
Interest in other children of similar age	1682 (88.8%)
Engages in pretend play	1650 (87.1%)
Parallel play	1819 (96%)

Table 3

Comparison of Caregivers' Knowledge on Social Attention and Communication Behaviours
($N = 1895$)

Variables	<u>Knowledge on social attention and communication behaviours</u>	
	SACB (Mean Rank)	ELB (Mean Rank)
Caregivers' filling survey		
Mothers	949.94	949.94
Fathers	907.44	930.26
Others	984.09	876.09
Difference	$H(2) = 1.012, p = .60$	$H(2) = .740, p = .69$
Age group		
16- 20 years	947.23	1006.65
21-25 years	987.70	981.00
26-30 years	938.32	938.20
31-35 years	946.30	938.65
>35 years	902.36	906.49
Difference	$H(4) = 5.916, p = .20$	$H(5) = 6.117, p = .19$
Education		
Primary education or less	944.84	888.30
Lower secondary	973.77	962.16
> secondary education	932.64	968.08
Difference	$H(2) = 2.929, p = .231$	$H(2) = 9.758, p = .008$
Caste		
Newar	915.29	959.28
Brahmin	934.81	924.58
Chhetri	967.95	968.76
Tamang	946.01	960.78
Magar	958.09	760.91
Others	1013.62	972.05
Difference	$H(5) = 9.275, p = .099$	$H(5) = 16.848, p = .005$

Note. SACB=Social attention and communication behaviours; ELB=Early language behaviours.

Knowledge of Autism

Of 1895 respondents, less than one-fourth (23%) reported that they had heard about autism, with their knowledge derived from television (9.8%), radio (5.2%), newspapers (5.3%), community workers (3.5%), awareness programs (3.3%),

brochures/pamphlets/flyers (2.6%) and training (2.6%). Table 4 presents caregivers' correct responses on autism knowledge across four subscales. The mean percentage of correct responses across all survey items was 18% (range: 6 - 27%). While knowledge of autism did not differ based on who completed the survey, significant differences were found for caregivers' age, education, and caste, as presented in Figures 1 to 3.

Table 4

Caregivers' Correct Response on Knowledge about Autism (N = 1895)

Subscale/Items	Correct response n (%)
Heard about autism	442 (23.3%)
Social communication and interaction behaviours (SCIB)	
Communication	397 (20.9%)
Eye contact	432 (22.8)
Gestures	385 (20.3%)
Friendships	429 (22.6%)
Pretend play	354 (18.7%)
Restricted, repetitive behaviour or interests (RRBI)	
Repetitive speech	287 (15.1%)
Repetitive movements	239 (12.6)
Preference for sameness	386 (20.4%)
Repetitive use of an objects	364 (19.2)
Unusual interest	328 (17.3%)
Hyper-sensitivities	299 (15.8%)
Hypo-sensitivities	249 (13.1%)
Epidemiology (EPI)	
Occurs in more boys than girls	257 (13.6%)
Occurs in higher socioeconomic levels	346 (18.3%)
Occurs in higher educational levels	378 (19.9)
Present in children <12 years	112 (5.9%)
Diagnosis and intervention (DIAGINT)	
Neuro developmental condition	468 (24.7%)
Just an intellectual disability	148 (7.8%)
Early identification	378 (19.9%)
Diagnosis is important	444 (23.4%)
Treatment	470 (24.8%)
Early intervention	509 (26.9)

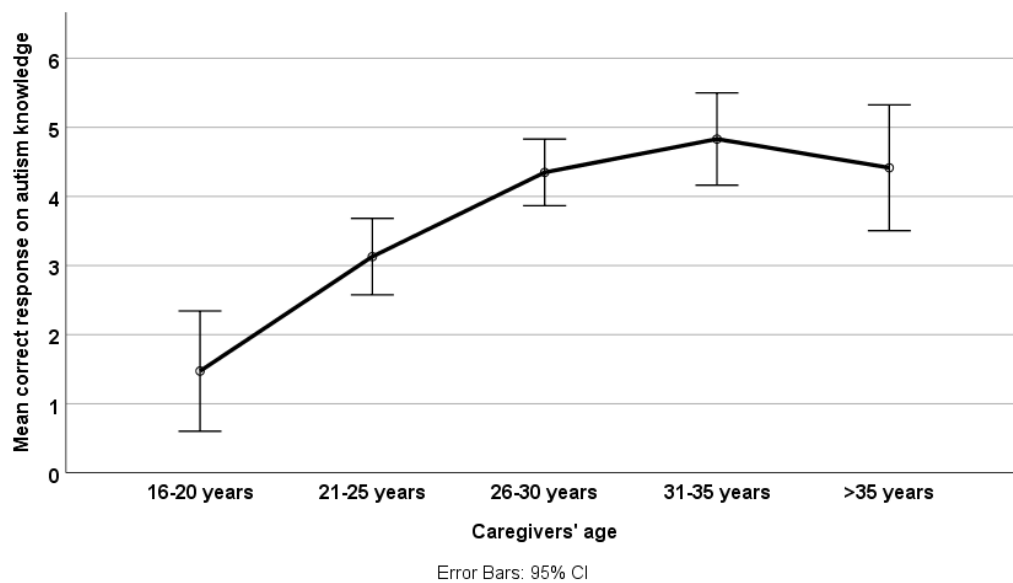


Figure 1. Comparison of caregivers' knowledge of autism based on the age group.

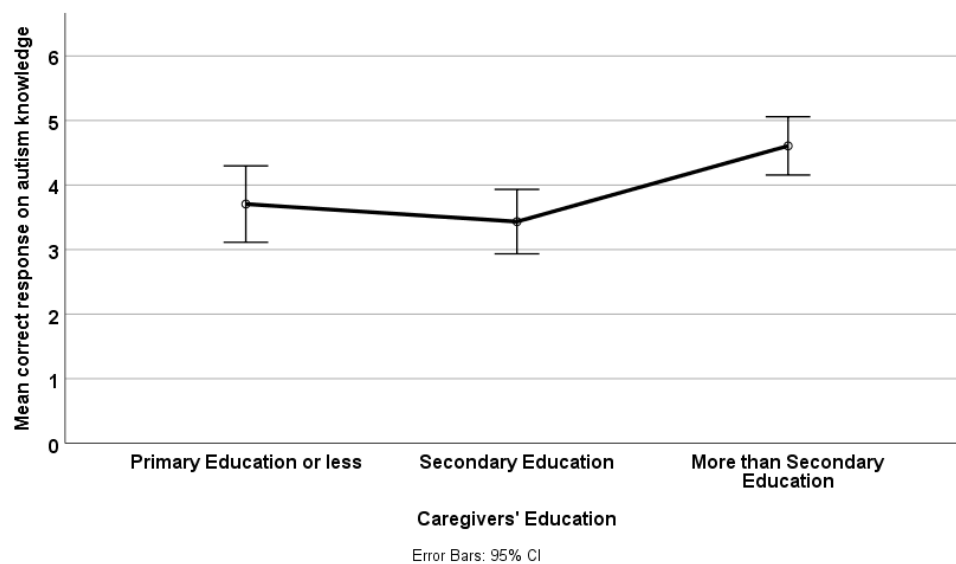


Figure 2. Comparison of caregivers' knowledge of autism based on education.

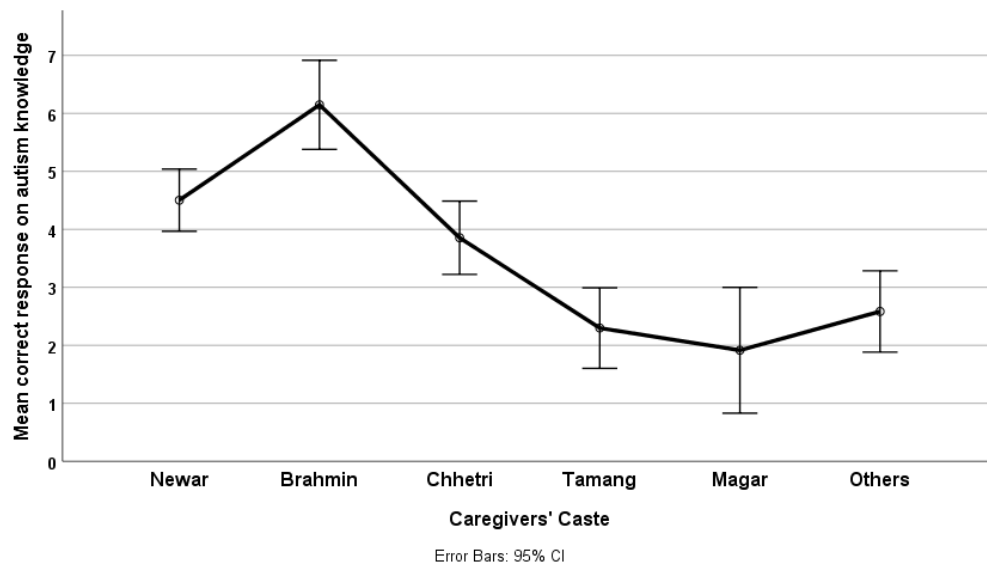


Figure 3. Comparison of caregivers' knowledge of autism based on caste.

Caregivers demonstrated little knowledge on each of the subscales including SCIB (21%), RRBI (16%), EPI (14%) and DIAGINT (21%). As evident in Table 5, younger caregivers (within 16-25 years) had the least knowledge compared to those above 25 years on SCIB, $H(4) = 28.42, p < .001$; RRBI, $H(4) = 29.527, p < .001$; EPI, $H(4) = 26.336, p < .001$; and DIAGINT, $H(4) = 29.415, p < .001$. This was confirmed by pairwise comparisons which revealed that caregivers who were within “16-20 years” of age had significantly fewer correct responses compared to those aged “26-30 years” on SCIB ($p = .030$), RRBI ($p = .001$), EPI ($p = .003$), DIAGINT ($p = .001$); those aged “more than 35 years” on SCIB ($p = .007$), RRBI ($p = .002$), EPI ($p = .020$), DIAGINT($p = .003$); and those aged “31-35 years” on SCIB ($p < .001$), RRBI ($p < .001$), EPI ($p < .001$), and DIAGINT ($p < .001$). Those aged “21-25 years” similarly had lower knowledge compared to those aged “31-35 years” on SCIB ($p = .002$), RRBI ($p = .006$), EPI ($p = .003$), DIAGINT ($p = .006$).

Table 5

Comparison of Knowledge on Autism among Caregivers (N = 1895)

Demographic Variables	Knowledge on autism			
	SCIB (Mean Rank)	RRBI (Mean Rank)	EPI (Mean Rank)	DIAGINT (Mean Rank)
Survey respondents				
Mothers	948.66	950.84	949.72	948.90
Fathers	930.68	900.72	909.71	932.93
Others	976.59	943.02	991.05	946.59
Difference	$H(2) = .262$, $p = .87$	$H(2) = 1.313$, $p = .51$	$H(2) = 1.142$, $p = .56$	$H(2) = .124$, $p = .94$
Age group				
16- 20 years	784.23	774.16	797.99	771.31
21-25 years	889.65	891.04	896.64	887.15
26-30 years	968.03	969.22	964.41	973.44
31-35 years	998.89	992.84	999.91	992.63
>35 years	969.22	978.67	959.15	973.92
Difference	$H(4) = 28.42$, $p < .001$	$H(4) = 29.527$, $p < .001$	$H(4) = 26.336$, $p < .001$	$H(4) = 29.415$, $p < .001$
Education				
Primary or less	928.59	933.00	924.60	915.05
Lower secondary	906.34	904.08	915.50	918.86
>Secondary education	984.90	984.22	980.85	983.35
Difference	$H(2) = 12.410$, $p = .002$	$H(2) = 12.594$, $p = .002$	$H(2) = 10.368$, $p = .006$	$H(2) = 10.240$, $p = .006$
Caste				
Newar	994.66	971.03	973.99	982.86
Brahmin	1076.81	1082.15	1075.50	1088.85
Chhetri	930.24	943.68	940.09	946.18
Tamang	820.86	834.91	849.49	807.70
Magar	796.18	817.70	809.99	788.82
Others	851.51	858.35	854.85	852.37
Difference	$H(5) = 79.287$, $p < .001$	$H(5) = 69.302$, $p < .001$	$H(5) = 69.789$, $p < .001$	$H(5) = 82.806$, $p < .001$

Note. SCIB= Social communication and interaction behaviours; RRBI= Restricted, repetitive behaviour or interests; EPI= Epidemiology; DIAINT=Diagnosis and intervention.

Caregivers' knowledge also differed as a result of their educational level with regard to all subscales; SCIB, $H(2) = 12.410, p = .002$; RRBI $H(2) = 12.594, p = .002$; EPI, $H(2) = 10.368, p = .006$; DIAG, $H(2) = 10.240, p = .006$. Pairwise comparisons with post hoc analysis revealed that caregivers who had "more than secondary education" demonstrated the highest level of knowledge compared to caregivers with "primary education" and "secondary education" on SCIB ($p = .002$), RRBI ($p = .002$), EPI ($p = .010$), and DIAGINT ($p = .028$).

Furthermore, knowledge was higher amongst those from the Brahmin caste followed by Newar and Chhettris compared to, Magar and others on SCIB, $H(5) = 79.287, p < .001$; RRBI, $H(5) = 69.302, p < .001$; EPI, $H(5) = 69.789, p < .001$; and DIAGINT, $H(5) = 82.806, p < .001$. Pairwise comparisons revealed that knowledge of caregivers from the Brahmin upper caste group had higher knowledge compared to Magar, Tamang, Chhettris and Others on SCIB ($p < .001$), RRBI ($p < .001$), EPI ($p < .001$) and DIAGINT ($p < .001$). The Brahmin caste and those in the Newar group did not differ on SCIB ($p < .07$), but they did differ on knowledge regarding RRBI ($p = .002$), EPI ($p = .004$), and DIAGINT ($p = .007$).

Causes of Autism

Table 6 presents caregivers endorsements regarding the causes of autism, with caregivers endorsing multiple causal factors. Under a quarter of participants (22-23%) believed that heredity and abnormal brain development were the causes of autism. Some caregivers also attributed the causal factors to vaccines (7%), brain trauma (11%), childhood illness (9%), diet (3%), poor parenting (6%) and parental related factors (5-8%). Supernatural beliefs such as past karma (1%) and fate (1%) were rarely endorsed, and 4-5% reported that the exact cause of autism is unknown.

Table 6

Caregivers' Knowledge on Causal Factors of Autism (N = 1895)

Causes	<i>n</i> (%)
Heredity	409 (21.6)
Abnormal brain development	430 (22.7)
Environmental Influence (toxins)	127(6.7)
Vaccines	143 (7.5)
Brain trauma	217 (11.5)
Childhood illness	177 (9.3)
Diet	69 (3.6)
Poor parenting	122 (6.4)
Past Karma	24 (1.3)
Fate	29 (1.5)
God's Curse	11 (.7)
Factors related to mother	162 (8.5)
Factors related to father	104 (5.5)
The exact cause is unknown	85 (4.5)

Discussion

To our knowledge, this is the first study to examine Nepalese caregivers' knowledge about social attention and communication development in infants and toddlers, and caregivers' knowledge of autism and associated symptoms. In contrast to caregivers' strong knowledge on early social attention and communication behaviours in typical development, their knowledge of autism including symptoms, epidemiology, diagnosis and intervention was lacking. This finding is consistent with those from a study in China undertaken with pre-school teachers who demonstrated strong knowledge of typical child development but little knowledge regarding autism (Liu et al., 2016). Although overall awareness of autism in the current study was low, caregivers' knowledge differed depending on their age, education level and caste, highlighting the urgent need to disseminate information about autism at a community level.

It appears that caregivers do not know about autism as a distinct condition (Heys et al., 2017) and the behavioural features that constitute it. Perhaps this finding is not unusual as autism is a relatively new concept in Nepal, with little diagnosis prior to 2004 (Shrestha & Santangelo, 2014). The current finding corroborates with previous findings of a significant lack of knowledge about autism in medical professionals (Khatri, Onta, Tiwari, & Choulagai, 2011), community health workers (Shrestha, Dissanayake, & Barbaro, 2019b), and educators and parents in Nepal (Heys et al., 2017).

Caregivers' good knowledge on early social attention and communication behaviours in children did not differ as a result of age, education, or caste. This finding indicates that caregivers have good overall knowledge about young children's behaviours that are important developmentally. The good correct response percentages on eye contact, gestures, showing, and imitation behaviours is particularly important given they comprise key markers of autism (Barbaro & Dissanayake, 2013).

In contrast to SACBs, level of education did impact knowledge of early language behaviours (ELB), where caregivers with at least secondary education and above demonstrated better knowledge. Furthermore, those from the Magar caste (disadvantaged ethnic group) showed less knowledge of ELBs compared to the other caste groups. While Bhandari et al. (2007) found differences in knowledge of child health and access to services in disadvantaged and minority groups compared to upper caste advantaged groups (Bhandari et al., 2007), there has been no research undertaken on the Magar caste group to explain the current finding on differences in knowledge. It is possible that this is a spurious result given that this group had good knowledge about the SACB subscale.

Less than one-quarter of the caregivers who participated in this study reported hearing about autism, demonstrating a significant lack of knowledge regarding autism symptoms, epidemiology, diagnosis, and interventions. This finding is consistent with FCHVs in the same region (Shrestha et al., 2019b) and findings with parents, community

workers, primary school, and/or early childhood teachers (Heys et al., 2017) in Nepal. Given that these findings are also consistent with those from other studies investigating awareness of autism in LMICs, which included caregivers (Daley, 2004; Okandeji-Barry, Agofure, & Garba, 2015; Wang et al., 2012), teachers (Ayub et al., 2017; Liu et al., 2016) and health workers (Bakare, Ebigbo, et al., 2009; Bakare & Munir, 2011), they indicate an urgent need for increased autism awareness in Nepal and other LMICs in order to identify and diagnose affected children so that they may have access to the services they need.

Consistent with a previous study (Dillenburg et al., 2013), younger caregivers (16 – 25 years) had less knowledge about all aspects of autism compared to those who were older than 25 years of age. Furthermore, caregivers with more than a secondary education had significantly more knowledge compared to those with only primary level education. These results are also comparable to those from previous studies (Furnham & Buck, 2003; Holt & Christensen, 2013; Wang et al., 2012), demonstrating the link between education and autism knowledge. Research (Prickett & Augustine, 2016; Wang et al., 2012) suggests that education enhances caregivers' ability to access multiple resources of information on children's health compared to their less educated counterparts. These results suggest that being a young adult (16-25 years) with limited education results in little autism knowledge.

Caste had an impact on knowledge regarding autism; those from the Brahmin caste are more privileged socio-culturally with better access to education (Bhandari et al., 2007); thus, they had significantly more knowledge about autism than those from the Newar, Tamang, and Magar castes. This is consistent with the finding that more upper caste Nepalese children had a diagnosis of autism compared to those from other castes, as well as being diagnosed earlier than children in other caste groups (Shrestha et al.,

2019a). Given the presence of a knowledge gap between castes, awareness programs are needed at a community level to address this disparity.

As there is no conclusive evidence on the causes of autism (Mercer, Creighton, Holden, & Lewis, 2006), caregivers' beliefs consisted of combinations of genetic/heredity and other factors (abnormal brain development, environmental toxins, brain trauma), with a small proportion maintaining outdated beliefs such as bad parenting, comparable to previous studies in Nepal (Heys et al., 2017; Shrestha et al., 2019b). Parents also supported vaccinations as a causal factor comparable to some parents from HICs. Supernatural (past karma, fate or curse of God) beliefs were also endorsed, albeit rarely.

Limited knowledge and misconceptions among caregivers can affect their help-seeking behaviours (Mandell & Novak, 2005; Wang et al., 2012). Previous research in Nepal (Shrestha & Shrestha, 2014) found that children diagnosed with autism were taken to temples or traditional healers prior to seeking professional help, consistent with other LMICs (Bakare, Agomoh, et al., 2009; Daley, 2004; Tilahun et al., 2016). It is, therefore, essential that caregivers have knowledge of autism and the services available to help them (Wang et al., 2012).

Strengths and Limitations

A major strength in the current study was a large number of caregivers who participated from the local community. Nevertheless, there are some limitations that warrant consideration. Although the findings are representative of the local community in Kirtipur Municipality, they may not be generalisable to the whole country due to inherent cultural and ethnic differences across Nepal. Nonetheless, it is important to note that the current findings are consistent with those from previous studies in Nepal and other LMICs. It is also important to acknowledge that self-reporting can be susceptible to bias and social desirability, and the survey developed for this study has not been validated.

Conclusion

Caregivers in Kirtipur Municipality were familiar with social attention and communication development in young children, but lacked knowledge about autism, its symptoms, epidemiology, diagnosis, intervention, and causes. Those who heard about autism reported receiving information from audio/visual and print media as well as community workers. Caregivers over 25 years of age, with more than secondary education and belonging to the upper caste (Brahmin) had more autism knowledge. Inadequate knowledge and misconceptions about autism can delay caregivers' help-seeking behaviours, hindering timely identification and diagnosis of autism (Minhas et al., 2015; Tilahun et al., 2017; Wang et al., 2012). There is an urgent need for awareness programmes in Nepal (and other LMICs) to raise caregivers' knowledge and understanding about autism and available service provisions for affected individuals.

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Appendix 1

Knowledge on early social attention and communication development in children

Here are some statements about social attention and communication development in children between 12 to 24 months. Please tick (✓) the box which best describes your view.

SN	Statements	Agree	Disagree	Do not know
1.	A 12 month child speaks 1-3 words.			
2.	A 12 month child understands simple instructions.			
3.	A 12-24 month old child does not make regular eye contact with others.			
4.	A 12-24 month old child responds when someone calls his/her name.			
5.	A 12-24 month old child does not use gestures.			
6.	A 12-24 month child does not show toys or objects to parents.			
7.	A 12-24 month old child smiles when someone smiles at him/her.			
8.	A 12-24 month old child is not interested in other children of similar age.			
9.	A 12-24 month old child does not imitate other's actions.			
10	A 12-24 month old child follows someone's finger point by looking at the object where s/he is pointing.			
11	A 18-month old child speaks 5-10 clear words			
12	A 18-month old child does not point his/her facial features.			
13	A 18-24 month old child engages in pretend play.			
14	A 18-24-month old child does not follow simple commands.			
15	A 24-month old child does not use two-word phrases.			
16	A 24-month old child play near or next to, other children.			
17	A 24-month old child speaks 20-50 clear words.			

Scoring: Correct responses are summed to yield a total correct response per cent. Correct response to items 1, 2, 4,7,10,11,13,16, and 17 is Agree; correct response to items 3, 5, 6,8,9,12,14, and 15 is Disagree.

Appendix 2

Knowledge on autism

Here are some statements about autism. Please tick (✓) the box which best describes your view.

SN	Statements	Agree	Disagree	Do not know
1.	I have heard the word 'autism'.			
	If agree , how did you first hear about autism? (Please tick (✓) all that apply)			
	<input type="checkbox"/> Radio		<input type="checkbox"/> Television	
	<input type="checkbox"/> Newspaper		<input type="checkbox"/> Other community workers	
	<input type="checkbox"/> Awareness programs		<input type="checkbox"/> Training	
	<input type="checkbox"/> Brochure, pamphlets, flyers		<input type="checkbox"/> Others (please <i>specify</i>):	
2.	Autism is a neurodevelopmental condition.			
3.	Autism is just an intellectual disability.			
4.	A child with autism makes regular eye contact with others.			
5.	A child with autism shows deficits in communicating with others.			
6.	A child with autism understands and uses gestures.			
7.	A child with autism has difficulties in making friends.			
8.	A child with autism shows repetitive patterns of speech such as repeating words and phrases they hear in the exact tone of the original message.			
9.	A child with autism has imaginative play appropriate to his/her developmental level.			
10.	A child with autism does not show the repetitive movements such as body rocking, flapping hands.			
11.	A child with autism prefers sameness in his/her routine such as eating the same food or taking the same route to go to school.			
12.	A child with autism shows the repetitive use of an object such as lining up toys or spinning objects.			
13.	A child with autism shows hyper-sensitivities to the environment around them such as avoiding loud noises and getting upset in the crowd.			

14. A child with autism does not display an unusual interest or a strong attachment to an object.
15. A child with autism shows hypo-sensitivities to the environment around him/her such as excessive smelling or touching of objects.
16. A child with autism can be identified by the age of 24 months.
17. Autism occurs more in boys than girls.
18. Autism occurs more commonly among higher socioeconomic levels.
19. Autism occurs in more commonly higher educational levels.
20. If a child has autism, getting a diagnosis is important.
21. A child with autism can be treated.
22. Early intervention is important for a child with autism.
23. Autism is present in children less than 15 years.
24. What do you think may be the cause of autism? **(Please tick (✓) all that apply)**
 - ☐ Heredity
 - ☐ Abnormal development of brain
 - ☐ Environmental influences/toxins
 - ☐ Vaccines
 - ☐ Birth Trauma
 - ☐ Childhood illness
 - ☐ Diet
 - ☐ Poor parenting
 - ☐ Past karma
 - ☐ Fate
 - ☐ Curse of God
 - ☐ Factors to do with mother (e.g., age, illness, smoking, medication)
 - ☐ Factors to do with father (e.g., age, illness, smoking, medication)
 - ☐ The exact cause is not known.
 - ☐ Others, *please specify*: _____

Scoring: Correct responses are summed to yield a total correct response per cent. Correct response to items 2, 5, 7, 8, 11, 12, 13, 14, 15, 16, 17, 20, 21, and 22 is Agree; correct response to items 3, 4, 6, 9, 10, 18, 19 and 23 is Disagree.

CHAPTER 8

GENERAL DISCUSSION

Chapter Overview

The overall objective in undertaking the research reported in this thesis was to implement and evaluate the Nepali version of Social Attention and Communication Surveillance (SACS; Barbaro & Dissanayake, 2010, 2013) in a local community in Kathmandu, Nepal to enable earlier recognition of Autism Spectrum Disorder (ASD). This chapter begins with a summary of findings from each of the four empirical papers (one published and three submitted) highlighting how these findings contributed to the promotion of early identification of ASD in Nepal. The limitations of the current research are also outlined, followed by recommendations for future research, prior to concluding the thesis.

Study 1. Age of Diagnosis of Autism Spectrum Disorder in Nepal

Although a reliable diagnosis of ASD is possible by 24 months of age, children in low- and middle-income countries (LMICs) are diagnosed much later. To date, only one research study in Nepal, comprising a small sample of 50 children, had examined the age of diagnosis (AoD) of ASD (Shrestha & Shrestha, 2014). Hence, AoD was re-examined in 246 children with ASD registered at the AutismCare Nepal Society (ACNS) between 2010 and 2015. Changes in AoD was examined over these six years, and autism severity in the sample, including the frequency of ASD diagnosis with regards to gender, ethnicity, and geographical location (ecological regions and districts) was also investigated. While evidence suggests a significant variation in Nepal regarding access to healthcare facilities by gender, ethnicity, and ecological regions (Bhandari, Shrestha, & Ghimire, 2007; Goli, Bhandari, Atla, & Chattopadhyay, 2017), such research had not been conducted with regards to ASD. Investigating AoD of ASD provided an opportunity to examine the diagnostic trends in Nepal with a focus on underserved communities.

The mean AoD of ASD was found to be 58 months, with most children receiving their diagnosis after 36-months of age, highlighting the gap between diagnostic age and the age at which a reliable diagnosis can be made. The increase in the number of children with ASD diagnoses over six years of sampling, however demonstrates an increase in the awareness of ASD. However, the diagnosis of children with severe autistic symptoms, consistent with other LMICs (Juneja, Mukherjee, & Sharma, 2005; Shooshtari, Sadeghiyeh, Mohammadi, Ghanizadeh, & Akhondzadeh, 2009; Springer, van Toorn, Laughton, & Kidd, 2013) with the majority of male children (76%) indicate that children with milder behavioural autism presentations and those who are female may be missed.

Ethnic disparities were evident, with a higher number of children belonging to upper caste groups being diagnosed with ASD, corroborating the findings from previous health research in Nepal (Bhandari et al., 2007; Pandey, Dhakal, Karki, Poudel, & Pradhan, 2013). Likewise, most children diagnosed with ASD were living in Kathmandu valley, a capital city with better access to education, transportation, communication and health services. These findings highlight the need for decentralisation to enhance equity in the health system to serve all communities, so that all children with ASD can be identified earlier and referred for diagnosis and intervention.

In conclusion, the current study extended our knowledge of AoD in Nepal, where ASD research and resources are scarce. The findings showed a significant delay in AoD with gender, ethnic, and geographical disparities. Easily accessible and community-based early identification services are urgently needed to raise awareness and develop capacity, perhaps through task sharing. These findings served as impetus to develop a community-based developmental surveillance framework in Nepal.

Study 2: Implementing and Evaluating Social Attention and Communication

Surveillance (SACS) to Prospectively Identify Autism in Very Young

Children in Nepal

The current study was the first prospective, longitudinal, community-based study design conducted in Nepal to translate, adapt, implement and evaluate an autism-specific developmental surveillance approach (Barbaro & Dissanayake, 2010, 2013). The study evaluated the implementation of SACS-N by examining referral rates of children identified at “high likelihood” of ASD by FCHVs, the Positive Predictive Value (PPV) of the tool, charting developmental features of children who were identified as developing ASD and estimating prevalence of ASD in a cohort of children aged 11-30 months. The results showed good to excellent inter-rater agreement, consistent with the original SACS in Australia (Barbaro, Ridgway, & Dissanayake, 2011), as well as a good internal consistency for the Nepali version of SACS, indicating the appropriateness of this autism-specific tool for developmental monitoring of Nepalese infants/toddlers.

The SACS-N indicated a lower referral rate (0.57 per cent) of children at “high likelihood” of ASD, contrary to the referral rate of the original SACS (0.9 per cent) (Barbaro & Dissanayake, 2010). It seems possible that this result may be due to various factors including the lower prevalence estimates of disability in Kirtipur Municipality as informed by the last census report (Central Bureau of Statistics, 2014), FCHVs’ reluctance to raise concerns around social attention and communication difficulties in children because of caregivers’ limited knowledge (Shrestha, Dissanayake, & Barbaro, 2019b; Tilahun et al., 2016), and cultural differences in understanding early signs (Daley, 2004; Heys et al., 2017; Imran et al., 2011; Perera, Wijewardena, & Aluthwelage, 2009). The lower PPV (50%) of the SACS-N in comparison to the original SACS (81%) can also be ascribed to these factors. However, it is important to note that the PPV for identifying disability was 100%; an important finding given these children’s need for support and

early intervention. With no true false positives (i.e., typically developing children being identified), the current findings are encouraging for the adoption of developmental surveillance of ASD and other DDs in Nepal.

Although the FCHVs (and the PhD candidate) met with families to inform them of the developmental concerns identified following SACS-N administration, three children out of eleven referred children did not attend their scheduled developmental assessment sessions (and a further child had migrated from the area). They may have not attended the assessments due to lack of parental knowledge of early signs of ASD, and stigma as reported in previous studies (Samadi, Mahmoodizadeh, & McConkey, 2012; Tilahun et al., 2016).

All children attending the developmental/diagnostic assessments showed significant developmental delays. The prevalence of ASD was estimated between 0.16-0.26%, similar to a recent study in Nepal (Heys et al., 2018) and other LMICs (Non Communicable Diseases Control Programme, 2013; Poovathinal et al., 2016; Raina, Kashyap, Bhardwaj, Kumar, & Chander, 2015). However, this figure is much lower than international estimates of 1-2% (Elsabbagh et al., 2012). Therefore, it is likely that low referral rates and missing children with milder symptoms, and those without accompanying intellectual delays, may have contributed to these lower prevalence estimates.

The present study represents the first step towards implementing and evaluating the applicability of SACS-N in a local community in Nepal via training of FCHVs. With good internal consistency, inter-rater agreement and no false positives for general developmental concerns, the findings suggest that SACS-N is a promising tool for the developmental monitoring of social attention and communication behaviours in Nepalese children. Raising community awareness about autism is crucial to empower families to

feel confident in seeking professional advice and obtaining evaluations of their children's development.

Study 3: Changes in Knowledge on the Early Signs of Autism among Female

Community Health Volunteers (FCHVs) in Nepal

Limited knowledge, shortage of trained health workers and lack of early identification tools have significantly impacted the early identification of autism in LMICs. Community-based services achieved and delivered through task sharing in LMICs has been well acknowledged (Tilahun et al., 2017; World Health Organization, 2013). Study 3 described the training of sixty local FCHVs undertaken in Kirtipur Municipality to distinguish typical and atypical social attention and communication behaviours, the early signs of autism, and to monitor key markers relevant to the autism using SACS-N in children aged between 11-30 months who may be at "high likelihood" of autism, and how to refer them for further evaluation. Their knowledge of early signs of autism, and their confidence in monitoring and referring children at "high likelihood" of autism before training (T1), immediately after training (T2), and at a 12-month (T3) was examined.

After training, the FCHVs showed significantly improved autism knowledge and increased confidence in monitoring and referring of young children, which was sustained sustaining throughout one year. However, the findings revealed that knowledge about eye-contact returned to pre-training level at 12-months after training. While direct eye contact with elders as well as those with authority is not encouraged (Videbeck, 2010) in Asian culture (Daley, 2004; Freeth, Sheppard, Ramachandran, & Milne, 2013; Senju et al., 2013), there are no studies regarding social interactions between Nepalese infants/toddlers and their caregivers. Since eye contact characterises a critical marker of autism, it is important to understand the cultural aspects of this (and other) behaviour. This finding suggests that eye contact during early social interactions between young

children and caregivers as perceived in the Nepalese context should be discussed explicitly during SACS-N training.

Despite most FCHVs having over a decade of working experience, only one-fourth had knowledge of autism, including the behavioural characteristics, causal factors, epidemiology, diagnosis, and intervention, in accordance with previous LMICs studies (Bakare et al., 2009; Esegbe et al., 2015; Heys et al., 2018; Imran et al., 2011; Khatri, Onta, Tiwari, & Choulagai, 2011; Rahbar, Ibrahim, & Assassi, 2011). However, they showed significant improvement in their knowledge of autism and all related behavioural items from T1 to T2, with knowledge retained at T3. The current findings added to the few available studies to date (Atun-Einy & Ben-Sasson, 2018; Ben-Sasson, Atun-Einy, Yahav-Jonas, Lev-On, & Gev, 2018; Schwartz & Drager, 2008; Tilahun et al., 2017), which indicate changes in knowledge regarding autism among health professionals following training.

While a few FCHVs still supported supernatural reasons (past karma, fate or curse of God) as causes of autism, the findings showed reduced misconceptions (poor parenting, vaccine, and diet as causal factors) following training and beyond. Therefore, training focused on raising awareness and building capacity is vital for health workers in LMICs because of their ability to provide information to caregivers, which can then significantly influence families' help-seeking behaviours.

Although FCHVs showed little knowledge on the epidemiology of autism comparable to previous LMIC study (Imran et al., 2011), most FCHVs dismissed the outdated view that autism occurs commonly among highly educated or affluent people. Likewise, more FCHVs at T2 and T3 compared to T1 negated the statement that autism is just an intellectual disability. It is encouraging that most FCHVs recognised the importance of early identification, diagnosis, early intervention, and treatment post-training. Given that children in LMICs (Daley, 2004; Tilahun et al., 2017) including

Nepal (Shrestha & Shrestha, 2014; Shrestha, Dissanayake, & Barbaro, 2019a), are generally identified at later ages, improved knowledge amongst FCHVs can help facilitate early identification of children who are at “high likelihood” of autism.

Evaluation of training was also conducted immediately following the training (T2a) and after 6- (T2b) and 12- (T3) months. The FCHVs demonstrated increased confidence in monitoring and referring children at "high likelihood" of autism at both T2b and T3 comparable to the study by Barbaro et al. (2011) in Australia. FCHVs also reported a positive effect of training on their work, the suitability of implementing the SACS-N into their current practice, and parental comfort with the SACS-N being undertaken within their homes.

Frontline health workers’ confidence is vital to putting their knowledge into practice so that the general public will have access to autism-specific identification services within their community. The evidence from this study suggests the feasibility of developing cost-effective services to monitor, identify and refer children developing autism at an early age as part of routine family practice within primary care services.

Study 4: Caregivers’ Knowledge of Autism in a Local Peri-urban Community of

Nepal: A Cross-sectional Study in Kirtipur, Kathmandu

Despite the presence of early markers of autism within first two years of life (Barbaro & Dissanayake, 2010; Zwaigenbaum, Bryson, & Garon, 2013), the gap between parental concerns to a definitive diagnosis of ASD is relatively long in LMICs (Daley, 2004) including Nepal (Shrestha & Shrestha, 2014). Given the importance of early intervention, caregivers’ knowledge and help-seeking behaviours are crucial to facilitate earlier diagnosis. A deeper understanding of caregiver’s knowledge, and social disparities (such as caste and ethnic inequalities) in their knowledge, will allow health educators and policy makers to address gaps in autism knowledge at a community level.

Despite their good knowledge of social attention and communication behaviours in young children, less than a one-quarter of caregivers reported knowing about autism. They showed a substantial lack of knowledge about autism symptoms, epidemiology, diagnosis and intervention, comparable to previous studies in Nepal (Heys et al., 2017; Shrestha, Dissanayake, & Barbaro, 2019c) as well as in other LMICs (Ayub et al., 2017; Daley, 2004; Liu et al., 2016; Okandeji-Barry, Agofure, & Garba, 2015; Wang et al., 2012).

The present findings showed an association between caregivers' knowledge about autism and their age and educational level consistent with previous studies (Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013; Furnham & Buck, 2003; Holt & Christensen, 2013; Wang et al., 2012). Caregivers who were above 25 years and had more than secondary education possessed more autism knowledge indicating that educated parents (compared to less educated ones) have more access and/or are more able to source relevant information (Wang et al., 2012).

Knowledge disparities were also evident between caregivers' caste groups, with caregivers belonging to the upper caste group (Brahmin) displaying higher percentages of correct responses about autism. A small proportion of caregivers presented beliefs such as bad parenting or vaccines as causal factors comparable to previous studies in Nepal (Heys et al., 2017; Shrestha et al., 2019c). Insufficient knowledge and misconceptions about autism can delay caregivers' help-seeking behaviours, hampering timely identification and diagnosis of ASD.

The findings indicated a significant lack of knowledge among Nepalese caregivers, highlighting a need for awareness campaigns on autism, and the importance of early identification. Analysis of socio-demographic factors highlighted the knowledge disparities, which can be used to inform health educators and policy makers to develop targeted community-based autism awareness programs in Nepal.

Limitations and Future Directions

Limitations in the studies conducted need to be acknowledged. Study 1 was conducted using data from children registered at ACNS. It is important to acknowledge the strong potential for selection bias of those having access to the centre. Those children who were diagnosed but not recorded in the ACNS registry or diagnosed very late, and thus not registered, are not represented, possibly skewing the data. Therefore, the AoD reported in this study may be an underestimate of the true AoD in Nepal. Future research should examine the possible under-identification of children with milder behavioural symptoms, and issue also identified in Study 2.

Since most cases in Study 1 were clinically diagnosed, the reliability of their diagnoses could not be evaluated by administration of an ADOS-G. Only 52 children out of 246 had recorded ADOS-G scores. Moreover, Study 1 was limited by the lack of data on child characteristics, including birth order, intellectual level, and co-morbid conditions. Similarly, demographic factors (parental concerns, literacy, and socioeconomic status), which could also have affected AoD, were not recorded. Future studies should consider the potential impact of the above mentioned clinical and demographic factors on AoD to develop more effective early identification programs.

A key limitation in Study 2 was our inability to calculate the sensitivity and specificity of the tool due to the small size of the referred sample. Furthermore, the entire sample could not be monitored at a later point as some families were migrant workers in a brick factory in Kirtipur. Children were also missed out during monsoon season when families are busy in their paddy fields. Thus, future work is required to establish these key psychometrics of SACS-N. Moreover, regular training and supervision of FCHVs would likely further improve the use of SACS-N to identify children with autism, resulting in increased referral rates.

Since four of the 11 children identified “at high likelihood” of ASD and referred to ACNS did not participate in a diagnostic/developmental assessment (three did not attend their scheduled assessment and one migrated), the prevalence of ASD in the SACS-N sample was estimated on the basis of all referrals instead of only those evaluated at ACNS. Thus, the prevalence estimates should be treated cautiously. However, the finding provides a preliminary estimate of the prevalence of autism in Nepalese infants and toddlers, which serves as a good starting point for future epidemiological autism research in Nepal.

As indicated by the developmental status of children assessed at ACNS, those children with relatively mild symptoms and without accompanying cognitive delay are likely to have been missed. Despite efforts to work with parents regarding the developmental concerns of three children who were referred to ACNS for further diagnostic/development assessments, the parents did not attend their children’s scheduled assessments, possibly due to lack of knowledge and stigma, as indicated in Study 4. Further work is necessary to raise public awareness of autism and its early signs, and to address stigma and cultural interpretations of behaviours of concern so that parents are confident to seek timely help.

Limitations associated with the research design used in Study 3 should also be acknowledged. Changes in knowledge of children's behaviours and autism were examined using a simple pre-post follow-up design, as no similar research had been conducted in Nepal to date, and because the study was based on that of Barbaro et al. (2011) for comparability. Although it was developed through a comprehensive review of the literature, the survey instrument itself has not been validated. In addition, the majority of statements in the evaluation survey were worded positively, which could lend itself to response bias.

Future research should also examine the impact of training on knowledge and confidence among other frontline service providers such as other community workers, nurses, and early childhood educators, given the lack of knowledge of autism found amongst FCHVs and caregivers.

Despite the noted limitations, the findings from this thesis make an important contribution to the early identification of autism in Nepal. Firstly, the feasibility of task sharing with FCHVs has been established following their training to recognise important autism characteristics using SACS-N at a community level in Nepal. Since FCHVs are part of a larger network of community-based health workers with strong socio-cultural and geographical advantages, and access to families and children, there is tremendous potential to promote early identification of autism. Training of caregivers, pre-/primary school teachers, and nurses is strongly recommended to raise awareness and enhance their skills using SACS-N to increase early detection of autism in Nepal. The findings from the studies presented here will serve to inform government and non-government organisations in Nepal to develop programs and policies regarding the provision of resources across the population, to enhance information and access to early identification of autism. Particular emphasis should be directed to those underserved groups from disadvantaged and minority ethnic backgrounds and those living away from the Kathmandu valley.

Implications for Other Low- and Middle-Income Countries

Although the thesis findings should be generalised with caution, the current status of early identification of autism in Nepal is similar to the status in many other LMICs. The rising prevalence of ASD, inadequate local research and epidemiological data, limited knowledge of autism, shortage of trained professionals, and lack of early screening/surveillance tools are common issues across LMICs (Kakooza-Mwesige et al., 2014; Ruparelia et al., 2016; Tilahun et al., 2017). Findings from the present studies are

largely consistent with previous findings from LMICs and contributes additional evidence regarding the early identification of autism.

The current study is one of only a few pioneering studies to use a community-based, prospective research design to identify children at “high likelihood” of autism, using a developmental surveillance approach. The methodology reported here, including the process of translation, adaptation and implementation of SACS-N, should serve as a guideline for other researchers and policy makers to plan and facilitate early detection of ASD across cultures, in particular, in other low-resource settings.

Conclusion

In conclusion, the findings from the studies presented in this thesis make a significant contribution to the limited information available about ASD in Nepal, and other LMICs. This thesis adds new knowledge to promote the early identification of autism at a community level in Nepal, where child health research has predominantly been restricted to child survival strategies. The findings presented here expand the field of autism research by examining the current age of diagnosis of ASD and its association with important demographic variables like gender, geography and ethnicity. The research enabled successful implementation of a community-based, developmental surveillance approach using the SACS-N tool to facilitate early identification and referral of children who are at “high likelihood” of autism by training FCHVs. The knowledge of autism among FCHVs and caregivers was also investigated.

The findings showed that the mean AoD in children was 58 months, much later than the age at which a reliable diagnosis can be achieved, indicating the need to reduce this gap in AoD in Nepal. In the Kathmandu Valley and upper caste ethnic groups, a greater percentage of children were diagnosed with ASD, indicating ethnic and geographic disparities in access to health services.

The implementation and evaluation of SACS-N showed the feasibility of a community-based developmental surveillance approach as a possible cost-effective and sustainable solution to promoting early identification of ASD. However, further training and awareness of ASD, including regular supervision of FCHVs, is needed to increase the referral of children, particularly those who are more mildly affected. The findings resonate the WHO's call for action on autism, which recommended expanding the workforce involved by task sharing in collaboration with community health workers within primary health care settings.

Targeted training of 60 FCHVs on autism and SACS-N demonstrated significant improvement in their knowledge about autism and greater reported confidence in monitoring and referring young children at risk of autism, which was sustained one year later. Most FCHVs reported that training had a positive effect on their work. The effectiveness of training in improving FCHVs' knowledge and confidence indicates the feasibility of task sharing to identify early signs of autism in LMICs.

Although Nepalese caregivers are knowledgeable about social attention and communication development in young children, they lacked knowledge about autism, its symptoms, epidemiology, diagnosis, intervention and causes. Less than one-quarter of caregivers had heard about autism, and their knowledge differed according to their age, education and caste, highlighting the need to raise awareness, and targeting caregivers from all ages, educational levels and caste groups, to facilitate early recognition of autism.

Early identification and diagnosis of ASD is crucial for early intervention and support services, which foster positive developmental outcomes in young children and families. Training of FCHVs and implementation of SACS-N with young children to monitor and identify who may be at "high likelihood" of ASD is one step in a larger process toward diagnosis and provision of supports. The evidence from the series of

studies presented here has implications for developing and targeting community-based initiatives to facilitate earlier identification of ASD. Although the findings reported here relate to the Nepalese context, they are likely to be relevant to similar communities in other LMICs.

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APPENDICES

Appendix A-Recruitment Poster

सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

जसरी कुनै पनि बच्चाका लागि हिँड्न वा बोल्न जरूरी छ त्यसै गरी स्वस्थ मस्तिष्कको विकासका लागि उसले कसरी आफ्ना आमाबाबु, परिवारका सदस्यहरू अनि आफ्ना उमेरका अन्य केटाकेटीहरूसँग अन्तरक्रिया गर्छ, आफ्ना कुराहरू व्यक्त गर्छ र अरूका भावना र अभिव्यक्तिहरू बुझ्छ भन्ने कुरा पनि उत्तिकै महत्वपूर्ण हुन्छ ।
त्यसैले, बच्चाको सकारात्मक विकासलाई अघि बढाउनका लागि उनीहरूमा यी सामाजिक ध्यान र संचारको विकासक्रममा आउन सक्ने समस्याहरूलाई जति सक्दो सानो उमेरमा पहिचान गर्नु महत्वपूर्ण हुन्छ ।

बच्चाको पहिलो दुई वर्ष भित्रमा सामाजिक ध्यान र संचारका सीप अन्तर्गत यी कुराहरू पर्दछन्:

अरूसँग नियमित आँखा जुधाउने ।

कुनै वस्तु वा रुचि लागेको कुरालाई औँलाले देखाउने ।

नाम लिएर बोलाउँदा प्रतिक्रिया दिने ।

ईशाराको प्रयोग गर्ने, जस्तै: टाटा, नमस्ते गर्ने ।

अरूको नक्कल गर्ने ।

अरूले केही कुरा औँलाले देखाएको छ भने त्यतातिर हेर्ने ।

उमेर अनुसार बोल्ने र अरूले बोलेको बुझ्ने ।

अरू मान्छेहरू देखेपछि मुस्कुराउने, हाँस्ने ।



कीर्तिपुर नगरपालिकामा काम गरिरहेका महिला सामुदायिक स्वास्थ्य स्वयं सेविकाहरूसँगको सहकार्यमा हामी यस नगरपालिकाका ११ देखि ३० महिनाका बच्चाहरूको सामाजिक ध्यान र संचारको विकासका बारेमा अध्ययन गर्दैछौं ।

माथि उल्लिखित सामाजिक ध्यान र संचारका सिपहरू प्रत्यक्ष देख्न सकिने भएकाले तपाईंको वडाका महिला स्वास्थ्य स्वयं सेविकाले ११ देखि ३० महिनाका बच्चामा यी व्यवहारहरू कसरी विकास भइरहेका छन् भनेर अनुगमन गर्ने छन् । उनले अनुगमनका क्रममा बच्चाको सामाजिक ध्यान र संचारसँग सम्बन्धित केही क्रियाकलापहरू (जस्तै र कुनै वस्तु वा खेलौनालाई हेर्न लगाउने, बच्चाको नाम लिएर बोलाउने) गराउन सक्ने छन् ।

महिला स्वास्थ्य स्वयं सेविकाले तपाईंको बच्चामा केही समस्याहरू देखेमा / पाएमा बालविकास ईकाइ, अटिजम केयर नेपाल सोसाइटी, काठमाडौंमा तपाईंका बच्चाको विकासको विस्तृत मूल्याङ्कनका लागि पठाइने छ । अटिजम केयर नेपाल सोसाइटीले यस अध्ययनमा कीर्तिपुर नगरपालिकामा काम गरिरहनु भएका महिला स्वास्थ्य स्वयं सेविकाहरूले सामाजिक ध्यान र संचारको व्यवहारमा समस्या भएर पठाएका बच्चाहरूका विकासको विस्तृत मूल्याङ्कनका लागि सहयोग गरेको छ । यस क्रममा तपाईंका बच्चाको निःशुल्क विस्तृत मूल्याङ्कन गरी उसको विकास कसरी भइरहेको छ भनेर सुनिश्चित गर्ने अवसर मिल्ने छ ।

यो अध्ययन स्कूल अफ साइकोलोजी, ला ट्रोब विश्वविद्यालयमा विद्यावारिधिका लागि अध्ययनरत रेना श्रेष्ठले गर्दै हुनुहुन्छ । तपाईंलाई यस अध्ययनसित सम्बन्धित केही जिज्ञासा छन् भने तपाईंको वडाका महिला सामुदायिक स्वास्थ्य स्वयं सेविकालाई सोध्न सक्नु हुने छ । अथवा रेना श्रेष्ठलाई निम्न फोन नम्बर वा ईमेलमा सम्पर्क गर्नु हुने छ । फोन नम्बर : ९८४१-४८४१६२, ईमेल: shrestha.r@latrobe.edu.au/renashrestha@gmail.com)



LA TROBE
UNIVERSITY



कीर्तिपुर नगरपालिका



AutismCare
Nepal Society
"A National Center for Autism"



महिला सामुदायिक स्वास्थ्य स्वयं सेविका

Appendix B – Nepali Version of Participant Information Statement (FCHVs' Survey)



AutismCare
Nepal Society
"A National Center for Autism"

कीर्तिपुर नगरपालिका

सहभागीका लागि जानकारी

अध्ययनको शीर्षक : सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

शोधकर्ताहरू: रेना श्रेष्ठ
प्राध्यापक शेरिल दिसानायेके
डाक्टर जोसेफिन बारबरो

परिचय

म _____, तपाईंको वडाको महिला सामुदायिक स्वास्थ्य स्वयंसेविका हुँ र हाल अटिजम केयर नेपाल सोसाएटी, काठमाडौं तथा स्कुल अफ साइकोलोजी एन्ड पब्लिक हेल्थ, लाट्रोब विश्वविद्यालय, अस्ट्रेलियाको टोलीसँग यस अध्ययनमा काम गर्दै छु ।

यो जानकारी विवरणले यस अध्ययनका बारेमा बताउने छ र यस अध्ययनमा हामी तपाईं र तपाईंको बच्चालाई सहभागी हुन अनुरोध गर्दछौं । यदि कुनै कुरा बुझ्न कठिनाई भएमा मलाई सोध्न सक्नु हुने छ ।

अध्ययनका बारेमा

यस अध्ययनको उद्देश्य कीर्तिपुर नगरपालिकाका ११ देखि ३० महिनाका बच्चाको सामाजिक ध्यान र संचारमा केही समस्याहरू छन् भने जतिसक्दो सानो उमेरमा नै तिनको पहिचान गर्न प्रोत्साहन गर्नु हो । यो अध्ययन ला ट्रोब विश्वविद्यालयको सहायतामा संचालन भइरहेको छ ।

सामाजिक ध्यान र संचारको सिप बच्चाको विकासका महत्वपूर्ण चरणहरू हुन् । यो बेलामा उनीहरूले अरूसँग नियमित आँखा जुघाउने, अरू मान्छेहरू देखेपछि मुस्कुराउने, हाँस्ने, कुनै वस्तु वा रुचि लागेको कुरालाई आँलाले देखाउने, आवाजहरू निकाल्ने, एक शब्द वा दुई शब्द बोल्ने जस्ता व्यवहार देखाउँछन् ।

सहभागिताको किसिम

यस अध्ययनमा निम्नलिखित क्रियाकलाप हुने छन् :

- बच्चाको सामाजिक ध्यान र संचारको विकासका बारेमा आमबुबाको ज्ञान सम्बन्धी सर्वेक्षणमा तपाईं सहभागी हुनु हुने छ । यसका लागि करिब १० मिनेट लाग्ने छ ।
- महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले बच्चाको सामाजिक ध्यान र संचारका व्यवहारहरूको मूल्याङ्कन गर्ने छन् । यसका लागि करिब १५ देखि २० मिनेट लाग्ने छ ।

गोपनीयता

यस अध्ययनका लागि सङ्कलित जानकारी अनुसन्धानका लागि प्रयोग गरिने छ साथै यसबाट आएका नतिजाहरू शोधप्रबन्धमा समावेश गरिनुका साथै प्राज्ञिक पत्रिकाहरूमा प्रकाशित र सेमिनारमा प्रस्तुत गरिने छन् । तर तपाईं वा तपाईंको बच्चाको पहिचान खुल्ने कुनै पनि जानकारीको प्रयोग गरिने छैन । त्यसैले तपाईंका सबै व्यक्तिगत विवरण गोप्य रहने छन् । तपाईं वा तपाईंको बच्चासँग सम्बन्धित सबै जानकारीमा नामको सट्टा नम्बर हुने छ । यस अध्ययनका शोधकर्ताहरूलाई मात्र तपाईंको नम्बर थाहा हुने छ । तपाईंको सबै जानकारी भएको फाइल तथा नतिजाहरू पहिचान गर्न नसकिने तरिकाले सुरक्षित रूपमा अटिजम केयर नेपाल सोसाएटी र बाल विकास इकाइ, ला ट्रोब विश्वविद्यालयमा राखिने छ । त्यस्तै गरी यस अध्ययनका लागि सङ्कलित जानकारी, बच्चाहरूको सामाजिक ध्यान र संचारको विकाससँग सम्बन्धित यस्तै अरू अध्ययनहरूमा प्राध्यापक शेरेल दिसानायेके, डाक्टर जोसेफिन बारबरो, रेना श्रेष्ठ र उँहाहरू अन्तर्गतका विद्यार्थीहरूले प्रयोग गर्न सक्ने छन् ।

अध्ययनबाट बाहिरिनेबारे

यो अध्ययनमा तपाईंको सहभागिता स्वैच्छिक हुने छ । तपाईंलाई कुनै पनि समयमा अध्ययनबाट बाहिरिन सक्ने अधिकार छ । साथै अध्ययनमा सहभागी भएको चार हप्ताभित्र तपाईंको विवरण र उत्तरहरू यस अध्ययनमा प्रयोग नगर्नका लागि पनि अनुरोध गर्न सक्नु हुने छ । यसका लागि तपाईंलाई अध्ययनबाट बाहिरिने फाराम पुरा गर्न आग्रह गरिने छ वा तपाईंले यस अध्ययनमा तपाईंको विवरण र उत्तरहरू प्रयोग नगरिदिनका लागि शोधकर्तालाई टेलिफोन वा ईमेलबाट पनि खबर गर्न सक्नु हुने छ । यस अध्ययनसँग सम्बन्धित जिज्ञासाका लागि रेना श्रेष्ठलाई फोन नम्बर : ९८४१४८४९६२, +६१४५०३९२०१०, ईमेल : shrestha.r@latrobe.edu.au, renashrestha@gmail.com मा सम्पर्क गर्न सक्नु हुने छ । तपाईंको यस अध्ययनमा आफ्नो सहभागिताका बारेमा कुनै गुनासाको उत्तर शोधकर्ताले सन्तोषपूर्ण तरिकाले दिन नसकेमा तल उल्लिखित फोन नम्बर वा ईमेलमा सम्पर्क गर्न सक्नु हुने छ ।

सदस्य सचिव, नेपाल स्वास्थ्य अनुसन्धान परिषद्, काठमाडौं, नेपाल (फोन : ४२५४२२०, ४२२७२६०, ईमेल : nhrc@nhrc.org.np) वा सिनियर ह्युमन एथिक्स अफिसर एथिक्स एन्ड इन्टेग्रिटी, अनुसन्धान कार्यालय Senior Human Ethics Officer, Ethics and Integrity, Research Office, ला ट्रोब विश्वविद्यालय, अस्ट्रेलिया (फोन : +६१३९४७९१४४३, ईमेल : humanethics@latrobe.edu.au) ।

सहभागीको चयन

तपाईंको बच्चाको उमेर ११-२० महिनाको भएको हुनाले हामी तपाईंलाई यस अध्ययनमा सहभागी हुन अनुरोध गर्दछौं । यस अध्ययनमा बच्चाको विकासका महत्वपूर्ण चरणहरूका बारेमा आमाबुबालाई के-कस्तो जानकारी छ भनेर अध्ययन गर्दै छौं । तपाईंले दिने जानकारीले सानो उमेरका बच्चाहरूको विकासमा आउन सक्ने समस्याहरूका बारेमा जनचेतनाका कार्यक्रमहरू बनाउन हामीलाई सहयोग पुर्याने छ ।

त्यसै गरी, तपाईंको बच्चाको सहभागिताले विशेष गरी नेपाली बच्चाहरूको प्रारम्भिक सामाजिक ध्यान र संचारको विकासका चरणहरूका बारेमा अझ राम्रोसँग बुझ्न सहयोग गर्ने छ । साथै यस सहभागिताबाट समयमा नै बच्चामा आउन सक्ने सामाजिक ध्यान तथा संचारको समस्याका प्रारम्भिक संकेतलाई पहिचान गर्नका लागि विश्वसनीय विधिको विकास गर्न योगदान गर्ने छ जसले गर्दा यस्ता समस्याहरूका जोखिममा भएका बच्चाका परिवारले आफ्नो बच्चाको सकारात्मक विकासका लागि समयमा नै आवश्यक सहायता पाउन सक्ने छन् ।

कार्यविधि

तपाईंको बच्चाको प्रारम्भिक सामाजिक ध्यान र संचारको विकासका व्यवहारहरूलाई तपाईंको बच्चाको महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले ऊ २४ महिना उमेरको नहुन्जेल हरेक ६ महिनामा तपाईंको घरमा आएर अनुगमन गर्ने छन् । यदि महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले तपाईंको बच्चामा केही समस्याहरू पाएको खण्डमा तपाईंको बच्चालाई बालविकास इकाइ, अटिजम केयर नेपाल सोसाइटी, काठमाडौंमा उसको विकासको विस्तृत मूल्याङ्कनका लागि पठाइने छ । अटिजम केयर नेपाल सोसाइटीले यस अध्ययनमा कीर्तिपुर नगरपालिकामा काम गरिरहनु भएका महिला सामुदायिक स्वास्थ्य स्वयं सेविकाहरूले सामाजिक ध्यान र संचारको व्यवहारमा समस्या भएर पठाएका बच्चाहरूको विकासको विस्तृत मूल्याङ्कनका लागि सहयोग गरेको छ । यसमा तपाईंको बच्चाले निःशुल्क विस्तृत मूल्याङ्कन गरी उसको विकास कसरी भइरहेको भनेर सुनिश्चित गर्न मौका पाउने छ ।

अध्ययनमा सहभागी हुँदाको फाइदा

हामीले तपाईंको बच्चाको सामाजिक ध्यान र संचारको विकासका व्यवहारलाई सानो उमेरमा पहिचान गर्न र अनुगमन गर्न सक्छौं जसले गर्दा तपाईंको बच्चाको विकासमा केही समस्याहरू पाउँ भने उसले निःशुल्क विस्तृत मूल्याङ्कनको मौका पाउने छ ।

सहमति फारममा हस्ताक्षर गरेर तपाईं यस अध्ययन अन्तर्गत माथि उल्लिखित आमाबुबाको सर्वेक्षणमा सहभागी हुनाका साथै तपाईंको बच्चालाई १२-१८-२४ महिनाको उमेरमा मूल्याङ्कन गर्ने अनुमति दिनु भएको छ । बच्चाको पहिलो मूल्याङ्कनका बेलाको उमेर अनुसार उसको अर्को मूल्याङ्कनको समय निर्धारण हुने छ । त्यसै गरी यो सहमतिले तपाईंका बच्चाको विकासको विस्तृत मूल्याङ्कनका लागि पठाउन पनि अनुमति दिनु भएको छ ।

Appendix C – Nepali Version of Consent Form (FCHVs' Survey)

सहमती फाराम

सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

तलको फाराम पुरा गर्नु होस्:

म _____ ले सहभागीका लागि जानकारी र सहमती फाराम पढेको छु/महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले पढेर सुनाउनु भएको छ । मैले यो जानकारी विवरण बुझेको छु र मेरा सबै जिज्ञासाहरूको सन्तोषपूर्ण उत्तर पाएको छु । म यस अध्ययनमा भाग लिन सहमत छु र कुनै पनि समयमा यो अध्ययनबाट बाहिरिन सक्छु भन्ने मलाई जानकारी छ ।

यस अध्ययनका बेलामा मेरा अनुमतीमा दिइएको जानकारी, मेरो नाम वा पहिचान खुलाउने अरु कुनै सूचनाको प्रयोग नगरी शोधप्रबन्धमा समावेश गर्न, प्राज्ञिक पत्रिकाहरूमा प्रकाशन र सेमिनारमा प्रस्तुत गर्न दिनका लागि सहमत छु ।

☐ लिखित सहमती

☐ मौखिक सहमती

_____ महिला सामुदायिक स्वास्थ्य स्वयं सेविकाको नाम

मिति: _____ / _____ / _____

_____ महिला सामुदायिक स्वास्थ्य स्वयं सेविकाको सही

रेना श्रेष्ठ

_____ शोधकर्ताको नाम

_____ शोधकर्ताको सही

प्राध्यापक शेरील दिसानायके, डाक्टर जोसेफिन बारबरो

_____ सुपरभाइजरहरूको नाम

Appendix D- Nepali Version of Participant Information Statement (SACS-N Administration)



सहभागीका लागि जानकारी

अध्ययनको शीर्षक : सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

शोधकर्ताहरू: रेना श्रेष्ठ
प्राध्यापक शेरिल दिसानायेके
डाक्टर जोसेफिन बारबरो

परिचय

म _____, तपाईंको वडाको महिला सामुदायिक स्वास्थ्य स्वयंसेविका हुँ र हाल अटिजम केयर नेपाल सोसाएटी, काठमाडौं तथा स्कुल अफ साइकोलोजी एन्ड पब्लिक हेल्थ, लाट्रोब विश्वविद्यालय, अस्ट्रेलियाको टोलीसँग यस अध्ययनमा काम गर्दै छु ।

यो जानकारी विवरणले यस अध्ययनका बारेमा बताउने छ र यस अध्ययनमा हामी तपाईं र तपाईंको बच्चालाई सहभागी हुन अनुरोध गर्दछौं । यदि कुनै कुरा बुझ्न कठिनाई भएमा मलाई सोध्न सक्नु हुने छ ।

अध्ययनका बारेमा

यस अध्ययनको उद्देश्य कीर्तिपुर नगरपालिकाका ११ देखि ३० महिनाका बच्चाको सामाजिक ध्यान र संचारमा केही समस्याहरू छन् भन्ने जतिसक्दो सानो उमेरमा नै तिनको पहिचान गर्न प्रोत्साहन गर्नु हो । यो अध्ययन ला ट्रोब विश्वविद्यालयको सहायतामा संचालन भइरहेको छ ।

सामाजिक ध्यान र संचारको सिप बच्चाको विकासका महत्वपूर्ण चरणहरू हुन् । यो बेलामा उनीहरूले अरूसँग नियमित आँखा जुधाउने, अरू मान्छेहरू देखेपछि मुस्कुराउने, हाँस्ने, कुनै वस्तु वा रुचि लागेको कुरालाई औँलाले देखाउने, आवाजहरू निकाल्ने, एक शब्द वा दुई शब्द बोल्ने जस्ता व्यवहार देखाउँछन् ।

सहभागिताको किसिम

यस अध्ययनमा निम्नलिखित क्रियाकलाप हुने छन् :

- बच्चाको सामाजिक ध्यान र संचारको विकासका बारेमा आमबुबाको ज्ञान सम्बन्धी सर्वेक्षणमा तपाईं सहभागी हुनु हुने छ । यसका लागि करिब १० मिनेट लाग्ने छ ।
- महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले बच्चाको सामाजिक ध्यान र संचारका व्यवहारहरूको मूल्याङ्कन गर्ने छन् । यसका लागि करिब १५ देखि २० मिनेट लाग्ने छ ।

सहभागीको चयन

तपाईंको बच्चाको उमेर ११-३० महिनाको भएको हुनाले हामी तपाईंलाई यस अध्ययनमा सहभागी हुन अनुरोध गर्दछौं । यस अध्ययनमा बच्चाको विकासका महत्त्वपूर्ण चरणहरूका बारेमा आमाबुबालाई के-कस्तो जानकारी छ भनेर अध्ययन गर्दै छौं । तपाईंले दिने जानकारीले सानो उमेरका बच्चाहरूको विकासमा आउन सक्ने समस्याहरूका बारेमा जनचेतनाका कार्यक्रमहरू बनाउन हामीलाई सहयोग पुग्ने छ ।

त्यसै गरी, तपाईंको बच्चाको सहभागिताले विशेष गरी नेपाली बच्चाहरूको प्रारम्भिक सामाजिक ध्यान र संचारको विकासका चरणहरूका बारेमा अझ राम्रोसँग बुझ्न सहयोग गर्ने छ । साथै यस सहभागिताबाट समयमा नै बच्चामा आउन सक्ने सामाजिक ध्यान तथा संचारको समस्याका प्रारम्भिक संकेतलाई पहिचान गर्नका लागि विश्वसनीय विधिको विकास गर्न योगदान गर्ने छ जसले गर्दा यस्ता समस्याहरूका जोखिममा भएका बच्चाका परिवारले आफ्नो बच्चाको सकारात्मक विकासका लागि समयमा नै आवश्यक सहायता पाउन सक्ने छन् ।

कार्यविधि

तपाईंको बच्चाको प्रारम्भिक सामाजिक ध्यान र संचारको विकासका व्यवहारहरूलाई तपाईंको वडाको महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले ऊ २४ महिना उमेरको नहुन्जेल हरेक ६ महिनामा तपाईंको घरमा आएर अनुगमन गर्ने छन् । यदि महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले तपाईंको बच्चामा केही समस्याहरू पाएको खण्डमा तपाईंको बच्चालाई बालविकास इकाइ, अटिजम केयर नेपाल सोसाइटी, काठमाडौंमा उसको विकासको विस्तृत मूल्याङ्कनका लागि पठाइने छ । अटिजम केयर नेपाल सोसाइटीले यस अध्ययनमा कीर्तिपुर नगरपालिकामा काम गरिरहनु भएका महिला सामुदायिक स्वास्थ्य स्वयं सेविकाहरूले सामाजिक ध्यान र संचारको व्यवहारमा समस्या भएर पठाएका बच्चाहरूको विकासको विस्तृत मूल्याङ्कनका लागि सहयोग गरेको छ । यसमा तपाईंको बच्चाले निःशुल्क विस्तृत मूल्याङ्कन गरी उसको विकास कसरी भइरहेको भनेर सुनिश्चित गर्न मौका पाउने छ ।

अध्ययनमा सहभागी हुँदाको फाइदा

हामीले तपाईंको बच्चाको सामाजिक ध्यान र संचारको विकासका व्यवहारलाई सानो उमेरमा पहिचान गर्न र अनुगमन गर्न सक्छौं जसले गर्दा तपाईंको बच्चाको विकासमा केही समस्याहरू पायौं भने उसले निःशुल्क विस्तृत मूल्याङ्कनको मौका पाउने छ ।

सहमति फारममा हस्ताक्षर गरेर तपाईं यस अध्ययन अन्तर्गत माथि उल्लिखित आमाबुबाको सर्वेक्षणमा सहभागी हुनाका साथै तपाईंको बच्चालाई १२-१८-२४ महिनाको उमेरमा मूल्याङ्कन गर्ने अनुमति दिनु भएको छ । बच्चाको पहिलो मूल्याङ्कनका बेलाको उमेर अनुसार उसको अर्को मूल्याङ्कनको समय निर्धारण हुने छ । त्यसै गरी यो सहमतिले तपाईंका बच्चाको विकासको विस्तृत मूल्याङ्कनका लागि पठाउन पनि अनुमति दिनु भएको छ ।

गोपनीयता

यस अध्ययनका लागि सङ्कलित जानकारी अनुसन्धानका लागि प्रयोग गरिने छ साथै यसबाट आएका नतिजाहरू शोधप्रबन्धमा समावेश गरिनुका साथै प्राज्ञिक पत्रिकाहरूमा प्रकाशित र सेमिनारमा प्रस्तुत गरिने छन् । तर तपाईं वा तपाईंको बच्चाको पहिचान खुल्ने कुनै पनि जानकारीको प्रयोग गरिने छैन । त्यसैले तपाईंका सबै व्यक्तिगत विवरण गोप्य रहने छन् । तपाईं वा तपाईंको बच्चासँग सम्बन्धित सबै जानकारीमा नामको सट्टा नम्बर हुने छ । यस अध्ययनका शोधकर्ताहरूलाई मात्र तपाईंको नम्बर थाहा हुने छ । तपाईंको सबै जानकारी भएको फाइल तथा नतिजाहरू पहिचान गर्न नसकिने तरिकाले सुरक्षित रूपमा अटिजम केयर नेपाल सोसाएटी र बाल विकास इकाइ, ला ट्रोब विश्वविद्यालयमा राखिने छ । त्यस्तै गरी यस अध्ययनका लागि सङ्कलित जानकारी, बच्चाहरूको सामाजिक ध्यान र संचारको विकाससँग सम्बन्धित यस्तै अरू अध्ययनहरूमा प्राध्यापक शेरील दिसानायेके, डाक्टर जोसेफिन बारबरो, रेना श्रेष्ठ र उँहाहरू अन्तर्गतका विद्यार्थीहरूले प्रयोग गर्न सक्ने छन् ।

अध्ययनबाट बाहिरिनेबारे

यो अध्ययनमा तपाईंको सहभागिता स्वैच्छिक हुने छ । तपाईंलाई कुनै पनि समयमा अध्ययनबाट बाहिरिन सक्ने अधिकार छ । साथै अध्ययनमा सहभागी भएको चार हप्ताभित्र तपाईंको विवरण र उत्तरहरू यस अध्ययनमा प्रयोग नगर्नका लागि पनि अनुरोध गर्न सक्नु हुने छ । यसका लागि तपाईंलाई अध्ययनबाट बाहिरिने फाराम पुरा गर्न आग्रह गरिने छ वा तपाईंले यस अध्ययनमा तपाईंको विवरण र उत्तरहरू प्रयोग नगरिदिनका लागि शोधकर्तालाई टेलिफोन वा ईमेलबाट पनि खबर गर्न सक्नु हुने छ । यस अध्ययनसँग सम्बन्धित जिज्ञासाका लागि रेना श्रेष्ठलाई फोन नम्बर : ९८४१४८४१६२, +६१४५०३९२०१०, ईमेल : shrestha.r@latrobe.edu.au, renashrestha@gmail.com मा सम्पर्क गर्न सक्नु हुने छ । तपाईंको यस अध्ययनमा आफ्नो सहभागिताका बारेमा कुनै गुनासाको उत्तर शोधकर्ताले सन्तोषपूर्ण तरिकाले दिन नसकेमा तल उल्लिखित फोन नम्बर वा ईमेलमा सम्पर्क गर्न सक्नु हुने छ ।

सदस्य सचिव, नेपाल स्वास्थ्य अनुसन्धान परिषद्, काठमाडौं, नेपाल (फोन : ४२५४२२०, ४२२७२६०, ईमेल : nhrc@nhrc.org.np) वा सिनियर ह्युमन एथिक्स अफिसर एथिक्स एन्ड इन्टेग्रिटी, अनुसन्धान कार्यालय Senior Human Ethics Officer, Ethics and Integrity, Research Office, ला ट्रोब विश्वविद्यालय, अस्ट्रेलिया (फोन : +६१ ३९४७९१४४३, ईमेल : humanethics@latrobe.edu.au) ।

Appendix E- Nepali Version of Consent Form (SACS-N Administration)**सहमती फाराम**

सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

तलको फाराम पुरा गर्नु होस्:

म _____ ले सहभागीका लागि जानकारी र सहमती फाराम पढेको छु/महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले पढेर सुनाउनु भएको छ । मैले यो जानकारी विवरण बुझेको छु र मेरा सबै जिज्ञासाहरूको सन्तोषपूर्ण उत्तर पाएको छु । म यस अध्ययनमा भाग लिन सहमत छु र कुनै पनि समयमा यो अध्ययनबाट बाहिरिन सक्छु भन्ने मलाई जानकारी छ ।

यस अध्ययनका बेलामा मेरा अनुमतीमा दिइएको जानकारी, मेरो नाम वा पहिचान खुलाउने अरू कुनै सूचनाको प्रयोग नगरी शोधप्रबन्धमा समावेश गर्न, प्राज्ञिक पत्रिकाहरूमा प्रकाशन र सेमिनारमा प्रस्तुत गर्न दिनका लागि सहमत छु ।

☐ लिखित सहमती☐ मौखिक सहमती

_____ महिला सामुदायिक स्वास्थ्य स्वयं सेविकाको नाम

मिति: _____ / _____ / _____

_____ महिला सामुदायिक स्वास्थ्य स्वयं सेविकाको सही

रेना श्रेष्ठ

_____ शोधकर्ताको नाम

_____ शोधकर्ताको सही

प्राध्यापक शेरील दिसानायके, डाक्टर जोसेफिन बारबरो

_____ सुपरभाइजरहरूको नाम

Appendix F – Nepali Version of Participant Information Statement (ACNS Assessment)



सहमती फाराम

सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

तलको फाराम पुरा गर्नु होस् :

म _____ ले सहभागीका लागि जानकारी र सहमती फाराम पढेको छु । महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले पढेर सुनाउनु भएको छ । मैले यो जानकारी विवरण बुझेको छु र मेरा सबै जिज्ञासाहरूको सन्तोषपूर्ण उत्तर पाएको छु । म यस अध्ययनमा भाग लिन सहमत छु र कुनै पनि समयमा यो अध्ययनबाट बाहिरिन सक्छु भन्ने मलाई जानकारी छ ।

यस अध्ययनका बेलामा मेरा अनुमतीमा दिइएको जानकारी, मेरो नाम वा पहिचान खुलाउने अरू कुनै सूचनाको प्रयोग नगरी शोधप्रबन्धमा समावेश गर्ने, प्राज्ञिक पत्रिकाहरूमा प्रकाशन र सेमिनारमा प्रस्तुत गर्न दिनका लागि सहमत छु ।

☐ लिखित सहमती

☐ मौखिक सहमती

_____ (बच्चाको नाम)

जन्म मिति : ____ / ____ / ____

_____ आमाबुबाको नाम / हेरचाह गर्ने व्यक्तिको नाम

मिति : ____ / ____ / ____

_____ आमाबुबाको सही / हेरचाह गर्ने व्यक्तिको सही

(यदि यो कुरा तपाईंलाई लागु भएमा)

Appendix G – Nepali Version of Consent Form (ACNS Assessment)



सहमती फाराम

सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

तलको फाराम पुरा गर्नु होस् :

म _____ ले सहभागीका लागि जानकारी र सहमती फाराम पढेको छु । महिला सामुदायिक स्वास्थ्य स्वयं सेविकाले पढेर सुनाउनु भएको छ । मैले यो जानकारी विवरण बुझेको छु र मेरा सबै जिज्ञासाहरूको सन्तोषपूर्ण उत्तर पाएको छु । म यस अध्ययनमा भाग लिन सहमत छु र कुनै पनि समयमा यो अध्ययनबाट बाहिरिन सक्छु भन्ने मलाई जानकारी छ ।

यस अध्ययनका बेलामा मेरा अनुमतीमा दिइएको जानकारी, मेरो नाम वा पहिचान खुलाउने अरू कुनै सूचनाको प्रयोग नगरी शोधप्रबन्धमा समावेश गर्न, प्राज्ञिक पत्रिकाहरूमा प्रकाशन र सेमिनारमा प्रस्तुत गर्न दिनका लागि सहमत छु ।

☐ लिखित सहमती☐ मौखिक सहमती

(बच्चाको नाम)

जन्म मिति : __/__/__

आमाबुवाको नाम /हेरचाह गर्ने व्यक्तिको नाम

मिति : __/__/__

आमाबुवाको सही /हेरचाह गर्ने व्यक्तिको सही

(यदि यो कुरा तपाईंलाई लागु भएमा)

कार्यालय प्रयोगको लागि मात्र

शोधकर्ता/साइकोलोजिस्ट, अटिजम केयर नेपाल सोसाइटी

मिति : ____/____/____

शोधकर्ता/साइकोलोजिस्टको सही

शोधकर्ताको नाम

शोधकर्ताको सही

Appendix H– Nepali Version of Withdrawal Form



ला ट्रोब विश्वविद्यालय

विश्वविद्यालय ह्युमन एथिक्स कमिटी

सूचनाको प्रयोग गर्ने सहमतीबाट बाहिरिने फाराम

सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

म मेरा सहभागिताबाट आएको विवरण प्रयोग गर्ने सहमतीबाट बाहिरिन चाहन्छु । सहभागीका लागि जानकारी र सहमती फाराममा उल्लेख भए अनुसार मेरा सहभागिताबाट आएको विवरण यस अध्ययनमा प्रयोग हुने छैन । मैले बुझेको छु कि यस अध्ययनमा सहभागी भएको चार हप्ताभित्र मेरो यो आग्रह प्राप्त भएमा मेरा सहभागिताबाट आएका विवरण नष्ट गरिने छन् । यो सूचना मेरा सहभागिताबाट प्राप्त विवरणको प्रयोग गर्ने सहमतिबाट बाहिरिएको प्रमाणका रूपमा सहमती पत्रसँगै राखिने कुरा मैले बुझेको छु ।

☐ लिखित सहमती

☐ मौखिक सहमती

सहभागीको नाम :

.....

सही (यदि यो कुरा तपाईंलाई लागु भएमा) :

.....

मिति :

.....

Appendix I- Nepali Translation of SACS (12-month checklist)

1

सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल

१२- महिने मुल्याङ्कन

सुचक	क्याकलाप	उत्तर
औलाले देखाउँछ (प्रमुख सुचक)	पुतली लिनुस्, त्यो बच्चालाई देखाउनुस् र भन्नुस् "यो पुतली हेर त" । त्यसपछि पुतलीलाई कोठामा तपाईंको पारीपट्टी (बच्चाको देख्न सक्ने तर भेटाउन नसक्ने ठाउँमा) राख्नुस् र भन्नुस्, "पुतली कहाँ छ?" बच्चाको औलाले पुतलीलाई देखाउँदै तपाईंको अनुहारमा हेर्छ ?	हो / हैन
आँखामा आँखा जुघाएर हेर्छ (प्रमुख सुचक)	के बच्चाको यो सत्रको दौरानमा तपाईंसँग स्वतस्फुर्त रूपमा आँखामा आँखा जुघाएको छ ? यदि छैन भने, उसँग अन्तर्कृया गर्नुस् ताकि बच्चाको तपाईंसँग आँखामा आँखा जुघाएर हेरोस् । उसले तपाईंसँग आँखामा आँखा जुघाएर हेर्छ ?	हो / हैन
बाइ बाइ गर्छ (प्रमुख सुचक)	कोठा छोडेर गएको बहाना गर्दै बच्चालाई बाइ- बाइ गर्नुस् । उसले पनि तपाईंलाई हात हल्लाएर बाइ बाइ गर्छ ?	हो / हैन
नक्कल गर्छ (प्रमुख सुचक)	बच्चाको ध्यान आकर्षित गर्नुस् । आफ्नो कपालमा ब्रश / काइयो प्रयोग गर्नुस् । बच्चालाई दिनुस् "अब तिम्रो पालो ।" बच्चाको तपाईंको नक्कल गर्छ ?	हो / हैन
नाम लिएर बोलाईउदा प्रतिक्रिया दिन्छ (प्रमुख सुचक)	बच्चाको नाम लिएर बोलाउनुस् । उ तपाईंलाई हेर्नेको लागि तपाईंतिर फर्किन्छ ? (यो गर्नु भन्दा अगाडि बच्चाको पहिले देखिनै तपाईंलाई हेरीरहेको छैन भन्ने सुनिस्चित गर्नुस्) ।	हो / हैन
औलाले देखाएको पछ्याउँछ	बच्चाको ध्यान आकर्षित गर्नुस् र कोठामा तपाईंको पारीपट्टी भएको कुनै वस्तुलाई देखाउनुस् र भन्नुस् "आहा, त्यो हेर त!" उसले तपाईंले देखाउनु भएको तिर हेर्छ ? (न कि तपाईंको हात/पाखुरामा मात्र)	हो / हैन
सामाजिक मुस्कान	तपाईंलाई/ तिर हेर्दा बच्चा मुस्कराएको छ ? यदि छैन भने, बच्चातिर हेरेर मुस्कराउनुस् । ऊ पनि मुस्कराउछ ? (बच्चा मुस्कराओस् भनेर शरीरमा छुने/ चलाउने नगर्नुस्)	हो / हैन
कुराकानी गरेको जस्तो आवाज निकाल्छ	के बच्चाको कुराकानी गरेको जस्तो गरी आवाज (उदाहरणका लागि, अगागा, अदावा, मामा, बाबा, दादा) निकाल्छ ?	हो / हैन
१-३ शब्दहरू बोल्छ	बच्चाको १ देखि ३ वटा सम्म चित्र सकिने शब्दहरू बोल्छ ?	हो / हैन
साधारण निर्देशनहरू बुझ्छ	बच्चालाई पुतली देखाउनुस् र त्यसलाई उसको छेउमा राख्नुस् । त्यसपछि सोध्नुस्, "पुतली कहाँ छ?" उसले पुतलीलाई हेर्छ, त्यसलाई उठाउँछ वा त्यसलाई तपाईंलाई दिन्छ ?	हो / हैन
आवाजहरू तिर ध्यान दिन्छ	सत्रको दौरानमा बच्चाको आवाजहरू तिर ध्यान दिएको/ रुची देखाएको जस्तो गरेको छ ?	हो / हैन

यदि ५ प्रमुख सुचकहरूमा ३ हैन उत्तर आएमा, बच्चा "अटिजमको जोखिममा" छ । कृपया बच्चाको विकासको विस्तृत मुल्याङ्कन को लागि "सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल" टीम कहाँ पठाउनु होस् ।

Appendix J - Nepali Translation of SACS (18-month checklist)

2

१८- महिने मुल्याङ्कन

सूचक	कृयाकलाप	उत्तर
औलाले देखाउँछ (प्रमुख सूचक)	पुतली लिनुस्, त्यो बच्चालाई देखाउनुस् र भन्नुस् "यो पुतली हो"। त्यसपछी पुतलीलाई कोठामा तपाईंको पारीपट्टी (बच्चाले देख्न सक्ने तर भेटाउन नसक्ने ठाउँमा) राख्नुस् र भन्नुस्, "पुतली कहाँ छ?" बच्चाले औलाले पुतलीलाई देखाउँदै तपाईंको अनुहारमा हेर्छ ?	हो / हैन
आँखामा आँखा जुधाएर हेर्छ (प्रमुख सूचक)	के बच्चाले यो सत्रको दौरानमा तपाईंसँग स्वतस्फुर्त रूपमा आँखामा आँखा जुधाएको छ ? यदि छैन भने, उसँग अन्तर्कृया गर्नुस् ताकि बच्चाले तपाईंसँग आँखामा आँखा जुधाएर हेरोस् । उसले तपाईंसँग आँखामा आँखा जुधाएर हेर्छ ?	हो / हैन
बाइ बाइ गर्छ (प्रमुख सूचक)	कोठा छोडेर गएको बहाना गर्दै बच्चालाई बाइ- बाइ गर्नुस् । उसले पनि तपाईंलाई हात हल्लाएर बाइ बाइ गर्छ ?	हो / हैन
देखाउँछ (प्रमुख सूचक)	बच्चाले खेलौना/वस्तु समाई आँखामा आँखा जुधाएर तपाईंलाई वा आमाबुवालाई देखाएको छ ? (यदी यस्तो गरेको नदेखिएमा आमा बुवालाई सोधनुस्)	हो / हैन
काल्पनिक खेल खेल्छ (प्रमुख सूचक)	बच्चालाई पुतली, खेलौना कप , चम्चा र भाँडो दिनुस् । "तिमिले चिया खनाएर पिउन (खान?) सक्छौ ?" भन्नुस् । बच्चाले चिया खनाएर पिएको वा खनाएको वा पिएको जस्तो बहाना गर्छ ? अरू उदाहरणहरू पुतलीलाई चम्चाले खुवाएको वा पुतलीलाई पानी पिउन दिएको जस्तो पनि समावेश गर्न सकिन्छ ।	हो / हैन
नक्कल गर्छ	बच्चाको ध्यान आकर्षित गर्नुस् । आफ्नो कपालमा ब्रश / काइयो प्रयोग गर्नुस् । बच्चालाई दिनुस् र भन्नुस् "अब तिम्रो पालो ।" बच्चाले तपाईंको नक्कल गर्छ ?	हो / हैन
नाम लिएर बोलाउँदा प्रतिक्रिया दिन्छ	बच्चाको नाम लिएर बोलाउनुस् । उ तपाईंलाई हेर्नको लागि तपाईंतिर फर्किन्छ ? (यो गर्नु भन्दा अगाडि बच्चाले पहिले देखिने तपाईंलाई हेरीरहेको छैन भने सुनिस्चित गर्नुस्) ।	हो / हैन
औलाले देखाएको पछ्याउँछ	बच्चाको ध्यान आकर्षित गर्नुस् र कोठामा तपाईंको पारीपट्टी भएको कुनै वस्तुलाई देखाउनुस् र भन्नुस् "आहा, त्यो हेर त!" उसले तपाईंले औलाले देखाउनु भएको तिर हेर्छ ? (न कि तपाईंको हात/पाखुरामा मात्र) ।	हो / हैन
सामाजिक मुस्कान	तपाईंसँग आँखामा आँखा जुधाउँदा बच्चा मुस्कुराएको छ ? यदि छैन भने, बच्चातिर हेरेर मुस्कुराउनुस् । ऊ पनि मुस्कुराउँछ ? (बच्चा मुस्कुराओस् भनेर शरीरमा छुने / चलाउने नगर्नुस्)	हो / हैन
५ - १० शब्दहरू बोल्छ	बच्चाले ५ देखी १० वटा सम्म शब्दहरू बोल्छ ?	हो / हैन
शब्दहरू बुझ्छ	बच्चाले आफुले प्रयोग बोल्ने भन्दा धेरै शब्दहरू बुझ्छ ?	हो / हैन
साधारण निर्देशनहरू पछ्याउँछ	बच्चालाई ब्लक / बल देखाउनुस् र त्यसलाई उसको छेउमा राख्नुस् । त्यसपछी मागनुस्, "मलाई ब्लक / बल देउ "(तपाईंले हात दिएर कुनै इशारा नगर्नुस्) । उसले तपाईंलाई ब्लक / बल दिन्छ ?	हो / हैन
अनुहारका भागहरू औलाले देखाउँछ	बच्चाको ध्यान आकर्षित गर्नुस् । "तिम्रो आँखा/नाक/मुख औलाले देखाउ" भन्नुस् । उसले आफ्नो आँखा/नाक/मुख मध्य कुनै एक अनुहारका भागलाई लाई औलाले देखाउँछ ?	हो / हैन
सीपहरूमा हास	बच्चाको कुनै उमेरमा कुनै भाषिक वा सामाजिक सीपमा कमी आएको छ कि भनेर आमा बुवालाई सोधनुस् । (उदाहरणका लागि, उसले पहिला प्रयोग गर्ने 'आमा', 'बाबा', 'मामा' जस्ता शब्दहरू प्रयोग कम गर्ने वा नगर्ने, त्यस्तै आँखा जुधाएर हेर्ने, वस्तुहरू देखाउने, अरू बच्चाहरूमा रुची देखाउने जस्ता कुराहरू कम गर्ने वा नगर्ने भएको छ ?)	हो / हैन

यदि ५ प्रमुख सूचकहरूमा ३ हैन उत्तर आएमा, बच्चा "अटिजमको जोखिममा" छ । कृपया बच्चाको विकासको विस्तृत मुल्याङ्कन को लागि "सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल" टीम कहाँ पठाउनु होस् ।

Appendix K- Nepali Translation of SACS (24-month checklist)

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२४-महिने मुल्याङ्कन

सूचक	कृयाकलाप	उत्तर
औलाले देखाउँछ (प्रमुख सूचक)	पुतली लिनुस्, त्यो बच्चालाई देखाउनुस् र भन्नुस् "यो पुतली हो"। त्यसपछि पुतलीलाई कोठामा तपाईंको पारीपट्टी (बच्चाले देख्न सक्ने तर भेटाउन नसक्ने ठाउँमा) राख्नुस् र भन्नुस्, "पुतली कहाँ छ?" बच्चाले औलाले पुतलीलाई देखाउँदै तपाईंको अनुहारमा हेर्छ ?	हो / हैन
आँखामा आँखा जुधाएर हेर्छ (प्रमुख सूचक)	के बच्चाले यो सत्रको दौरानमा तपाईंसँग स्वतस्फुर्त रूपमा आँखामा आँखा जुधाएको छ ? यदि छैन भने, उसँग अन्तर्कृया गर्नुस् ताकि बच्चाले तपाईंसँग आँखामा आँखा जुधाएर हेरोस् । उसले तपाईंसँग आँखामा आँखा जुधाएर हेर्छ ?	हो / हैन
बाइ बाइ गर्छ (प्रमुख सूचक)	कोठा छोडेर गएको बहाना गर्दै बच्चालाई बाइ- बाइ गर्नुस् । उसले पनि तपाईंलाई हात हल्लाएर बाइ बाइ गर्छ ?	हो / हैन
देखाउँछ (प्रमुख सूचक)	बच्चाले खेलौना/वस्तु समाई आँखामा आँखा जुधाएर तपाईंलाई वा आमाबुबालाई देखाएको छ ? (यदी यस्तो गरेको नदेखिएमा आमा बुबालाई सोध्नुस्)	हो / हैन
काल्पनिक खेल खेल्छ (प्रमुख सूचक)	बच्चालाई पुतली, खेलौना कप , चम्च र भाँडो दिनुस् । "तिमिले चिया खनाएर पिउन (खान) सक्छौ ?" भन्नुस् । बच्चाले चिया खनाएर पिएको वा खनाएको वा पिएको जस्तो बहाना गर्छ ? अरू उदाहरणहरू पुतलीलाई चम्चले खुवाएको वा पुतलीलाई पानी पिउन दिएको जस्तो पनि समावेश गर्न सकिन्छ ।	हो / हैन
नक्कल गर्छ	बच्चाको ध्यान आकर्षित गर्नुस् । आफ्नो कपालमा ब्रश / काइयो प्रयोग गर्नुस् । बच्चालाई दिनुस् "अब तिम्रो पालो ।" बच्चाले तपाईंको नक्कल गर्छ ?	हो / हैन
नाम लिएर बोलाउँदा प्रतिक्रिया दिन्छ	बच्चाको नाम लिएर बोलाउनुस् । उ तपाईंलाई हेर्नको लागि तपाईंतिर फर्किन्छ ? (यो गर्नु भन्दा अगाडि बच्चाले पहिले देखिनै तपाईंलाई हेरीरहेको छैन भन्ने सुनिस्चित गर्नुस्) ।	हो / हैन
औलाले देखाएको पछ्याउँछ	बच्चाको ध्यान आकर्षित गर्नुस् र कोठामा तपाईंको पारीपट्टी भएको कुनै वस्तुलाई देखाउनुस् र भन्नुस् "आहा, त्यो हेर त!" उसले तपाईंले औलाले देखाउनु भएको तिर हेर्छ ? (न कि तपाईंको हात/पाखुरामा मात्र)	हो / हैन
सामाजिक मुस्कान	तपाईंसँग आँखामा आँखा जुधाउँदा बच्चा मुस्कुराएको छ ? यदि छैन भने, बच्चातिर हेरेर मुस्कुराउनुस् । ऊ पनि मुस्कुराउछ ? (बच्चा मुस्कुराओस् भनेर शरीरमा छुने / चलाउने नगर्नुस्)	हो / हैन
२०- ५० शब्दहरू बोल्छ	बच्चाले २० देखि ५० शब्दहरू बोल्छ ?	हो / हैन
दुई शब्दको वाक्यांश प्रयोग गर्छ	बच्चाले दुई शब्दको वाक्यांश प्रयोग गर्छ (उदाहरण: माम खाने, पानी खाने) ?	हो / हैन
साधारण निर्देशन हरू पालना गर्छ	पुतली बच्चालाई देखाउनुस् र कोठामा त्यसलाई तपाईंको पारीपट्टी राख्नुस् । त्यसपछि मागनुस्, "जाउ र मलाई पुतली ल्याइदेउ" (पुतलीतिर कुनै ईशारा नगर्नुस्) । उसले तपाईंलाई पुतली दिन्छ ?	हो / हैन
सीपहरूमा हास आएको छ	बच्चाको कुनै उमेरमा कुनै भाषिक वा सामाजिक सीपमा कमी आएको छ कि भनेर आमा बुबालाई सोध्नुस् । (उदाहरणका लागि, उसले पहिला प्रयोग गर्ने 'आमा', 'बाबा', 'मामा' जस्ता शब्दहरू प्रयोग कम गर्ने वा नगर्ने, त्यस्तै आँखा जुधाएर हेर्ने, वस्तुहरू देखाउने, अरू बच्चाहरूमा रुची देखाउने जस्ता कुराहरू कम गर्ने वा नगर्ने भएको छ ?)	हो / हैन
समानान्तर खेल	बच्चाले अरू बच्चाहरू नजिकै (सँगै नै खेल्न जरुरी छैन) खेल्छ ? (आमा बुबालाई सोध्नुस् ।)	हो / हैन
अरू बच्चाहरू मा रुची देखाउँछ	बच्चाले उसको उमेरका अरू बच्चाहरू प्रती रुची देखाएको जस्तो गर्छ ? (आमा बुबालाई सोध्नुस्)	हो / हैन

यदि ५ प्रमुख सूचकहरूमा ३ हैन उत्तर आएमा, बच्चा "अटिजमको जोखिममा" छ । कृपया बच्चाको विकासको विस्तृत मुल्याङ्कन को लागि "सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल" टीम कहाँ पठाउनु होस् ।

Appendix L- Nepali Version of Demographic Survey

सर्वे फाराम
तलका प्रश्नहरूका उत्तर दिनु होस्:

खण्ड १ : जनसङ्ख्या सम्बन्धी जानकारी	
बच्चाको विवरण	
बच्चाको आइडी नम्बर	
बच्चाको नाम / थर	
जन्म मिति	____/____/____ (साल/महिना/गते) उमेर (महिनामा): _____
आमाबुबाको विवरण	
आमाको नाम / थर	
जन्म मिति	____/____/____ (साल/महिना/गते) उमेर: _____
कृपया, तपाईंको धारणासँग सबैभन्दा मिल्ने कोठामा (✓) चिन्ह लगाउनु होस् ।	
शिक्षा	<input type="checkbox"/> पढ्न र लेख्न सक्छ <input type="checkbox"/> प्राथमिक शिक्षा (१-५), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> निम्न माध्यमिक शिक्षा (६-८), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> माध्यमिक शिक्षा (९-१०), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> माध्यमिक शिक्षाभन्दा बढी, कृपया उल्लेख गर्नु होस् : _____
पेसा	<input type="checkbox"/> कृषि, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> सरकारी जागिर, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> गैरसरकारी जागिर, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> व्यापार, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> दैनिक ज्यालादारी काम, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> वैदेशिक रोजगारी, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
महिनाको आम्दानी (नेपाली रुपैयाँ)	<input type="checkbox"/> ≥ ४५,७५१ <input type="checkbox"/> २२,८५१-४५,७५० <input type="checkbox"/> १७,१५१-२२,८५० <input type="checkbox"/> ११,४५१-१७,१५० <input type="checkbox"/> ६,८५१-११,४५० <input type="checkbox"/> २,३०१-६,८५० <input type="checkbox"/> ≤ २,३००
जन्मेको देश	<input type="checkbox"/> नेपाल <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____

जात	<input type="checkbox"/> नेवार <input type="checkbox"/> ब्राम्हण <input type="checkbox"/> छेत्री <input type="checkbox"/> तामाङ <input type="checkbox"/> मगर <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
धर्म	<input type="checkbox"/> हिन्दु <input type="checkbox"/> बौद्ध <input type="checkbox"/> किराँत <input type="checkbox"/> इस्लाम <input type="checkbox"/> इसाई <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
बुवाको नाममा	
जन्म मिति	____/____/____ (साल/महिना/गते) उमेर: _____
कृपया, तपाईंको धारणासँग सबैभन्दा मिल्ने कोठामा (✓) चिह्न लगाउनु होस् ।	
शिक्षा	<input type="checkbox"/> पढ्न र लेख्न सक्छ <input type="checkbox"/> प्राथमिक शिक्षा (१-५), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> निम्न माध्यमिक शिक्षा (६-८), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> माध्यमिक शिक्षा (९-१०), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> माध्यमिक शिक्षाभन्दा बढी, कृपया उल्लेख गर्नु होस् : _____
पेसा	<input type="checkbox"/> कृषि, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> सरकारी जागिर, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> गैरसरकारी जागिर, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> व्यापार, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> दैनिक ज्यालादारी काम, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> वैदेशिक रोजगारी, कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
महिनाको आम्दानी (नेपाली रुपैयाँ)	<input type="checkbox"/> ≥ ४५,७५१ <input type="checkbox"/> २२,८५१-४५,७५० <input type="checkbox"/> १७,१५१-२२,८५० <input type="checkbox"/> ११,४५१-१७,१५० <input type="checkbox"/> ८,५११-११,४५० <input type="checkbox"/> २,३०१-८,५१० <input type="checkbox"/> ≤ २,३००

जन्मेको देश	<input type="checkbox"/> नेपाल <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
जात	<input type="checkbox"/> नेवार <input type="checkbox"/> ब्राम्हण <input type="checkbox"/> क्षेत्री <input type="checkbox"/> तामाङ <input type="checkbox"/> मगर <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
धर्म	<input type="checkbox"/> हिन्दु <input type="checkbox"/> बौद्ध <input type="checkbox"/> किराँत <input type="checkbox"/> इस्लाम <input type="checkbox"/> इसाई <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
आमाबुबा	<input type="checkbox"/> विवाहित <input type="checkbox"/> छुटेको <input type="checkbox"/> पारपावुके (छोडपत्र गरेको) <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
बच्चालाई हेरचाह गर्ने मुख्य व्यक्ति	<input type="checkbox"/> दुबै आमाबुबा <input type="checkbox"/> आमा मात्र <input type="checkbox"/> बुबा मात्र <input type="checkbox"/> हजुरआमा हजुरबुबा <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____
सामाजिक आर्थिक वर्ग	<input type="checkbox"/> उच्च वर्ग <input type="checkbox"/> उच्च मध्यम वर्ग <input type="checkbox"/> निम्न मध्यम वर्ग <input type="checkbox"/> माथिल्लो मध्यम वर्ग <input type="checkbox"/> तल्लो वर्ग
सम्पर्क ठेगाना	जिल्ला : _____ नगरपालिका/गाविस : _____ नगर/गाउँ : _____ घर नम्बर : _____ वार्ड नम्बर : _____ टेलिफोन (घर छ भने मात्र) : _____ मोबाइल (आमा बुबा) : _____ इमेल (आमाबुबा) (छ भने मात्र) : _____

Appendix M-Nepali Version of FCHVs' Demographic Survey

सर्वे फाराम (पहिलो पटक तालीम अघि)

खण्ड १ : महिला सामुदायिक स्वास्थ्य स्वयं सेविकाको विवरण

आइडी नम्बर	
मिति	(साल/महिना/गते)
नाम/थर	
जन्म मिति	(साल/महिना/गते) उमेर : ____
सम्पर्क ठेगाना	जिल्ला : _____ नगरपालिका / गाविस : _____ नगर / गाउँ : _____ घर नम्बर : _____ वार्ड नम्बर : _____ टेलिफोन (घरमा छ भने मात्र) : _____ मोबाइल : _____ ईमेल (छ भने मात्र) : _____
कृपया तपाईंको धारणासँग सबैभन्दा मिल्ने कोठामा (✓) चिन्ह लगाउनु होस् ।	
शिक्षा	<input type="checkbox"/> पढ्न र लेख्न सक्छ <input type="checkbox"/> प्राथमिक शिक्षा (१-५), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> निम्न माध्यमिक शिक्षा (६-८), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> माध्यमिक शिक्षा (९-१०), कृपया उल्लेख गर्नु होस् : _____ <input type="checkbox"/> माध्यमिक शिक्षाभन्दा बढी, कृपया उल्लेख गर्नु होस् : _____
कामको अनुभव	<input type="checkbox"/> १ - ५ वर्ष <input type="checkbox"/> ६ - १० वर्ष <input type="checkbox"/> १० वर्ष भन्दा बढी
जात	<input type="checkbox"/> नेवार <input type="checkbox"/> ब्राम्हण <input type="checkbox"/> क्षेत्री <input type="checkbox"/> तामाङ <input type="checkbox"/> मगर <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नुहोस् : _____
धर्म	<input type="checkbox"/> हिन्दु <input type="checkbox"/> बौद्ध <input type="checkbox"/> किराँत <input type="checkbox"/> इस्लाम <input type="checkbox"/> इसाई <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____

Appendix N -Nepali Version of Knowledge on Early Social Attention and Communication Development in Children

खण्ड २ : सामाजिक ध्यान तथा संचारको विकासका बारेमा ज्ञान

यहाँ १२ देखि २४ महिनाका बच्चाहरूको सामाजिक ध्यान तथा संचारको विकाससँग सम्बन्धित बुँदाहरू छन् । कृपया तपाईंको धारणासँग सबैभन्दा बढी मिल्ने कोठामा (v) चिन्ह लगाउनु होस् ।

क्र.सं.	सामाजिक ध्यान तथा संचारको विकाससँग सम्बन्धित बुँदा	सहमत	असहमत	थाहा छैन
१.	१२ महिनाको बच्चाले १ देखि ३ शब्दहरू बोल्छ ।			
२.	१२ महिनाको बच्चाले साधारण निर्देशनहरू बुझ्छ ।			
३.	१२ देखि २४ महिनाको बच्चाले अरूसँग नियमित आँखामा आँखा जुधाएर हेर्दैन ।			
४.	१२ देखि २४ महिनाको बच्चाले नाम लिएर बोलाउँदा प्रतिक्रिया दिन्छ ।			
५.	१२ देखि २४ महिनाको बच्चाले इशाराहरूको प्रयोग गर्दैन ।			
६.	१२ देखि २४ महिनाको बच्चाले खेलौना/वस्तु समाई आमाबुबालाई देखाउँदैन ।			
७.	१२ देखि २४ महिनाको बच्चातिर हेरेर कोही मुस्कुराएमा ऊ पनि मुस्कुराउँछ ।			
८.	१२ देखि २४ महिनाको बच्चाले उसको उमेरका अरू बच्चाहरूप्रति रुचि देखाउँदैन ।			
९.	१२ देखि २४ महिनाको बच्चाले अरूको नक्कल गर्दैन ।			
१०.	१२ देखि २४ महिनाको बच्चाले कुनै वस्तुलाई अरूले औँलाले देखाउँदा त्यतातिर हेर्छ ।			
११.	१८ देखि २४ महिनाको बच्चाले ५ देखि १० शब्दहरू बोल्छ ।			
१२.	१८ देखि २४ महिनाको बच्चाले आफ्नो अनुहारका भागहरू देखाउँदैन ।			
१३.	१८ देखि २४ महिनाको बच्चा काल्पनिक खेलमा संलग्न हुन्छ ।			
१४.	१८ देखि २४ महिनाको बच्चाले साधारण निर्देशनहरू पालना गर्दैन ।			
१५.	२४ महिनाको बच्चाले दुई शब्दको वाक्यांश प्रयोग गर्दैन ।			
१६.	२४ महिनाको बच्चा अरू बच्चाहरू नजिकै खेल्छ ।			
१७.	२४ महिनाको बच्चाले २० देखि ५० शब्दहरू बोल्छ ।			

Appendix O – Nepali Version of Knowledge on Autism

खण्ड ३ : अटिजम सम्बन्धी ज्ञान

तल दिइएका अटिजमसँग सम्बन्धित बुँदाहरूमा तपाईंको धारणासँग सबैभन्दा मिल्ने कोठामा (✓) चिन्ह लगाउनु होस् ।

क्र.सं.	अटिजमसँग सम्बन्धित बुँदा	सहमत	असहमत	थाहा छैन
१.	मैले 'अटिजम' भन्ने शब्द सुनेको छु ।			
	यदि सहमत हुनुहुन्छ भने तपाईंले पहिलो पटक अटिजम भन्ने शब्द कहाँ सुन्नु भयो ? कृपया, सबै मिल्ने बक्समा (✓) चिन्ह लगाउनु होस् । <div style="display: flex; justify-content: space-between;"> <div> <input type="checkbox"/> रेडियो <input type="checkbox"/> पत्रपत्रिका <input type="checkbox"/> जनचेतनाका कार्यक्रमहरू <input type="checkbox"/> पर्चा, प्रचार पुस्तिका (brochure) </div> <div> <input type="checkbox"/> टेलिभिजन <input type="checkbox"/> अरू सामुदायिक कार्यकर्ताहरू <input type="checkbox"/> तालिम <input type="checkbox"/> अन्य, कृपया उल्लेख गर्नु होस् : _____ </div> </div>			
क्र.सं.	अटिजमसँग सम्बन्धित बुँदा	सहमत	असहमत	थाहा छैन
२.	अटिजम मस्तिष्कको विकासका क्रममा देखिने समस्याबाट उत्पन्न हुने अवस्था (condition) हो ।			
३.	अटिजम बौद्धिक विकासको कमी मात्र हो ।			
४.	अटिजम भएको बच्चा/ले अरूसँग नियमित रूपमा आँखामा आँखा जुधाएर हेर्छ ।			
५.	अटिजम भएको बच्चा/ले अरूसँग कम अन्तरक्रिया गर्छ ।			
६.	अटिजम भएको बच्चा/ले इशाराहरू बुझ्छ र प्रयोग गर्छ ।			
७.	अटिजम भएको बच्चा/लाई साथीहरू बनाउन समस्या हुन्छ ।			
८.	अटिजम भएको बच्चा/ले आफुले सुनेका वाक्यांशलाई त्यही स्वर र शैलीमा दोहोर्याउँ/तेह्र्याउँ भन्ने गर्छ ।			
९.	अटिजम भएको बच्चा/ले उसको उमेर अनुसारको कल्पना गरेर खेल्ने खेलहरू खेल्छ ।			
१०.	अटिजम भएको बच्चा/ले दोहोर्याउँ/तेह्र्याउँ शरीर हल्लाउने, हात फडफडाउने जस्ता क्रियाकलापहरू गर्दैन ।			
११.	अटिजम भएको बच्चा/ले आफ्नो दिनचर्यामा एउटै कुरा एकै किसिमले गर्न रुचाउँछ (जस्तै : सधैं एउटै खानेकुरा खाने, स्कुल जाँदा एउटै बाटो जाने आदि) ।			
१२.	अटिजम भएको बच्चा/ले कुनै वस्तुहरू बारम्बार दोहोर्याएर प्रयोग गर्छ (उदाहरणका लागि : हरेक पटक उस्तै तरिकाले खेलौनाहरूलाई नलगाएर राख्ने, वस्तुहरू घुमाउने आदि) ।			
१३.	अटिजम भएको बच्चा/ले उसको वरिपरिको वातावरणप्रति अति संवेदनशीलता देखाउँछ (जस्तै : चर्को/ठुलो आवाजमा कान थुन्ने, भीडमा अत्तालिन) ।			

क्र.सं.	अटिजमसँग सम्बन्धित बुँदा	सहमत	असहमत	थाहा छैन
१४.	अटिजम भएको बच्चाले कुनै वस्तुप्रति असामान्य रुचि वा अत्यधिक लगाव देखाउँदैन ।			
१५.	अटिजम भएको बच्चाले आफ्ना इन्द्रियहरूलाई उत्तेजित गर्न खोज्छ (जस्तै : कुनै वस्तुलाई अत्यधिक सुँध्ने वा छुने) ।			
१६.	अटिजम भएको बच्चालाई २४ महिनाको उमेरभित्र पहिचान गर्न सकिन्छ ।			
१७.	अटिजम केटीहरूमा भन्दा केटाहरूमा बढी हुन्छ ।			
१८.	सामान्यतः सामाजिक आर्थिक रूपले सम्पन्न वर्गमा अटिजम बढी हुन्छ ।			
१९.	सामान्यतः धेरै पढेलेखेका वर्गमा अटिजम बढी हुन्छ ।			
२०.	बच्चामा अटिजम छ भने त्यसको निदान (diagnosis) हुनु महत्त्वपूर्ण छ ।			
२१.	अटिजम भएको बच्चाको उपचार गर्न सकिन्छ ।			
२२.	अटिजम भएका बच्चाको लागि प्रारम्भिक थेरापीका कार्यक्रमहरू महत्त्वपूर्ण छन् ।			
२३.	अटिजम १२ वर्ष उमेर मुनिका बच्चाहरूलाई हुन्छ ।			
२४.	तपाईंको विचारमा अटिजमको कारण के होला ? कृपया, तपाईंको धारणासँग मिल्ने सबै बक्समा (✓) चिन्ह लगाउनु होस् । <input type="checkbox"/> वंशाणुगत <input type="checkbox"/> मस्तिष्कको असामान्य विकास <input type="checkbox"/> वातावरणको असर/विषादी <input type="checkbox"/> खोप <input type="checkbox"/> जन्मने बेलामा चोट/आघात <input type="checkbox"/> बाल्यावस्थाको रोग <input type="checkbox"/> भोजन/खानपिन <input type="checkbox"/> हुर्काउने क्रममा आमाबुबाबाट बेवास्ता <input type="checkbox"/> पूर्वजन्मको कर्मको फल <input type="checkbox"/> भाग्य <input type="checkbox"/> भगवानको श्राप <input type="checkbox"/> आमाका कारणहरू (उदाहरणका लागि : उमेर, रोग, धुम्रपान, औषधि प्रयोग) <input type="checkbox"/> बुबाका कारणहरू (उदाहरणका लागि : उमेर, रोग, धुम्रपान, औषधि प्रयोग) <input type="checkbox"/> वास्तविक कारण पत्ता लागेको छैन । <input type="checkbox"/> अन्य (कृपया, उल्लेख गर्नु होस्) : _____			

Appendix P- Nepali Version of Confidence in Monitoring and Referring Children

खण्ड ४ : अटिजमको पहिचान गरी निगरानी गर्न र विस्तारपूर्वक मूल्याङ्कन गर्न पठाउने आत्मविश्वास बारेमा

यहाँ अटिजमको जोखिममा रहेक बच्चाको व्यवहार पहिचान गरी निगरानी गर्न र सम्बन्धित ठाउँमा उनीहरूको विकासको विस्तारपूर्वक मूल्याङ्कन गर्न पठाउने बारेका बुँदाहरू छन्। कृपया तपाईंको धारणासँग सबैभन्दा बढी मिल्ने कोठामा (✓) चिन्ह लगाउनु होस्।

क्र.सं.	आत्मविश्वास बारेका बुँदा	सहमत	असहमत	थाहा छैन
१.	म १२ देखि २४ महिनाका बच्चामा अटिजमका सङ्केतहरू दुक्कसँग पहिचान गरी तिनको निगरानी गर्न सक्छु।			
२.	म १८ देखि २४ महिनाका बच्चामा अटिजमका सङ्केतहरू दुक्कसँग पहिचान गरी तिनको निगरानी गर्न सक्छु।			
३.	म २ देखि ३० महिनाका बच्चामा अटिजमका सङ्केतहरू दुक्कसँग पहिचान गरी तिनको निगरानी गर्न सक्छु।			
४.	म ३१ देखि ६० महिनाका बच्चामा अटिजमका सङ्केतहरू दुक्कसँग पहिचान गरी तिनको निगरानी गर्न सक्छु।			
५.	म ६० भन्दा बढी महिनाका बच्चामा अटिजमका सङ्केतहरू दुक्कसँग पहिचान गरी तिनको निगरानी गर्न सक्छु।			
६.	म १२ देखि २४ महिनाका अटिजमको जोखिममा रहेका बच्चालाई तिनका विकासको विस्तारपूर्वक मूल्याङ्कन गर्नका लागि दुक्कसँग पठाउन सक्छु।			
७.	म १८ देखि २४ महिनाका अटिजमको जोखिममा रहेका बच्चालाई तिनको विकासको विस्तारपूर्वक मूल्याङ्कन गर्नका लागि दुक्कसँग पठाउन सक्छु।			
८.	म २४ देखि ३० महिनाका अटिजमको जोखिममा रहेका बच्चालाई तिनको विकासको विस्तारपूर्वक मूल्याङ्कन गर्नका लागि दुक्कसँग पठाउन सक्छु।			
९.	म ३१ देखि ६० महिनाका अटिजमको जोखिममा रहेका बच्चालाई तिनको विकासको विस्तारपूर्वक मूल्याङ्कन गर्नका लागि दुक्कसँग पठाउन सक्छु।			
१०.	म ६० भन्दा बढी महिनाका अटिजमको जोखिममा रहेका बच्चालाई तिनको विकासको विस्तारपूर्वक मूल्याङ्कन गर्नका लागि दुक्कसँग पठाउन सक्छु।			

Appendix Q – Nepali Version of Evaluation Form

सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल
मुल्याङ्कन फाराम

कृपया “सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल” प्रयोगको मुल्याङ्कन का लागि तल दिइएका बुँदागत विवरणमा तपाईंको धारणासँग सबैभन्दा मिल्ने कोठामा चिन्ह (✓) लगाउनुहोस्।

मुल्याङ्कन सम्बन्धी विवरण	एकदमै सहमत	सहमत	असहमत	एकदमै असहमत
१. महिला स्वास्थ्य स्वयंसेविकाका रूपमा मैले अहिले गरिरहेको काम अन्तर्गत सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल को प्रयोग गर्न सजिलो भएको छ ।				
२. महिला स्वास्थ्य स्वयंसेविकाका रूपमा मैले अहिले गरिरहेको काममा सामाजिक ध्यान र संचार अनुगमन विधि-नेपालले सकारात्मक प्रभाव पारेको छ ।				
३. सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल टीमसँग सम्बन्धित ब्यक्तीहरुबाट मैले मेरा जिज्ञासाहरुको समयमै उचित सुझाव वा उत्तर पाएकी छु । (यदि यो कुरा तपाईंलाई लागू भएमा)				
४. घरमा सामाजिक ध्यान र संचार सम्बन्धी अनुगमन विधि-नेपाल को प्रयोगलाई बच्चाका आमा-बुवाले सहज रूपमा लिएका छन ।				
५. बच्चाको विस्तृत मुल्याङ्कनका लागि अटिज्म केयर नेपाल सोसाएटीमा पठाएका आमाबाबुले सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल मा सहभागी हुनु आफु र बच्चाको लागि लाभदायक भएको महसुस गरेका छन ।				

अरु कुनै टिप्पणी वा प्रतिक्रिया?

तपाईंको समुदायमा सामाजिक ध्यान र संचार अनुगमन विधि-नेपाल को प्रयोगलाई अझै सहज र प्रभावकारी बनाउनका लागि के गर्न सकिन्छ ?

सहयोगका लागि धन्यवाद ।

Appendix R – La Trobe University Ethics**HEC16-073 (Finalised - Approved) - Application finalised as Approved**

ResearchMasterEthics@latrobe.edu.au

Tue 23/08/2016 10:53 AM

To: ResearchMasterEthics <ResearchMasterEthics@latrobe.edu.au>; Cheryl Dissanayake <c.dissanayake@latrobe.edu.au>;

Cc: RENA SHRESTHA <18179887@students.latrobe.edu.au>; Josie Barbaro <J.Barbaro@latrobe.edu.au>;

Dear Cheryl Dissanayake,

The following project has been assessed as complying with the National Statement on Ethical Conduct in Human Research. I am pleased to advise that your project has been granted ethics approval and you may commence the study.

Application ID: HEC16-073

Application Status/Committee: Finalised - Approved

Project Title: Identifying Young Children with Autism Spectrum Disorder (ASD) in Nepal: Implementing and Evaluating Social Attention and Communication Surveillance

Chief Investigator: Cheryl Dissanayake

Other Investigators: Josephine Barbaro, Rena Shrestha

Date of Approval: 23/08/2016

Date of Ethics Approval Expiry: 31/12/2018

The following standard conditions apply to your project:

- Limit of Approval. Approval is limited strictly to the research proposal as submitted in your application.
- Variation to Project. Any subsequent variations or modifications you wish to make to your project must be formally notified for approval in advance of these modifications being introduced into the project.
- Adverse Events. If any unforeseen or adverse events occur the Chief Investigator must immediately notify the UHEC immediately. Any complaints about the project received by the researchers must also be referred immediately to the UHEC.
- Withdrawal of Project. If you decide to discontinue your research before its planned completion, you must inform the relevant committee and complete a Final Report form.
- Monitoring. All projects are subject to monitoring at any time by the University Human Ethics Committee.
- Annual Progress Reports. If your project continues for more than 12 months, you are required to submit a Progress Report annually, on or just prior to 12 February. The form is available on the Research Office website. Failure to submit a Progress Report will mean approval for this project will lapse.
- Auditing. An audit of the project may be conducted by members of the UHEC.

- Final Report. A Final Report (see above address) is required within six months of the completion of the project.

You may log in to ResearchMaster (<https://rmenet.latrobe.edu.au>) to view your application.

If you have any further questions, please contact the:

UHEC at humanethics@latrobe.edu.au

SHE College Human Ethics Sub-Committee at chesc.she@latrobe.edu.au

ASSC College Human Ethics Sub-Committee at chesc.assc@latrobe.edu.au

Appendix S-Nepal Health Research Council



Government of Nepal
Nepal Health Research Council (NHRC)

Estd. 1991



Ref. No.: 643

06 October 2016

Ms. Rena Shrestha
 Principal Investigator
 La Trobe University
 Australia

Subject: Approval of Research Proposal entitled **Identifying Young Children with Autism Spectrum Disorder(ASD) in Nepal: Implementing and Evaluating Social Attention and Communication Surveillance**

Dear Ms. Shrestha,

It is my pleasure to inform you that the above-mentioned proposal submitted on **09 September, 2016** (**Reg.no. 267/2016** please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on **05 October 2016**.

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol before the expiration date of this approval. Expiration date of this study is **March 2019**.

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission. The researchers will not be allowed to ship any raw/crude human biomaterial outside the country; only extracted and amplified samples can be taken to labs outside of Nepal for further study, as per the protocol submitted and approved by the NHRC. The remaining samples of the lab should be destroyed as per standard operating procedure, the process documented, and the NHRC informed.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, the total research amount is **USD 9,731.38** and accordingly the processing fee amount to **NRS. 10,652.00**. It is acknowledged that the above-mentioned processing fee has been received at NHRC.

If you have any questions, please contact the Ethical Review M & E section of NHRC.

Thanking you,

.....
Dr. Khem Bahadur Karki
 Member Secretary

Tel: +977 1 4254220, Fax: +977 1 4262469, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
 Website: <http://www.nhrc.org.np>, E-mail: nhrc@nhrc.org.np

Appendix T – AutismCare Nepal Society Approval



**AutismCare
Nepal Society**

"A National Society for Autism"

156-Nil Saraswati Marg, Gairidhara-2
Kathmandu, Nepal
P.O.Box: 23729
Tel: 00977-01-4419010
E-mail: autismnepal@gmail.com
www.autismnepal.org

Ref. No: 072/073/202
March 4, 2016

Olga Tennison Autism Research Centre
School of Psychological Science
La Trobe University, Bundoora 3083

Letter of Support

On behalf of AutismCare Nepal Society (ACNS), I am pleased to write this letter of support for Ms. Rena Shrestha in conducting the research "Identifying Young Children with Autism Spectrum Disorder (ASD) in Nepal: Implementing and Evaluating Social Attention and Communication Surveillance."

I also provide my consent

- to use de-identified data from ACNS registry
- to conduct the comprehensive diagnostic assessment of children identified by Social Attention and Communication Surveillance (SACS-N) at ACNS
- to organize meetings with families and concerned stakeholders when needed

I support this effort made by Ms. Shrestha, and will be happy to provide any further assistance necessary in the course of implementation of this study.


If you have any questions please do not hesitate to contact me at cell: +977 9841761273 or email: autismnepal@gmail.com

Sincerely,




Dr. Sunita Malekhu Amatya
Chairperson
AutismCare Nepal Society

Appendix U- Kirtipur Municipality Approval



कीर्तिपुर नगरपालिका कार्यालय
Kirtipur Municipality Office
विद्यु नगरपालिका

पत्र संख्या:
च.नं.:



मिति:

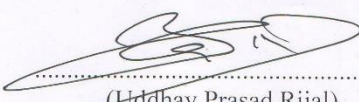
Date : 25th Feb. 2016

Ref. No. 322

The School of Psychological Science
College of Science, Health and Engineering
La Trobe University
Bundoora, Victoria, 3083
Australia

The Letter of Approval

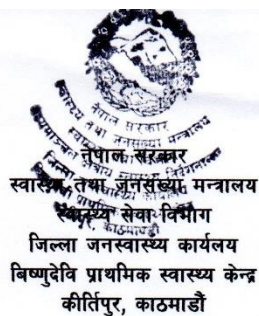
I hereby approve a research proposal submitted by Rena Shrestha (Student Number : 18179887, La Trobe University) in partial fulfillment of the requirements for the doctor of philosophy on “Identifying Young Children with Autism Spectrum Disorder (ASD) in Nepal implementing and Evaluating Social Attention and Communication Surveillance” to conduct study in this Municipality. Please let her submit a set of research report in this office after completion of the study.



(Uddhav Prasad Rijal)
Chief and Executive Officer
Kirtipur Municipality
Executive Officer

कीर्तिपुर, काठमाडौं, फोन नं. ९७७-१-४३३१६९३, ४३३१६०५, फ्याक्स नं.: ९७७-१-४३३१३८१
Kirtipur, Kathmandu, Phone No.: 977-1-4331605, 4331693, Fax No.: 977-1-4331381, E-mail: ict.munkirtipur@gmail.com

Appendix V- Primary Health Centre, Kirtipur Approval Letter



March 18-2016
School of Psychological Science
La Trobe University
Bundoora, Victoria, 3083
Australia

Approval Letter

Ms. Rena Shrestha,

This letter of approval is given as a permission for the Female Community Health Volunteers (FCHVs) in Kirtipur Municipality to participate in the research "Identifying Young Children with Autism Spectrum Disorder (ASD) in Nepal: Implementing and Evaluating Social Attention and Communication Surveillance."

The FCHVs are allowed to:

- participate in survey "Knowledge of autism among female community health volunteers in Kirtipur Municipality"
- use their registry to track the children (12-24 months) and their contact details
- receive training in Social Attention and Communication Surveillance-Nepal (SACS-N)
- monitor children in Kirtipur Municipality between 12-24 months using Social Attention and Communication Surveillance-Nepal (SACS-N) after training from October 2016 to December 2017.
- attend feedback meetings during study period

Best Wishes for your research.

Sincerely,


Gopal Prasad Kumar

Senior AHW
Bishnu Devi Primary Health Centre
Kirtipur Municipality
Kathmandu, Nepal

Appendix W- Manuscript of Study 1 (Chapter 4)

Journal of Autism and Developmental Disorders (2019) 49:2258–2267
<https://doi.org/10.1007/s10803-019-03884-7>

ORIGINAL PAPER



Age of Diagnosis of Autism Spectrum Disorder in Nepal

Rena Shrestha¹ · Cheryl Dissanayake¹ · Josephine Barbaro¹

Published online: 30 January 2019
 © Springer Science+Business Media, LLC, part of Springer Nature 2019

Abstract

The current study investigated the age of diagnosis (AoD) of autism spectrum disorder (ASD) in Nepal by using de-identified data on 246 children with a diagnosis of ASD registered at AutismCare Nepal Society from 2010 to 2015. The mean AoD in children was 58 months (range 14–187 months). Majority of children were male (76%), lived in the Kathmandu valley (75%), and were from upper caste groups (62%). The mean diagnostic age of ASD in Nepal is much later than the age at which a reliable diagnosis is possible, indicating the need to reduce the gap between the age at which it is possible to diagnose ASD, and the average age at which ASD is currently diagnosed.

Keywords Autism spectrum disorder · Age of diagnosis · Low- and middle-income countries · Nepal

Introduction

Early markers of autism spectrum disorder (ASD) are present within the first two-years of life making diagnoses possible by 24 months (Barbaro and Dissanayake 2013). Timely diagnosis enables access to early intervention programs, known to promote better developmental outcomes in young children due to early brain plasticity (Dawson 2008). The age of entry to early intervention is associated with better cognitive, language and adaptive improvements in children with ASD (Clark et al. 2017; Flanagan et al. 2012). These gains in child functioning eventually reduce the significant individual, family and societal costs associated with ASD across the lifespan (Barbaro and Halder 2016; Peters-Scheffer et al. 2012). Therefore, early diagnosis of ASD which enables earlier access to early intervention is critical to maximise children's developmental outcomes and reduce lifetime costs associated with these conditions.

Although ASD can be diagnosed as early as 24 months, children in low- and middle-income countries (LMICs) are typically diagnosed at a later age, missing the opportunities for better outcomes. Previous studies in LMICs including Nigeria (Lagunju et al. 2014), India (Daley 2004; Preeti

et al. 2017; Kommu et al. 2017), Colombia (Talero-Gutiérrez et al. 2012) and Mexico (Bravo Oro et al. 2012) reported mean age of diagnosis (AoD) of children with ASD that varied between 45- and 72-months. Similar to LMICs, several studies across high-income countries (HICs) such as the United States (Baio et al. 2018), Canada (Coo et al. 2012), Australia (Bent et al. 2015), and the UK (Brett et al. 2016; Petrou et al. 2018) have also found substantial delay in the AoD of children with ASD, with mean AoD ranging from 50- to 60-months.

Although the AoD reported in LMICs appear similar to that in HICs, these data must be interpreted with caution. Unlike population-based studies in HICs (Idring et al. 2012; Randall et al. 2016; Williams et al. 2008), where the AoD of children is examined across the spectrum of ASD, nearly all studies in LMICs are either hospital-based or specialist centre-based (Bravo Oro et al. 2012; Preeti et al. 2017; Kommu et al. 2017; Lagunju et al. 2014; Montiel-Nava et al. 2017; Talero-Gutiérrez et al. 2012). Thus most of these studies include children with severe autism symptoms (Bravo Oro et al. 2012; Lagunju et al. 2014; Montiel-Nava et al. 2017) and intellectual delay (Kommu et al. 2017), possibly missing children with milder behavioural presentations. Research suggests that children with severe autism features have more learning impairments including intellectual disability (Vivanti et al. 2013), possibly leading to earlier concerns amongst parents and professionals. In addition to greater symptom severity, other child factors such as developmental regression (Daniels and Mandell 2014; Rosenberg et al.

✉ Cheryl Dissanayake
 c.dissanayake@latrobe.edu.au

¹ School of Psychology and Public Health, Olga Tennison Autism Research Centre, La Trobe University, Kingsbury Drive, Bundoora, Melbourne, VIC 3086, Australia

2011) and having a sibling with ASD (Bickel et al. 2015; Coo et al. 2012) are associated with an earlier age at diagnosis, while comorbid neurological and psychiatric conditions have been linked to delayed diagnosis (Brett et al. 2016; Kommu et al. 2017; Mandell et al. 2005).

A number of sociodemographic and geographic factors also have been associated with AoD of ASD (Daniels and Mandell 2014). For example, studies in HICs (Brett et al. 2016; Coo et al. 2012; Giarelli et al. 2010; Mandell et al. 2010) and LMICs (Preeti et al. 2017; Kommu et al. 2017; Lagunju et al. 2014; Talero-Gutiérrez et al. 2012) have consistently reported a male to female ratio of about 4–5:1, with no gender difference in AoD despite a growing recognition that there may be under-diagnosis of females with ASD (Petrou et al. 2018). Studies regarding the association of AoD and ethnicity across HICs have shown mixed findings reporting either no difference in AoD between ethnicities (Mandell et al. 2005) or the later diagnosis of children from an ethnic minority background (Montiel-Nava et al. 2017; Valicenti-McDermott et al. 2012). Likewise, other factors such as socio-economic status, parental education, their knowledge on early signs of ASD, their concerns about child development (Daniels and Mandell 2014; Fountain et al. 2011) and stigma associated with a diagnosis of ASD (Tilahun et al. 2016) have been found to contribute to delayed diagnosis of ASD.

With respect to geographic factors, children living in semi-urban or rural settings are likely to receive a diagnosis at a later age compared to children living in urban areas due to inadequate access to early identification and diagnostic services (Antezana et al. 2017; Bello-Mojed et al. 2014; Chen et al. 2008). Previous research in a HIC has similarly reported that children in metropolitan regions were diagnosed earlier than children living in non-metropolitan and rural areas (Bent et al. 2015). Although these studies provide important information regarding factors that are associated with the AoD of ASD, they are from HICs, and the studies in LMICs have rarely examined the association between ethnicity and geographic factors with AoD of children with ASD.

Research suggests that many of the factors associated with diagnostic age are modifiable, and it is vital to plan and deliver ASD-specific early identification services (Daniels and Mandell 2014; Rosenberg et al. 2011) to lower the age at which children with ASD are diagnosed. However, limited research exists regarding the AoD and the factors affecting the AoD among ethnically and geographically diverse populations in LMICs, including Nepal. Previous studies in Nepal (Pandey et al. 2013) have also revealed gender, ethnic and geographic disparities in access to health services. For example, girls in Nepal have reduced opportunities for healthcare facilities compared to boys due to a high preference for male children (Bhandari et al. 2007). Ethnically, the children with a disadvantaged (lower castes) and

other minority ethnic backgrounds have less access to health facilities compared to upper caste groups who are at the top of the social hierarchy (Bhandari et al. 2007; Pandey et al. 2013). Geographically, the mountain region, due to its rugged terrain and poor health infrastructure poses a significant barrier to healthcare facilities (Goli et al. 2017; Ministry of Health and Population et al. 2012). ; Pandey et al. 2013). Likewise, geopolitically, the Kathmandu valley—the capital city—has always received significant attention from the government in terms of transportation, communication and healthcare facilities (Goli et al. 2017; Ministry of Health and Population et al. 2012; Pandey et al. 2013). Given this background, an understanding of gender, ethnic and geographic disparities in AoD of ASD is necessary to increase and strengthen early identification services at the local level in Nepal.

To date, there has been only one study in Nepal that has examined AoD comprising 50 children derived from the AutismCare Nepal Society (ACNS) registry (Shrestha and Shrestha 2014), where the mean AoD of ASD was 56 months. The age of the sample ranged from 12- to 180-months, and the male to female ratio was 3.5:1. The current study addressed this gap in the literature by examining the AoD of children with ASD in an extended sample by accessing the ACNS registry from 2010 to 2015. The change in AoD across the 6 years of sampling was also examined to ascertain change over time, as well as autism severity in the sample. The frequency of children diagnosed with ASD was also studied with regard to gender, ethnicity and geographical location (ecological regions and districts) to facilitate a deeper understanding of the epidemiology of those being diagnosed with ASD in this LMIC.

Methods

Ethics approval was obtained from the Nepal Health Research Council (112/2016) and the La Trobe University Human Ethics Committee (HEC16-073). A written request to use the organisation's data registry was approved by the ACNS.

Sample

The study included de-identified data of 246 children registered at the ACNS from January 2010 to December 2015 and diagnosed with ASD. The ACNS, established in 2008 in Kathmandu, is the only active autism society in Nepal and is run by a group of parents of children with ASD (AutismCare Nepal Society 2018; Shrestha and Santangelo 2014). The ACNS serves as a major ASD resource centre for referrals for ASD evaluation from health professionals, educators, teachers and other therapists. The organisation provides

assessment and diagnostic services, intervention programs, parent training and counselling, day care facilities, vocational training for adults with ASD, and capacity building for health, educational and other paraprofessionals (AutismCare Nepal Society 2018). It also engages in awareness raising regarding ASD. The ACNS has a data registry, with a record of each child visiting the centre, including documentation of diagnosis as confirmed by pediatricians, child or adult psychiatrists, and psychologists.

Diagnosis of ASD in Nepal is generally conducted at the pediatric unit, the child guidance clinic or the psychiatric outpatient department at government hospitals or private clinics. These clinical diagnoses are based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth edition (DSM-V; American Psychiatric Association 2013), the Diagnostic and Statistical Manual of Mental Disorders, Fourth edition, text revised (DSM-IV-TR; American Psychiatric Association 2000) or International Classification of Diseases, tenth revision (ICD-10; Shakya 2010; Tulachan et al. 2014; World Health Organization 1993). It is rare that autism-specific diagnostic tools are used in these contexts. The ACNS also undertakes some diagnostic assessments. Here, a part-time pediatrician and a psychologist trained on the Autism Diagnosis Observation Scale (ADOS-G; Lord et al. 2000) provide diagnoses for children (Shrestha and Santangelo 2014). The diagnostic category of ASD is used here which comprises the individual categories under the Pervasive Developmental Disorder (PDD) heading in DSM-IV-TR (American Psychiatric Association 2000; Autistic Disorder, Asperger's Disorder and PDD-Not Otherwise Specified).

Measures and Procedures

The age of an ASD diagnosis (in months) of children, their gender, ethnicity, postcode of residence and the ADOS-G scores (where available) were extracted from the registry. Other information, such as birth order, intellectual level, and co-morbidities, are not included in the registry. Children's AoD was calculated by subtracting their date of birth from the date that diagnosis was confirmed and rounded to the closest month. The postcodes of residences were categorized into districts and ecological regions (Central Bureau of Statistics 2012).

Ecological Regions and Districts

Geographically, Nepal is divided into three ecological regions: the Terai, the hills, and the mountains (Central Bureau of Statistics 2012). The mountains in the north constitute the Himalayan region, elevates from 4877 to 8848 meters in altitude and covers 35% of the land (Ministry of Health and Population et al. 2012). The mountain

region is the most deprived region in terms of resources, infrastructure and access to health services compared to the hills and the Terai (Bhandari et al. 2007; Goli et al. 2017). Only seven per cent of the total population lives here, and therefore represents a remote region. The hills in the central region range between 610 and 4877 m above sea levels and cover 42% of the land. Around 43% of people live in the hill region (Ministry of Health and Population et al. 2012). Due to variations in landscape and the concentration of population, significant rural–urban disparities exist within the hills regarding infrastructure development and healthcare access (Bhandari et al. 2007). The Terai in the south is the open terrain below 610 m, covers 23% of Nepal and has the most fertile land which is home to 50% of the total population of Nepal (Ministry of Health and Population et al. 2012). Ecologically, this region is privileged compared to the hills and the mountains regarding transport, communication facilities and other infrastructure (Ministry of Health and Population et al. 2012).

Administratively, Nepal is divided into 75 districts (Central Bureau of Statistics 2012). The Kathmandu valley comprises three districts of Kathmandu (the capital city of Nepal) and the surrounding two districts, Lalitpur and Bhaktapur. The Kathmandu valley represents the most urbanised area in the hill region and has received significant government priority (Ministry of Health and Population et al. 2012). The majority of the children registered at ACNS were from the Kathmandu valley, and there were only a few children (range 1–6) from other districts. Based on the small sample sizes in these other districts, they were collapsed into a single group resulting in two groups: those within Kathmandu Valley and the remainder of the districts (others).

Ethnicity

Ethnicity in Nepal constitutes a hierarchy-based caste system with shared social and cultural practices (Pandey et al. 2013). The 2011 Census identified 125 castes/ethnic groups in Nepal (Central Bureau of Statistics 2012). The current study utilised the six ethnic codes developed by the Health Management Information System, Department of Health Services, Nepal (Bhandari et al. 2014; Pandey et al. 2013). The six classifications were grouped into three: 'Disadvantaged Groups,' 'Relatively Advantaged Janajatis,' and 'Upper Caste Groups.' The first category 'Disadvantaged Groups' combined the most underprivileged caste groups including 'Dalits,' 'Disadvantaged Janajatis,' 'Disadvantaged Non-Dalit Terai Caste Groups', and 'Religious Minorities' (see Table 1) given the low prevalence of these groups in the sample.

Table 1 Ethnic codes as defined by the health management information system

Ethnic Codes	Classification of ethnicity	Regrouping of ethnicity
1	Dalits: Hills of Kami, Damai, Sharki, Gaine, Badi	Disadvantaged Groups
2	Disadvantaged Janajatis: Hills of Magar, Tamang, Rai, Limbu, Sherpa, Bhote, Walung, Sunuwar, Kumal, Jirel, Danuwar, Thami, Raji	
3	Disadvantaged Non-Dalit Terai Caste Groups: Yadav Teli	
4	Religious Minorities: Muslims, Chureto	
5	Relatively Advantaged Janajatis: Newar, Thakali, Gurung	Relatively Advantaged Janajatis
6	Upper Caste Groups: Brahmin, Chhetri, Thakuri, Sanyashi, Raajput, Kaayastha, Baniya, Marwadi, Jaire, Nurang, Bengali	Upper Caste Groups

In the current study, the six classifications were grouped into three: 'Disadvantaged Groups,' 'Relatively Advantaged Janajatis,' and 'Upper Caste Groups'. The first category 'Disadvantaged' Groups combined the most underprivileged caste groups including 'Dalits,' 'Disadvantaged Janajatis,' 'Disadvantaged Non-Dalit Terai Caste Groups', and 'Religious Minorities' given the low prevalence of these groups in the sample

Autism Severity

Data on ASD severity were derived from the ADOS-G (Lord et al. 2000) which is a semi-structured, standardised assessment of communication, social interaction, play and imaginative use of materials for assessing individuals with possible ASD. The ADOS-G comprises different modules based on the expressive language skills of the child. The total cut-off scores from the three modules of ADOS-G were used in this study. Module 1 is administered to children who are preverbal and do not use spontaneous phrase speech. Module 2 is used for children who use phrase speech. Module 3 is intended for children with fluent speech for whom playing with toys is age appropriate. The ADOS-G calibrated scores ranging from 1 to 10 is derived from the sum of the communication and social interaction scores which were used to determine the severity of their symptoms following the revised algorithm procedure (Gotham et al. 2009). The children are classified into one of three classification ranges on the basis of the ADOS-G calibrated score: 'non-spectrum' (1–3), 'ASD' (4–5) or 'Autism' (6–10). The ADOS-G calibrated scores were available for only 52 (21%) of the 246 cases. The subset of children with ADOS-G scores were those who had received a diagnosis at ACNS.

Statistical Analysis

The AoD was non-normal in distribution, as assessed by Shapiro–Wilk's test ($p < 0.05$). Further, inspection of the boxplot revealed outliers in the data. Given the importance of wide variability in the AoD and limited data from low-resource settings, the outliers were included in the analysis. Attempts at transforming the data were unsuccessful. Thus, both parametric (Independent t-test and One-way ANOVA) and non-parametric (Mann–Whitney U-Test and Kruskal–Wallis test) tests were run before and after transformation, revealing similar results. As Tabachnick and Fidell (2013) suggest that parametric tests, including independent t-tests and One-way ANOVA, are considered "robust" to a violation of normality, the parametric statistics on untransformed data are presented here. A p -value < 0.05 was considered statistically significant. Data analysis was conducted using the Statistical Package for Social Sciences version 25.0 (SPSS; IBM Corp 2017).

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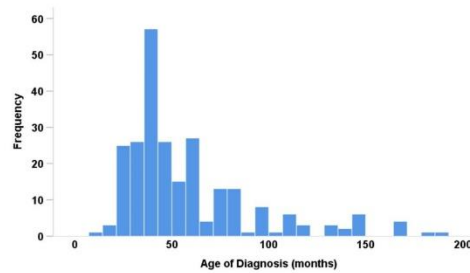


Fig. 1 Distribution of age at diagnosis of ASD in children registered at AutismCare Nepal Society

Table 2 Frequency and proportion of children diagnosed with ASD across age groups (N=246)

Age group	n	% [95% CI]
≤ 36 months	87	35.4% [29.03, 40.96]
> 36 months	159	64.6% [59.03, 70.96]

Results

Age and Frequency of Diagnosis of ASD

The average AoD in children registered at ACNS between 2010 and 2015 in Nepal was 58 months ($SD = 34.38$) ranging from 14- to 187-months (see Fig. 1). A total of 65% of the children registered at ACNS were diagnosed after 36 months of age (Table 2). An overall increase in the number of children registered at ACNS is apparent from 2010 to 2015, with slight decreases seen in 2013 and 2015 (Fig. 2). Significant differences in AoD were evident across six years of sampling, $F(5, 90.85) = 3.09$, $p = 0.013$, $d = 0.04$ (Fig. 3). Games-Howell post hoc analysis indicated mean AoD for 2015 ($M = 43.13$, $SD = 25.28$) was significantly different from 2013 (22.59, 95% [0.31, 44.87], $p = 0.04$) and 2014 (18.22, 95% [0.30, 36.14], $p = 0.04$).

Age of Diagnosis by Gender and Ethnicity

Boys constituted 76% of the sample (Table 3), with the male-to-female ratio for the sample being 3:1. There were no gender differences on AoD, $t(244) = 0.15$, $p = 0.88$, $d = 0.02$; males: $M = 57.79$, $SD = 34.71$; females: $M = 57.02$, $SD = 33.61$. The majority of the children (62%, $n = 152$) were from the upper caste group, with 63 children (26%) from relatively advantaged groups, and 31 (13%)

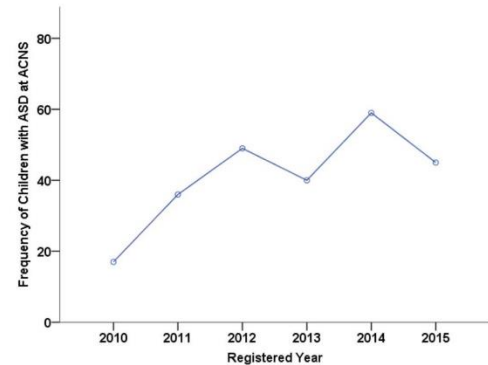


Fig. 2 Frequency of children with an ASD diagnosis registered at AutismCare Nepal Society from 2010 to 2015

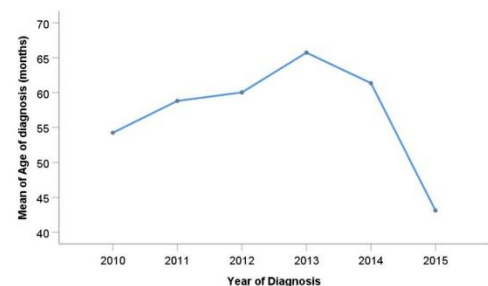


Fig. 3 Change in the mean age of diagnosis of children with ASD from 2010 to 2015. Significant differences in AoD were found across 6-years of sampling

from disadvantaged groups. Although the AoD was 7 months lower among the upper caste group ($M = 53.97$, $SD = 30.43$) compared to the relatively advantaged group ($M = 60.24$, $SD = 37.04$), and 16 months lower than the disadvantaged group ($M = 70.03$, $SD = 57.60$), the difference in AoD between these ethnic groups was not statistically significant, $F(2, 67.54) = 2.30$, $p = 0.10$, $d = 0.02$.

Age of Diagnosis by Ecological Zones and Districts

The hill region had the highest number of diagnosed children ($n = 211$, 86%) in contrast to the Terai ($n = 33$, 13%) and the Mountain regions ($n = 2$, 1%). However, there was no difference in mean AoD between the hills ($M = 57.66$, $SD = 35.65$) and the Terai ($M = 54.58$, $SD = 21.81$) $t(242) = 0.48$, $p = 0.63$, $d = 0.10$. In particular, 75% of the children from the hill region lived in the metropolitan Kathmandu valley

Table 3 Frequency of diagnoses and comparison of AoD of ASD (N = 246)

Categorisations	n (% of total)	Mean age [95% CI]	Group differences
Gender			
Male	187 (76%)	57.79 [52.78, 62.79]	$t(244)=0.15, p=0.88, d=0.02$
Female	59 (24%)	57.02 [48.26, 65.78]	
Ethnicity			
Upper caste groups	152 (61.8%)	53.97 [49.10, 58.85]	$F(2, 67.54)=2.30, p=0.10, d=0.02$
Relatively advantaged groups	63 (25.6%)	60.24 [50.91, 69.57]	
Disadvantaged groups	31 (12.6%)	70.03 [53.98, 86.08]	
Ecological regions			
Hills	211 (85.8%)	57.66 [52.82, 62.50]	$t(242)=0.48, p=0.63, d=0.10$
Terai	33 (13.4%)	54.58 [46.84, 62.31]	
Districts			
Kathmandu valley	185 (75.2%)	56.96 [51.77, 62.15]	$t(244)=0.51, p=0.60, d=0.07$
Other districts	61 (24.8%)	59.56 [51.89, 67.22]	

There were no significant differences in the AoD between gender, ecological regions or districts and ethnicity

CI confidence interval

Table 4 ADOS administration and ADOS calibrated scores (N = 52)

Age group	n (%)
Modules	
Module 1	45 (86.5%)
Module 2	5 (9.6%)
Module 3	2 (3.9%)
ADOS administration year	
2010–2013	11 (21.2%)
2014–2015	41 (78.8%)
ADOS calibrated score	
ASD (4–5)	6 (11.5%)
AUT (6–10)	46 (88.5%)

ADOS Autism Diagnostic Observation Schedule, ASD autism spectrum disorder classification on the ADOS, AUT Autism classification on the ADOS

including Kathmandu, Bhaktapur and Lalitpur districts (see Table 3). Although, ASD was diagnosed 3 months earlier in the Kathmandu Valley ($M=56.96$, $SD=35.78$) compared to the other districts ($M=59.56$, $SD=29.92$), the difference in mean AoD between the two groups were not significant; $t(244)=0.51, p=0.60, d=0.07$.

Autism Severity

Table 4 presents the available data on the ADOS-G. Of the 52 ADOS-G administrations, 46 children (88%) scored between 6 and 10 indicating the classification of autism, with that large majority of children administered module 1. Moreover, the majority of ADOS administrations (79%) were conducted during the years 2014–2015.

Discussion

The study revealed that the mean AoD of ASD among 246 children registered at ACNS from 2010 to 2015 was 58 months, confirming that for most children with ASD in Nepal, diagnosis occurs much later than what research suggests is possible. This finding is consistent with the previous small study undertaken in Nepal (Shrestha and Shrestha 2014), and other LMICs which have reported the mean AoD of children with ASD at between 45- and 57-months. Further, the findings show wide variability in the AoD of children with ASD ranging from as young as 14- to 187-months of age.

Overall, the majority of the children (65%) were diagnosed after they reached 36-months-of-age, missing the critical period of early development when the malleability of the brain is at its greatest. Encouragingly, despite the increasing frequency of children with ASD diagnosed over the study period, there was an apparent decrease in the diagnostic age over time, potentially attributable to an increasing awareness of ASD. Indeed, the awareness programs on ASD among health professionals and the public in recent years (Shrestha and Santangelo 2014) has possibly resulted in the recent drop in AoD over the 6-year period of this dataset.

The majority of children (88%) had more severe symptom presentations as indicated by their ADOS-G severity scores. However, it is important to note that only 21% of children had been administered the ADOS-G, representing only one-fifth of the sample. The diagnosis of severely affected children as demonstrated by ADOS-G is comparable with other studies across LMICs that have also reported the diagnosis of a higher number of children with severe autistic symptoms (Juneja et al. 2005; Shooshtari et al. 2009; Springer

et al. 2013). These studies indicate that children with milder symptom presentations may miss out on being diagnosed. Despite increasing awareness of ASD, there remains a need for more knowledge on the broader autism spectrum including the more subtle behavioural markers of ASD amongst clinicians and other health professionals, including the general population (Daley 2004).

The majority of children diagnosed with ASD were males, with the data comparable to previous gender ratios (Elsabbagh et al. 2012; Van Wijngaarden-Cremers et al. 2014), and there were no differences in the AoD between males and females. Given the growing concern that the female children might have been underdiagnosed, it is likely that Nepalese girls are also at more risk of being underdiagnosed compared to boys, particularly as they have less access to healthcare facilities due to the high value attached to male children (Bhandari et al. 2007). Research suggests that fewer girls with disabilities compared to boys in Nepal are brought to specialised centres for diagnosis, treatment and rehabilitation (Thapa 2016).

The current findings indicate that a significant proportion of the children diagnosed were from the upper caste groups compared to the disadvantaged group, which may be explained by the fact that high caste groups in Nepal are the most privileged people with regard to their sociocultural position and economic status; it is established that they have better access to educational and healthcare services compared to other disadvantaged ethnic groups (Bhandari et al. 2007; Pandey et al. 2013). Although the differences in AoD were not significant among ethnic groups comparable to previous findings (Bent et al. 2015; Mandell et al. 2005), it is important to note that the higher caste group had an earlier AoD than the disadvantaged groups; this trend, despite not being significant has clinical and public health relevance indicating the need to target ethnically marginalised populations in terms of early identification and diagnostic services. It seems reasonable to speculate that their access to support services would also be limited.

Similarly, regional disparities were apparent in the number of children diagnosed with ASD across the three ecological zones, although there was no significant difference in their mean AoD. The majority of children who received a diagnosis were from the hill region, primarily from the Kathmandu valley—a metropolitan region which is a political, economic and administrative centre (Central Bureau of Statistics 2014). This finding is consistent with other child health research in Nepal which identified far fewer children from the remote mountain regions, probably because of limited access to services which are generally being more prevalent in Kathmandu, which is also where ACNS is based (Bhandari et al. 2007; Ministry of Health and Population et al. 2012). As evidence of this, rural parts of both the hill and the Terai regions were less represented in the ACNS

registry. These differences are likely to be the outcome of limited access to transportation, communication and health services for those living away from the Kathmandu valley. Moreover, a larger number of children from the upper caste group and diagnosed with ASD were living in Kathmandu within the urban area of the hill region which may have given them added benefit for better access to educational and health care services. Research also suggests that the rural and remote areas characterised by geographic challenges, poorer socioeconomic status, lower educational level and lack of ASD awareness further contribute to delayed or missed diagnosis of ASD (Antezana et al. 2017).

Strength and Limitations

The strength of the study includes the relatively large sample size compared to an earlier study. However, there are also some limitations, including a strong potential for selection bias as it only investigated the AoD of those children registered at ACNS. It appears that our sample included those children with a severe presentation of ASD and who had access to the centre. Thus, other children who were diagnosed but not recorded on the ACNS registry, or were diagnosed very late and thus not registered, were not able to be included in this study. Because of this potential selection bias, the AoD reported here may be an underestimation of true AoD in Nepal. As most of the cases had been clinically diagnosed, the reliability of their diagnoses could not be examined by confirmation with the administration of an ADOS-G. In order to address these issues, it is important to undertake population-based surveillance for ASD to ascertain the true prevalence of ASD in Nepal and the AoD of ASD.

Furthermore, the study is limited by the lack of information on child characteristics such as birth order, intellectual level, developmental regression, and co-morbid conditions. Further, as already noted, only 52 children had ADOS-G scores, indicating a need for further professional training in the use of diagnostic measures for diagnosis of ASD in Nepal. Finally, family factors including their concerns, education, and socioeconomic status were not evaluated, which could also have affected the AoD of children with ASD.

Conclusion

The current study provides important information on the mean AoD of ASD in Nepal, an LMIC where autism resources and studies are scarce. The findings demonstrate a delay in AoD of ASD to what is possible, with wide variability in diagnostic age. However, the increase in the number of children with ASD diagnoses with a decreasing

diagnostic age over 6 years of sampling is promising and indicates a growing awareness of ASD. Nonetheless, the diagnosis of children with severe symptoms indicates the lack of knowledge on less severe presentations of ASD among the public and professionals alike, calling for greater and widespread community education on the many manifestations of ASD during the early years of life. Further, the higher proportion of children with a diagnosis of ASD from the Kathmandu valley and the upper caste ethnic groups illustrate a significant geographical disparity and ethnic inequality in accessing identification and diagnostic services. Although not a focus of the current study this would also be reflective of access to support services for children and their families, indicating the need to build capacity, perhaps using task shifting/task sharing, to serve all communities.

Given the importance of early identification of ASD leading to subsequent diagnosis and early intervention, there is a great need to advance the knowledge of ASD, and efforts are needed to reduce the disparity in available services to identify and diagnose ASD across the population in Nepal. The findings highlight the need to develop cost-effective, reliable and easily-accessible early identification services in local communities in Nepal to lower the diagnostic age of ASD and to ensure that all children despite their gender, ethnicity, and place of residence have the opportunity to access and benefit from the positive impacts of early diagnosis and intervention.

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Author Contributions RS participated in the conception and design of the study, conducted the analysis and interpretation of data and drafted the manuscript. CD and JB participated in the conception and design of the study, advised on the analysis and interpretation of data and supervised the manuscript preparation, including editing the manuscript. All authors read and approved the final manuscript.

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Compliance with Ethical Standards

Conflict of interest All authors declare that they have no conflict of interest.

Ethics Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Formal consent was not required for this study given the use of de-identified data.

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