THE PREVALENCE OF CO-MORBID AUTISM SPECTRUM DISORDER AMONG PERSONS WITH INTELLECTUAL DISABILITY

BY

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A Research Project submitted in Partial Fulfilment of the requirements for the Master of Science in Clinical Psychology Degree, College of Health Sciences, Department of Psychiatry, The University of Nairobi

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DECLARATION

I Everlyne Mercy Khabala do hereby declare that this is my original work and that it has not been presented for the award of any degree to any other university.

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APPROVAL

This is to satisfy that this bona fide research work was carried out independently by Everlyne Mercy Khabala under our guidance and supervision.

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DEDICATION

I dedicate this study to all caregivers of persons with intellectual disability with co-morbid autism spectrum disorder for the burden they bear to care for these special people.

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The Master of Science Clinical Psychology program has been a very long, taxing andchallenging journey, the successful completion of which has been the result of the support and encouragement from many people. With a lot of reverence, I thank the Almighty God, for He led me all through and has done it all.Praise be to God!

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ABBREVIATIONS/ACRONYMS

ABA -	Applied Behavioural Analysis
AD –	Autistic Disorder
ADDM Network -	Autism and Developmental Disabilities Monitoring Network
ADI-R –	Autism Diagnostic Interview – Revised
ASD -	Autism Spectrum Disorder
ASSQ –	Autism Spectrum Screening Questionnaire
CDC –	Centers for Disease Control and Prevention
DBC-T –	Developmental Behavioural Checklist – Teacher version
DSM – 5 –	Diagnostic and Statistical Manual, Version 5
EARC –	Educational Assessment Resource Centre
GARS – 3 -	Gilliam Autism Rating Scale, Third Edition
ICD – 10 –	International Classification of Disease, Tenth Edition
ID -	Intellectual Disability
IQ -	Intelligence Quotient
KABC – II -	Kaufman Assessment Battery for Children, Second Edition
NACOSTI –	National Commission for Science, Technology and Innovation
NHB –	Non-Hispanic Black
NHS –	Non-Hispanic White
NS-CSHCN –	National Survey of Children with Special Health Care Needs
PDD –	Pervasive Developmental Disorder
PRISMA –	Preferred Reporting Items for Systematic reviews and Meta-Analysis
PWID –	Persons With Intellectual Disability
SPSS -	Statistical Package for the Social Sciences
WHO –	World Health Organization

ABSTRACT

The simultaneous presence of one or more additional disorders with the initially identified illness in the same person has been a topic receiving considerable attention in the study of mental disorders in children that are diagnosed during childhood. Autism spectrum disorders (ASDs) and intellectual disability (ID) manifest together at significant higher rates. In a similar way, the seriousness of one of these two disorders appears to have effects on the other disorder. ASD are a group of disorders that are typically first diagnosed in childhood. These disorders are characterized by a set of three impairments that often require early detection, identification and effective evidence based interventions in order to increase the likelihood of assisting these children reach their full potential throughout their lifespan and having improved long term outcomes. The study will result in increased knowledge and awareness of ASD and associated comorbidity with intellectual disability.

Objectives: The study aimed at identifying the prevalence of Autism Spectrum Disorder as co-morbid disorders in persons with Intellectual Disability in special needs schools in a rural Kenyan setting.

Method: The study was a cross-sectional descriptive design study using quantitative data collection method. It used primary data of 163 pupils categorized as Mentally Handicapped who attended Nangina and Lwanya special schools. Assessment of Autism Spectrum Disorder was by screening using the researcher designed socio-demographic questionnaire and the APA_DSM5_Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders scale.

Results: 30 out of a total of 115 respondents in the age group of 6-28 were diagnosed as cases of ASD yielding a prevalence of 26.1% 95% C.I (18.3-34.8). Majority of these 30 diagnosed of comorbid ASD with ID (28.6%; 16/56) were male and (23.7%; 14/59) were female a male: female ratio of 1.14: 1. Respondents aged 6-8 (15.4%), 9-12 (31.6%), 13-17 (28.6%) and 18-28 (25.0%) were identified as cases of comorbid ASD with ID. A higher proportion was observed in respondents age 9-12 (31.6%).

Conclusion: Results suggest that intellectual disability and autism spectrum disorders commonly coexist. Lack of awareness and similar clinical manifestations lead to under diagnosis of autism spectrum disorder.

These findings stress the importance of identifying persons with autism spectrum disorders at the earliest age so that early interventions can be made and the outcome may be more successful for such persons.

CHAPTER 1

1.0 INTRODUCTION

1.1 Background Information

Neurodevelopmental disorders are a group of conditions with onset in the developmental period. The disorders typically manifest early in development, often before the child enters primary school, and are characterized by developmental deficits that produce impairments of personal, social academic or occupational functioning. The range of developmental deficits ranges from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence. The neurodevelopmental disorders frequently co-occur for example, individuals with autism spectrum disorder often have intellectual disability (APA, 2013).

1.2 Intellectual Disability

Intellectual disability (ID, formerly referred to as "mental retardation") is characterized by a significant impairment in intellectual function and is associated with impairment in adaptive behavior (communication, domestic personal care, social skills, use of community resources, autonomy, health and safety, school, leisure, as well as work) (Schalock, et al. 2010).

ID is known by different names in different countries. According to data collected from 147 countries common terminology include mental retardation (most common term in 76% of the countries), intellectual disability (57%) and mental handicap/ disability (40%) (Maulik & Harbour, 2010). Other terms like learning/developmental disability and mental deficiency/sub-normality are also used (WHO 2007).

People with intellectual disability end up with bad health than those who don't have intellectual disability and their health needs are complex.The average period that men and women having an intellectual disability may expect to live is 13 and 20 years lesser, respectively, compared to the general population (Awan & Chauhan, 2017).

1.2.1History

Some of the very first references to intellectual disability date back to the ancient Egyptians, where this concept is mentioned in the Papyrus of Thebes over 3500 years ago.

The ancient Romans and Greeks believed that children are born with an intellectual disability because the gods are angry. Many of these children were simply left to die in the wild. Non –consensual sterilization was one of the characteristic historical abuses that took place mainly in the first half of the 20th century. People with intellectual disability were a prime target as part of the ideology of negative eugenics (Rowlands & Amy, 2017)

Jean-Marc Itard is appreciated for creating the first organized program for the improvement of persons with intellectual disability (PWID) in late 18th century France, and the first boarding institution was began in the mid19th century in Switzerland. Psychological tests such as Binet–Simon tests to assess intelligence were developed in the 20th century, which increased case identification, but for some cases also led to interventions that today would be considered unnecessary if not cruel (Maulik & Harbour, 2010).

Research has progressed in the behavioral field. Behaviorally, early and more recent work has allowed for better diagnoses and classification. Nearly a century ago, psychologists invented tests of motor, nonverbal intelligence, achievement, adaptive behavior, and other skills. Following similar work with typically developing children, psychologists have recently learned much about the development of cognitive, linguistic, social, and adaptive skills in persons with mental retardation. In addition, many studies now examine the presence of psychiatric disorders in children and adults with mental retardation (Sadock & Sadock, 2005).

1.2.2 Prevalence of ID

It has been estimated that ID prevalence ranges from 1 to 3% but wider variations have been reported (Karam, et al. 2016).

A review based on a literature search involving electronic databases of peer-reviewed published studies with emphasis on studies published after 1980 by Maulik & Harbour, (2010) revealed that prevalence estimates rates among children are between 3-14/1000.

Among children the rates vary a lot depending on diagnostic systems, the age of the child, and source of the administrative data.

A rough calculation of the prevalence of intellectual disabilities and its relationship with age in village and town populations in India by Lakhan, Ekundayo & Shahbazi, 2015 found that overall, India had a prevalence of 10.5/1000 in ID. Urban population had a slightly higher rate (11/1000) than rural (10.08/1000).

Christianson, et al. 2002 in a study on Prevalence and associated disability in Children found to have Intellectual disability in villages of South Africa found a minimum observed prevalence of 35.6 per 1000 children. Intellectual disability may be the largest impairment grouping on the African continent. A few studies originating from the African continent it self have been done (Mckenzie, McConkey & Adnams, 2013)

1.2.3 Diagnostic criteria

Intellectual disability is a disorder with an onset during the developmental period and includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains. According to the DSM 5 APA, (2013), the following three criteria A, B and C must be met:

A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized standardized intelligence testing. Individuals with intellectual disability have scores of approximately two standard deviations or more below the population mean, including a margin for measurement error (generally + 5 points). On tests with a standard deviation of 15 and a mean of 100, this involves a score of 65-75 (70 +-5).

B. Shortcomings in adaptive functioning that lead to failure to meet developmental and social-cultural standards for personal independence and social responsibility. Without continous assistance, the adaptive shortcomings limit functioning in one or more activities of daily life, such as communication, social participation and independent living across multiple environments, such as home, school, work, and community. To meet diagnostic criteria for intellectual disability, the shortcomings in adaptive functioning must be directly related to the intellectual impairments described in criterion A.

C. The beginning of intellectual and adaptive shortcomings is during the early years of development. The extent to which one is affected is categorized as Mild, Moderate, Severe or Profound. The different extents are arrived at on the basis of adaptive functioning, and not intelligent quotient scores, because it is the adaptive functioning that defines the level of assistance required. In the lower end of the intelligent quotient range, the intelligent quotient scores are less valid.

1.2.4 Sex ratio

Intellectual disability is higher among males than females especially among children less than 15 years of age (Kuper, et al. 2014). Intellectual disability is higher in boys than in girls generally in the range of 1.3 – 1.4 fold higher (Maulik & Harbour (2010). According to the Australian Institute of Health and Welfare (AIHW) 2004, sex differences in children with intellectual disability show that the rate among boys aged 0 – 14 years is 2.6 times that of girls.

1.3 Autism Spectrum Disorder (ASD)

1.3.1 History

Leo Kanner first documented accounts of autism in 1943, when he described seemingly incompatible and atypical characteristics shared in a number of case studies. The children seemed non-communicative, aloof, and engaged in nonproductive and meaningless activity, including an obsessive need for sameness (Wilmshurst, 2005).

A defining moment in classification was arrived at in 1978 when Michael Rutter made a suggestion of a definition of autism based on; Social delay and deviance (not just due to mental retardation); Communication problems (not just due to mental retardation); Un-usual behaviors, such as stereotyped movements and mannerisms (insistence on sameness) with an onset before age 30 months (Sadock & Sadock, 2005).

Today, the spectrum of autistic disorders (or ASD) is recognized as a set of common developmental disorders. There is common agreement today that ASD is a neurodevelopmental disorder that has a genetic basis (perhaps in interaction with the environment) (Feinstein, 2012).

1.3.2 Prevalence of ASD

According to the International Society of Autism Research 2012, the autism spectrum disorders median of prevalence estimates was 62/10,000 globally. In recent years, reported frequencies for autism spectrum disorder across U.S. and Non- U.S. countries have approached 1% of the population with similar estimates in child and adult samples (APA, 2013).

A review on autism in Africa by Bakare & Munir, 2011 could not identify published data on population-based estimates of prevalence of Pervasive Developmental Disorders (PDD) from African region (Elsabbagh, et al., 2012).

In Kenya, there are no official and accurate records on the prevalence of autism, as is the case with the population with disability, but there are cases abound country wide.

Estimates by the Autism Society of Kenya, an NGO dealing with ASD since the year 2003, approximated that 4% of the population in Kenya was autistic back in 2007 (Kithii, 2016).

1.3.3 Diagnostic criteria

According to DSM 5 APA, (2013) the following is the diagnostic criteria for autism spectrum disorder;

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging for example from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging for example from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

B. Restricted, repetitive patterns of behavior, interests or activities as manifested by at least two of the following, currently or by history:

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

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

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

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

1.3.4 Sex ratio

Autism spectrum disorder is diagnosed four times more often in males than in females.Females tend to be more likely to show accompanying intellectual disability, suggesting that girls without accompanying intellectual impairments or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties (APA, 2013). Studies based on both clinical and epidemiological samples have suggested a higher incidence of autism in boys than in girls, with ratios reported averaging around 3.5 or 4.0 to 1. The ratio varies, however, as a function of intellectual functioning. Some studies have reported ratios of up to 6.0 or higher to 1 in individuals with autism without intellectual disability, whereas ratios within the moderately to severely intellectually disabled range have been reported to be as low as 1.5 to 1(Sadock & Sadock, 2005).

1.3.5 Co-morbidity

A similar finding in general population studies of the prevalence of autism is that co-morbidity with ID is common. Among those who meet the identification and labeling of disease based on its signs and symptoms,1 up to 75% have been estimated to be intellectually disabled, whether defined in terms of IQ and (or) level of adaptive skills (Bryson, et al. 2008).

A study by Ramanujam, Abdulrahuman and Nagendran 2016 on Prevalence of Autism among Children with Intellectual Disability on a group of children from two special schools in Palayamkottai in Tamilnadu revealed that children were diagnosed to have Autism with a prevalence rate of 23.6% with a male: female ratio of 3.1:1.

In a study conducted by Mpaka, et al, 2016 on Prevalence and comorbidities of autism among children referred to the outpatient clinics for neurodevelopmental disorders, a cross sectional study was conducted in three outpatient centers receiving patients referred for neurodevelopmental disorders in Kinshasa, DRC. 120 out of 450 respondents (29.3%) received the diagnosis of ASD. Boys were more than girls (OR 3:1). Intellectual disability (75.83 %) was the main co-morbidity associated with autism. Males seemed to be more affected than females.

A study on Prevalence of Autism Spectrum Disorder among Nigerian Children with Intellectual Disability: A stopgap Assessment by Bakare, Ebigbo & Ubochi, (2012), undertaken at the Therapeutic Care Center (TCC), Abakpa, Enugu, South-Eastern Nigeria found 4 (9.1%) males and 1 (2.3%) females with a diagnosis of childhood autism. The prevalence of childhood autism among children with intellectual disability was 11.4%.

1.3.6 Management

There is no cure for autism and there is no one specific treatment that is more effective than others. Programs may differ but there is growing consensus that effective early childhood intervention for children with ASD includes entry into intervention as soon as an ASD diagnosis is seriously considered. Applying interventions like Applied Behavioural Analysis (ABA) that are based on the principles of learning to systematically change behavior are important.

ABA strategies are used to ensure that desirable adaptive behavior is increased and maintained, a reduction in negative behaviours or lessen the conditions under which they occur, new skills are taught and behaviours are generalized to new environments or situations (Myers & Johnson, 2007).

A curriculum focusing on the areas of attention and compliance, motor imitation, communication, appropriate use of toys, and social skills, highly structured teaching environments with a low student-to-staff ratio.

Systematic strategies for generalizing newly acquired skills to a wide range of situations, maintenance of predictability and routine in the daily schedule, a functional approach to problem behaviors and focus on skills needed for successful transitions from the early intervention program to the regular preschool or kindergarten classroom and a high level of family involvement (Mash & Barkley, 2003).

It is very stressful for families receiving a diagnosis of autism. Psycho-education is the first step in providing an opportunity to parents to understand the disorder. A life long neuro-developmental condition like autism is sometimes distressing and confusing and parents must learn to cope and manage their child's behavious. It has been suggested that foods containing gluten and casein may play a role in the difficulties associated with autism. However research in this area is scarce. No medicine has proven curative, but some specifi symptoms may be allievated by certain medications. Such symptoms include self-injury, aggression, stereotyped movements, and over-activity (Chowdhury, 2009).

1.4 Problem Statement

Special needs institutions of learning focus on identifying children as having learning disabilities. Unfortunately, these children present with other difficulties like social interaction and anxiety problems, verbal and non-verbal communication and repetitive interests or patterns of behavior which require a different approach including what is currently being practiced. Autism Spectrum Disorder may not be picked early enough in a child with Intellectual Disability as there is no awareness of comorbidity and this would result in poorer outcomes.

1.5 Justification of the study

1. The study will provide information on the prevalence of ASD among children with ID in Kenya.
2. The study will provide educational administrators with the indicators for policy guidance on learning disability.
3. The study will show the importance of early diagnosis and early intervention for children with ASD which will result in good prognosis and better outcomes.
4. The study will elucidate mental health needs of children with ASD and ID.
5. This research will form a base for other scholars to do more research in the field as well as add a pool of scientific knowledge to the existing information.

1.6 Significance of the study

The results of the study will assist policy makers in planning better for provision of services which include early detection, diagnosis and effective evidence based interventions for ASD with comorbid ID, special education as needed and family support. This will eventually help these children realize their full potential.

The study will also enable the stake holders such as schools to put in place structures and educational intervention programs like Applied Behavioural Analysis (ABA) that are based on the principles of learning to systematically change behavior that will improve the lives of children.

It will also help the stakeholders such as schools involve the caregivers in the therapeutic process.

1.7 Objectives

1.7.1 Broad Objective

The overall objective of this study is to find out the prevalence of Autism Spectrum Disorder as co-morbid disorders among children with Intellectual Disability in special schools in a rural Kenyan setting.

1.7.2 Specific objectives

1. To assess the prevalence of co-morbid Autism Spectrum Disorder in children with Intellectual Disability in Kenya.
2. To determine the correlates of Autism Spectrum Disorder in children with Intellectual Disability.

1.8 Hypothesis

1.8.1 Alternative hypothesis

Autism Spectrum Disorder co-occur in children with Intellectual Disability.

1.8.2 Null hypothesis

Autism Spectrum Disorder does not co-occur in children with Intellectual Disability.

CHAPTER 2: LITERATURE REVIEW

2.1 Prevalence of autism spectrum disorder

10 per 10000 is considered to be the prevalence of autistic disorder currently. Changes in study methodology; a genuine rise in autism risk factors; increase in services available, including diagnostic; increased awareness among educational and clinical professionals; and growing acceptance that autism can coexist with a range of other conditions may be the reasons for observed increase in prevalence estimates (Williams, Higgins & Brayne, 2005).

A study by Jo, Schieve, Rice, Allsopp, Tian, Blumberg, Kogan & Boyle 2015 looked at the prevalence of diagnosed autism spectrum disorder (ASD) in National Survey of Children with Special Health Care Needs (NS-CSHCN) which was carried out in the year 2009-2010. It was found that ASD prevalence estimates were 15.3 Non-Hispanic White (NHW), 10.4 Non-Hispanic black (NHB), 14.1 (Hispanic – English) and 5.2 (Hispanic – Other) per 1000 children.

In a study by Kogan, et al, 2009 on Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the US, 2007 among US children aged 3 to 17 years was estimated from the 2007 National Survey of Children's Health (sample size: 78 037). Results showered that the weighted ASD point-prevalence was 110 per 10,000. It was estimated that 673,000 US children have ASD.

Findings from Centers for Disease Control and Prevention (CDC)'s Autism and Developmental Disabilities Monitoring (ADDM) Network (2014) estimated that, children with ASD are at a high percentage. Based on tracking in 11 communities across the United States in 2014, 1 in 59 children were identified with ASD.

Estimates for combined Pervasive Developmental Disorder (PDD) as well as Autistic Disorder (AD) were provided by the United Kingdom, Iceland, Denmark and Sweden. Prevalence rates varied from 1.9/10,000 to 72.6/10,000 with a median value of 10.0/10,000. Prevalence rates for studies from Japan and China varied from 2.8/10,000 to 94/10,000 with a median value of 11.6/10,000. The estimated rate of AD in Indonesia was found to be 11.7/10,000. The estimated prevalence of PDD in Australia was found to be 39.2/10,000.

A Korean study had the highest rate of PDD internationally estimating the prevalence to be 189/10,000 followed by 181.1/10,000 an estimated prevalence found by a study from Japan (Autism Research, 2012).

In a study using a population-based sample to estimate the Prevalence of Autism Spectrum Disorders in a Total Population by Kim, et al, 2011 the target population was 7- to 12-year-old children (N=55,266) in a South Korean community; the study used a high-probability group from special education schools and a disability registry and a low-probability, general-population sample from regular schools. Results showed that the prevalence of ASDs was estimated to be 2.64% (95% CI=1.91–3.37), with 1.89% (95% CI=1.43–2.36) in the general-population sample and 0.75% (95% CI=0.58–0.93) in the high-probability group.

In Africa at present, there are very few researches relating to autism spectrum disorders. Even with the few that have been done, they confirm that autism spectrum disorders are present in Africa (Bakare & Munir, 2011).

A systematic review of research on autism spectrum disorders in Sub-Sahara Africa by Abubakar, et al, 2016 Guidelines for Preferred Reporting Items for Systematic reviews and meta-analyses (PRISMA) were used. Four databases were searched i.e Medline, PsychINFO, CINAHL and Child Development and Adolescent Studies (1935 to June 2016), through EBSCO. The results showed a study by Lagunju and colleagues recruited 2320 patients at a paediatric neurologic clinic. After a systematic screening, 54 of the 2320 patients were diagnosed with ASD, with estimated prevalence of 2.3%.

A community-based study was identified, in which 1169 Ugandan children aged 2-9 years were surveyed in the Kampala District (half urban and half rural). Eight children had a positive diagnosis of ASD. Unadjusted prevalence for ASD of 6.8/1000 was reported. Bakare et al (2012) in a study from Nigeria reported an ASD ratio of 4:1 for boys and girls respectively.

A study by Hussein, Taha & Almanaser, 2011 on Characteristics of Autism Spectrum Disorders in a sample of Egyptian and Saudi patients: Transcultural Cross sectional study compared characteristics of autism in two groups of Egyptian as well as Saudi children. The sample included 48 children with autism spectrum disorder. They were recruited from the Okasha Institute of Psychiatry, Ain Shams University, Cairo, Egypt and Al-Amal Complex for Mental Health, Dammam, Kingdom of Saudi Arabia. They were grouped into an Egyptian group (n=20) and a Saudi group (n=28). They were assessed both clinically and psychometrically using GARS, The Vineland Adaptive Behavioral Scale and The Stanford Binet IQ Test. They concluded that typical autism was more prevalent than atypical autism in both groups.

Literature cited in pubmed related to various aspects of ASD over the last decade in Africa was reviewed by Bakare & Munir, 2011. A prevalence study on autism by Seif Eldin et al (2008) which focused on Arab countries, but included two African countries (Egypt and Tunisia) in North Africa was found. 33.6% and 11.5% were the respective ASD prevalence rates found among children with developmental disorders in Egypt and Tunisia.

2.2 Co-morbidity of Autism Spectrum Disorder with ID

Published studies involving representative populations of children with ID have demonstrated a three to four-fold increase in prevalence of co-occurring mental disorders (Munir, 2016).

A study by Ramanujam, Abdulrahuman and Nagendran 2016 on Prevalence of Autism among Children with Intellectual Disability, a group of children from two special schools in Palayamkottai in Tamilnadu who were previously diagnosed to have intellectual disability were assessed by direct observation and screened using the DSM IV-TR for AUTISM criteria with the help of the teachers responsible. The children positive for autism in DSM IV-TR criteria were reassessed with age related checklist such as the Modified Checklist for Autism in Toddlers and the Indian Scale for Assessment of Autism. The results revealed that 37 of the 156 children analysed were diagnosed to have Autism with a prevalence rate of 23.6% with a male: female ratio of 3.1:1. Since the prevalence of autism and other pervasive developmental disorder in children with mental retardation was high it was concluded that all cases of intellectual disability must be screened for them.

The prevalence estimate for both ASD and ID in U.S populations by a study by Schieve, et al, (2015) on Comparison of Perinatal Risk factors associated with Autism Spectrum Disorders (ASD), Intellectual Disability (ID), and co-occurring ASD and ID was between 1 and 2%. In 2010 the co-occurrence of the two conditions was common. Children with ASD who had co-occurring ID were estimated to be 31%.

A study on Canadian population of adolescents with ID by Bryson, et al. 2008, on the Prevalence of Autism among Adolescents with Intellectual Disabilities found an overall prevalence for ID to be 7.18/1000. Those identified with autism in the target population were 28% of individuals, or 2.0 of the 7.1/1000 with ID.

In a study conducted by Mpaka, et al, 2016 on Prevalence and comorbidities of autism among children referred to the outpatient clinics for neurodevelopmental disorders a cross sectional study was conducted in three outpatients centers receiving patients referred for neurodevelopmental disorders in Kinshasa, DRC, from June 2008 to June 2010. A total of 450 subjects aged from 1-18 years old were referred and included in the study. The clinical diagnosis for ASD was made using the DSM-IV-R and the ADIR. All patients were subject to an intellectual quotient evaluation and an electroencephalogram reporting.

Of the 450 subjects referred, 120 (29.3%) received the diagnosis of ASD, with boys outnumbering girls (OR 3:1). The mean age was 7.9 years. Intellectual disability (75.83 %) and epilepsy (72.50%) were the main co-morbidities significantly associated with autism. Males seem to be more affected than female.

In a study on the Prevalence of Autism Spectrum Disorder among Nigerian Children with Intellectual Disability by Bakare, Ebigbo & Ubochi, (2012), was done at the Therapeutic Care Center (TCC), Abakpa, Enugu, South-Eastern Nigeria. In this study socio-demographic Questionnaire was used to obtain information from teachers and nursing staff in the facility about each child. Parents of children identified as having childhood autism were further interviewed for corroborative information. ICD -10 diagnostic criteria for mental retardation (F70-F30) was employed. IQ assessment was determined by the use of the Ratio IQ Score . ICD-10 criteria for Childhood Autism (F84.0) was employed. Forty four (44) children with intellectual disability participated in the study. The age range of the children was from 4 to 18 years.

There were 4(9.1%) males and 1(2.3%) females with diagnosis of childhood autism. The prevalence of childhood autism among children with intellectual disability was 11.4%.

A study by Mankoski, et al. 2006 on Etiologies of Autism in a Case – Series from Tanzania examined twenty autistic children and adults. Ten attended the autism unit at the Msimbazi Mseto primary school in Dar es salaam. Four of the eight children from the school's waiting list were examined and additional six were recruited from the community by school staff from among fourteen families who they knew had a child with clinically diagnosed autism. The Autism Diagnostic Interview Revised (ADI-R) that was used was translated into Kiswahili. Fourteen met research criteria for autism. It was found that a diagnosis of autism spectrum disorder in Africa is always accompanied by the presence of intellectual disability. Non –verbal cases were higher (11/14).

CHAPTER 3: METHODOLOGY

3.1 Study Design

The study was a cross-sectional design study using quantitative methods. Primary data of persons in Nangina and Lwanya special schools for the intellectually disabled was used.

3.2 Study area description

The study was carried out at Nangina and Lwanya special schools for the intellectually disabled on persons who were attending the special schools following placement as being mentally handicapped.

Nangina and Lwanya Special Schools for the intellectually disabled are located in Busia County which is one of the forty seven counties of Kenya situated at the extreme western region of the country. Part of lake Victoria is in the county on the south east and borders the lake with the Republic of Uganda to the west.

Nangina special school for the intellectually disabled was established in 1988 as a unit of St. Catherine Nangina girls primary boarding school. In 1990 it sourced for funding locally and abroad and managed to purchase its own land and set up its own infrastructure. Lwanya special school for the intellectually disabled was established in 1987 as a unit of Lwanya primary school. In 2010 it sourced for funding locally and abroad and managed to purchase its own land and set up its own infrastructure. Both schools are government public schools under the county government of Busia.

The schools are run by a board of management which is appointed by the County educational board and the parents association. The day to day activities of the school are managed by the principal, deputy principal and the senior teacher.

Nangina special school has 75 pupils aged 6 to 24 years. Forty of the pupils are categorized as mentally handicapped and 35 are categorized as hearing impaired. Lwanya special school has 123 pupils aged 6 to 29 years. They are all categorized as mentally handicapped.

The pupils come from all over the country and from Uganda but majority of the population is from Busia county where the schools are located. Prior to admission into the schools, a teacher who has undergone special education training based at the school does the initial screening of the pupils.

The county assessment officers from Educational Assessment Resource Centre (EARC) and Association of the Physically Disabled in Kenya (APDK) are informed to organize for an assessment of the pupils and placement. The assessment comprises of physical observation of the child and a detailed interview with the child's parents regarding the history of the pregnancy, medical history and attainment of developmental milestones. The medical team is called in from the county hospital of Busia for medical examination which includes, testing for various disorders and prescribing various medications.

3.3 Study population

The study population was all persons classified as mentally handicapped who were attending the special schools aged 6 years to 29 years. One hundred sixty three persons met the study population criteria.

3.3.1 Inclusion criteria

Persons in the schools classified as mentally handicapped who were aged between 6 to 29 years.Parents/guardians of persons classified as mentally handicapped and had consented to the study. School authorities who cared for persons classified as mentally handicapped and had consented to the study.

3.3.2 Exclusion criteria

Persons confirmed to be of normal intelligence and had a hearing impairment.
Persons whose parents/guardians refused to give consent for the persons to participate in the study.Persons whose parents/guardians could not be reached to give consent.
Parents/guardians who refused to participate in the study. School authorities who cared for the persons and refused to participate in the study.Parents who did not have children classified as mentally handicapped.

3.4 Sampling procedure and sample size determination

Purposive method of sampling was used to select participants to represent the sample in school.All persons classified as mentally handicapped and within the age range of 6 to 29 years their socio demographic information was obtained by the use of the researcher designed demographic questionnaire and then they were assessed by the use of APA_DSM5_Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders Scale. In a population of more than 10,000 individuals, 384 is the recommended desired sample size (Mugenda & Mugenda, 1999). The population in this study is 163. Mugenda & Mugenda recommend the formula: nf = n/1+(n/N) to be used to calculate sample size. According to the above formula;

nf = desired sample size when the population is less than 10,000

n = desired sample size when population is more than 10,000

N = estimate of the population size

Using the above formula sample size is nf = 384/1+(384/163) = 114.2 = **115 pupils.**

3.5 Data collection instruments

3.5.1 Researcher designed demographic questionnaire

Enrolled participant's parents/guardians were subjected to a social demographic questionnaire designed by the researcher to collect data on age, gender, the number of children the mother of the child has, if all the children belong to the same father, if the child's parents are still married, if the child's parents are alive or deceased, who lives with the child when out of school, education level of parents and occupation of parents.

3.5.2 APA_DSM5_Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders.

The Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders is a 2-item measure that assesses the level of interference in functioning and support required as a result of difficulties in 1) SOCIAL COMMUNICATION and 2) RESTRICTED INTERESTS and REPETITIVE BEHAVIORS that are present for the individual being assessed.

The measure is completed by the researcher at the time of the clinical assessment. The researcher is asked to rate the level of interference and support required in functioning due to difficulties in each domain as experienced by the individual during the past seven days.

3.6 Data collection procedure

Stage 1

Ethical approval was obtained from the University of Nairobi/ Kenyatta National Hospital/research and ethical review board.

A Research Permit from National Commission for Science, Technology and Innovation (NACOSTI) was taken to the county education offices to inform them of the intended research. A copy of the Research permit and a letter of transmittal were presented to the schools administration on confirmation of appointment to sort permission to be allowed access the participants while in school.

Stage 2

Approval was sought from the head teachers to interact with parents and teachers. A list of parents of persons with intellectual disabilities was sought from the school administration. Data collection was carried out in the school hall on closing day when parents came to collect their children from school.Also the whole week of official opening of the school term when parents brought their children to school, on the third, fifth and last week of the school terms when parents had their meetings in the schools to ease getting consent from parents and also saving them on time and money.

Purpose of study was explained to parents/guardians, caregiver teachers and the participants. Assurance of confidentiality was done, thereafter parents were allowed to ask questions.

Parent's consent forms, teacher's consent forms, children's assent forms and the socio-demographic questionnaire were presented to the parents, teachers and the children. Those who declined to sign the consent and assent forms were excluded from the study at that point.

Parents who required help in completing the socio-demographic questionnaire were assisted by the researcher who read out the questions to them.

Completed consent, assent forms and the socio-demographic questionnaires were collected by the researcher.

Each person was then assessed by the researcher in the presence of the parent/guardian and the teacher using the APA_DSM5_Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders. Psychological support was provided to any participant who experienced emotional distress. There was no serious self- injurious behavior and discovery of a new illness in the respondents, psycho-education was provided to parents/guardians.

There was no referral to Moi Teaching and Referral hospital in Eldoret for further psychiatric and psychological management. Completed APA_DSM5_Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders forms were collected by the researcher. The respondents were given snacks. The researcher thanked each participant in the study and ended the meeting. Data was entered into a data base.

3.7 Ethical consideration

The proposal was sent to the KNH/UON research and ethics committee for approval. The informed consent explanation will include an explanation of the purpose of the research and risks involved, namely invasion of personal and family life on questions related to autism and intellectual disability. A research permit from (National Commission for Science, Technology and Innovation) NACOSTI and a transmittal letter to the principal of the special school was processed.

Benefits: The results of the study will increase knowledge and awareness of ASD, encourage early detection, diagnosis and effective evidence based interventions, family support, access to health care as early as possible and access to special education as needed which will Increase the likelihood of assisting children with ASD to reach their full potential throughout their lifespan and having improved long-term outcomes.

Risk/discomfort: Researcher recognized that some of the questions especially those regarding the child's illness may have caused the parent, teacher and child to experience distress and discomfort and may have made one to remember painful experiences and also there may have been a risk of discovering a new illness.

In the event that a new illness was discovered, the researcher is a trained psychologists and was able to provide supportive therapy to any of the study participants who became distressed during the study process.

Researcher recognized that the study was conducted on a vulnerable population. The researcher ensured that the participation of the children was voluntary, there was no coercion and the decision of the children and parents was respected.

Privacy and confidentiality: Privacy and confidentiality was maintained throughout the study whether on a one on one basis with individual pupils, teachers or parents/guardians. Participants were assured that the assessments and deliberations discussed during the study remained private and confidential.

The results of the assessments done on the child, and what was talked about was kept private to the extent allowed by law. To protect participant's privacy, researcher kept the records under a code number and not the name of the child. Researcher kept the records in a safe place under lock and key.

Reimbursement: There was no reimbursement to the parents/guardians and Caregiver teachers. The children were given a snack after assessment.

Referral: For a child who met the criteria of ASD the researcher is a trained psychologist and therefore provided psycho-education to the parents/guardians and caregiver teachers. In the event that a new illness was discovered and the child displayed serious self- injurious behavior the parents/guardians were advised to seek further psychiatric and psychological management from Moi teaching and referral hospital Eldoret.

Voluntary participation: Participation was voluntary, those who refused to participate were not penalized and did not lose benefits to which they were otherwise entitled and that the subject could discontinue participating in the study any time without penalty or loss of benefits.

3.8 Data management

All assessment and interview files were given a code. Socio-demographic data and assessment results were entered directly into SPSS version 20 for descriptive statistical analysis. The descriptive statistics included calculations of means, median and percentages.

Further inferential statistics included T test, Spearman correlates for continuous variables and Chi Square for categorical variables which were used to ascertain the Correlation and significant difference between the social demographic factors and autism spectrum disorder symptom variables. The distribution in different categories was presented using frequency tables and pie charts.

CHAPTER 4: RESULTS

4.1 Introduction

The study involved 115 respondents aged 6-29 years with their caregivers.Aresearcher designed socio-demographic questionnaire was used to collect data on the Age of the respondent, Gender of the respondent, Problems reported by the caregiver, Caregiver gender, Age of the caregiver, Person living with the respondent when out of school, Siblings, Sibling with intellectual disability, Children from the same father, Orphan-hood status, Marital status of parents, Highest level of education of the parents and Monthly income in Kenya shillings (Table 1,2,3,4 and 5 and Figure 1,2 and 3).

Comorbid ASD in respondents with ID was the main study outcome and it was assessed using Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders which was used to collect data on the level of interference in functioning and support required as a result of SOCIAL COMMUNICATION deficits for the respondent and the level of interference in functioning and support required as a result of RESTRICTED INTERESTS and REPETITIVE BEHAVIORS for the respondent (Table 6 and 7 and Figure 4, 5, 6, 7 and 8).

4.2 Socio-demographic characteristics

Variable	**Category**	**Overall (N=115)** n(%)	**Males (n=53)** n(%)	**Females (n=62)** n(%)
Age of the respondent	Mean; Median; Range	12.5; 12.0; 6-28	12.7; 12.0; 6-28	12.29; 12.0; 6-28
Problem reported by the caregiver	Behavioral	84(73.0)	39(69.6)	45(76.3)
	Cognitive / learning	115(100.0)	56(100.0)	59(100.0)
	Poor communication	101(87.8)	48(85.7)	53(89.8)
	Lack of independence	35(30.4)	22(39.3)	13(22.0)
Caregiver gender	Male	53(46.1)	28(50.0)	25(42.4)
	Female	62(53.9)	28(50.0)	34(57.6)
Age of caregiver	18-30	26(22.6)	12(21.4)	14(23.7)
	31-40	45(39.1)	25(44.6)	20(33.9)
	41-50	25(21.7)	9(16.1)	16(27.1)
	Above 50	19(16.5)	10(17.9)	9(15.3)
Person living with the respondent when out of school	Parents	80(69.6)	38(67.9)	42(71.2)
	Grand Parents	25(21.7)	13(23.2)	12(20.3)
	Others	10(8.7)	5(8.9)	5(8.5)
Siblings	No	16(13.9)	9(16.1)	7(11.9)
	Yes	99(86.1)	47(83.9)	52(88.1)
Sibling with intellectual disability (N=99)	No	85(85.9)	40(85.1)	45(86.5)
	Yes	14(14.1)	7(14.9)	7(13.5)
Children from same father	Yes	81(81.8)	36(76.6)	45(86.5)
	No	18(18.2)	11(23.4)	7(13.5)

Orphan hood status	Both Alive	79(68.7)	37(66.1)	42(71.2)
	One Deceased	23(20.0)	11(19.6)	12(20.3)
	Both Deceased	13(11.3)	8(14.3)	5(8.5)
Marital status of parents	Married	66(64.7)	31(64.6)	35(64.8)
	Lives alone	36(35.3)	17(35.4)	19(35.2)
Highest level of education of the caregiver	Primary	33(28.7)	19(33.9)	14(23.7)
	Secondary	41(35.7)	21(37.5)	20(33.9)
	Tertiary	39(33.9)	14(25.0)	25(42.4)
	Missing	2(1.7)	2(3.6)	0(0)
Monthly income in Kshs.	Less than 10,000Ksh	60(52.2)	33(58.9)	27(45.8)
	10,001-30,000Ksh	30(26.1)	14(25.0)	16(27.1)
	Above 30,000	23(20.0)	8(14.3)	15(25.4)
	Missing	2(1.7)	1(1.8)	1(1.7)

Table 1: ***Socio-Demographic Characteristics of the Respondents and their Caregivers by respondent's gender***

Majority of the caregivers were female (53.9%). Most of the respondents (69.6%) lived with their parents when out of school, 21.7% lived with their grandparents while the rest lived with relatives and well-wishers. Most of the respondents (86.1%) had siblings of which about 14.1% had intellectual disability and most (81.8%) siblings were from the same father. More than half of the respondents (68.7%) had both parents, with 20% having one of the parent's deceased while 11.3% were orphaned. Most (64%) of the respondents had parents who were married while the rest were either single/divorced/separated or widowed. More than half of the caregivers (52.2%) were earning a monthly income of less than 10,000Ksh, 26% earning between 10,000-30,000Ksh, while 20% earning above 30,000Ksh.In terms of level of education of the caregivers (34%) had tertiary level of education, 35.7% secondary and 28.7% primary education. Age-wise, majority of the caregivers were aged 31-40 years (39%), 41-50 years (21.7%); 18-30 years (22.6%) and above 50 (16.5%).

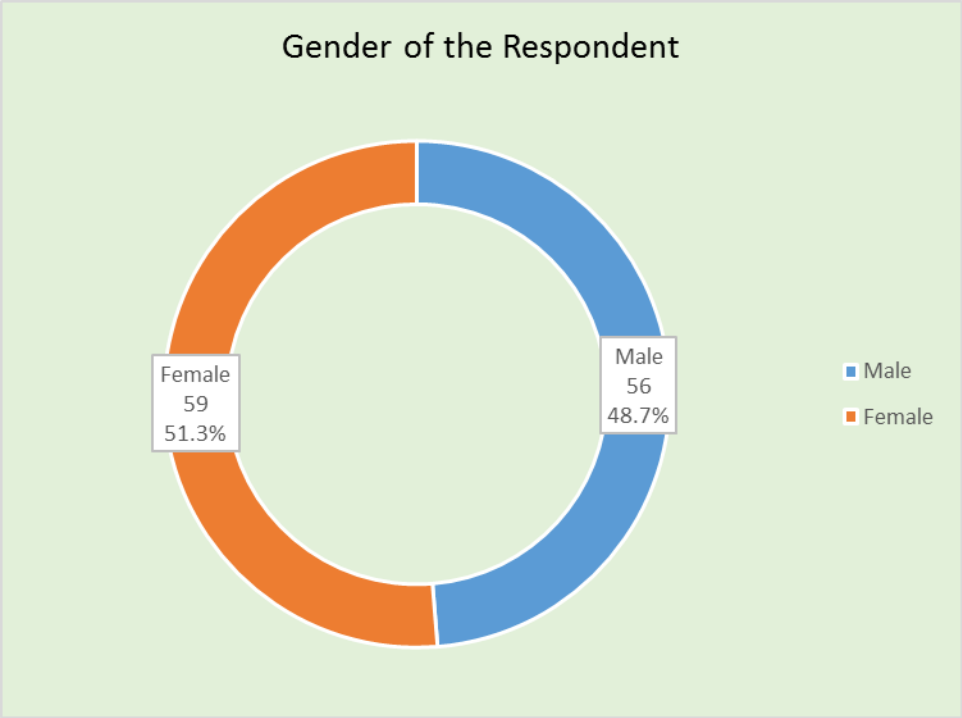

Figure 1: ***Gender of the respondents***

The population sample included 56 male respondents and 59 female respondents. The proportion of female respondents 51.3% was higher as compared to the male proportion (48.7%).

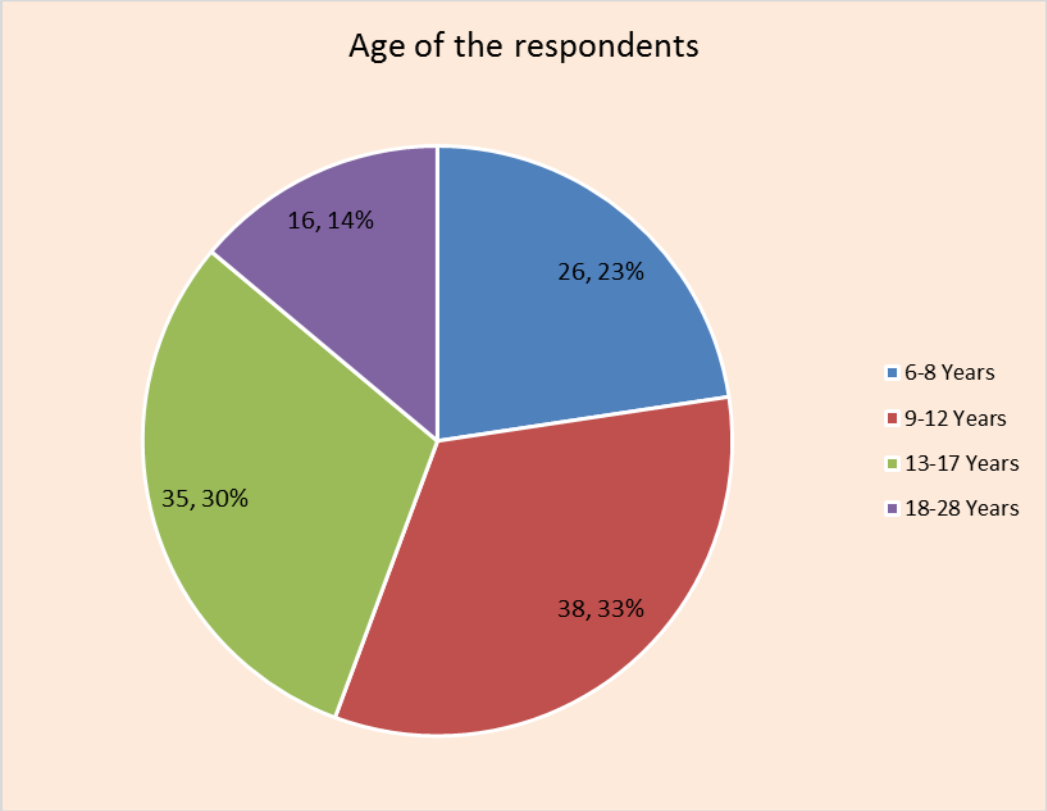

Figure 2: ***Age of the respondents***

Twenty six point twenty three percent(26.23% were respondents aged 6-8 years, 38.33% aged 9-2 years, 35.30% aged 13-17 years and 16.14% aged 18-28 years of age. The mean age of the respondents screened was 12.5, median 12 and ranged from 6-28 years. The mean age of males was higher (12.7) as compared to females (12.3).

4.3 Problems reported by the caregivers

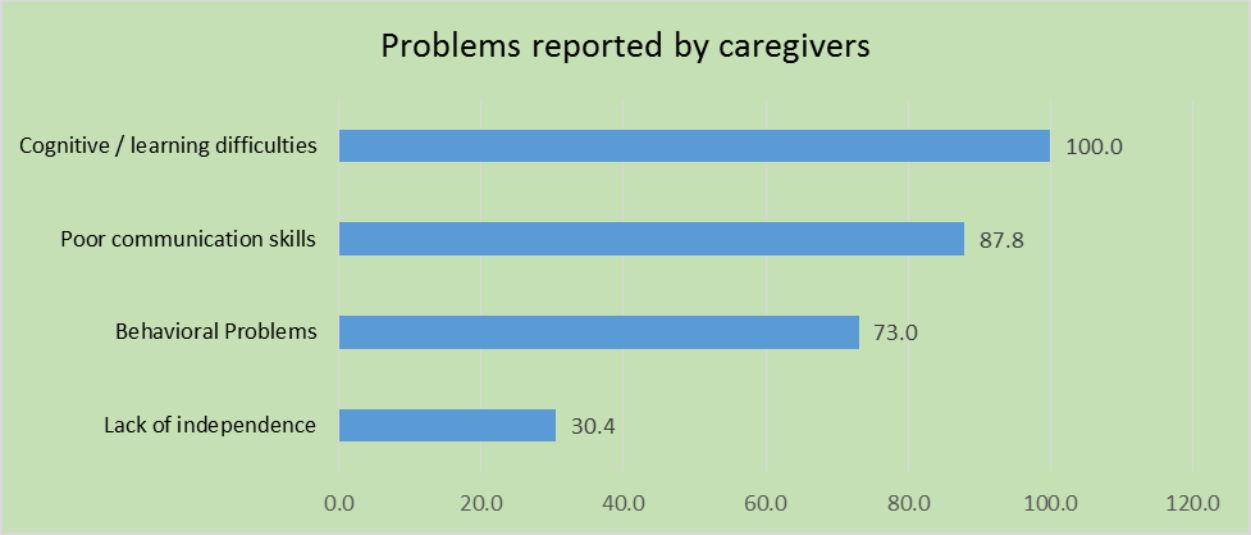

Figure 3: ***Problems reported by caregivers***

With regards to problems reported by the caregivers (Figure 3) 73% reported behavioral problems with a higher percentage of (76.3%) among the females as compared to 69.6% among the males. All of the caregivers (100%) reported cognitive/learning problems.

About 85.7% reported poor communication overall, males 85.7% and females 89.8%. Lack of independence was the least reported behavior with 30.4% overall, 39.3% males and 22.0% females.

Binary Logistic Regression analysis of respondents by the problems reported by their caregivers

Parameter	Category	Behavioral problems		O.R(95%C.I)	P-Value
		No (n=31)	Yes (n=84)		
Gender	Male	17(30.4)	39(69.6)	Ref.	
	Female	14(23.7)	45(76.3)	1.40(0.61-3.20)	0.4242
Age of the respondent	6-8 Years	10(38.5)	16(61.5)	Ref.	
	9-12 Years	3(7.9)	35(92.1)	7.29(1.76-30.15)	**0.0061**
	13-17 Years	12(34.3)	23(65.7)	1.20(0.42-3.44)	0.7371
	18-28 Years	6(37.5)	10(62.5)	1.04(0.29-3.76)	0.9503

Table 2: ***Behavioral problems***

Thirty nine male and 45 female respondents were reported to have a behavioral problem. The proportion of female respondents was higher (76.3%) as compared to male respondents (69.6%). Of the reported 84 respondents, 16 (61.5%) aged 6-8 years, 35 (92.1%) aged 9-12 years, 23 (65.7%) aged 13-17 years and 10 (62.5%) aged 18-28 years had a behavioural problem. A higher proportion of 92.1% was reported in respondents aged 9-12 years.

Parameter	Category	Cognitive / learning		O.R(95%C.I)	P-Value
		No (n=115)	Yes (n=0)		
Gender	Male	0(0.0)	56(100.0)	-	-
	Female	0(0.0)	59(100.0)	-	-
Age of the respondent	6-8 Years	0(0.0)	26(100.0)	-	-
	9-12 Years	0(0.0)	38(100.0)	-	-
	13-17 Years	0(0.0)	35(100.0)	-	-
	18-28 Years	0(0.0)	16(100.0)	-	-

Table 3: ***Cognitive/learning problem***

With regards to cognitive/learning problem 56 male and 59 female respondents were reported to have a cognitive/learning problem. All the respondents 100% were reported to have a cognitive/learning problem.

Parameter	Category	Poor communication skills		O.R(95%C.I)	P-Value
		No (n=14)	Yes (n=101)		
Gender	Male	8(14.3)	48(85.7)	Ref.	
	Female	6(10.2)	53(89.8)	1.47(0.48-4.55)	0.5017
Age of the respondent	6-8 Years	6(23.1)	20(76.9)	Ref.	
	9-12 Years	1(2.6)	37(97.4)	11.10(1.25-98.76)	**0.0309**
	13-17 Years	5(14.3)	30(85.7)	1.80(0.48-6.70)	0.3809
	18-28 Years	2(12.5)	14(87.5)	2.10(0.37-11.96)	0.4033

Table 4: ***Poor communication skills***

Forty eight male and 53 female respondents were reported to have poor communication skills. The proportion of females was higher (89.8%) as compared to male (85.7%) respondents. Of the reported 101 respondents, 20 (76.9%) aged 6-8 years, 37 (97.4%) aged 9-12 years, 30 (85.7%) aged 13-17 years and 14 (87.5%) aged 18-28 years had a poor communication problem. A higher proportion of 97.4% was reported in respondents aged 9-12 years.

Parameter	Category	Lack of independence		O.R(95%C.I)	P-Value
		No (n=80)	Yes (n=35)		
Gender	Male	34(60.7)	22(39.3)	Ref.	
	Female	46(78.0)	13(22.0)	0.44(0.19-0.99)	**0.0467**
Age of the respondent	6-8 Years	23(88.5)	3(11.5)	Ref.	
	9-12 Years	27(71.1)	11(28.9)	3.12(0.78-12.57)	0.1089
	13-17 Years	23(65.7)	12(34.3)	4.00(1.00-16.07)	**0.0508**
	18-28 Years	7(43.8)	9(56.3)	9.86(2.08-46.75)	**0.0040**

Table 5: ***Lack of independence***

Twenty two male and 13 female respondents were reported to lack independence. The proportion of male was higher (39.3%) as compared to female (22.0%).Of the reported 35 respondents, 3 (11.5%) aged 6-8 years, 11 (28.9%) aged 9-12 years, 12 (34.3%) aged 13-17 years and 9 (56.3%) aged 18-28 years had lack of independence. A higher proportion of 56.3% was reported in respondents aged 18-28 years.

4.4 Prevalence of ASD with ID Disaggregated by their socio-demographic characteristics

Variable	**Category**	**Children Diagnosed as ASD with ID**		**ID**		**Total**
		n(%)	95% C.I	n(%)	95% C.I	n(%)
Overall	**Overall**	**30(26.1)**	**(18.3-34.8)**	**85(73.9)**	**(65.2-81.7)**	**115(100)**
Gender of the	Male	16(53.3)	(36.7-70.0)	40(47.1)	(36.5-57.6)	56(48.7)
respondent	Female	14(46.7)	(30.0-63.3)	45(52.9)	(42.4-63.5)	59(51.3)
Age of the respondent	6-8 Years	4(15.4)	(3.8-30.8)	22(84.6)	(69.2-96.2)	26(22.6)
	9-12 Years	12(31.6)	(18.4-44.7)	26(68.4)	(55.3-81.6)	38(33.1)
	13-17 Years	10(28.6)	(14.3-45.7)	25(71.4)	(54.3-85.7)	35(30.4)
	18-28 Years	4(25.0)	(6.3-43.8)	12(75.0)	(56.3-93.8)	16(13.9)
Caregiver gender	Male	11(36.7)	(20.0-53.3)	42(49.4)	(40.0-60.0)	53(46.1)
	Female	19(63.3)	(46.7-80.0)	43(50.6)	(40.0-60.0)	62(53.9)
Age of caregiver	18-30	7(23.3)	(10.0-40.0)	19(22.4)	(14.1-32.9)	26(22.6)
	31-40	12(40.0)	(23.3-56.7)	33(38.8)	(29.4-49.4)	45(39.1)
	41-50	7(23.3)	(10.0-40.0)	18(21.2)	(12.9-30.6)	25(21.7)
	Above 50	4(13.3)	(3.3-26.7)	15(17.6)	(9.4-25.9)	19(16.5)
Person living with the	Parents	22(73.3)	(56.7-86.7)	58(68.2)	(57.6-78.8)	80(69.6)
respondent when out	Grand Parents	4(13.3)	(3.3-26.7)	21(24.7)	(15.3-34.1)	25(21.7)
of school	Others	4(13.3)	(3.3-26.7)	6(7.1)	(2.4-12.9)	10(8.7)
Siblings	No	5(16.7)	(3.4-30.0)	11(12.9)	(7.1-21.2)	16(13.9)
	Yes	25(83.3)	(70.0-96.6)	74(87.1)	(78.8-92.9)	99(86.1)
Sibling with	No	22(88.0)	(76.0-100.0)	63(85.1)	(77.0-93.2)	85(85.9)
intellectual disability	Yes	3(12.0)	(0.0-24.0)	11(14.9)	(6.8-23.0)	14(14.1)
(N=99)						

Children from same	Yes	20(80.0)	(64.0-96.0)	61(82.4)	(73.0-90.5)	81(81.8)
father	No	5(20.0)	(4.0-36.0)	13(17.6)	(9.5-27.0)	18(18.2)
Orphan hood status	Both Alive	21(70.0)	(53.3-86.7)	58(68.2)	(58.8-77.6)	79(68.7)
	One Deceased	6(20.0)	(6.7-33.3)	17(20.0)	(11.8-29.4)	23(20.0)
	Both Deceased	3(10.0)	(0.0-23.2)	10(11.8)	(4.7-20.0)	13(11.3)
Marital status of	Married	15(55.6)	(37.0-74.1)	51(68.0)	(57.3-77.3)	66(64.7)
parents	Lives alone	12(44.4)	(25.9-63.0)	24(32.0)	(22.7-42.7)	36(35.3)
Highest level of	Primary	11(37.9)	(20.7-55.2)	22(26.2)	(16.7-35.7)	33(28.7)
education of the	Secondary	11(37.9)	(20.7-55.2)	30(35.7)	(25.0-46.4)	41(35.7)
caregiver	Tertiary	7(24.1)	(10.3-37.9)	32(38.1)	(27.4-48.8)	39(33.9)
Monthly income in	Less than 10,000Ksh	14(48.3)	(31.0-65.5)	46(54.8)	(45.2-65.5)	60(52.2)
Kshs.	10,001-30,000Ksh	11(37.9)	(20.7-55.2)	19(22.6)	(14.3-32.1)	30(26.1)
	Above 30,000	4(13.8)	(3.4-27.6)	19(22.6)	(13.1-32.1)	23(20.0)

Table 6: ***Confirmed cases of ASD with ID Overall by their Socio-demographic characteristics***

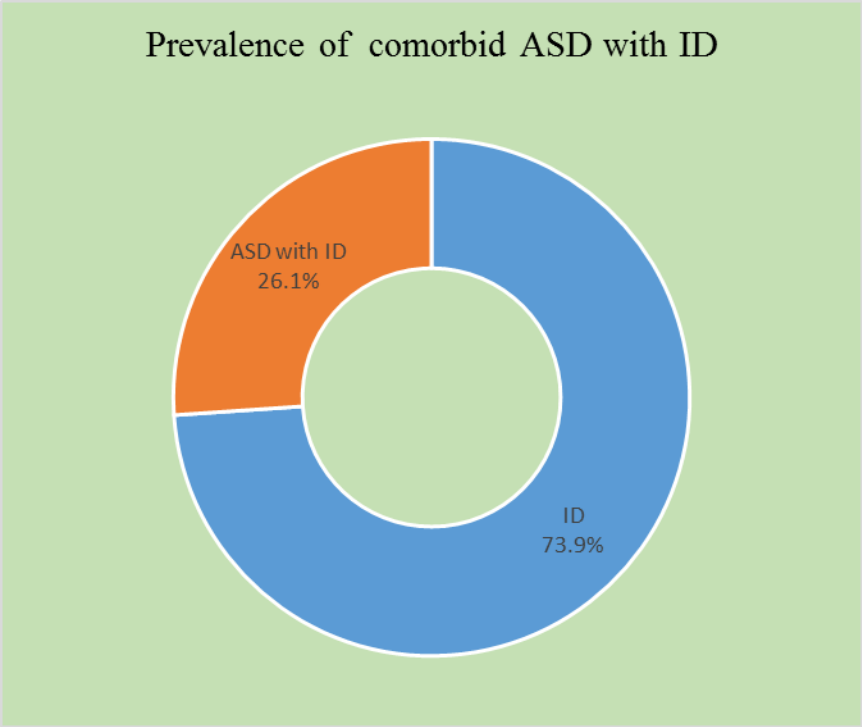

Figure 4: ***Prevalence of comorbid ASD with ID***

After evaluation in the selected schools, 30 out of a total of 115 respondents in the age group of 6-28 were diagnosed as cases of ASD yielding a prevalence of 26.1% 95% C.I (18.3-34.8). (Table 6, Figure 4).

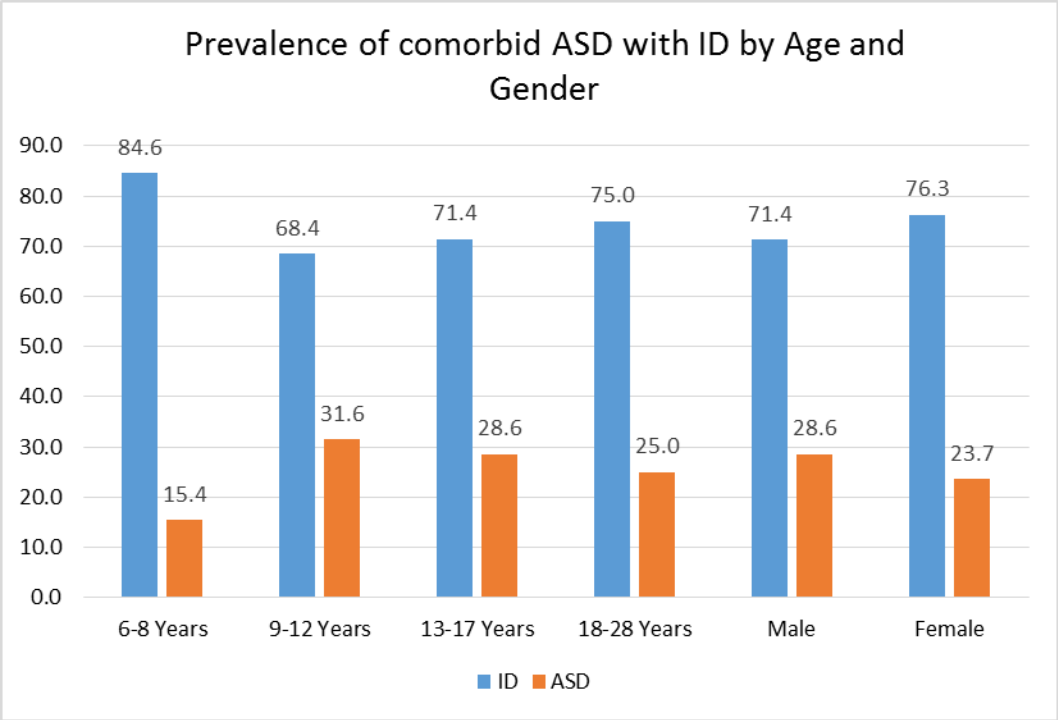

Figure 5: ***Prevalence of comorbid ASD with ID by Age and Gender***

Majority of these 30 diagnosed of comorbid ASD with ID (28.6%; 16/56) were male and (23.7%; 14/59) were female, a male to female ratio of 1.14: 1. Respondents aged 6-8 (15.4%), 9-12 (31.6%), 13-17 (28.6%) and 18-28 (25.0%) were identified as cases of comorbid ASD with ID. A higher proportion was observed in respondents age 9-12 (31.6%) (Figure 5).

4.5 Factors associated with comorbid ASD with ID

Logistic regression models were run with respondents diagnosed with comorbid ASD with ID as dependent variable and gender, age, caregiver characteristics as independent variables (Table 7).

Variable	Category	ASD with ID	ID	Total	O.R (95% C.I)	P-Value
		n(%)	n(%)	n(%)		
Gender of the	Male	16(28.6)	40(71.4)	56(100)	1.29(0.56-2.96)	0.555
Respondent	Female	14(23.7)	45(76.3)	59(100)	Ref.	
Age of the	6-8 Years	4(15.4)	22(84.6)	26(100)	Ref.	
Respondent	9-12 Years	12(31.6)	26(68.4)	38(100)	2.54(0.72-9.00)	2.54
	13-17 Years	10(28.6)	25(71.4)	35(100)	2.20(0.60-8.02)	2.20
	18-28 Years	4(25.0)	12(75.0)	16(100)	1.83(0.39-8.67)	1.83
Caregiver gender	Male	11(20.8)	42(79.2)	53(100)	Ref.	
	Female	19(30.6)	43(69.4)	62(100)	1.69(0.72-3.97)	0.231
Age of Caregiver	18-30	7(26.9)	19(73.1)	26(100)	1.38(0.34-5.62)	0.652
	31-40	12(26.7)	33(73.3)	45(100)	1.36(0.38-4.93)	0.636
	41-50	7(28.0)	18(72.0)	25(100)	1.46(0.36-5.95)	0.599
	Above 50	4(21.1)	15(78.9)	19(100)	Ref.	
Person living	Parents	22(27.5)	58(72.5)	80(100)	Ref.	
with the	Grand Parents	4(16.0)	21(84.0)	25(100)	0.50(0.15-1.63)	0.251
respondent when	Others	4(40.0)	6(60.0)	10(100)	1.76(0.45-6.83)	0.415
out of school						
Siblings	No	5(31.3)	11(68.8)	16(100)	1.35(0.43-4.25)	0.613
	Yes	25(25.3)	74(74.7)	99(100)	Ref.	
Sibling with	No	22(25.9)	63(74.1)	85(100)	1.28(0.33-5.02)	0.723
Intellectual	Yes	3(21.4)	11(78.6)	14(100)	Ref.	
disability (N=99)						
Children from	Yes	20(24.7)	61(75.3)	81(100)	Ref.	
same father	No	5(27.8)	13(72.2)	18(100)	1.17(0.37-3.70)	0.785
Orphan hood	Both Alive	21(26.6)	58(73.4)	79(100)	1.21(0.30-4.81)	0.790
status	One Deceased	6(26.1)	17(73.9)	23(100)	1.18(0.24-5.77)	0.841
	Both Deceased	3(23.1)	10(76.9)	13(100)	Ref.	
Marital status of	Married	15(22.7)	51(77.3)	66(100)	Ref.	
parents	Lives alone	12(33.3)	24(66.7)	36(100)	1.70(0.69-4.19)	0.248

Highest level of education of the caregiver	Primary	11(33.3)	22(66.7)	33(100)	2.29(0.77-6.81)	0.138
	Secondary	11(26.8)	30(73.2)	41(100)	1.68(0.57-4.89)	0.344
	Tertiary	7(17.9)	32(82.1)	39(100)	Ref.	
Monthly income in Kshs.	Less than 10,000Ksh	14(23.3)	46(76.7)	60(100)	Ref.	
	10,001-30,000Ksh	11(36.7)	19(63.3)	30(100)	1.90(0.73-4.94)	0.186
	Above 30,000	4(17.4)	19(82.6)	23(100)	0.69(0.20-2.37)	0.558

Note: O.R-Odds Ratio; C.I-Confidence interval; Ref.-Reference Category

Table 7: ***Binary Logistic Regression analysis of respondents diagnosed with ASD with ID.***

The researcher found no statistically significant association between comorbid ASD with ID and socio-demographic characteristics in all the factors (P>0.05). However male sex had a 29% higher chance of getting diagnosed with comorbid ASD with ID as compared to female sex who had a 24% (O.R. 1.29; 95%C.I 0.56-2.96; P=0.555). Respondents aged (9-12 years) had a 31.6% higher chance of being diagnosed with comorbid ASD with ID as compared to the other age groups who had 15.4% (6-8 years), 28.6% (13-17 years) and 25.0% (18-28 years) respectively.

4.6 Responses to Clinician-rated severity of autism spectrum and social communication disorders

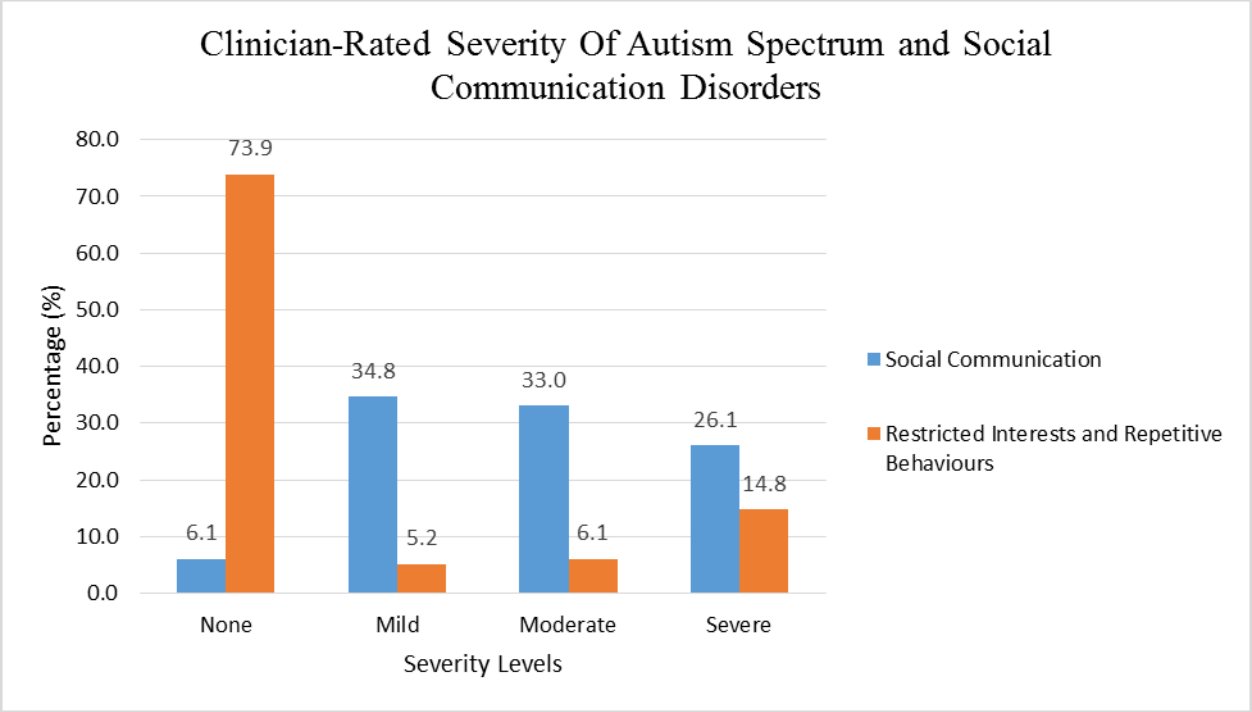

Figure 6: ***Clinician-rated severity of autism spectrum and social communication disorders***

The responses to a two item Clinician-rated severity of autism spectrum and social communication disorders are presented in Figure 6. 6.1 %; 34.8%; 33.0% and 26.1% scored in the None, Mild Moderate and severe categories respectively for the social communication scale. While 73.9%; 5.2%; 6.1% and 14.8% scored in the None, Mild Moderate and severe categories respectively for the restricted interests and repetitive behaviors scale.

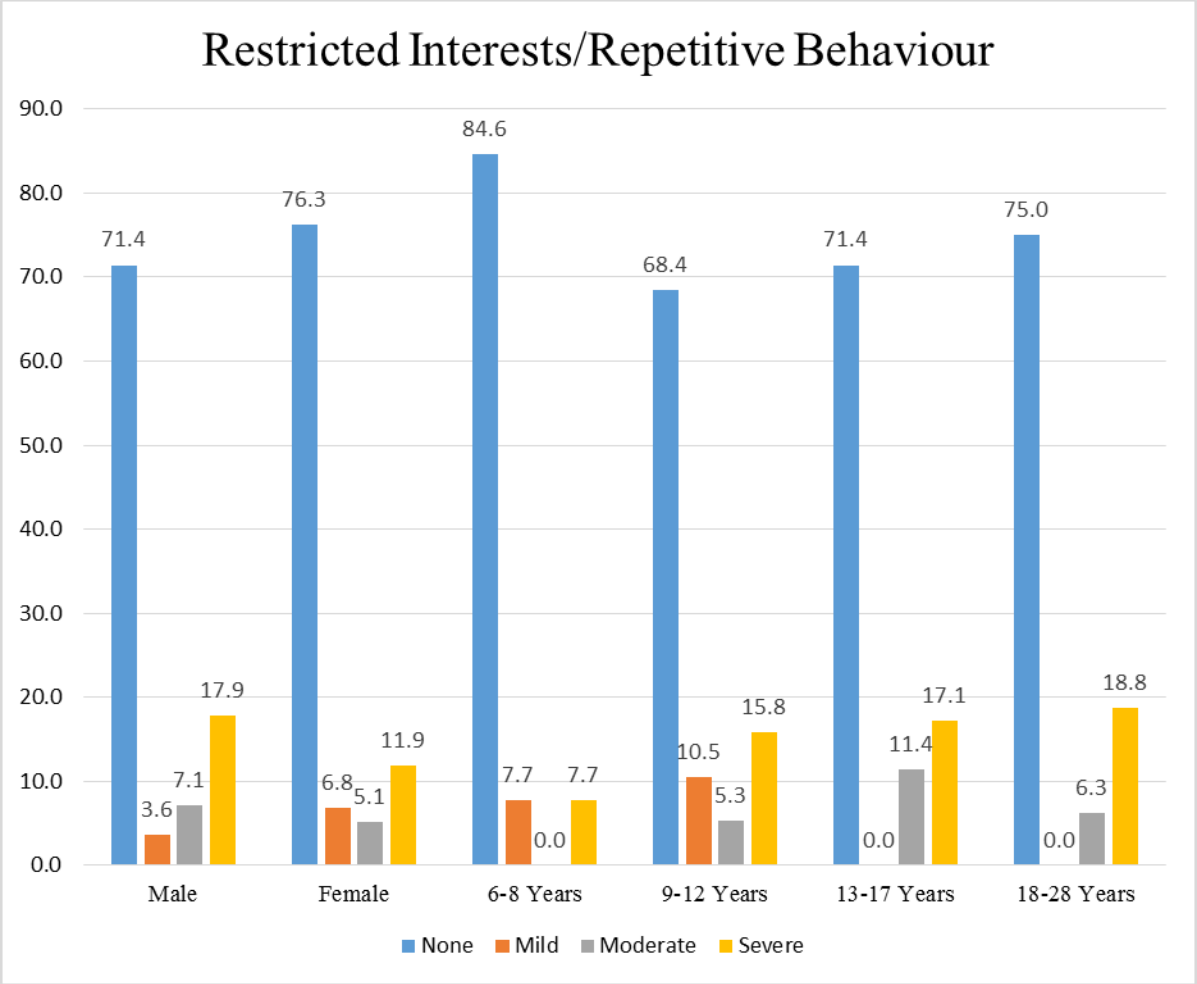

Figure 7: ***Restricted interests/repetitive behaviour***

In the restricted interests/repetitive behaviours respondents aged 6-8 years scored 84.6%, 7.7%, 0.0% and 7.7% in the None, Mild, Moderate and Severe categories respectively. Respondents aged 9-12 years scored 68.4%, 10.5%, 5.3% and 15.8% in the None, Mild, Moderate and Severe categories respectively. Respondents aged 13-17 years scored 71.4%, 0.0%, 11.4% and 17.1% in the None, Mild, Moderate and Severe categories respectively.

Respondents aged 18-28 years scored 75.0%, 0.0%, 6.3% and 18.8% in the None, Mild, Moderate and Severe categories respectively. Older respondents (18-28 years) had the highest score 18.8% in the severe category.

The male respondents scored 71.4%, 3.6%, 7.1% and 17.9% in the None, Mild, Moderate and Severe categories respectively while the female respondents scored 76.3%, 6.8%, 5.1% and 11.9% in the None, Mild, Moderate and Severe categories respectively. The male respondents had the highest score 17.9% in the severe category.

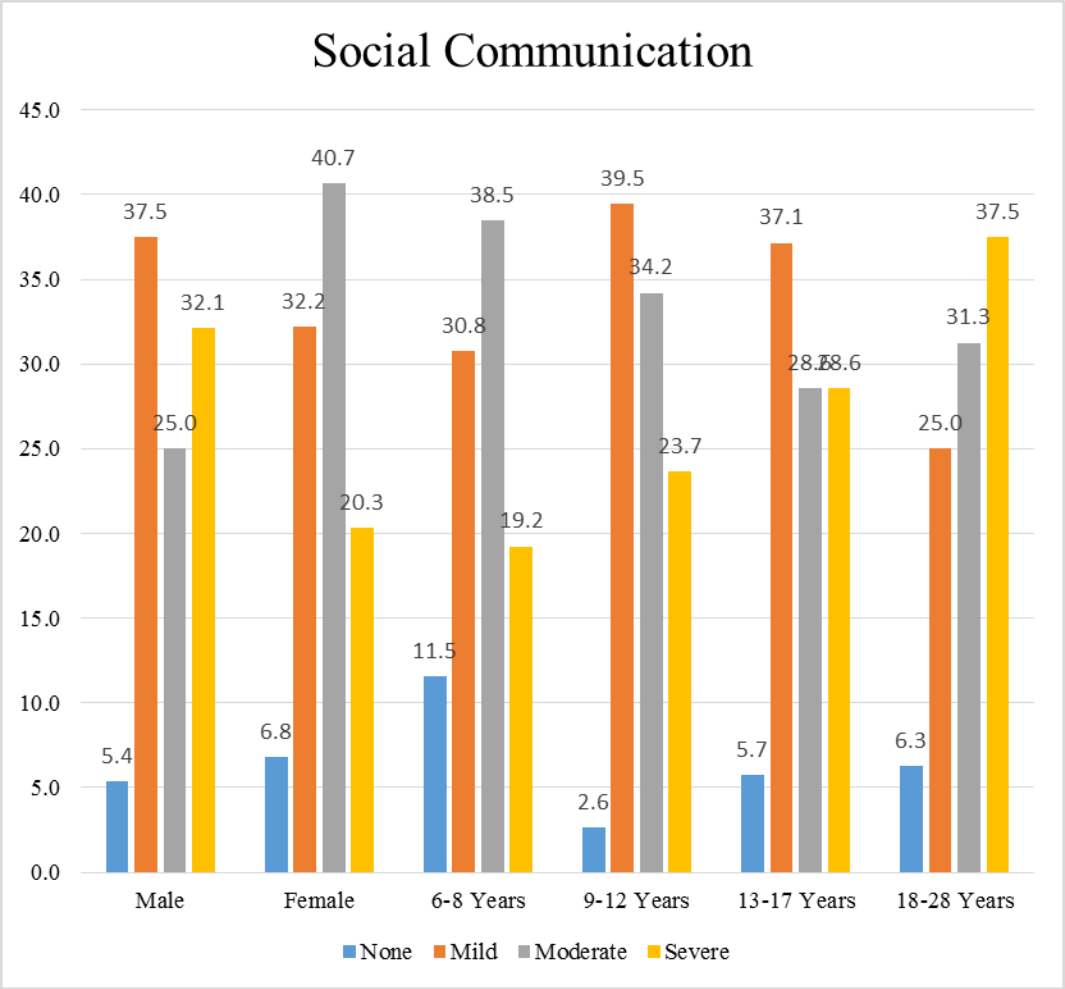

Figure 8: ***Social communication***

In the social communication respondents aged (6-8 years) scored 11.5%, 30.8%, 38.5% and 19.2% in the None, Mild, Moderate and Severe categories respectively.

Respondents (9-12 years) had 2.6%, 39.5%, 34.2% and 23.7% in the None, Mild, Moderate and Severe categories respectively. Respondents aged (13-17 years) scored 5.7%, 37.1%, 28.6% and 28.6% in the None, Mild, Moderate and Severe categories respectively.

Respondents aged (18-28 years) scored 6.3%, 25.0%, 31.3% and 37.5% in the None, Mild, Moderate and Severe categories respectively. The older respondents aged (18-28 years) scored the highest 37.5% in the severe category.

The male respondents scored 5.4%, 37.5%, 25.0% and 32.1% in the None, Mild, Moderate and Severe categories respectively while the female respondents scored 6.8%, 32.2%, 40.7% and 20.3% in the None, Mild, Moderate and Severe categories respectively**.** The male respondents scored higher 32.1% in the severe category.

CHAPTER 5: DISCUSSION, LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Discussion

Presence of autism spectrum disorder in persons with intellectual disability cannot be overlooked. The finding in the study population among 115 persons with intellectual disability was that the prevalence of ASD was (26.1%). Higher prevalence of autism spectrum disorder in persons with intellectual disability may be due to neurodevelopmental cause.

In a study of 156 children with intellectual disability 37 were found to have autism spectrum disorder with a prevalence rate of 23.6% (Ramanujam, Abdulrahuman & Nagendran, 2016). In a study of 154 adolescents with intellectual disability 43 were found to have autism with a prevalence of 27.9% (Bryson, et al. 2008).

In a study of 166 Italian people with ID the prevalence of PDD in this population was found to be 39.2% (La Malfa, et al. 2004). In another study the percentage of autism spectrum disorder in children with intellectual disability was slightly low 11.4 % (Bakare, Ebigbo & Ubochi, 2012).

In the current study more male than female had autism spectrum disorder at a ratio of 1.14:1 which agrees with the other studies with male: female ratio of 3.1:1 (Ramanujam, et al, 2016), 4:1 (Bakare, et al, 2012) and 2.3:1 (Bryson, et al. 2008). This bias towards male sex may be biological but also may be due to ascertainment bias. ASDs affect females less frequently than males, and several sex-differential genetic and hormonal factors may contribute (Werling, Geschwind & Daniel, 2013).

The study demonstrated that the prevalence rates vary by age with a higher proportion of persons aged 9-12 years having a prevalence of 31.6% followed by those aged 13-17 years with a prevalence of 28.6%, 18-28 years with a prevalence of 25.0% and the lowest proportion observed in younger persons aged 6-8 years with a prevalence of 15.4%. In a study by Ramanujam, Abdulrahuman and Nagendran (2016) more prevalence was seen in the age group of 11-12 years 32.4% followed by 7-8 year olds 10% and least in the age group of 3-4 year olds 2.7%.

The study also demonstrated that the severity of ASD vary by age with a higher proportion of persons aged 18-28 years having a severity rate of 18.8% in the severe category followed by those aged 13-17 years with 17.1%, 9-12 years with 15.8% and 6-8 years with 7.7% Male had a higher severity rate of 17.9% in the severe category as compared to female who rated 11.9%.

Younger children have lower prevalence and severity rates than older children since many young children may not yet have come to the attention of professionals. As the diagnosis of autism spectrum disorders is based on the presence of unusual behavioural patterns, determining prevalence and severity is challenging. There is no medical or genetic screening or diagnostic laboratory test for autism spectrum disorders, and clinicians apply clinical criteria differently to arrive at a diagnosis of autism spectrum disorders. Lack of treatment seeking behavior and lack of knowledge about the disease result in later diagnosis thus resulting in lack of early intervention for autism spectrum disorders.

Communication and restricted interests/ Repetitive/Stereotyped Patterns were useful in diagnosing ASDs in children with IDs. This concurred with a study by Sigan and Darryn (2010) in which the Communication domain, stereotyped, repetitive, or idiosyncratic language and lack of make-believe/imitative play differentiated the ASD and no-ASD groups.

The researcher found no statistically significant association between ASD and socio-demographic characteristics in all the factors. Bryson, et al. 2008 found that Socio-economic status did not distinguish the groups with and without autism.

From the current study, the presence of autism spectrum disorder in persons with intellectual disability is unquestionable. Our current education system does not consider other disorders that may co- occur with intellectual disability. There are no structures in the special schools to accommodate persons with comorbidities rather they are all considered to be intellectually disabled. It is a high time that the education system recognizes that most children with intellectual disabilities have comorbidities such as autism spectrum disorders and put structures in place for example educational intervention programs like Applied Behavioural Analysis (ABA) that are based on the principles of learning to systematically change behavior that will improve the lives of children.

5.2 Limitations

1. The strongest limitations of this study lied in the small sample size of 115. It is important to note that the participants selected for this study were drawn from a convenience sample of special schools in Busia County which is a rural area and may not reflect the general population of children with intellectual disabilities in Kenya.

2. A standardized measure for IQ assessment was not included. It was challenging to administer KABC –II to the respondents due to the non comprehension of the items used in the instrument by the respondents. It was not culture sensitive to this particular population.

3. A measure for the assessment of autism spectrum disorders (for example, Autism Diagnostic Observation Schedule ADOS or Autism Diagnostic Interview – Revised ADI-R) was not included.

4. A parent – rated measure that gives the parent the opportunity to record the observed behavior of the child was not included since the interview took place while the respondents were back in school where they board.

5.3 Conclusion

Lack of awareness and similarity in clinical presentations lead to less diagnosed cases of autism spectrum disorder. These findings emphasize the importance of identifying children with autism spectrum disorders at the earliest age so that early interventions can be made and the outcome may be more successful for such children.

There is need for more studies of autism spectrum disorders among Kenyan children. This would help in better educational policy formulation for children with autism spectrum disorder and intellectual disability in the country. Such studies would help further elucidate the inter-relationship between autism spectrum disorder and intellectual disability among Kenyan children.

5.4 Recommendations

It is important to routinely screen children with intellectual disability for autism spectrum disorder symptoms.

This will enable enable the stake holders such as schools detect earlier and put in place structures and educational intervention programs like Applied Behavioural Analysis (ABA) that are based on the principles of learning to systematically change behavior that will improve the lives of these children.

Larger populations randomly selected from a national sample may be the focus in future studies to determine with more precision the prevalence of comorbid autism spectrum disorder amomg persons with intellectual disability.

This study will serve as a reference point pending availability of large scale studies on autism spectrum disorders and intellectual disability in the country.

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APPENDICES

Appendix I: Researcher Designed Demographic Questionnaire

THE PREVALENCE OF CO-MORBID AUTISM SPECTRUM DISORDER AMONG PERSONS WITH INTELLECTUAL DISABILITY

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

1. Interviewer code:_____Child code:_____Date of interview:_____

2. What is the date of birth of your child? ……./……/……./(dd/mm/yy)

3. What is the age of your child?……../……../ (years/months)

4. What is the gender of your child?

Male [ ] Female [ ]

5. Age when you first suspected child's diagnosis_____

6. Actual age when child was diagnosed with disorder_____

7. Kind of difficulties parents face with the child

a) Behavioral [ ] b) Cognitive / learning difficulties [ ]

c) Poor communication skills [ ] d) Lack of independence [ ]

8. What is your gender ?

Male [ ] Female [ ]

9. Indicate your age in years by ticking appropriately:

a) 20 and below [ ] b) 21 – 30 [ ] c) 31 – 40 [ ]

d) 41 – 50 [ ] e) 51 – 60 [ ] f) 61 – 70 [ ]

g) Above 70 [ ]

10. Race / Ethnicity

African [ ] Asian [ ] European [ ] Arab [ ] Others [ ]

11. Who does the child live with when out of school?_____

12. How many children does the mother have? _____

13. Number of children diagnosed with Intellectual Disability (ID)?_____

14. Are the children of the same father?

Yes [ ] No [ ]

15. Are the parents alive or deceased?

Both alive [ ] One deceased [ ] Both deceased [ ]

16. Marital status

Married [ ] Separated [ ] Divorced [ ] Single [ ]

17. How long have you been married?

a) Less than a year [ ] b) 1- 5years [ ] c) 6-10 years [ ] d) 11-15 years [ ]

e) 16-20 years [ ] f) Over 20years [ ]

18. What is the highest level of your education?

a) KCPE/CPE [ ]

b) Secondary school [ ]

c) College/polytechnic [ ]

d) University [ ]

19. What is your highest professional qualification?

a) PhD [ ] b) Masters [ ] c) 1st Degree [ ]

d) Diploma [ ] e) Certificate [ ] f) Student [ ]

g) Others (Specify) _____

20. What is the scale of monthly income in Ksh.?

a) Less than 10,000 b) 10,001 – 30,000 c) 30,001 – 50,000 d) 50,001 – 70,000

e) 70,001 – 90,000 f) 90,001 – 100,000 g) Above 100,000

Appendix II: Clinician-Rated Severity of Autism Spectrum and Social Communication Disorders

THE PREVALENCE OF CO-MORBID AUTISM SPECTRUM DISORDER AMONG PERSONS WITH INTELLECTUAL DISABILITY

CLINICIAN-RATED SEVERITY OF AUTISM SPECTRUM AND SOCIAL COMMUNICATION DISORDERS

Participant Code No: _____ Age: ____ Sex: ❑ Male ❑ Female Date:_____

Instructions:

This clinician-rated severity measure is used for the assessment of the **level of interference in functioning and support required as a result of**:

a) Any social communication problems AND

b) Any restricted interests and repetitive behaviors

for the individual diagnosed with (please select [✓] the disorder that applies to the individual receiving care):

❑Autism Spectrum Disorder

OR

❑Social Communication Disorder

Based on all the information you have on the individual receiving care and using your clinical judgment, please rate (✓) the social communication problems and restricted interests and repetitive behaviors as experienced by the individual **in the past seven (7) days**.

	Level 0	**Level 1**	**Level 2**	**Level 3**
SOCIAL COMMUNICATION: Rate the level of interference in functioning and support required as a result of SOCIAL COMMUNICATION deficits for this individual.	❑ **None**	❑ **Mild** ***Requiring support*** (i.e., Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or	❑ **Moderate** ***Requiring SUBSTANTIAL support*** (i.e., Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions	❑ **Severe** ***Requiring VERY SUBSTANTIAL support*** (i.e., Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and

		unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.)	and reduced or abnormal response to social overtures from others.)	minimal response to social overtures from others.)
RESTRICTED INTERESTS and REPETITIVE BEHAVIORS: Rate the level of interference in functioning and support required as a result of RESTRICTED INTERESTS and REPETITIVE BEHAVIORS for this individual.	❑ **None**	❑ **Mild** ***Requiring support*** (i.e., Rituals and repetitive behaviors [RRBs] cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRBs or to be redirected from fixated interest.)	☐ **Moderate** ***Requiring SUBSTANTIAL support*** (i.e., RRBs and/or preoccupations and/or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRBs are interrupted; difficult to redirect from fixated interest.)	❑ **Severe** ***Requiring VERY SUBSTANTIAL support*** (i.e., Preoccupations, fixed rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.)

Appendix III: Research Permit from NACOSTI

Everlyne Mercy Khabala
P.O. Box 10732 – 00200
Nairobi

National Commission for Science, Technology and Innovation (NACOSTI)
Utalii House, 8th Floor,
P.O. Box 30623
Nairobi

Dear Sir/Madam

RE: REQUEST FOR A RESEARCH PERMIT

Iam a second year student of Msc. Clinical Psychology at the University of Nairobi at the College of Health Sciences, department of Psychiatry. I request for permission to be allowed to conduct a research on the prevalence of co-morbid autism spectrum disorder among children with intellectual disability at Nangina and Lwanya Special schools in Busia County. There are no risks involved in this study.

The results of the study will increase knowledge and awareness of ASD, encourage early detection, diagnosis and effective evidence based interventions, family support, access to health care as early as possible and access to special education as needed which will increase the likelihood of assisting children with ASD to reach their full potential throughout their lifespan and having improved long-term outcomes.

Please note that all the information provided for this study will be treated with utmost confidentiality and will be used only for the purpose of my academic research.

Your assistance will be highly appreciated.

Thank you.

Yours faithfully,

Everlyne Mercy Khabala
Email: everlyne.khabala@gmail.com
Cell phone: 0722 383 148

THIS IS TO CERTIFY THAT:
MISS. EVERLYNE MERCY KHABALA
of UNIVERSITY OF NAIROBI, 0-200 NAIROBI,has been permitted to conduct research in *Busia County*

on the topic: *THE PREVALENCE OF CO-MORBID AUTISM SPECTRUM DISORDER AMONG CHILDREN WITH INTELLECTUAL DISABILITY*

for the period ending:
5th September,2019

Permit No : NACOSTI/P/18/99951/24789
Date Of Issue : 6th September,2018
Fee Recieved :Ksh 1000

Khabala.
.....
Applicant's Signature

.....
Director General
National Commission for Science, Technology & Innovation

Appendix IV: Letter of Transmittal

Everlyne Mercy Khabala

P.O. Box 10732 – 00200

Nairobi

Dear Principal,

RE: ACADEMIC RESEARCH

Iam a second year student of Msc. Clinical Psychology at the University of Nairobi at the College of Health Sciences, department of Psychiatry. I am conducting an academic research on the prevalence of co-morbid autism spectrum disorder among children with intellectual disability in a rural setting in Kenya. I have chosen your school for the study.

I humbly request you to allow me to administer a socio-demographic questionnaire to the parents/guardians and carry out an assessment on the pupils in your school. There are no risks involved in this study. The results of the study will increase knowledge and awareness of ASD, encourage early detection, diagnosis and effective evidence based interventions, family support, access to health care as early as possible and access to special education as needed which will Increase the likelihood of assisting children with ASD to reach their full potential throughout their lifespan and having improved long-term outcomes.

Please note that all the information provided for this study will be treated with utmost confidentiality and will be used only for the purpose of my academic research.

Thank you for your cooperation.

Yours faithfully,

Everlyne Mercy Khabala

Email: everlyne.khabala@gmail.com

Cell phone: 0722 383 148

UNIVERSITY OF NAIROBI

College of Health Sciences

SCHOOL OF MEDICINE

DEPARTMENT OF PSYCHIATRY

Telegrams: "Medken" Nairobi

Kenyatta National Hospital
P.O Box 19676
NAIROBI, KENYA

Telephone: Nairobi 2723719/3
2726300 Ext. 43562
Email: dept-psychiatry@uonbi.ac.ke

May 28, 2018

Lwanya Special School
Busia

Dear Sir/Madam,

RE: LETTER OF INTRODUCTION – H56/74693/2014

The above named is a student of the University of Nairobi, School of Medicine, Department of Psychiatry. She is pursuing a Master of Science degree in Clinical Psychology.

She intends to collect data on her research entitled "The Prevalence of Co-morbid Autism Spectrum Disorder among Children with Intellectual Disability".

Kindly accord her any assistance necessary.

Thank you.

UNIVERSITY OF NAIROBI
DEPARTMENT OF PSYCHIATRY
P. O. Box 19676 - 00202 KNH
TEL: 2726300 EXT. 43562

Prof. Anne Obondo
Chairman, Dept. of Psychiatry

UNIVERSITY OF NAIROBI

College of Health Sciences

SCHOOL OF MEDICINE

DEPARTMENT OF PSYCHIATRY

Telegrams: "Medken" Nairobi

Kenyatta National Hospital
P.O Box 19676
NAIROBI, KENYA

Telephone: Nairobi 2723719/3
2726300 Ext. 43562
Email: dept-psychiatry@uonbi.ac.ke

May 28, 2018

Nangina Special School
Busia

Dear Sir/Madam,

RE: LETTER OF INTRODUCTION – H56/74693/2014

The above named is a student of the University of Nairobi, School of Medicine, Department of Psychiatry. She is pursuing a Master of Science degree in Clinical Psychology.

She intends to collect data on her research entitled "The Prevalence of Co-morbid Autism Spectrum Disorder among Children with Intellectual Disability".

Kindly accord her any assistance necessary.

Thank you.

UNIVERSITY OF NAIROBI
DEPARTMENT OF PSYCHIATRY
P. O. Box 19676 - 00202 KNH
TEL: 2726300 EXT. 43562

Prof. Anne Obondo
Chairman, Dept. of Psychiatry

Appendix V: Consent forms

CONSENT FORM FOR PARTICIPANTS IN THE STUDY OF THE PREVALENCE OF COMORBID AUTISM SPECTRUM DISORDER AMONG CHILDREN WITH INTELLECTUAL DISABILITY.

CONSENT EXPLANATION FOR PARENTS/GUARDIANS

I am a final year student of Msc. Clinical Psychology at the University of Nairobi at the College of Health Sciences, department of Psychiatry. I request to assess your child as part of this research study and use the information for research. The information I am looking for is about the illness in your child who is attending school at Nangina or Lwanya special schools. This assessment will be carried out in your presence and that of the child's teacher. Following your agreement for me to use your child in this research; you can still refuse. There will be no loss of benefits or any victimization whatsoever.

Risk/discomfort: Some of the questions especially those regarding your child's illness may cause you to experience distress and discomfort and may make you remember painful experiences and also there may be a risk of discovering a new illness. In the event that this happens the researcher is a trained psychologists and will provide supportive therapy to any of the study participants who might become distressed during the study process.

Benefits: The results of the study will increase knowledge and awareness of ASD, encourage early detection, diagnosis and effective evidence based interventions, family support, access to health care as early as possible and access to special education as needed which will increase the likelihood of assisting children with ASD to reach their full potential throughout their lifespan and having improved long-term outcomes.

Confidentiality: The results of the assessments done on the child, and what we talk about will be kept private to the extent allowed by law. To protect your privacy, I will keep the records under a code number and not your name. I will keep the records in a safe place.

Reimbursement: There is no payment for participation in this study.

Referral: If your child is observed to have serious self-injurious behaviours and also a new illness is discovered, you will be advised to go to Moi Teaching and Referral hospital for further management.

Voluntary participation: To be in this study is your choice. If you do not want me to use your child in the study, your child will still benefit from the recommendations that will be suggested. If you agree I use your child in the study but then have questions or decide you do not want to go on with it, you can withdraw. If you have questions about your rights as a participant you can call the researcher on 0722 383 148 or Ethics Research Committee secretary on 0722 392 219 or write a letter using postal address P.O. Box 20723 – 00202 Nairobi.

CONSENT FORM

Participant's Code No……..**Date**……

Parent/guardian's name:…….

Parent/guardian's statement

The above study has been explained to me and I agree to take part. If I change my mind, I understand that my child will not be victimized.

Parent/guardian's signature:……

(Or mark of consent)

Witness signature……

Investigator signature…….

Mimi ni mwanafunzi wa mwaka wa mwisho wa uzamili wa Kliniki ya Kisaikologia chuo kikuu cha Nairobi, chuo cha sayansi ya afya, idara ya Psychiatry. Naomba kutathmini mtoto wako kama sehemu ya utafiti huu na kutumia habari hii kwa utafiti. Habari ambayo natafuta ni kuhusu ugonjwa ambao uko kwa mtoto wako ambaye yuko shule maalum ya Nangina au Lwanyal. Huu utathmini utafanywa mbele yako na mbele ya mwalimu wa mtoto. kufuatia makubaliano yako kwangu kutumia mtoto wako katika utafiti huu, pia unaweza kataa. Ukikataa, hakutakuwa na kupoteza faida yeyote au uonevu wowote.

Hatari/Usumbufu: Maswali mengine kuhusu ugonjwa wa mtoto wako yanaweza sababisha dhiki na usumbufu na yanaweza kukukumbusha hisia chungu na pia kuna weza kuwa na hatari ya kugunduliwa kwa ugonjwa mpya. Ikipatikana ya kwamba mtoto wako yuko na ugonjwa mwingine mpya, mtafiti amehitimu Kisaikologia na ataweza kupeana kuunga mkono tiba kwa yeyote yule ambaye atajihisi kuwa na dhiki na usumbufu wakati wa utafiti.

Faida: Matokeo ya utafiti yataongeza maarifa na ufahamu wa (yaliyo katika wigo machafuko) ASD, kuhamasisha kutambua mapema, utambuzi na ufanisi hatua ushahidi makao, msaada wa familia, upatikanaji wa huduma za afya mapema iwezekanavyo na upatikanaji wa elimu maalum kama inahitajikaa ambayo itaongeza uwezekano wa kuwasaidia watoto waliyo katika wigo machafuko kufikia uwezo kamili maishani mwao na kuboresha matokeo ya muda mrefu.

Siri: matokeo ya tathmini kwa mtoto wako na maneno yote ambayo tutaongea, yatawekwa kisiri kwa kiasi kuruhusiwa na sheria. Kulinda faraga yako, nitaweka kumbukumbu kwenye msimbo na sio kwa jina lako. Nitaweka kumbukumbu mahali salama.

Kulipia: Hakuna malipo kwa ushiriki katika utafiti huu.

Rufaa: Ikiwa mtoto wako anaonekana kuwa na binafsi tabia za kudhuru kubwa na pia ugonjwa mpya kugunduliwa, utashauriwa kwenda kwa hospitali ya kufundisha na rufaa ya Moi Eldoret kwa udhibiti zaidi.

Ushiriki wa hiari: Kuwa kwa utafiti huu ni uwamuzi wako. Ikiwa hautaki nimtumie mtoto wako kwa utafiti huu, mtoto wako bado atafaidika na mapendekezo ambayo nitapendekeza. Ukikubali nimtumie mtoto wako kwenye utafiti huu na unamaswali au unaamua ya kwamba hautaki kuendelea kushiriki kwenye utafiti huu, unaweza kujitoa. Ikiwa una maswali kuhusu haki zako kama mshiriki unaweza kupigia mtafiti simu kwa nambari 0722383148 au Katibu wa Ethics Research Committee kwa nambari 0722 392 219 au uandike barua na kutuma kwa sanduku la posta P.O. Box 20723 – 00202 Nairobi.

FOMU YA RIDHAA

Mshiriki Msimbo ……..Tarehe……

Jina la Mzazi/mlezi……..

Kauli ya mzazi/mlezi

Utafiti juu umeelezwa kwangu na ninakubali kushiriki. Nikibadilisha akili yangu, naelewa ya kwamba mtoto wangu hataonewa.

Sahihi ya mzazi/mlezi:…….

(Au alama ya ridhaa)

Sahihi ya shahidi……..

Sahihi ya mtafiti……...

CONSENT FORM FOR PARTICIPANTS IN THE STUDY OF THE PREVALENCE OF COMORBID AUTISM SPECTRUM DISORDER AMONG CHILDREN WITH INTELLECTUAL DISABILITY.

CONSENT EXPLANATION FOR SELECTED CAREGIVER TEACHERS.

I am a final year student of Msc. Clinical Psychology at the University of Nairobi at the College of Health Sciences, department of Psychiatry. The information I am looking for is about the illness in children who are under your care and are attending school at Nangina or Lwanya special schools. I ask if you would like to be part of this research study. If you agree, I would like to ask you some questions regarding the illness in the children under your care. Following your agreement to participate in the research study; you can still refuse to answer any questions. You can stop being in the study at any time. There will be no loss of benefits or any victimization whatsoever.

Risk/discomfort: Some of the questions especially those regarding the children's illness may cause you to experience distress and discomfort and may make you remember painful experiences and also there may be a risk of discovering a new illness. In the event that this happens the researcher is a trained psychologists and will provide supportive therapy to any of the study participants who might become distressed during the study process.

Benefits: The results of the study will increase knowledge and awareness of ASD, encourage early detection, diagnosis and effective evidence based interventions, family support, access to health care as early as possible and access to special education as needed which will Increase the likelihood of assisting children with ASD to reach their full potential throughout their lifespan and having improved long-term outcomes.

Confidentiality: The results of the assessments done on the children, and what we talk about in the interviews will be kept private to the extent allowed by law. To protect your privacy, I will keep the records under a code number and not your name. I will keep the records in a safe place. You will not be paid to take part in this study.

Reimbursement: There is no payment for participation in this study.

Referral: If the child is observed to have serious self-injurious behaviours and also a new illness is discovered, the child through the parents/guardians will be advised to go to Moi Teaching and Referral hospital for further management.

Voluntary participation: To be in this study is your choice. If you do not want to participate in the study, the children will still benefit from the recommendations that will be suggested. If you agree to participate in the study but then have questions or decide you do not want to go on with it, you can withdraw. If you have questions about your rights as a participant you can call the researcher on 0722 383 148 or Ethics Research Committee secretary on 0722 392 219 or write a letter using postal address P.O. Box 20723 – 00202 Nairobi.

CONSENT FORM

Participant's Code No……..**Date**……

Caregiver Teacher statement

The above study has been explained to me and I agree to take part. If I change my mind, I understand that the child will not be victimized.

Teacher's signature:……

(Or mark of consent)

Witness signature……

Investigator signature…….

Mimi ni mwanafunzi wa mwaka wa mwisho wa uzamili wa Kliniki ya Kisaikologia chuo kikuu cha Nairobi, chuo cha sayansi ya afya, idara la Psychiatry. Habari ambayo natafuta ni kuhusu ugonjwa ambao uko kwa watoto ambao wako chini ya huduma yako na wanahudhuria shule maalum ya Nangina au Lwanya. Naomba kama ungependa kuwa sehemu ya utafiti huu. Ukikubali, ningelipenda kukuuliza maswali kuhusu ugonjwa kwenye watoto waliyo chini ya huduma yako. kufuatia kukubali kwako kushiriki katika utafiti huu, pia unaweza kataa kujibu maswali. Unaweza kuacha kuwa kwa utafiti huu wakati wowote. Hakutakuwa na kupoteza faida yeyote au uonevu wowote.

Hatari/Usumbufu: Maswali mengine kuhusu ugonjwa wa watoto yanaweza sababisha dhiki na usumbufu na kuhisi maumivu na pia kuna weza kuwa na hatari ya kugunduliwa kwa ugonjwa mpya. Haya yaliyotajwa yakitendeka, mtafiti amehitimu Kisaikologia na ataweza kupeana kuunga mkono tiba kwa yeyote yule ambaye atajihisi kuwa na dhiki na usumbufu wakati wa utafiti.

Faida: Matokeo ya utafiti yataongeza maarifa na ufahamu wa (yaliyo katika wigo machafuko) ASD, kuhamasisha kutambua mapema, utambuzi na ufanisi hatua ushahidi makao, msaada wa familia, upatikanaji wa huduma za afya mapema iwezekanavyo na upatikanaji wa elimu maalum kama inahitajikaa ambayo itaongeza uwezekano wa kuwasaidia watoto waliyo katika wigo machafuko kufikia uwezo kamili maishani mwao na kuboresha matokeo ya muda mrefu.

Siri: matokeo ya tathmini kwa watoto na maneno yote ambayo tutaongea, yatawekwa kisiri kwa kiasi kuruhusiwa na sheria. Kulinda faraga yako, nitaweka kumbukumbu kwenye msimbo na sio kwa jina lako. Nitaweka kumbukumbu mahali salama.

Kulipia: Hakuna malipo kwa kushiriki katika utafiti huu.

Rufaa: Ikiwa mtoto yeyote anaonekana kuwa na binafsi tabia za kudhuru kubwa na pia ugonjwa mpya kugunduliwa, mtoto kupitia kwa mzazi/mlezi atashauriwa kwenda kwa hospitali ya kufundisha na rufaa ya Moi Eldoret kwa udhibiti zaidi.

Ushiriki wa hiari: Kuwa kwa utafiti huu ni uwamuzi wako. Ikiwa hautaki kushiriki kwa utafiti huu watoto bado watafaidika na mapendekezo ambayo nitapendekeza. Ukikubali kushiriki kwa utafiti huu na unamaswali au unaamua ya kwamba hautaki kuendelea kushiriki kwenye utafiti huu, unaweza kujitoa. Ikiwa una maswali kuhusu haki zako kama mshiriki unaweza kupigia mtafiti simu kwa nambari 0722383148 au Katibu wa Ethics Research Committee kwa nambari 0722 392 219 au uandike barua na kutuma kwa sanduku la posta P.O. Box 20723 – 00202 Nairobi.

FOMU YA RIDHAA

Mshiriki Msimbo ……..**Tarehe**……

Kauli ya mwalimu mlezi

Utafiti juu umeelezwa kwangu na ninakubali kushiriki. Nikibadilisha akili yangu, naelewa ya kwamba watoto hawataonewa.

Sahihi ya mwalimu mlezi:……

(Au alama ya ridhaa)

Sahihi ya shahidi……

Sahihi ya mtafiti…….

ASSENT FORM FOR PARTICIPANTS IN THE STUDY OF THE PREVALENCE OF COMORBID AUTISM SPECTRUM DISORDER AMONG CHILDREN WITH INTELLECTUAL DISABILITY.

ASSENT EXPLANATION FOR SELECTED CHILDREN

I will read this assent to the child at the time of enrolment.

Introduction

Even though I got the permission of your parent/guardian to talk to you, I want to explain to you what I want so that you can decide whether you want to participate.

I am a final year student of Msc. Clinical Psychology at the University of Nairobi at the College of Health Sciences, department of Psychiatry. I request to assess you as part of this research study and use the information for research. The information I am looking for is about your illness. Following your agreement; you can still refuse. There will be no loss of benefits or any victimization whatsoever.

Risk/discomfort: Some of the questions especially those regarding your illness may cause you to experience distress and discomfort and may make you remember painful experiences and also there may be a risk of discovering a new illness. In the event that this happens the researcher is a trained Psychologists and will provide supportive therapy to any of the study participants who might become distressed during the study process.

Benefits: The results of the study will increase knowledge and awareness of ASD, encourage early detection, diagnosis and effective evidence based interventions, family support, access to health care as early as possible and access to special education as needed which will Increase the likelihood of assisting children with ASD to reach their full potential throughout their lifespan and having improved long-term outcomes.

Confidentiality: The results of the assessments done on you, and what we talk about will be kept private to the extent allowed by law. To protect your privacy, I will keep the records under a code number and not your name. I will keep the records in a safe place.

Reimbursement: As a participant in this study, you will be given some snacks after the assessment.

Referral: If you are observed to have serious self-injurious behaviours and also a new illness is discovered, you will be advised through the assistance of your parents/guardians to go to Moi Teaching and Referral hospital for further management.

Voluntary participation: To be in this study is your choice. If you do not want me to use you in the study, you will still benefit from the recommendations that will be suggested. If you agree I use you in the study but then have questions or decide you do not want to go on with it, you can withdraw. If you have questions about your rights as a participant you can call the researcher on 0722 383 148 or Ethics Research Committee secretary on 0722 392 219 or write a letter using postal address P.O. Box 20723 – 00202 Nairobi.

ASSENT FORM

Participant's Code No……..**Date**…….

Parent/guardian's name:……

Participant's statement

The above study has been explained to me and I agree to take part. If I change my mind, I understand that I will not be victimized.

Participant's signature:……

(Or mark of consent)

Witness signature……

Investigator signature…….

Utangulizi

Ijapo kuwa nilipata ruhusa kutoka kwa mzazi wako/ mlezi kuongea na wewe, nataka kukueleza kile ambacho nataka ili uweze kuamua kama utataka kushiriki.

Mimi ni mwanafunzi wa mwaka wa mwisho wa uzamili wa Kliniki ya Kisaikologia chuo kikuu cha Nairobi, chuo cha sayansi ya afya, idara la Psychiatry. Naomba Kukutathmini kama sehemu ya utafiti huu na kutumia habari hii kwa utafiti. Habari ambayo natafuta ni kuhusu ugonjwa wako. kufuatia kukubali kwako, pia unaweza kataa. Hakutakuwa na kupoteza faida yeyote au uonevu wowote.

Hatari/Usumbufu: Maswali mengine kuhusu ugonjwa wako yanaweza sababisha dhiki na usumbufu na kuhisi maumivu na pia kuna weza kuwa na hatari ya kugunduliwa kwa ugonjwa mpya. Haya yaliyotajwa yakitendeka, mtafiti amehitimu uzamili wa Kliniki ya Kisaikologia na ataweza kupeana kuunga mkono tiba kwa yeyote yule ambaye atajihisi kuwa na dhiki na usumbufu wakati wa utafiti.

Faida: Matokeo ya utafiti yataongeza maarifa na ufahamu wa (yaliyo katika wigo machafuko) ASD, kuhamasisha kutambua mapema, utambuzi na ufanisi hatua ushahidi makao, msaada wa familia, upatikanaji wa huduma za afya mapema iwezekanavyo na upatikanaji wa elimu maalum kama inahitajikaa ambayo itaongeza uwezekano wa kuwasaidia watoto waliyo katika wigo machafuko kufikia uwezo kamili maishani mwao na kuboresha matokeo ya muda mrefu.

Siri: Matokeo ya tathmini kwako na maneno yote ambayo tutaongea, yatawekwa kisiri kwa kiasi kuruhusiwa na sheria. Kulinda faraga yako, nitaweka kumbukumbu kwenye msimbo na sio kwa jina lako. Nitaweka kumbukumbu mahali salama.

Kulipia: Kama mshiriki katika tafiti hii utapewa vitafunio baada ya tathmini.

Rufaa: Ikiwa utaonekana kuwa na binafsi tabia za kudhuru kubwa na pia ugonjwa mpya kugunduliwa, kupitia kwa mzazi/mlezi utashauriwa kwenda kwa hospitali ya kufundisha na rufaa ya Moi Eldoret kwa udhibiti zaidi.

Ushiriki wa hiari: Kuwa kwa utafiti huu ni uwamuzi wako. Ikiwa hautaki kushiriki kwa utafiti huu bado utafaidika na mapendekezo ambayo nitapendekeza. Ukikubali kushiriki kwa utafiti huu na unamaswali au unaamua ya kwamba hautaki kuendelea kushiriki kwenye utafiti huu, unaweza kujitoa. Ikiwa una maswali kuhusu haki zako kama mshiriki unaweza kupigia mtafiti simu kwa nambari 0722383148 au Katibu wa Ethics Research Committee kwa nambari 0722 392 219 au uandike barua na kutuma kwa sanduku la posta P.O. Box 20723 – 00202 Nairobi.

FOMU YA KUTIWA SAHIHI

Mshiriki Msimbo ……..**Tarehe**…….

Jina la Mzazi/mlezi……..

Kauli ya mshiriki

Utafiti juu umeelezwa kwangu na ninakubali kushiriki. Nikibadilisha akili yangu, naelewa ya kwamba sitaonewa.

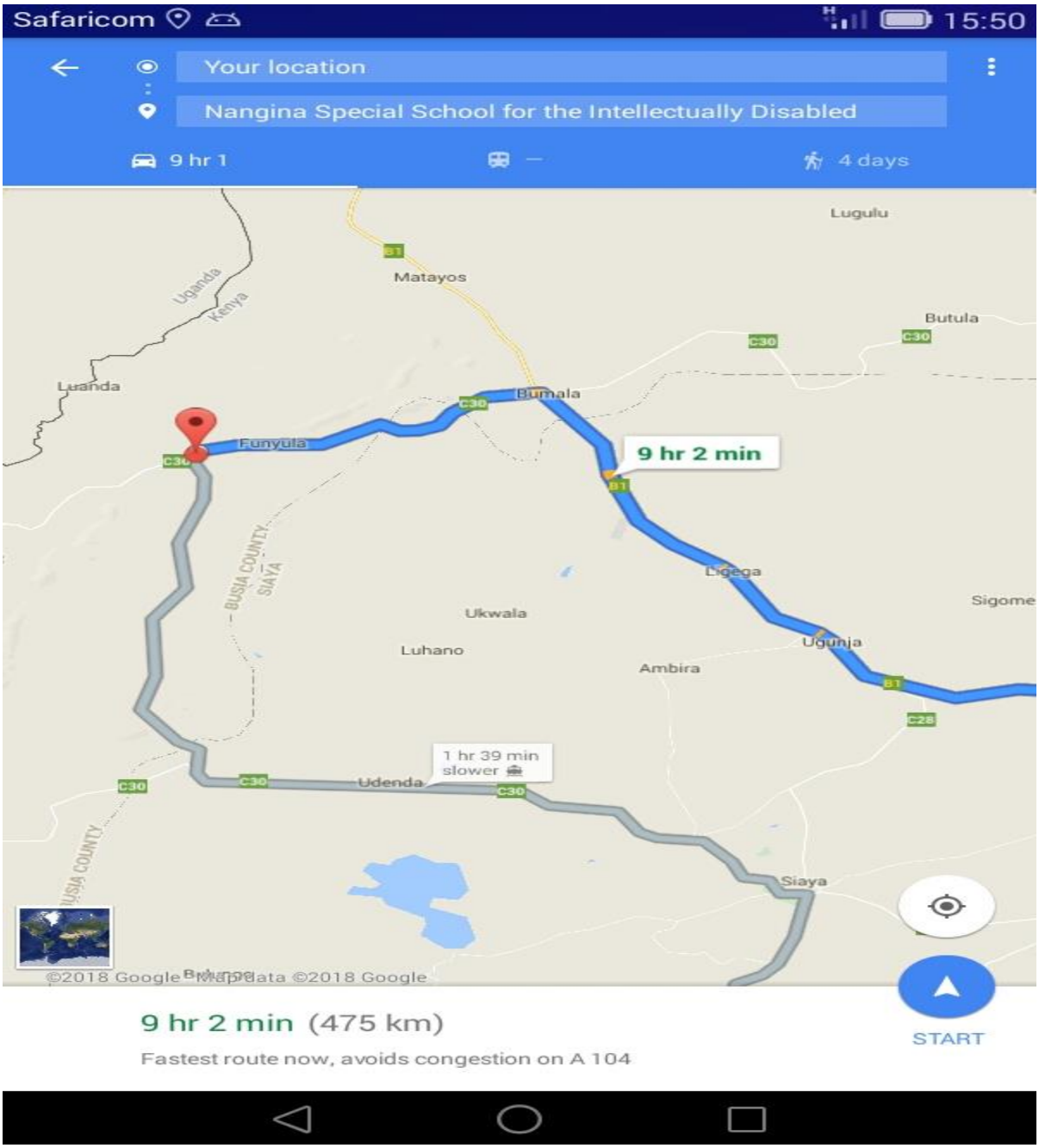
Sahihi ya mshiriki:……

(Au alama ya kutiwa sahihi)

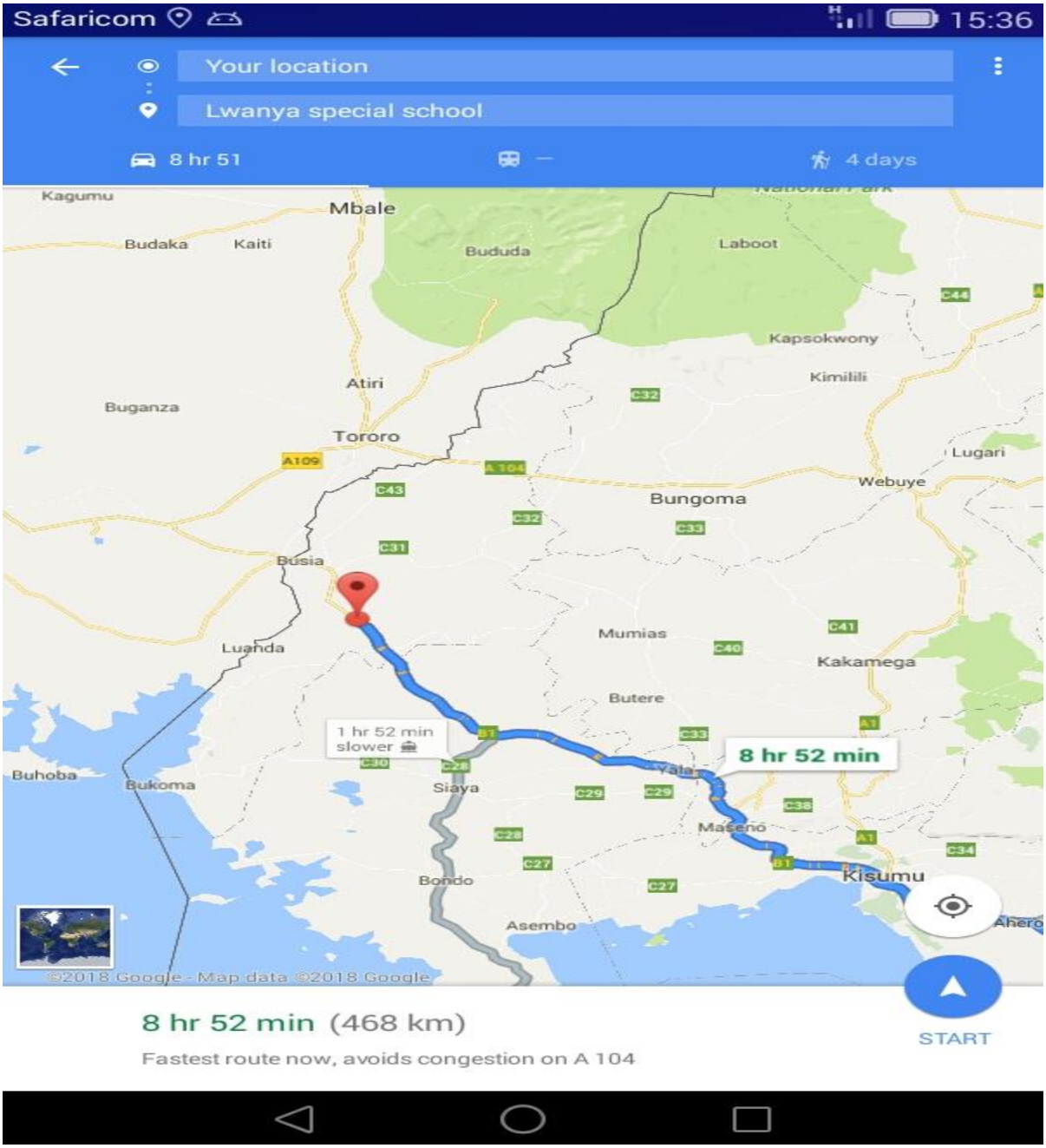
Sahihi ya shahidi……..

Sahihi ya mtafiti……...

Appendix VI: Location of Nangina special school for the Intellectually Disabled



Appendix VII: Location of Lwanya Special school for the Intellectually Disabled



Appendix VIII: Timeline

Activity	**Timeline**
Proposal presentation	January 2018
Ethical review	February 2018 to April 2018
Data collection	May 2018
Data analysis	July 2018
Results presentation	August 2018

Appendix IX: Budget

Item	**Item cost**	**Cost**
Researcher's transport	1	10,000
Stationery (Photocopies, pens, pencils, stapler & pins, files)	1	10,000
Snacks for participating children	1	6,000
Ethic fees	1	2,000
Statistician	1	30,000
Miscellaneous	1	8,000
Publishing expenses	1	10,000
Total		**76,000**

Appendix X: KNH-UON Ethics approval

UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KENYATTA NATIONAL HOSPITAL APPROVED
21 MAY 2018
KNH/UoN-ERC
P.O.Box 20723-00202 NRB.

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
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Ref: KNH-ERC/A/182

May 21, 2018

Everlyne Mercy Khabala
Reg. No.H56/74693/2014
Dept.of Psychiatry
School of Medicine
College of Health Sciences
University of Nairobi

Dear Mercy

RESEARCH PROPOSAL – THE PREVALENCE OF CO-MORBID AUTISM SPECTRUM DISORDER AMONG CHILDREN WITH INTELLECTUAL DISABILITY (P31/01/2018)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is from 21st May 2018 – 20th May 2019.

This approval is subject to compliance with the following requirements:

a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
c) Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
f) Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website **http://www.erc.uonbi.ac.ke**

Yours sincerely,

PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Deputy Director, CS, KNH
The Chairperson, KNH-UON ERC
The Assistant Director, Health Information, KNH
The Dean, School of Medicine, UoN
The Chair, Dept. of Psychiatry, UoN
Supervisors: Dr. Judy Kamau, Dr. Rachel Kang'ethe, Dr. Lincoln Khasakhala

Appendix XI: Anti Plagiarism Report

Turnitin Originality Report

THE PREVALENCE OF CO-MORBID AUTISM SPECTRUM DISORDER AMONG PERSONS WITH INTELLECTUAL DISABILITY by Everlyne Mercy Khabala

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