THE PREVALENCE OF DEPRESSIVE SYMPTOMS AND STIGMATIZATION AMONG PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN PUBLIC PRIMARY SPECIAL SCHOOLS IN NAIROBI

A RESEARCH PROPOSAL PRESENTED AS PART FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN CLINICAL PSYCHOLOGY IN THE DEPARTMENT OF PSYCHIATRY, THE UNIVERSITY OF NAIROBI

BY

GITHARA N. MERCY

H56/79579/2012

2016

DECLARATION

I Mercy Njeri Githara 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.

Author: Mercy Njeri Githara

Signature ………………………….

Date ………………………………..

APPROVAL

This is to satisfy that this bona fide research work has been carried out independently by Mercy Njeri Githara under our guidance and supervision

Supervisors:

1. Dr. Kumar Manasi,

   Senior Lecturer,

   Department of Psychiatry,

   University of Nairobi

   Contacts 0717379687; m.kumar@ucl.ac.uk.

   Signed ………………………………………….. Date ………………………………..

2. Prof. Obondo Anne A

   BA Sociology (India), PG Dip. Psychiatric Social Work (UK), MSW (India), PhD (Nbi)

   Associate Professor,

   Department of Psychiatry,

   University of Nairobi

   Contacts 0721849686; nnobondo2@gmail.com

   Signed ………………………………………….. Date ………………………………..

DEDICATION

I generously dedicate this study to my father, late mother, brothers, sisters and dear friends for their overwhelming support and patience during the duration of this research. Their words of encouragement, tolerance and financial assistance rendered to me throughout this research. I also dedicate this study to all parents of children with intellectual disabilities for the burden they bear to care for their children.

ACKNOWLEDGEMENT

First I am grateful to Almighty God for the privilege and grace of the opportunity to study and acquire this degree.

I am also grateful to the following individuals and organizations for their knowledgeable support without which this study would not have been initiated, implemented and the final results arrived at:

- My Supervisors:
    - Dr. Manasi Kumar– for her timely responses, inspiration and guidance right from the inception of the study to the completion of this report.
    - Prof. Anne Obondo – for her knowledgeable insight into the study and critique over important issues in the research.
    - To my ever helpful classmates namely Judy Mbuthia, Rachel Maina, Ruth Wambui and Janet Kuria
    - Lucas Malla for his professionalism in data analysis and dissemination of final results

I would also like to appreciate head teachers of Nile road special school, Tree-side special school, Dagoretti special school and Jacaranda Special School who supported me in the study.
Finally am grateful to the Almighty God for the privilege and grace of the opportunity yo study and acquire this degree.

Thank you to everyone who made this study possible and successful.

TABLE OF CONTENTS

Pages

Declaration ………………………………………………………………………….…….. i

Approval ……………………………………………………………………………. ii

Dedication ...……………………………………………………………………………..Iii

Acknowledgement ……………………………………………………………………. iv

Abbreviations / Acronyms ……………………………………………………………. v

Definition of Key Terms ……………………………………………………………… vi

Abstract ………………………………………………………………………….……. vii

1.0 CHAPTER ONE……………………………………………………………………. 13

1.1 Introduction ……………………………………………………………. ….. 13

1.2 Background of the Study……………………………………………………. . 14

1.2.1. Stigma and discrimination………………………...……………………………. 15

1.2.2 Social demographic factors of parents…………………….……………………… 15

1.2.3 Poor social support systems……………………………..………………………… 16

1.2.4 Disability parameters of child……………………………..………………………. 16

1.2.5 Cultural Beliefs………………………………………………………………………16

1.2.6 Coping Strategies…………………………………………………………………… 17

1.2.7 Burden of Care…………………………………………..………………………… 17

1.3 Theoretical framework…………………………………………………………………17

1.4 Statement of the research problem…………………………………………………… 19

1.5 Justification of study………………………………………………………………… 20

1.6 Objectives of the study……………………………………………………………….. 21

1.6.1 General Objectives ………………………………………………………………. 21

1.6.2 Specific Objectives …………………………….…………………………………. 21

1.7 Hypothesis …………………………………………………………………………… 21

1.7.1 Alternative hypothesis ………………………………………………………………… 21

1.7.2 Null hypothesis……………………………………………………………… 22

1.8 Scope of the study……………………………………………………………… 22

2.0 CHAPTER TWO : LITERATURE REVIEW …………………………………… 23

2.1 Introduction ……………………………………………………………………….. 23

2.1.1 Levels / Severity of Depression ………………………………………... 25

2.2 Parental stress ………………………………………………………………. 25

2.3 Stigma and discrimination ……………………………………………….. 26

2.3.1 Stigma defined ……………………………………………………. 26

2.3.2 Forms of stigma ……………………………………………………. 26

2.3.3 Drivers of stigma ……………………………………………………………… 26

2.3.3.1 Stereotypes ……………………………………………………………… 27

2.3.3.2 Prejudice and discrimination ………………………………………… 28

2.3.4. Outcomes of stigma ………………………………………………………… 28

2.3.4.1 Increased morbidity and mortality ……………………………………………28

2.3.4.2 Reduced Quality of Social Networks ..……………………………………28

2.3.4.3 Poorer Quality of Life …………………………………………………………29

2.3.4.4 Harmful Coping Strategies ………………………………………………… 29

2.3.4.5 Secrecy / Isolation ………………………………………………………… 29

2.4 Prevalence of parental depression ……………………………………….. 30

2.4.1 Gender differences ……………………………………………………... 31

2.5 Predictors of depression among parents ………………………………. 31

2.5.1 Burden of Care ………………………………………………………………….. 31

2.5.2 Child Behavior Problems ………………………………………………………… 32

2.5.3 Marital Dissatisfaction …………………………………………………………… 32

2.5.4 Socio Economic Status (SES) ………………………………………………… 32

2.6 Contextual factors ……………………………………………………………… 33

2.6.1 Social Support 34

2.6.2 Life Satisfaction and Family Happiness 34

2.6.3 Coping Skills and Resiliency 34

3.0 CHAPTER THREE : RESEARCH METHODOLOGY 35

3.1 Introduction.. 35

3.2 Study design 35

33. Study area description 35

3.4 Study population 35

3.4.1 Inclusion criteria 36

3.4.2 Exclusion criteria.. 36

3.5 Sample size determination 36

3.6 Sampling method 36

3.7 Data Collection procedures 37

3.8 Data Management and Analysis 38

3.9 Presentation of results 39

3.10 Data collection instruments 39

3.10.1 Socio Demographic questionnaire 39

3.10.2 Becks Description Inventory (BDI – II) 39

3.10.3 Discrimination and Stigma Scale Version 12 (DISK 12) 39

3.11 Ethical Consideration 40

3.11.1 Quality Assurance Procedures 40

CHAPTER FOUR: RESULTS 42

4.0 Introduction 42

4.1 Socio Demographic features of the sample. 42

4.2 Prevalence of depression 46

4.3 Stigma Prevalence 52

4.5 Factors associated with each Stigma subscale ………………………………… 55

CHAPTER FIVE: DISCUSSION …………………………………………….. 60

CHAPTER 6: ………………………………………………………………….. 64

6.0 Limitations ……………………………………………………….………… 64

6.1 Conclusion …………………………………………………………………. 65

6.2 Recommendations …………………………………………………………. 65

APPENDICES ……………………………………………………………………… 75

Appendix I : Participants informed consent form explanation …………………………... 75

Appendix II: Participants consent form ………………………………………………… 80

Appendix III: Socio Demographic Questionnaire ……………………………………… 82

Appendix IV: Becks Depression Inventory …………………………………………. 89

Appendix V: Letter of Approval from Ethics and Research Committee ……………… 112

Appendix VI: Proposed Work Plan - Flow Chart Time schedule ……………………….. 113

Appendix VII: Budget ………………………………………………………..... 114

LIST OF TABLES

Table 1: Population Distribution among Schools …………………………………….. 37

Table 2: Socio Demographic Characteristics of Caregivers ………………………… 42

Table 3: Symptom Severity ……………………….…………………………….. 46

Table 4: Prevalence of Depression …………….……………………………………….. 47

Table 5: Socio Demographic Correlates of Depression ……………………………….. 48

Table 6: Depression Scores and Other Demographics of Family Responsibilities and Burden of Care ……………………………………………………………………….. 49

Table 7: Mean scores for Stigma Sub Scale …………………………………………….. 51

Table 8: Stigma Prevalence …………………………………………..………….. 52

Table 9: Logistic Regression for Stigma Subscale……………………..…….……….. 55

LIST OF FIGURES

Figure 1: Gender Distribution of the Caregiver Sample ………………………………….. 44

Figure 2: Level of Education ……………………………………………………….…….. 45

Figure 3: Caregiver Income ……………………………………………………………….. 46

Figure 4: Prevalence of Depression ……………………………………………………... 47

Figure 5: Gender Distribution ……………………………………………………..…….. 49

ABBREVIATIONS/ACRONYMS

AAIDD	American Association of Intellectual Development Disorder
BDI II	Beck Depression Inventory
DSM-5	Diagnostic and Statistical Manual Versions 5
DISC-12	Discrimination and stigma scale version 12
ID	Intellectual Disability
KNH	Kenyatta National Hospital
MDD	Major Depressive Disorder
SES	Social Economic Status
SPSS	Statistical Package for Social Sciences
WHO	World Health Organisation
UNICEF	United Nations Children Education Fund

DEFINITION OF KEY TERMS

Depressive symptoms are characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy and poor concentration. Other

symptoms include loss of confidence and self-esteem, inappropriate guilt, thoughts of death and suicide, diminished concentration, and disturbance of sleep and appetite.

Intellectual disability this is disability that originates before the age of 18 and it is characterized by significant limitations in both **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills (AAIDD).

Stigma: Goffman (1963) defined stigma as “an attribute that is deeply discrediting and reduces the bearer ‘from whole and usual person’ to a tainted discounted one.

ABSTRACT

Background: Parents of children with intellectual disabilities may develop depressive symptoms and are prone to stigmatization due to stressful challenges encountered when providing care for their children.

Objectives: The research aimed at establishing the prevalence of depressive symptoms and stigmatization among parents of children with intellectual disabilities.

Method: A cross-sectional descriptive study design was used. A sample of 121 parents in four public primary special schools in Nairobi were recruited .Data was collected by use of Three (3) questionnaires. Researcher designed -Socio-demographic questionnaire was used to obtain socio demographic information. BDI- II was used to screen depressive symptoms while DISC-12 was used to determine stigmatization among parents of children with intellectual disabilities.

Results : Most of the parents were female(77.8%) married(69.9%), had post-secondary level of education (61.1%) employed (78.5%) with an income over Ksh 10,000/-(68.8%). 41.3 % of parents met the criterion for being at risk of depression, Stigma and discrimination was found to be significantly related to parent's depressive symptoms independently of other variables.

Conclusion: Results suggest that parents of children with intellectual disabilities are likely to be at risk for depression and to be highly stigmatized. Interventions could be developed that have a focus on the health or well- being of parents. Reduction of society stigma could also help promote and shun stigma likely to yield psychological distress to parents.

1.0 Chapter One

1.1. *Introduction*

According to DSM 5 (APA, 2013) intellectual disability is a disorder with onset during the development period that includes both intellectual and functioning deficits in the conceptual, social and practical domains. The criterion for ID diagnosis is based on the following three domains:

Deficits in intellectual function such as reasoning; problem solving; planning; abstract thinking; judgment; academic learning; as well as, real consideration established by both medical validation and personalized uniform aptitude tests.

Such deficits lead to failure of socio and progressive roles. Without ongoing support the adaptive deficits limit functioning in one or more activities of daily life such as communities, social participation and independent living and across multiple environments such as home, school work and recreation.

The above deficits are manifested during the development period and are only present during childhood and adolescence.

As a result of the above diagnosis to a child, parenting of children with intellectual disabilities can be a stressful experience. Children with intellectual disability require extra or special care that may cause burden of care placing parents at risk of depressive symptoms.

According to DSM 5 (APA, 2013) an approximate of 1% of the overall general population has intellectual disability. A further 0.06% of every 1000 persons are estimated to have severe intellectual disability.

1.2. *Background of the study*

A child's health, socio-emotional, cognitive and physical development is important to the parents' psychological wellbeing. Difficulties in functioning in the above areas as portrayed by children with intellectual disabilities often than not lead to distress in the parenting role that may be of short term effects or long term effects. Depression may result from poor physical health and lower family satisfaction. (Resch et al , 2012). The parents are at a risk for higher stress levels than parents of children without disabilities (Estes et al 2013).

Having children with intellectual impairment can be a stressful task to parents (Norizon & Shamsuddin ; 2010).The level of stress experienced by parents can lead to psychological disorders such as depression. Research has shown that parents of children with intellectual disability are at higher risk for developing depression. (Lloyd & Hastings, 2008).Psychological disress may be experienced due to variables such as acceptance of child's condition, mindfulness , avoidant coping , negative perceptions of the child stigma and discrimination from society. (Norlin &Broberg; 2013).

A number of risk factors have been shown to contribute to poor psychological functioning of the parents leading to the development of depressive symptoms. This may include:

1.2.1. Stigma and discrimination

In many countries of the world a disability is a stigma (UNICEF, 2012). Children with disability have experienced a significant level of stigma and discrimination .Due to the stigma children are abandoned or hidden away from society by their parents. Stigma increases the perceived burden of care giving tasks in parents (Green, 2003) and parents sometimes blame themselves for their child's condition (Mak & Kwok, 2010).

In a study done in Tanzania, stigma and discrimination was shown in gestures such as pointing, laughing and staring (Mannan & McNally, 2013) rejection was also shown by putting blame on parent for siring a child with disability.In kenya there is a belief that children with disabilities have a

demonic possession or have been bewitched(Otieno ,2013).Anecdotal reports show that this problem is prevalent in Kenya. Cases of children being locked up for years in their houses because of disabilty particularly those who are mentally handicapped are reported in the media almost daily. As recent as 1/02/2015 it was reported on a local television that a mentally handicapped child had just been rescued from captivity after being locked in for 3 years by the parents. This was due mainly to the stigma surrounding having a child with disability.

This causes discrimination against the children and parents. Social stigma is associated with interaction of social institutions such as the extended family members, schools, neighborhoods and churches. Children with disabilities are often rejected in community due to type of disability as well as severity of the disability. Parents are also faced with blame and embarrassment to an extent they do not feel comfortable going into social gatherings with the children. The discomfort and constant criticism faced by the parents could lead to stress that could in turn cause depressive symptoms.

1.2.2. Social demographic factors of parents

Depression has been found to be more prevalent in parents with low educational and social economic levels (Thabet et al , 2013). A research in the USA showed that parents of children with learning disabilities are at increased risk for depression if they were single and unemployed . Higher levels of education and income help improve coping skills which inturn improve parenting and thus reduce depressive symptoms. (Churchill et al , 2010). Parents often are faced with financial constraints due extra cost on health and provision of services (Green 2007).

1.2.3. Poor social support systems

High poverty rates in Africa have led to neglect of children with disabilities due to lack of finances to provide better services to them. In Kibera a slum in Nairobi, Kenya parents of children with disabilities especially mothers cannot hold full time jobs as they have to dedicate quality time to take care of the children. (WHO, 2012) This has forced the women to take up menial jobs to fend for their children.

Inadequate medical facilities, ever rising cost of maintenance for these children such as cost of personnel, food and lack of schools to accommodate them and trained personnel to deal with the children are all possible contributors to depression in these parents (WHO 2012).

There is also lack of social support in terms of education and facilities for these children especially in developing countries such as Kenya (*Ibid).* Inadequate education services and facilities for the children further creates a high dependency rate on parents as these children entirely depend on their primary caregivers for day to day living depending on the severity of their challenges. (Mireles et al 2010) (Worcester, et al 2008).

1.2.4. Disability parameters of child

Children's type of disability predicts the trajectories of development in cognition, social skills and daily living skills. (Cram;et al , 2001). Research indicates that childs behavioral problems and lack of social skills were the main contributors of parental stress. Maternal stress was noted to reduce as child developed from early childhood to middle childhood (Azad ; et al , 2013) .

1.2.5. Cultural beliefs

Haihambo (2004) found the following myths about the causes of disability among some African ethnic groups;

1. Mother slept with multiple partners during pregnancy`
2. Disability is contagious
3. The family tried to get rich through use of traditional doctors but failed to follow doctors instructions to the latter

In Africa there are stereotype beliefs about giving birth to children with disabilities such as bad omen, punishment from forefathers, curses and witchcraft are believed to be causes of disability.

This is also a contributor to the poor psychological wellbeing of parents as they may feel guilty to the allegations made on them.

1.2.6. Coping strategies

Use of active coping, positive growth and behavior disengagement as coping strategies have been reported to help increase parenting efficacy. Parents who lack coping skills of child's behavioral problem have been found to experience greater symptoms of depression (Woodman, 2013).

1.2.7. Burden of care

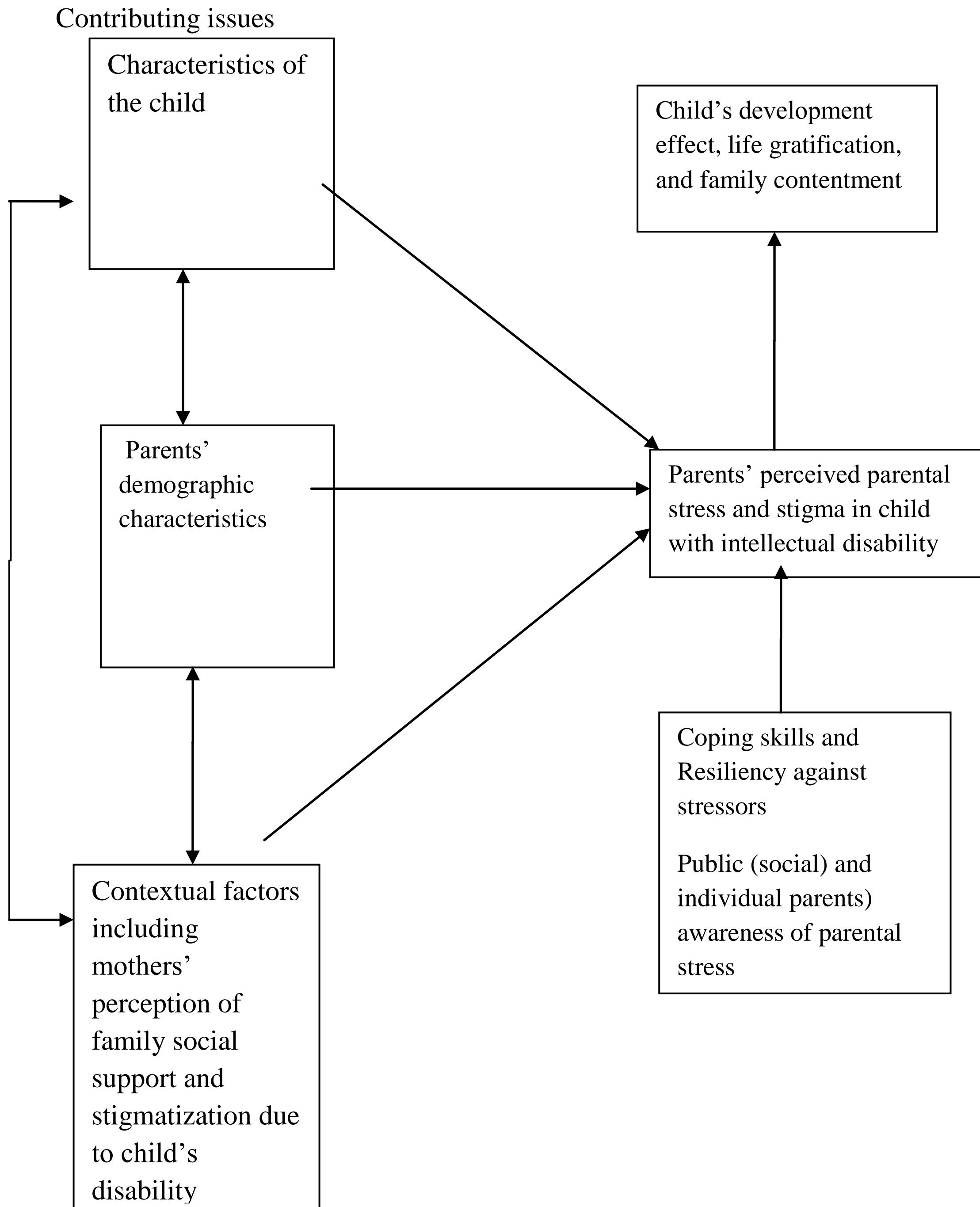
In the past the care of a child with disability in Kenya was the responsibility of the extended family (Mbugua; et al, 2011).However times have changed and burden of care has entirely been left to primary caregivers mainly parents especially mothers. Some parents are not able to work as they have to dedicate most of the day to providing care for the children. Physical pain was experienced by mothers in Moshi Tanzania as it involved carrying of the child from place to place causing pain and subsequent health risks in parents. (McNally& Manaan, 2013).

The above risk factors pose numerous potential challenges and daily stressors associated with parenting a child with disabilities. This may lead to disruption of family and social relationships leading to fatigue, economic difficulties, guiltiness and stress (Estes ;et al, 2009).

1.3. *Conceptual framework*

A conceptual framework was adapted from Abidin (1990, 1995) which proposes the characteristics of the child, the parent, and related issues as the bases of stress among parents. However, initially it was steered by a hypothetical model of the causes of dysfunctional families, but did not embrace "family social support" (Leung et al., 2005) and "stigma and discrimination" (Baffoe , 2013) components, which leads to stress in parents as per prior studies. To suit the needs of the current study the model was partially adapted.

Figure 1: Theoretical model for Parental stress and stigmatization in children with intellectual disability.



The current study mutually incorporated the two approaches to fulfill the study objective of intellectual disability including parent's own knowledge and judgment.

1.4. *Statement of the research problem*

Parenting is a challenge to most parents more so when it comes to parenting of children with intellectual disability. Depression may occur in such parents because of rare demands that include disruption of family and social relationships, fatigue due to extra care required and economic problems experienced due to treatment and other services , stigmatization from society and cultural beliefs and general parenting distress.

Often children with intellectual disabilities are usually rejected by their peers, school authorities and the society at large. This creates an overwhelming responsibility for the parents causing despair, hopelessness, guilt and even helplessness, leading to depressive symptoms which are largely unrecognized.

In the developing countries like Kenya, depressive symptoms of parents of children with intellectual disability have been unrecognized due to limited research in this area. A study done by Mbugua et al (2011) on the prevalence of depression and burden of care among family caregivers of mentally retarded children at Gachie Catholic Parish in Kiambu mainly concentrated on the rural setting and did not consider the urban setting which has a more diverse population. It was also biased as it looked at caregivers in a community church. In addition to the limited studies that have been carried out on prevalence of depressive symptoms in parents of children with intellectual disability, anecdotal reports show that the incidence of children with intellectual disability is high suggesting the burden of care of such children could be overwhelming to parents in this country leading to depressive symptoms.

Previous research mainly concentrated on the caregiver's burden in hospital setting. Otieno (2013) carried a research on the prevalence of depressive symptoms among caregivers of children with mental disorders at Kenyatta National Hospital. This mainly looked at the experiences of medical caregivers but could not give insight on the plight of parents who are the primary caregivers. Another

research done in Kilifi also looked at the caregiver's experiences for children with disabilities. This was a general view of all the disabilities but the current study concentrated on intellectual disabilities as they are taking a bigger percentage of overall disabilities and have a higher impact in families. The current research took place in schools in the capital city of Kenya thus results were a representation of the urban setting.

It is out of this experience that the researcher's interest arose and found it necessary to carry out research in this area to help find if the parents are in danger of depression and give suggestions to help parents cope and provide quality care and be symptom free.

1.5. *Justification of study*

Psychological distress and depressive symptoms of parents affect the mental well-being of the child placed under their care. Research has demonstrated that children are better able to cope with their vulnerabilities when the parent is healthy and able to provide love and cognitive stimulation (Richter et al 2006).

This study is significant to the educational stakeholders like schools and community based organizations as information collected will help them educate and create awareness on intellectual disabilities. This will help to reduce stigmatization of parents which will go a long way in reducing the depressive symptoms among parents. Reduced stigmatization will also ensure children with intellectual disabilities are embraced in society and more support system established to support parents and their children.

The study will also enable the stake holders to put in place structures that will improve the lives of parents. It will also help the stakeholders such as schools involve the parents in the therapeutic process. This will in turn improve the lives of children with intellectual disabilities as they will have more stable parents who are able to provide quality care.

Based on the findings of the study, it will help and guide stakeholders to make recommendations that will focus on educating the community on the adverse effects of stigmatization and lack of social support to parents of these children.

This research work will also 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. *Objectives of the study*

1.6.1. General objectives

The research aimed at establishing the prevalence of depressive symptoms and stigmatization among parents of children with intellectual disabilities.

1.6.2. Specific objectives

1. To determine the socio -demographic characteristics of parents of children with intellectual disabilities.
2. To determine levels and severity of depressive symptoms among parents of children with disabilities.
3. To determine stigmatization and discrimination among parents of children with disabilities.
4. To establish the association between stigmatization and depressive symptoms among parents of children with intellectual disabilities.

1.7. *Hypothesis*

1.7.1. Alternative hypothesis

Depressive symptoms and stigmatization are significantly high among parents of children with intellectual disabilities. .

1.7.2. Null hypothesis

Depressive symptoms and stigmatization are insignificant among parents of children with intellectual disabilities.

1.8. *Scope of the study*

This study focused on parents of children with intellectual disability aged below 18 years who attend public primary special schools in Nairobi County.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Kenya acknowledges disability as a phenomenon that cuts across all spheres of society. According to the Kenya National Survey for persons with disabilities (2009), the overall disability rate in Kenya is 3.5% which translates to 1.3million. Of this 44.8% have mental disability. A draft education policy (2012) stipulates that 21,050 learners have been enrolled in special schools. The National Development Plan (2002-2008) estimates there are1.8 million children aged 0-19 years with special needs and disabilities in the country. Nairobi which is the capital city of Kenya has several schools both private and public catering for children with different special needs and disabilities. The number keeps on fluctuating as some schools open and close. There are six (6) public special schools that the ministry of education has fully fledged in Nairobi catering for children with mental disabilities. In addition there are 34 special units in mainstream schools that provide inclusive education to learners with different mental disabilities.

Admission to the schools is done through formal assessment centers under the guidance of Kenya Institute of Special Education (KISE). Once the child has been assessed and a primary diagnosis done placement in the specific schools or unit is done conveniently.

Depression

According to DSM5 (APA, 2013) depression is characterized by Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning: at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, and hopeless) or observation made by others (e.g., appears tearful).

2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).

3. Significant weight loss when not dieting or weight gain (e.g., a change of more than

5% of body weight in a month), or decrease or increase in appetite nearly every day.

4. Insomnia or Hypersomnia nearly every day.

5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).

6. Fatigue or loss of energy nearly every day.

7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).

8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).

9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The depressive episode is not attributable to the physiological effects of a substance use or to another medical condition.

2.1.1 Levels/ severity of depression

Mild to Moderate Depression- This category includes symptoms like self-doubt, poor peer relations, negative self-concepts, poor adjustment, poor coping skills, low self-esteem, and social withdrawal. A score of 10-19 on the BDI is interpreted as mild to moderate depression.

Moderate to Severe Depression- This category is explained as loss of emotional expression (flat affect); a persistently sad, anxious or empty mood; feelings of hopelessness, pessimism, guilt, worthlessness, or helplessness; social withdrawal; unusual fatigue, low energy level, a feeling of being slowed down; sleep disturbance with insomnia, early-morning awakening, or oversleeping; trouble concentrating, remembering, or making decisions; unusual restlessness or irritability; persistent physical problems such as headaches, digestive disorders, or chronic pain that do not respond to treatment; thoughts of death or suicide or suicide attempts. A score of 20-63 on the BDI is interpreted as moderate to severe depression. .

2.2 Parental stress

Parental stress includes the challenges encountered while parenting, the subsequent behavior, well-being and the adjustment of the child. (Anthony et al., 2005).

Parental stress continues to be a center of attention of research because it has been linked with many negative outcomes such as parent depression, marital conflict, poor physical health and ineffective parenting (Neece & Baker, 2009).

Researchers agree that parenting of children with disabilities causes greater levels of distress than parenting those without (Chao, 1999; Esdile, 2003). As a consequence, more depressive symptoms are experienced. Risk factors involved with higher levels of stress include: maladaptive parenting, behavior of child (Williford et al, 2007), challenges with tasks involving parenting, and lack of contact between child and parent (Abidine, 1995).

A study by Cram (2012) found that parental stress was a major affecter of parents' psychological wellbeing. Samadi (2014) did a study on parental wellbeing of Iranian families. The study showed that poorer emotional wellbeing of parents contributed to higher stress and was frequent among mothers and single parents.

A study on Malaysian mothers of children with Down syndrome showed that mothers experienced parental stress. The main predictors of maternal stress were due to children having behavioral problems and lack of acceptance of the disability. (Norizan, 2010).

2.3 Stigma and discrimination

2.3.1 Stigma

Stigma has been defined as "an attribute that is deeply discrediting and reduces the bearer 'from whole and usual person' to a tainted discounted one (Goffman 1963, p.3)". In a revised definition of Stigma by Thornicroft et al (2007) stigma has three elements a) problems of knowledge (ignorance or misinformation) b) problems of attitudes (prejudice) c) problems of behavior discrimination

Intellectual disabilities have been one of the most stigmatized groups in society. Research has shown that individuals and family caregivers of people with ID experience stigma which negatively impacts on their psychological wellbeing (Ali, et al , 2012).

2.3.2 Forms of stigma

The current study will look at personal stigma experienced by parents of children with intellectual disability. Personal stigma is considered in three forms

Perceived stigma : Zelaya et al (2012) defines perceived stigma as "individuals experience of the negative meanings associated with stigma ".Mak & Kwok (2010) found that caregivers of children with ID felt stigma due to perceived responsibility for the child's condition. Perceived stigma has also been repeatedly reported to increase anxiety and depression among mothers of children with disabilities (Link & Phelan , 2011). Another study by Shibre et al (2007) in a in Ethiopia found 75%

of family members of people with mental illness reported some form of perceived stigma from others due to their mentally ill family members .A study in Morocco reported high levels of perceived stigma and burden on families of patients suffering from Schizophrenia a form of mental illness. (Girma et al , 2014).

Experienced stigma: Brakel et al (2006) defined experienced stigma as “the experience of actual discrimination and participation on the part of the person affected”. Studies have shown that children with various disabilities have been discriminated against participation of various school and social activities (Goofman 1963). A study in Zambia shown that children were restricted to play with others due to lack of safety measures during play. Children who displayed self inurious behaviour were restricted from play as parents, family members and teachers feared the child hurting others or self (Hansen et al, 2014).

Self-stigma: This is the reaction to public stigma. It is a product of internalization of shame, guilt and blame. (Rao et al 2012). A study in Ethiopia showed that 38.63% (n=3,163) caregivers and parents of children with mental illness felt the need to hide the children and keep their illness as a secret. A further 36% avoided going to social events with the children and cited shame and embarrassment about children’s illness. This was due to self-stigma that the family members had or thought about the illness. (Girma et al, 2014).

2.3.3 Drivers of Stigma

2.3.3.1. Stereotypes

Stereotypes are beliefs about groups learned while growing up in a specific society (Corrigon et al, 2000). These beliefs are carried on from generation to another and the society is made to believe that it is the truth. However, most of these beliefs are just myths. Research has shown that stereotype beliefs are great drivers of stigma leading to prejudice and discrimination (Link & Phelan, 2011).

Studies done in Kilifi (Kenya) showed those parents of children with disability were stigmatized due to the stereotype beliefs accompanied by the disability. According to the community, disability was viewed to be a form of punishment from God for doing wrong, or work of evil spirits and witchcraft (Elsharkway et al 2006). Gona et al (2011) in Tanzania found that parents feared seclusion of their children.

2.3.3.2 Prejudice and discrimination

This involves emotions, attitudes and behaviors towards stigmatized groups (Goffman, 1963). According to the labeling theory, stigma is mostly a sequential practice that begins with labeling and devaluation which further leads to separation and identity loss of the labeled person and subsequently discrimination (Mukolo et al, 2011).

2.3.4 Outcomes of Stigma

2.3.4.1 Increased Morbidity and Mortality

Parents and families of children with disabilities internalize society's negative attitudes towards them sequentially feeling of self-blame, guilt, shame and embarrassments, anger and low self-esteem are the result of these attitudes (Avoke – 2002). These feelings subsequently pose health risks both physical and psychological. In fatal cases mortality has been experienced due to the psychological effects of stigma (Quinn et al, 2014).

2.3.4.2 Reduced quality of social networks

Studies have shown that parents of children who are disabled have restricted or minimal social interactions either due to stigma or burden. (Ahmedani, 2011). A study in India showed that the cast system highly discriminated against the mentally challenged in the community; this caused social discrimination as they were not allowed to attend social gatherings such as weddings. This has

shown reduced social networks as socialization is restricted to family only. (Upadhyaya & Havallappanavar, 2008).

Mbugua et al (2011) in their study reported that caregivers of children with intellectual disabilities were vulnerable to depression due to social isolation, loss of previous close friendships and stigma associated with taking care of the children.

2.3.4.3 Poorer Quality of life

Quality of life is dependent on various factors for one to thrive. Persons with disabilities who have been discriminated against social activities are likely to have poorer quality of life. A study in Tanzania showed that persons with mental disorders were viewed as having no future; they were considered to be unproductive in marriage and childbearing opportunities and were automatically disregarded in making personal choices. Self-stigma imposed by the public leads to poor quality of life as parents and caretakers conceptualizes what has been said about them.

Parents of children with intellectual disability worry of the future as they have witnessed discrimination of other children further decreases the quality of life for the parents Persons with disabilities in Ghana are considered as second class citizens. They are excluded from participation in meaningful social activities and also restricted to employment opportunities and right to education services. These have greatly affected the quality of life led by people with disabilities in Ghana (Baffoe, 2013).

2.3.4.4 Harmful coping strategies

Stigma predisposes parents to harmful coping strategies such as withdraw and restricted /minimal interaction with the society. Withdraw and isolation from society further leads to poor psychological outcomes such as increased depressive symptoms, anxiety, and sleep disturbance (Wong, 2000).

2.3.4.5 Secrecy/isolation

Parents prefer to remain secretive about the child's condition rather than open up and face stigma. Studies in Kenya have shown that caregivers of children with disabilities keep the disability of the children as a family secret for fear of isolation, segregation and discrimination (Gona et al , 2011).A study in Ethiopia on self stigma among caregivers of people with mental illness found that caregivers and parents felt the need to hide children and keep the illness as a family secret. They cited shame and embarrasement especially because of child's behavior problems and avoided going to social events with the children. (Girma et al , 2014).

2.4 Prevalence of parental depression

Depression has been linked with high levels of stress from increased daily care giving burden of children with intellectual disability. (Tomoka et al , 2012). Research has shown that unlike fathers, mothers used extra hours offering different forms of care and burden (Saied, 2006).

Mbugua et al (2011) did a study in Gachie parish Kiambu (Kenya) shown that 79% of family caregivers of children with intellectual disability in rural settings were at risk of clinical depression as shown from the Beck Inventory score administered to one hundred and fourteen participants. A study in Pakistan showed high rates of anxiety and depression among parents of children with ID. Even higher rates of clinical depression were met among mothers (40%) than fathers (31.3%) where 99 participants were recruited consecutively (Azeem et al , 2013). A study conducted in Austria showed 6.8% of fathers of children with intellectual disabilities between the ages of 3-15 years had symptoms of severe depression as measured by Depression Anxiety Stress Scale (DASS).

2.4.1 Gender differences

Various studies have shown gender differences in parental stress. Mothers of children with disabilities are at risk of physical and psychological stress. (Brobst, 2009); Yeh, 2002). Moreover, mother's higher levels of stress and lack of coping skills are associated with negative emotional states (Deater 2004). Saloviita et al (2003) found that the predictor of parental stress between male and female parents was the adverse explanation of the illness. However, female parents linked the

adverse explanation with the behavioral difficulties of the children, while fathers' associated it with the proficient social response of the child. Baker & Norris, (2001) suggested that physical and psychological abuse was not a predictor of domestic violence while , mothers' stress was associated to physical abuse on their spouses .

Esdail (2003) in her study acknowledged the main gender effects. She proposed that higher distress levels were experienced by mothers unlike fathers on role limit, unhappiness, competency, bond with partner, and well-being. This role alteration was notable in forms of stress management. A study on coping skills in 92 families of children below 12 years old and who had been recently contracted congenital heart illness. Results shown that mothers coping abilities linked with incorporation of the family, positivity, and therapeutic communication, whereas fathers' coping abilities was linked to sustaining social support, self-assurance, and mental stability.

2.5 Predictors of depression among parents

2.5.1 Burden of care

High depression and anxiety scores have been noted in family caregivers of children with intellectual disabilities due to caregiver burden and its guilt component (Gallagher, et al , 2008). Olsson and Hwang (2006) in their study found that parents of children with ID had lower levels of psychological wellbeing due to less involvement with paid work . The study showed that parents were more involved in child care than in paid work..

2.5.2 Child behavior problems

Children with intellectual disabilities are at heightened risk for behavior problems (Eisenhower et al , 2005). Researchers have found that parent of children with ID have increased levels of stress due to childs behaviour problem (Baker et al 2002). Parents spend significantly more time issuing commands and working on childs' compliancy to social norms. Behavior mangement challenges and negative parent -child interactions were experienced resulting to greater parental stress due to

increased child behaviour problems (Baker et al, 2003). In an Australian study, father's depressive symptoms were predicted by behavioral problems of the child, daily stressors arising from individual needs of the father as well as child's individual needs. The father's expressed low parenting satisfaction from caring for children with ID (Giallo et al , 2015).Hastings et al (2006) found that child behavior problems and maternal stress were bidirectional in relation. Maternal stress increased as child behavior problems increased.

2.5.3 Marital dissatisfaction

Marital satisfaction has been seen to be a predictor for parental depression. There are several explanations why families separate such as in financial constraints, habits, exploitation, health, or just plain lack of happiness.

Being a parent to a child with intellectual disabilities can also lead to separation of couples. A study done by Yeh (2006) found greater marital discontent among couples whose children had been diagnosed with a disability two months before the study. Another survey study done in the United States shown that twenty four percent of parents worked fewer hours so as to focus on the care of the child (United Press International, 2008), further increasing the economic problem, and consequently, created more problems and sadness in the families. A study in Hongkong by Kwok et al (2014) found that that Chinese mothers of children with autism and intellectual disabilities shown marital frustration to be a predictor of stigma and care giving burden which additional lead to psychological distress, developmental problems and social problems. These were great predictors of parental stress likely to cause depression. Norlin et al (2013) reported that the quality of marriage suggested simultaneous wellbeing. Mothers of children with ID were shown to have parental stress as compared to those without children with ID. Couple relationship showed prospective wellbeing among parents of children with ID.

2.5.4 Socio economic status (SES)

In a study done by Anderson (2008),families with low SES are least expected to get family support due to high levels of long-lasting levels stress, financial problems, resulting to exhaustion of family resources required for daily care of the family. According to Shirley and McBride (2007) earners with low wages and those who are less-educated were less likely than high-income earners and more-educated parents to recognize the importance of highly specialized health care for their families due to unawareness, or lack of access to health services.

In Turkey a study that sought to determine the role of socio- demographic factors in relation to depression among mothers of children with intellectual disability, found that inadequate income and low- education levels were at high risk of developing depression (Yildirim et al , 2010).

2.6 Contextual factors

Many questions may arise as to why certain caregivers of children with intellectual disabilities are stronger than others, and have abilities change and adjust to crisis. Adjustment to an individual's disability is deeply influenced by family resourcefulness and their survival skills.

Consequently, the impact of disability of a child on a parent is dependent upon outside situations and individual features (Brobst et al, 2009). The following emotional aspects help build resilience in parents.

2.6.1 Social support

Family, friends, relatives, society, learning institutions, support groups, private association, or government services form most of the social support (Spina, et al 2005). Positive attitudes towards parenting among mothers' are predicted by their awareness towards existing social support (Suarez & Baker, 1997), this also helps to improve their mental wellbeing (Rodgers, 1998) and reduce stress levels (Pinderhughes, et al , 2001).

2.6.2 Life satisfaction and family happiness

A study by Minnes et al , (2014) showed that parental perceptions were predictors of distress and wellbeing in parents of young children with developmental delays and disabilities. Parent coping strategies showed positive gain and lower parental distress among 26% (n=155) of mothers recruited in the study.

2.6.3 Coping skills and resiliency

A study in Kilifi (Kenya) by Gona et al (2010) showed that parents had devised ways of dealing with parental stress. They had two approaches to the stress a) problem focused, b) emotional focused. The problem focused looked into ways of finding help in regards to cause and management of the disability. Search for materials from well wishers and sponsors for children were used. Emotional distress was reduced by use of spiritual intervention. Children with ID were taken to spiritual healers for prayer and spiritual intervention. Sharing with one another also helped to reduce emotional burden.

3.0 CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter describes the study site, population of interest and discusses the research design, sampling design, data collection methods and data analysis techniques which were employed.

3.2 Study design

The study was conducted through a descriptive cross sectional design to determine the prevalence of depressive symptoms and level of stigmatization among parents of children with intellectual disability.

3.3 Study area description

This study was conducted in four public primary special schools in Nairobi County. Nairobi is the capital city of Kenya with several special schools closely located within proximity and easily accessible. Nairobi County has a total number of six public primary special schools governed by the Ministry of Education. There are also thirty four (34) units in public primary schools which integrate children with special needs

This study included four public primary special schools which were conveniently chosen. The schools were: a) Jacaranda Special School b) Tree side Special School, c) Nile Road Special School, and d) Waithaka Special School. Enrollment of children in the schools is done through the Kenya Institute of Special Education (KISE) after an assessment to determine the type of disability. Current enrollment in the above schools is estimated at 690 learners.

3.4 Study population

The study consisted of parents of children with intellectual disabilities who were attending public primary special needs schools in Nairobi County. The population included parents aged 18 years and

above who had consented to participate in the study. The study included both male and female parents present in the schools.

3.4.1 Inclusion criteria

The inclusion criteria for the study involved:

- Parents who consented to voluntary participate in the study.
- Parents aged 18 and above.
- Parents who were conversant in English or Kiswahili.
- Parent or guardian to child/children with intellectual disability
- Both female and male parents were included in the study.

3.4.2 Exclusion criteria

- Parents who are below the age of 18 years old were excluded.
- Parents who did not have children with intellectual disabilities
- Parents who did not consent to the participation of the study.

3.5 Sample size determination

The Cochran's formula (Czaja & Blair, 2005) was used for the sample size calculation. The formula addresses continuous and categorical statistical variables and applies key risk factors like confidence level that is acceptable (95%) and a precision (alpha value, type 1 error) of 0.05(5%). Using Cochran, sampling formula (Czaja & Blair, 2005);

$$n=\frac{Z^2 p (1-p)}{d^2}$$

Where n = sample size

d is the desired level of precision = 0.05

p is the estimated prevalence of depression 79%(Mbugua et al 2011)

z is the critical value of a standard normal distribution for a 95% confidence level = 1.96

n= 1.96^2*0.79 (1-0.35)/0.05^2 = 186

Adjusted for finite population nf=n/ (1+n-1/N) where N is the population size

nf=149

This means that we required 186 parents. The total number of children in the 4 targeted schools is 682 as distributed in table below. The number was adjusted for a finite population; a total of 149 participants were required. Proportionate samplings were used to enroll the number of parents in each school as shown below.

School	Population	%	Proportionate Sample
Nile Road Special School	272	40%	59
Tree Side Special School	105	15%	23
Jacaranda Special School	150	22%	33
Waithaka Special School	155	23%	34
Total	682		149

Table 2; *population distribution among schools*

3.6 Sampling Method

Purposive method of sampling was used in schools to select participants to represent the sample in a particular school.

3.7 Data collection procedures

Ethical approval was obtained from the Kenyatta National Hospital/University of Nairobi research and ethical review board. Permission was obtained from the school heads to conduct research within

the schools. A pre-test of the questionnaires was carried out on a few of the subjects to establish the reliability and validity of data collection instruments.

The questionnaires were reviewed in close collaboration with the supervisors and other professional in field. The corrected versions of the instruments were compiled into one document. Data collection was done during school's parents meetings to ease in getting participants for the study. Communication with school head teachers was done prior to organize for meeting dates. Approval was sort from the head teachers to interact with parents. Data collection was carried out in the school halls after the parents meeting. A list having parents of children with intellectual disabilities will be sort from the school administration. Purpose of study was explained to parents and assurance of confidentiality was done, thereafter parents were given time to ask questions. An informed consent form was given to parents who volunteered to participate. Those who declined to sign the consent were excluded from the study at that point. Individual questionnaire were provided and participants who required help in completing the questionnaire were assisted by the researcher who read out the questions to them without interpreting them. The questionnaire took about 30-45 minutes for participants to fill in. Completed questionnaire were collected by the researcher. Reassurance and psychological support was done to parents who elicited emotional distress. No referral to KNH support center was done. The researcher thanked each and every participant for agreeing to participate in the study

3.8 Data Management and Analysis

All statistics were performed using the Statistical Package for Social Sciences (SPSS) version 20. Further inferential statistics were used to determine the significant differences between variables and correlation were run to determine the social demographic factors and depressive symptoms.

Confidentiality was ensured for all data collected. Data collected was under lock and key and only the researcher has access to it. The data is under safe custody for six months to facilitate reference for further corrections if deemed necessary by the ethical committee.

3.9 Presentation of results

The results were presented in frequency tables, graphs, charts and in narratives.

3.10. Data collection instruments

3.10.1. Socio-demographic questionnaire

Enrolled participants were subjected to social demographic questionnaire designed by the researcher to collect data about the age, sex, marital status, religion, education status and occupation of parents. As well as the information about the child's intellectual disability level, age of child/children, symptoms exhibited and current challenges.

3.10.2. Becks Depression Inventory (BDI - II)

The Becks Depression Inventory was administered to collect data on the risk of depression.BDI-11 is a depression scale developed by Aaron T Beck (1996).It is a 21 question multiple choice self-report inventory with each question on a scale value of 0 to 3. The inventory is used to measure the severity of depression. Higher total scales indicate more severe depressive symptoms.

A positive depression screen was defined as BDI score greater than 10; scores 0-10 are defined as normal; 10-16 indicate a Mild mood disturbance; 17-20 indicates Borderline clinical depression; 21-30 define Moderate depression; 31-40; define Severe depression; and over 40 or higher Extreme depression. A persistent score of 17 or above indicates need for treatment.

The Kiswahili version of the BDI was also be provided for those who had difficulties understanding English as Kiswahili is the national language in Kenya and is well understood by the majority of Kenyans.

3.10.3. Discrimination and Stigma scale version 12 (DISC – 12)

DISC-12 was used to determine the level of discrimination and stigma experienced by parents while caring for the children with ID.

DISC-12 is an self-administered scale developed by Graham Thornicroft (2009) and encompasses of 21 items on harmful mental health linked practices of discrimination in several life capacities in addition one other 'Catch all question' and four items to evaluate foreseen discrimination . All answers are set on a four point scale from 'not at all' to 'a lot'.

3.11. Ethical consideration

Prior to beginning the study, the study proposal was presented for approval and authority to the:

1. Department of psychiatry at University of Nairobi.
2. KNH/UON Ethics Research Committee
3. National Council for Education at the Ministry of Higher Education
4. Director of City Education Nairobi.

3.11.1 Quality assurance procedures

Before the research, the participants were briefed on the nature of the study and the necessary instructions. Each parent was presented with an informed consent form which contained the title of the study, the institution, identity of the researcher and supervisors the purpose and procedure of the study as well as the assurance that participation is entirely voluntary and that the subject was allowed to withdraw at any point of the study if they feel. Participants were also informed there were no material benefits for participation.

The questionnaires are all self-administered. Clear instructions were given to the participants before they filled them in so as to avoid confusion and thus reduced chances of yielding un-interpreted data. Follow up on double entries was done during collection.

A pretest of the questionnaires was also being done to assure quality of data collected. It helped to explain that confidentiality of the information collected would be assured and the researcher would undertake to abide by local and international laws and protocol governing research. The researcher used coded serial numbers on each questionnaire without names to ensure confidentiality.

Participation in the study was voluntarily and this was communicated to the schools. Information that was obtained was safely stored by the researcher to ensure confidentiality. Privacy and confidentiality was maintained all through the research period.

Chapter 4: Results

4.0 Introduction

The study involved 121 parents of children with intellectual disabilities. A researcher designed socio-demographic questionnaire was used to collect data on the parent's age, gender, marital status, level of education, employment, income, housing , number of children living in the home, age of the child with intellectual disability, quality of social life, marital satisfaction and happiness, self-blame and community blame, way of discrimination and caregiver burden(see Table 1).

Depression was the main study outcome and it was assessed using the Becks Depression Inventory, The BDI II, a 21 question self-report inventory was used to measure the levels/severity of depression among the parents (see Table 3).

DISC-12 was used to determine the level of discrimination and stigma experienced by parents while caring for the children with ID. All responses were given on a four (4) point scale from 'not at all' to 'a lot'. The tool was translated to Kiswahili, but most of the respondents preferred to use the English version and understood the questions well.

4.1 Socio-Demographic Features of the Sample

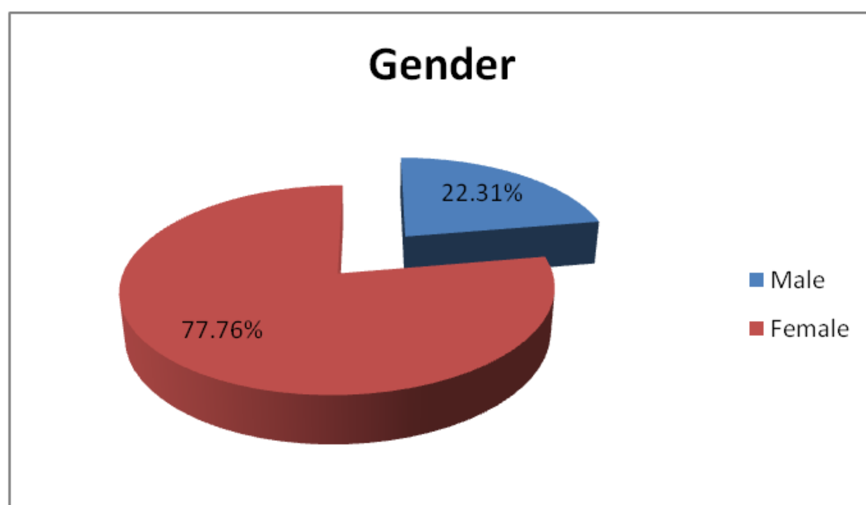
Table 1: socio demographic characteristics of caregivers

	Total		**Male**		**Female**	
	N	**%**	**N**	**%**	**N**	**%**
All	121		27	22.31	94	77.69
Respondents' Age						
18 - 25 years	18	14.9	7	25.9	11	11.7
26 - 35 years	15	12.4	4	14.8	11	11.7
36 - 45 years	41	33.8	10	37.0	31	32.9
45 + years	47	38.8	6	22.2	41	43.6
Employment Status						
Unemployed	26	21.4	2	7.4	24	25.5
Employed	95	78.5	25	92.6	70	74.8
Income						

<= Ksh.10,000	34	31.2	5	20.0	29	34.5
> Ksh.10,000	75	68.8	20	80.0	55	65.4
Marital Status						
Single	17	15.0	3	12.0	14	15.9
Married	79	69.9	17	68.0	62	70.4
Divorced/Separated	17	15.0	5	20.0	12	13.6
Education Level						
No Formal Education	2	1.7	0	0.0	2	2.2
Primary Education	11	9.7	3	12.0	8	9.0
Secondary Education	31	27.4	8	32.0	23	26.1
Post Secondary Education	69	61.0	14	56.0	55	62.5
Number of Children						
0	6	5.2	1	4.0	5	5.5
0 to 3	78	67.2	19	76.0	59	64.8
4+	32	27.6	5	20.0	27	29.6

Gender: Of the 121 parents who participated in the study 77.7 %(n=94) were female while 22.3% (n=27) were male.

Figure 1: Gender distribution of the caregiver sample



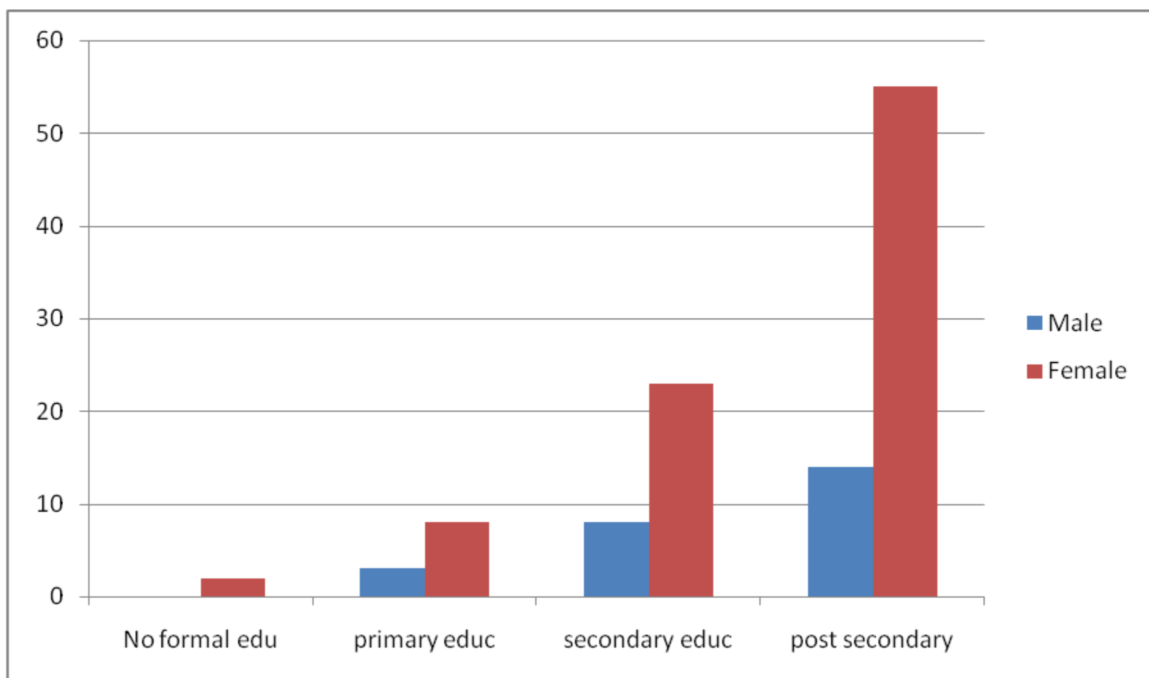
Age: Parent's age was categorized in groups from 18 years to above 45 years of age.

More than half of the parents 51.2 %(n=62) were in their middle adulthood (36-45years and above). Young adults parents (18 to 25 years) were 14.8% (n=18).

Marital Status: Most of the parents were married 69.9% (n=79), 15% were single, another 15.1%(n=17) were either separated or divorced from their spouses.

Education: Most of the parents 61.1% (n=69) had post-secondary education, 27.4% (n=31) had secondary education while 9.7% (n=11) were primary school graduates and others had dropped out at primary level. Of all the caregivers only 1.8% (n=2) did not have any formal education (see Figure 2).

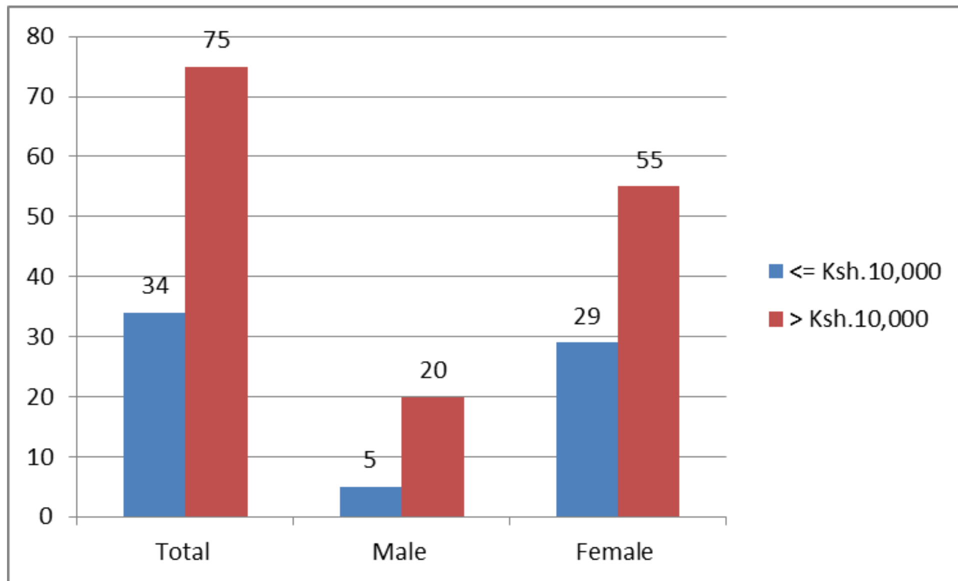
Figure 2: level of education



Employment: Most of the parents at the time of the study were employed 78.5% (n=95), either working part time, full time or self-employed. Most of those employed were self-employed 38.0 %(n=46). Another 24.8 %(n=30) were employed full time while 15.7%(n= 19) were employed as part time workers. Twenty one point forty nine percent (n=26) were unemployed.

Income status: Caregivers were classified according to level of income. Most of the participants (n=75) earned an income of Ksh 10,000 and above while 31.2% (n=34), earned less than Kshs. 10,000/-.

Figure 3: Caregiver income



Number of biological children: Besides the children with intellectual disabilities, parents had other children they were taking care of. Most parents 67.2% (n=78) have a total of 0 to 3 biological children, 27.6% (n=32) of caregivers had more than 4 biological children while 5.2% (n=6) had no 3 children in the home.

Number of people living within the home: More than half of the parents 55.2% (n=64) had 4 to 6 people living with them in the same household. 32.7% (n=38) lived with 0 to 3 people in their homes. Only 12.1% (n=14) had more than 6 people living with them.

Age of child with intellectual disability: Most of the parents 33.3% (n=39) during the period of study had a child whose age was 18 years and above meaning they were adults but still in primary school due to their intellectual impairments thus under the parents care. About thirty percent (n=25) of parents were caring for children whose age was between 10 to 12 years, those caring for children between 13and 18 years were 22.2% (n=26). Only 14.5% (n=9) parents had children below the age of 9 years.

II Prevalence of depression

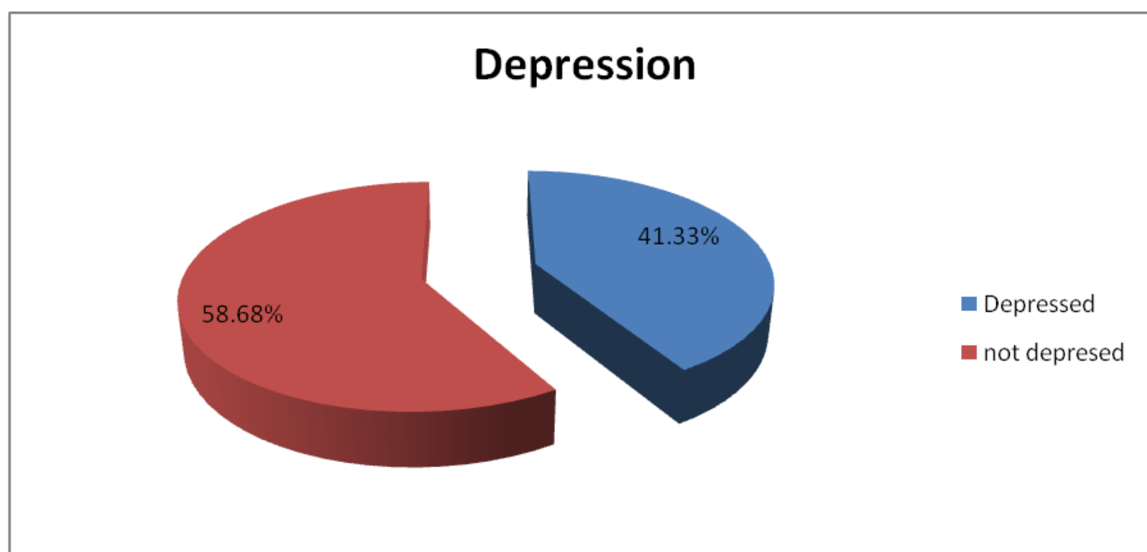
To determine the prevalence of and severity levels depressive symptoms among parents of children with intellectual disabilities, BDI II was used. Results showed that the parental BDI scores indicated presence of mild depression to severe depression.

Table 2: Symptom severity

Depression status	total sample %	male caregivers %(n=27)	female caregivers %(n=94)
No depression	58.7	40.5	63.8
Mild depression	17.4	9.6	13.8
Borderline depression	9.9	14.8	8.5
Moderate depression	11.6	14.8	10.6
Severe depression	2.5	-	3.2

From the study 41.3% of the participants were found to be clinically depressed as derived from Beck's Inventory score (see figure 4

Figure 4: Prevalence of depression



Socio demographic correlates of depression

Socio demographic factors that were associated with risk of depression included gender, age of caregiver, employment, marital status and education level.

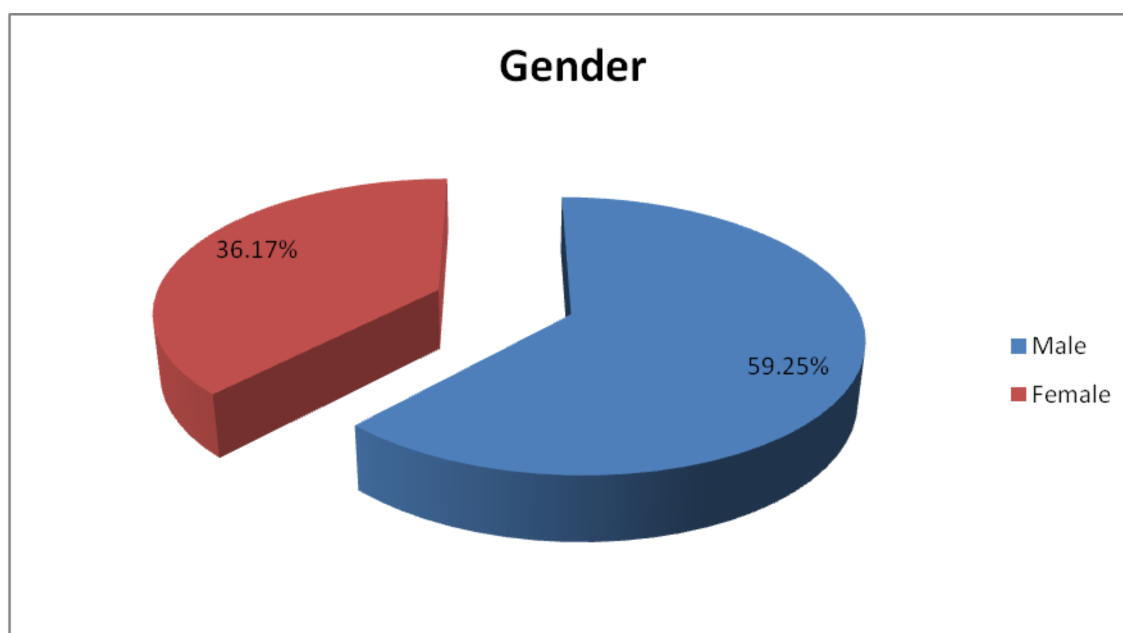
Table 3: Social demographic correlates of depression

Socio demographic characteristic	Depression		Chi-square Statistic P -value
	Yes (%)	No (%)	
All	41.3%	58.7%	
Gender			
Male	59.3%	40.7%	
female	36.2%	63.8%	0.139
Age			
18-25 years	56.6%	44.4%	
26-35 years	60.0%	40.0%	
36-45 years	24.4%	75.6%	
46+ years	44.7%	55.3%	0.077
Employment status			
Employed	46.2%	53.8%	
Unemployed	40.0%	60.0%	0.797
Income			
<= Kshs 10,000	38.2%	61.8%	
>Ksh 10,000	44.0%	56.0%	0.764

Marital status			
Single	41.2%	58.8%	
Married	32.9%	67.1%	
Divorced/separated	76.5%	23.5%	0.003
Education level			
No formal education		-	
Primary	63.6%	36.4%	
Secondary	25.8%	74.2%	
Post-secondary	40.6%	59.4%	0.0001

Gender: Male parents were more depressed (59.3%) than their female counterparts 36.2%.Women are the main caregivers in African societies and might have developed coping strategies.

Figure 5: Gender distribution



Age: Majority of the parents aged 26-35 years were highly depressed (60%). Young parents aged between 18-25years followed with depressive symptoms at 56.6%. Parents in the middle adulthood were least depressed (24.4%).

Employment status: Employed parents were more depressed (46.2%) those earning over Ksh 10,000 were more depressed 38.2% than those were earning less than Kshs 10,000. Those who are employed might have added work stressors plus burden of care for the children.

Marital status: There was a statistically significant association between marital status and depression (P=0.003). The divorced / separated parents had significant higher levels of depression (76.3%) than the single and the married. The married had spouse support and thus lower depression scores (32.9%). single parents shown lower scores of depression (41.2%) than the divorced or separated parents.

Education: There was a statistically significant association between level of education and depression (P=<0.0001). Parents who had primary education were found to be more depressed 63.6%.

Those with post-secondary education were also depressed at about forty percent. Parents with secondary education were least depressed (25.8%). There was no association between informal education and depression.

Depression scores and other demographics on family responsibilities and burden of care

Table 4: Depression scores and other demographics on family responsibilities and burden of care

socio demographics	Depression		Chi-square Statistic
	Yes	No	
	%	%	P value
Number of children			
0-3	37.2%	62.8%	
4+	53.1%	46.9%	0.089
Age of children with ID			
<=9yrs	41.2%	58.8%	
10-12 yrs	45.7%	54.3%	
13-18 yrs	34.6%	65.4%	
18+ yrs	41.1%	58.9%	0.119

Number of people living with			
0-3	42.1%	57.9%	
4-6p	31.3%	68.7%	
6+ persons	64.3%	35.7%	0.429
Marital satisfaction			
yes	47.1	52.9%	
no	32.0%	68.0%	0.196
Marital happiness			
yes	30.4%	69.6%	
no	45.1%	54.9%	0.267
Self-blame			
all the time/ mostly	40.6%	59.4%	
occasionally	33.5%	66.5%	
never	55.2%	44.8%	0.323
Community blame			
all the time/ mostly	43.4%	56.6%	
occasionally	40.5%	59.5%	
never	55.2%	44.8%	0.778
Way of discrimination			
Isolation	45.7%	54.3%	
Denied rights	14.3%	85.7%	
Made inferior	40.0%	60.0%	0.689
Care burden			
yes	38.4%	61.6%	
no	63.2%	36.8%	0.033

Number of children: Parents with more than 4 children were more depressed (53.1%) than parents with fewer children.

Age of children with ID: Parents of young children below the age of 12 years had higher levels of depression (89%). About 41.1% of parents with older children above 18 years old.

Number of people living at home: large families with more than six persons had higher levels of depression.

Self-blame and communities blame: Majority of parents (74.1%) experienced self-blame most of the time for having children with intellectual disabilities. About 84.1% were depressed due to community blaming them for having children with intellectual disabilities.

Discrimination; About 45.2% of parents experienced discrimination by way of isolation either themselves or their children with intellectual disabilities by others. Forty percent of parents were discriminated by being made to feel inferior to others while 14.3% were denied rights that they felt they needed.

Caregiver burden: There was a statistically significant association between caregiver burden and depression (P=0.033)

111. Stigmatization and Discrimination among Parents of Children with Intellectual Disabilities

Discrimination and stigma occur when people are treated unfairly because they are seen as being different from others. Levels of stigma were assessed using the DISC-12 which comprises of 32 questions that are rated on a 4-point Likert scale: not at all; a little; moderately; a lot. It contains a global scale and 4 subscales: Subscale 1 – Unfair treatment Subscale 2 – Stopping self, Subscale 3 – Overcoming stigma, Subscale 4 – Positive treatment (Thornicroft, 2013). This interview asks about how you've been affected by discrimination and stigma because of mental health problems.

Table 5: Mean scores for stigma subscales

Stigma Subscales	**All**		**Male**		**Female**	
	Mean	**S.D**	**Mean**	**S.D**	**Mean**	**S.D**
Unfair treatment	0.9	0.6	0.9	0.7	0.9	0.6
Stopping self	0.5	0.5	0.5	0.5	0.5	0.6
Overcoming stigma	1.1	0.8	1.3	0.8	1.1	0.8
Positive treatment	1.7	0.9	1.7	0.9	1.7	0.9

Stigma prevalence

Unfair treatment: About 36.4% of the respondents felt that they had been treated unfairly in at least one of life's domain. The responses had an overall mean score of 0.9 (SD = 0.6). This implies that the parents felt stigmatized and discriminated against due to having children with intellectual disabilities.

Stopping self: A relatively small percentage of parents (15.7%) felt that they had stopped themselves from initiating a close relationship, applying from work and from applying for education or training. Overall mean score of 0.5 (SD =0.5) was reported.

Overcoming stigma: About 54.6% of parents felt that they had difficulties overcoming fear thus were likely had hidden their child's condition or had made links with people who did not require mental health services; the mean distribution for the subscale was 1.5 with SD of 0.8.

Positive treatment: Most of parents (72.7%) reported positive experiences in various domains of life. The overall mean distribution for the responses was 1.7 with a SD of 0.9.

Table 6: Stigma Prevalence

	Unfair Treatment (Total Score > 21)	**Stopping Self (Total Score > 4)**	**Overcoming Stigma (Total Score > 2)**	**Positive Treatment (Total Score > 5)**
All	36.4 (27.8 - 44.9)	15.7 (9.2 - 22.2)	54.5 (45.7 - 63.4)	72.7(64.8 - 80.7)
Gender				
Male	37.0 (18.8 - 55.3)	11.1 (0.0 - 23)	51.8 (33- 70.7)	66.7 (48.9 - 84.5)
Female	36.2 (26.5 - 45.9)	17.0 (9.4- 24.6)	55.3 (45.3 - 65.4)	74.5 (65.6 - 83.3)
Respondents' Age				
18 - 25 years	22.2 (3.0- 41.4)	-	66.6(44.9 - 88.4)	55.56 (32.6 - 78.5)
26 - 35 years	6. (0.0 - 19.3)	6.6 (0.0 - 19.3)	40.0 (15.2 - 64.8)	73.3 (50.9- 95.7)
36 - 45 years	46.3 (31.1 - 61.6)	24.4 (11.3 - 37.5)	65.8 (51.3 - 80.3)	82.9 (71.4 - 94.4)
45 + years	42.5 (28.4- 56.6)	17.0 (6.3 -27.7)	44.7 (30.5 - 58.9)	70.2(57.1- 8.)
Employment Status				
Unemployed	11.5 (0.0 - 23.8)	19.2 (4.0 - 34.3)	38.4 (19.7 - 57.1)	61.5(42.8 - 80.2)
Employed	43.1 (33.2 - 53.1)	14.7(7.6- 21.8)	58.9 (49.0 - 68.8)	75.7 (67.1 - 84.4)
Income				
<= Ksh.10,000	23.5 (9.2 - 37.7)	14.7 (2.8 - 26.6)	52.9 (36.1- 69.7)	55.8 (39.1 - 72.6)

> Ksh.10,000	46.6 (35.3 - 57.9)	13.3 (5.6 - 21.0)	54.67 (43.4- 65.9)	82.6 (74.1 - 91.2)
Marital Status				
Single	17.6 (0.0- 35.7)	5.8 (0.0 - 17.0)	47.0 (23.3 - 70.7)	64.7 (41.9 - 87.4)
Married	35.4 (24.8 - 45.9)	13.9 (6.2 - 21.5)	50.6 (39.6 - 61.6)	72.1(62.2 - 82.04)
Divorced/Separated	64.7 (41.9 - 87.4)	29.4 (7.7 - 51.0)	94.1 (82.9 - 100.0)	100.0 (100.0-100.0)
Education Level				
No Formal Education	-	-	-	-
Primary Education	63.6 (35.2 - 92.0)	27.2 (0.9 - 53.5)	81.8 (59.0 - 100.0)	90.9(73.9 - 100.0
Secondary Education	22.5 (7.8- 37.3)	25.8 (10.4 - 41.2)	51.6 (34.0 - 69.2)	64.5 (47.6 - 81.3)
Post Secondary Education	39.1(27.6 - 50.6)	10.1(3.0 - 17.2)	56.5 (44.8 - 68.2)	76.8 (66.8 - 86.7)
Number of Children				
0	16.6(0.0 - 46.4)	16.6 (0.0 - 46.5)	50.0 (9.9 - 90.0)	50.0 (9.9 - 90.0)
1 to 3	39.7 (28.8 - 50.6)	15.3 (7.3 - 23.3)	56.4 (45.4 - 67.4)	84.6 (76.6 - 92.6
4+	31.2 (15.1 - 47.3)	18.7 (5.2 - 32.2)	46.8 (29.5 - 64.1)	53.1 (35.8 - 70.4)
Age of Child(ren) with Intellectual Disability				
<=9 years	17.6 (0.0- 35.7)	-	52.9 (29.2 - 76.6)	64.7 (41.9- 87.42)
10 - 12 years	42.8 (26.4 - 59.2)	34.2 (18.5 - 50.0)	74.2 (59.8 - 88.7)	85.7 (74.1 - 97.3)
13 - 18 years	46.1 (26.9 - 65.3)	7.6 (0.0 - 17.9)	50.0 (30.7 - 69.2)	80.7 (65.6 - 95.9)
18 + years	35.9 (20.8 - 50.9)	12.8 (2.3 - 23.3)	46.1 (30.5 - 61.8)	61.5 (46.2- 76.8)
Number of People Living With				
0 to 3	31.5 (16.8 - 46.3)	10.5 (0.7- 20.2)	63.1 (47.8 - 78.5)	68.4 (53.6 - 83.2)
4 to 6	42.1 (30.0- 54.2)	17.1 (7.9 - 26.4)	56.2 (44.1 - 68.4)	78.1 (68.0- 88.2)
More than 6	28.5 (4.9 - 52.2)	21.4 (0.0 - 42.9)	42.8 (16.9 - 68.7)	64.2 (39.1 - 89.3)
Marital Satisfaction				
Yes	33.8 (22.5 - 45.0)	17.6 (8.5 - 26.7)	57.3 (45.6 - 69.1)	73.5 (63.0 - 84.0)
No	38.0 (24.5 - 51.5)	10.0 (1.6 - 18.3)	50.0 (36.1 - 63.8)	72.0 (59.5 - 84.4)
Marital Happiness				
Yes	32.6 (19.0 - 46.1	10.8 (1.8- 19.8)	47.8 (33.3 - 62.2)	71.7 (58.7- 84.7)
No	36.6 (25.4 - 47.8)	16.9 (8.1 - 25.6)	56.34(44.8 - 67.8)	71.8 (61.3 - 82.2)
Self Blame				
All the time/Mostly	35.1 (19.7 - 50.5)	18.92 (6.3 - 31.5)	62.2 (46.5 - 77.8)	78.4(65.1 - 91.6)
Occasionally	40.0 (27.0 - 52.9)	16.36 (6.6 - 26.1)	52.7 (39.5 - 65.9)	67.3 (54.8 - 79.7)
Never	31.0(14.2 - 47.8)	10.34 (0.0 - 21.4)	48.3 (30.1 - 66.5)	75.8 (60.3 - 91.4)
Community Blame				
All the time/Mostly	36.8 (26.0 - 47.7)	11.8 (4.5 - 19.1)	52.6 (41.4 - 63.8)	76.3 (66.7 - 85.8)
Occasionally	40. (24.7 - 56.4)	24.3 (10.5 - 38.1)	56.7 (40.7 - 72.7)	64.8 (49.4 - 80.2)
Never	14.3 (0.0 - 40.2)	14.29 (0.0 - 40.2)	71.4 (37.9 - 100.0)	71.4 (37.9- 100.0)
Way of Discrimination				

Isolation	44.2 (32.6 - 55.9)	15.7 (7.1 - 24.2)	55.7 (44.0 - 67.3)	77.1(67.3 - 86.9)
Denied Rights	14.2 (0.0 - 40.2)	14.2 (0.0 - 40.2)	71.4 (37.9 - 100.0)	85.7 (59.7 - 100.0)
Made Inferior	40.0 (9.64 - 70.3)	10.0 (0.0 - 28.6)	60.0 (29.6 - 90.4)	70.0 (41.0 - 98.4)
Care Burden				
Yes	41.4 (31.7- 51.1)	17.1 (9.7 - 24.6)	62.6 (53.1 - 72.1)	77.7 (69.6 - 85.9)
No	15.7 (0.0 - 32.1)	5.2 (0.0 - 15.3)	15.7 (0.00 - 32.1)	42.1 (19.9 - 64.3)

Factors associated with each of the Stigma subscales

In assessing the explanatory variables that were correlated with each of the stigma subscales (unfair treatment, stopping self, overcoming stigma and positive treatment), a multivariate logistic regression was fitted. Here, the same variable selection strategy used in univariate (one response – per subscale) analysis was adopted (though here the 'dependent variable' consisted of all the four stigma subscale).

Table 8: logistic regression for stigma subscale

Factors	**Unfair Treatment**		**Stopping Self**		**Overcoming Stigma**		**Positive Treatment**	
	UOR (95% C.I)	**AOR (95% C.I)**	**UOR (95% C.I)**	**AOR (95% C.I)**	**UOR (95% C.I)**	**AOR (95% C.I)**	**UOR (95% C.I)**	**AOR (95% C.I)**
Gender								
Female	0.9(0.0-3251.2	-	36.0 (0.1 - 96207.3)	-	3.1 (0.0 - 9895.1)	-	7.0 (0.0 - 18780.0)	-
Male#								
Respondents' Age								
18 - 25 years#								
26 - 35 years	0.5 (0.1 - 1.5)	0.7 (0.2 - 1.8)	1.4 (0.8 - 2.5)	0.4 (0.0 - 1.4)	0.1 (0.0 - 2.0)	-	2.4 (0.5 - 30.3)	-
36 - 45 years	24.5 (1.2 - 65681.3*	1.7 (0.5 - 4.9)	112.8 (2.7 - 352386.8)*	**4.3 (1.0 - 39.6)***	1.0 (0.0 - 3444.7)	-	17.9 (0.0 - 47902.1)	-
45 + years	5.6 (1.9 - 39.7)*	1.7 (0.7 - 3.9)	4.1 (2.58 - 7.04)*	**3.8 (1.3 - 20.9)***	0.2 (0.0 - 1.5)	-	2.1 (0.7 - 7.3)	-
Employment Status								
Unemployed	0.1 (0.0 -	-	31.1 (0.0	-	0.1 (0.0	-	0.2 (0.0 -	-

	161.9)		- 104905.)		- 476.6)		609.3)	
Employed#								
Income								
<=Ksh. 10,000	0.1 (0.0 - 380.8)	-	8.4 (0.0 - 28417.6)	-	0.7 (0.0 - 2171.1)	-	0.1(0.0 - 377.1)	-
>Ksh. 10,000#								
Marital Status								
Married	1.7 (1.0 - 3.0)*	0.9 (0.4 - 1.9)	1.8 (1.4 - 2.3)*	0.4 (0.0 - 1.0)	1.1 (0.6 - 1.9)	-	1.3 (0.7 - 2.3)	-
Divorced/Separated	31.0 (0.0 - 96910.5)	**7.8 (2.8 - 118.9)***	108.9 (0.0 - 368124.5)	0.1 (0.0 - 1.3)	26.2 (0.0 - 70115.1)	-	23.5 (0.0 - 62903.7)	-
Single#								
Number of Children								
0	0.3 (0.0 - 3.8)	-	0.1 (0.0 - 187.8)	-	0.9 (0.1 - 2983.6)	-	0.8 (0.1 - 20.5)	-
1 to 3	10.5 (0.0 - 28085.2)	-	0.1 (0.0 - 436.8)	-	6.4 (0.0 - 17099.0)	-	19.6 (0.0 - 52378.6)	-
4+#								
Age of Child(ren) with Intellectual Disability								
<=9 years	0.3 (0.1 - 0.6)	**0.4 (0.2 - 0.9)***	0.5 (0.4 - 0.7)	1.0 (0.3 - 5.3)	1.2 (0.4 - 4.7)	-	1.1 (0.4 - 3.6)	1.0 (0.3 - 3.8)
10 - 12 years	2.8 (1.2 - 12.8)*	0.8 (0.4 - 1.9)	100.3 (0.1 - 268131.5)	**5.1 (1.1 - 76.2)***	15.9 (0.0 - 42725.8)	-	17.0 (1.8 - 45493.1) *	**15.6 (1.1 - 39047.2) ***
13 - 18 years	14.2 (0.5 - 44211.7)	1.1 (0.4 - 3.2)	0.7 (0.5 - 1.0)*	0.2 (0.0 - 1.6)	1.1 (0.4 - 3.1)	-	3.8 (1.3 - 50.3)*	2.1 (0.7 - 14.9)
18 + years#								
Number of People Living With								
0 to 3	1.3 (0.2 - 60.0)	-	0.0 (0.0 - 2.2)	-	11.3 (0.0 - 30107.0)	-	1.5 (0.1 - 8.9)	-
4 to 6	15.4 (0.0 - 41135.0)	-	0.1 (0.0 - 815.9)	-	2.7 (0.5 - 16.9)	-	11.6 (0.0 - 31134.5)	-
More than 6#								
Marital Satisfaction								

None	5.9 (0.0 - 18288.6)	-	0.0 (0.00 - 136.8)	-	0.4 (0.0 - 1045.3)	-	0.7 (0.0 - 2264.6)	-
Yes#								
Marital Happiness								
None	5.8 (0.0 - 15356.3)	-	34.7 (0.1 - 108479.8)	-	5.7 (0.0 - 15421.1)	-	1.1 (0.0 - 3361.6)	-
Yes#								
Self-Blame								
All the time/Mostly	1.7 (0.4 - 10.6)	-	46.6 (1.6 - 145674.1)*	1.0 (0.3 - 2.9)	8.8 (0.0 - 23677.3)	-	2.5 (0.0 - 7753.6)	-
Occassionally	10.8 (0.0 - 28862.5)	-	3.6 (2.1 - 7.3)*	1.1 (0.4 - 2.9)	1.4 (0.4 - 5.4)	-	0.3 (0.0 - 1.5)	-
Never#								
Community Blame								
All the time/Mostly	6.7 (1.2 - 59.1)*	1.7 (0.6- 5.3)	1.0 (0.5- 1.8)	-	0.2 (0.0 - 956.0)	-	6.9 (0.0 - 21848.7)	-
Occasionally	22.2 (0.01 - 69312.6)	1.7 (0.6 - 5.6)	61.1 (0.2 - 190745.)	-	0.2 (0.0 - 1195.0)	-	0.7 (0.0 - 7.0)	-
Never#								
Ways of Discrimination								
Isolation	5.5 (0.0 - 17467.0)	-	35.0 (0.1 - 109340.0)	2.4 (0.9 - 8.5)	0.9 (0.3 - 1.8)	-	2.4 (1.0 - 6.9)*	1.3 (0.3 - 4.3)
Denied Rights	0.2 (0.0 - 2.9)	-	1.6 (0.3 - 16.5)*	0.7 (0.1 - 5.5)	7.8 (0.0 - 26246.0)	-	11.5 (0.0 - 38893.6)	1.2 (0.2 - 21.8)
Made Inferior#								
Care Burden								
No	22.14(0.0 - 59163.8)	-	55.5 (0.3 - 148367.5)	-	19.0 (0.0 - 50856.)	-	19.6 (0.0 - 52272.)	-
Yes#								
Depression								
Normal#								
Mild Depression	1.7 (1.0 - 3.1)*	1.5(0.7 - 4.0)	0.0 (0.0 - 68.9)	-	0.1 (0.0 - 0.3)*	0.5 (0.3 - 2.1)	0.6 (0.4 - 0.8)*	0.6 (0.1 - 2.6)
Borderline Clinical Depression	0.5 (0.3 - 0.7)	**0.3 (0.1 - 0.5)***	0.0 (0.0 - 35.3)	-	0.6 (0.0 - 20.9)	0.7 (0.3 - 2.1)	0.4 (0.3 - 0.6)*	0.5 (0.1- 3.02)
Moderate Depression	29.9 (2.9 - 93693.2)*	15.6 (1.0 - 48845.0	0.0 (0.0 - 55.7)	-	2.9 (0.0 - 9810.2)	0.8 (0.3 - 3.1)	0.72 (0.48 - 1.07)	0.45 (0.07 - 2.7)

		)						
Severe Depression	3.3 (0.9 - 112.1)	3.0 (0.5 - 9654.9)	0.01 (0.0 - 29.8)	-	0.06 (0.0 - 0.2)*	**0.0 (0.0 - 0.1)***	12.5 (0.0 - 53379.)	0.0 (0.0 - 155.6)

The adjusted analyses on table 7 showed the following associations;

Associations with unfair treatment: Divorced or separated caregivers faced increased unfair treatment compared to single caregivers (OR: 7.8 [2.8 – 118.4], p – value = <0.0001).

Parents with older children faced increased odds of unfair treatment compared to parents with younger children (with intellectual disability).Increased unfair treatment is associated with higher levels of depression.

Associations with stopping self: Self-stopping was significantly associated with caregivers' older age, older age of child (ren) with intellectual disabilities.

Associations with overcoming stigma: Reduced ability to overcome stigma is associated with increased levels of depression.

Associations with Positive treatment: Parents with younger children have increased odds of positive treatment than parents with older children.

Chapter 5: Discussion

In the current study 41.3 % of parents met the criterion for being at risk of clinical depression (that is a score of 11 or higher on BDI scale). The parents had not previously been screened for depression. This finding is consistent with that of Family Caregiver Alliance, 2001 which reported a 30% to 59% rate of caregiver depressive disorders or symptoms.

A study done in rural Kenya showed a higher prevalence at 79% of caregiver (Mbugua et al, 2011). The study looked at prevalence of depression among caregivers of children with intellectual disability in a rural setting in Kenya. In a related study done on caregivers of children with mental illness in Kenyatta National Hospital showed 56.2% of caregivers at risk of clinical depression (Otieno Mary, 2013).

The study looked at prevalence of depression among caregivers of children with intellectual disability in a rural setting in Kenya. In the current study caregivers live and work in various parts of Kenya and their children are registered in Special public primary schools in Nairobi County. The schools are boarding schools thus the parents are not primary caregivers during the term and only take care of the children during the school holidays.

The socio demographic characteristics of the caregiver show that there was an association between gender and high risk of depression. *More females than male were present in the study*. The study was carried out during school meetings and it indicated that most females attended such meetings as they were regarded as visiting days which most females attend to check the wellbeing of their children. Most of the parents are married (69.2%), employed (78.5%) and have significant incomes to support burden of care of their children.

One of the most striking results of this study was the significantly higher scores of depression in fathers of children with intellectual disabilities than in mothers. Contrary to previous studies, where female are at more risk 51

for depression than men, it was found that men 22.3 %(N=27) were at higher risks for depression. This may be due to the reason that women are primarily the main caregivers in most families, thus may have developed coping strategies.

The current study found out that younger parents (26-35 years) were at a higher risk of depression (60%).Sandy et al., (2007), found that being a younger caregiver was predictive of higher levels of depressive symptoms. In a similar study, Goodhead and McDonald (2007) found that younger caregivers experience higher levels of burden.

Older parents had low risks of depression. Jung-Hwa (2010) found that older parents have more experiences parenting which may lead them to be less affected by the child's disability than younger parents. Further adaptation to stress over time may lead to lower stress levels and greater well -being as seen in older parents.

There was a statistically significant association between marital status and depression (P=0.003). The divorced / separated parents had significant higher levels of depression (76.5%) than the single and the married. In earlier studies, Frey et al.(1989) found that divorced/separated and single caregivers may have adopted coping strategies therefore had a lower risk of clinical depression compared to married caregiver. In this study, married caregivers were the majority (69.9%) and cited to have marital satisfaction and happiness thus lower depression scores Mbugua et al., (2011) found married caregivers to be at a higher risk of depression due to lack of emotional support from the spouse.

The other statistically significant risk factor to the development of depressive symptoms was caregiver burden with a p =0.033. In the current study, the results showed that 38.4 %(n= 47 experienced burden of care. Saunders J. C., (2003) found that caring exerts pressure on the caregiver. As the stressors increase and the condition persist, the caregiver symptoms may worsen. This deterioration of caregiver health may impact on their ability to continue their role responsibility.

The current study found statistically significant relationship between caregiver education and depressive symptoms P=<0.001. Most of the parents 61.1% (n=69) had post-secondary education, 27.4% (n=31) had secondary education while 9.7% (n=11) were primary school graduates and others had dropped out at primary level. Of all the caregivers only 1.8% (n=2) did not have any formal education. Of those with primary education(n=11) 63.6% had depressive symptoms .This is in consistent with McLearn et al., 2006; McLennan et al., 2001 who found that caregivers who had lower levels of education were more likely to report depressive symptoms. Higher level of education was associated with employment (business or self-employment), higher levels of income and lower risks of depressive symptoms.

Thornicroft et al (2009) in their study found that people with mental health problems experienced stigma and discrimination frequently. This is in keeping with current study that shown that 36.4% of caregivers experienced discrimination by family members, friends and the public, 15.7% had stopped themselves from applying for work, education and training. However the rates were lower than the study by Evans-Lacko et al (2014) as the participants had not been previously diagnosed with depression.

Ali et al (2012) explored the role of stigma in parental wellbeing. Their studies demonstrated that stigma is associated with caregivers' burden, marital satisfaction and experiences of social exclusion in parents of children with intellectual disabilities. The current study found stigma and discrimination to be significantly related to parent's depressive symptoms independently of other variables. In the study stigma reflects the extent to which parents felt fairly untreated, self-stigma, their ability to avoid stigma and areas of positive treatment in regards to the disability of their child. These study findings are in keeping with a study done on global patterns of experienced and anticipated discrimination (Aspen 2012)

The current study found stigma and discrimination to be significantly related to parent's depressive symptoms independently of other variables. Higher levels of experienced discrimination were

associated with greater levels of depression. Similar studies found that levels of discrimination were high in depressed persons (Corker et al., 2013; Lasalvia et al., 2013; G Thornicroft et al., 2009) In the DISC-12 anticipated discrimination occurs when a person limits their own involvement in important aspects of everyday life because of the expectation of being discriminated against (for example, when an individual does not apply for a job because he/she fully expects to fail in any such application) (Lasalvia et al., 2013). A study by Evans-Lacko et al (2014) showed higher levels of experienced discrimination in a population diagnosed with depression. Stigma and discrimination cut across all demographic factors with most parents feeling unfairly treated, this could be due to society stigma towards disability as well as lack of resources in our country to provide better services to people living with disabilities. These results are consistent with Seltzer et al 2001 study on the life course impacts of parenting a child with a disability which found that there are emotional burdens associated with the stigma of the disabilities.

The current study shows a significant association between depressive symptoms and unfair treatment. This is in keeping with a study done in Ireland that shown that parents of children with disabilities reported more depressive symptomology, higher stigma and lower self-esteem (J. Cantwell et al 2015). Inability to overcome stigma significantly increased levels of depression.

Higher levels of anticipated discrimination were moderately associated with increasing age**,** but the strongest association was with gender. Females anticipated higher levels of discrimination than males in several areas including housing, employment and family life.

In the current study 15.7% felt that they had stopped themselves from initiating a close relationship, applying for work and from applying for education or training. This is consistent with global study (Lasalvia et al., 2013) that reported 37% of participants had stopped themselves from initiating a close personal relationship using the same scale.

About 54.5% of parents felt that they had difficulties overcoming fear thus were likely had hidden their child's condition or had made friends with other people who did not use mental health services. Importantly 72.7% reported positive treatment in various domains of life. These findings suggest that

the social environment could be a source of support to caregivers, depending on the context or the personal resources of the individual.

Limitations

The study did not look into pre-existing depression which may have had an influence on the findings. The study was limited to urban schools, and thus the results will be generalized to the rural population.

It is important to note that the participants selected for this study were drawn from a convenience sample of caregivers whose children are registered in special schools in Nairobi which are few. The sample has a higher level of formal education and a greater percentage is married. The results may not reflect the general population of parents of children with intellectual disabilities.

Conclusion

Discrimination acts as a barrier to social participation and successful vocational participation for parents and in turn a contributor to development of depressive symptoms. The rates of parent's depressive symptoms and levels of stigmatization suggest that interventions should include attention to the mental health and recovery of parents in addition to their children. Young parents, male parents and those with lower levels of education are particularly at risk of depression and high levels of discrimination and stigma. The findings suggest that future interventions designed to decrease stigma in society should include parents of children with disabilities.

Recommendations

It is important to routinely screen caregivers of children with intellectual disability for depressive symptoms. There is need to avail a support system to prevent or reduce the risk of depression. This may include specialized information, caregiver training, education and family counselling aimed at a more holistic way of care. The introduction of methods to minimize discrimination towards people

with intellectual disabilities at individual, institutional, and structural levels and the identification of effective strategies to reduce anticipated discrimination by people with intellectual disabilities towards themselves might be necessary to tackle stigma and discrimination.

Providing parents with methods for dealing with perceived stigma and highlighting the importance of attending support groups for emotional support may mitigate some of the negative consequences of stigma, such as the impact on coping and support.

Larger populations randomly selected from a national sample may be the focus in future studies to determine with more confidence the prevalence of depression and levels of stigma among caregivers of children with intellectual disabilities.

References

Abidin, R. R. (1995). *Parenting Stress Index: Professional Manual* (3rd Ed.). Odessa,FL: Psychological Assessment Resources, Inc.

Ali et al . (2012). self stigam in people with Int

ellectual Disability and cortersy stigma in family caregivers ;a systemic review. *Res Dev Disabil* , 2122-2140.

Anderson, L. S. (2008). Predictors of parenting stress in a diverse sample of parents of early adolescents in high-risk communities. *Nurs Res,* 57(5), 340–350.

Anthony, L. G., Anthony, B. J., Glanville, D. N., Naiman, D. Q., Waanders, C. & Shaffer, S. (2005). The relationships between parenting stress, parenting behaviour and preschoolers' social competence and behaviour problems in the classroom, *Infant and Child Development, 14,* 133–154.

Azeem et al . (2013). Anxiety and depression among parents of children with intellectual disability in pakistan . *J Can Acad Adolesc Psychiatry* .

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual and Developmental Disabilities, 50,* 184-198.

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24,* 38-49. doi: 10.1177/1088357608323699.

Byrne, E.A., & Cunningham, C.C. (1985). The effects of mentally retarded children on families: A conceptual framework. *Child Psychology & Psychiatry, 26,* 847-864.

Crnic, K. A., Gaze, C. & Hoffman, C. (2005). Cumulative parenting stress across the Preschool period: relations to maternal parenting and child behaviour at age 5, *Infant and Child Development, 14*, 132–137.

Crnic, K., & Low, C. (2002). Everyday stresses and parenting. In M. Bornstein (Ed.),*Handbook of Parenting: Practical Issues in Parenting* (2nd ed.) (pp. 243–267). Mahwah, NJ: Lawrence Erlbaum Associates.

Deater-Deckard, K. (2004). *Parenting stress.* New Haven: Yale University Press..

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research, 49*, 657-671.

Esdaile, S. A. (2003). A comparison of mothers' and fathers' experience of parenting stress and attribution for parent-child interaction outcome. *Occupational Therapy International 10* (2), 115-126.

Gallagher et al . (2008). predictors of psychological morbidity in parents of children with intellectual disabilities. *j pediatr psychol* , 1129-1136.

Giallo et al . (2015). risk factors associated with tha mental health of fathers of children with an Intellectual disability in Austraria. *J intellect disabil Res* , 193-207.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. Social Science and Medicine, 64, 150–163.

Gupta, A., & Singhal, N. (2004). Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal.15* (1), 22-35.

Gupta, V. B. (2007). Comparison of parenting stress in different developmental disabilities. *Journal of Physical Disability, 19*, 417-425.

Hanson, M. J., & Hanline, M. F. (1990). Parenting a child with a disability: A longitudinal study of parental stress and adaptation. *Journal of Early Intervention, 14,* 234–248.

Hassall, R, Rose, J. & McDonald, J. (2005), Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*, 405-418.

Hung, J. W., Wu, Y., & Yeh, C. (2004). Comparing stress levels of parents of children with cancer and parents of children with physical disabilities. *Psycho-Oncology, 13*(12), 898 - 903.

Keller, D., & Honing, A. S. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry, 74*(3), 337-348.

Leung, C., Leung, S., Chan, R., Tso, K., & Ip, F. (2004). Child behaviour and parenting stress in Hong Kong families. *Hong Kong Med J 2005;*11:373-80.

Minnes et al . (2014). predictors of distress and wellbeing in parents of young children with developmental delay and disabilities : the importance of parent perceptions . *J intellect Disabil Res* , 10.

Neece & Baker ;. (2009). predicting parental stressin middle childhood: roles of child intellectual status behavior problems and social skills. *J Intellect Disabil Res* , 1114-1128.

Norizan . (2010). predictors of parenting stress among malaysian mothers of children with Down syndrome. *J intellect Disabil Res* , 992-1003.

Norlin et al . (2013). parents of with and without intellectual disability :couple relationship and individual wellbeing. *J intellect Disabil Res* , 552-66.

.Olsson, M. B. and Hwang, C. P. (2001), Depression in mothers and fathers of children with intellectual disability. Journal of Intellectual Disability Research, 45: 535–543. doi: 10.1046/j.1365-2788.2001.00372.x

Osborne, L. A. & Reed, P. (2009). The relationship between parenting stress and behavior problems of children with autistic spectrum disorders. *BNET.* Retrieved Feb, 4, 2010,from http://findarticles.com/p/articles/mi_hb3130/is_1_76/ai_n39315007/?tag=content;col1

Pinderhughes, E. E., Nix, R., Foster, A. M., & Jones, D. (2001). Parenting in context: Impact of neighborhood poverty, residential stability, public services, social networks, and danger on parental behaviors. *Journal of Marriage and Family,* 63, 941–953.

Rao PA, Beidel DC. The impact of children with high-function autism on parental stress, sibling adjustment, and family functioning. Behavior Modification. 2009;33:437–451. doi: 10.1177/0145445509336427. [Pub Med]

Resch, J. A., Elliott, T. R., Benz, M. R. (2012). Depression among parents of children with disabilities. *Families, Systems, & Health*. Advance online publication. doi: 10.1037/a0030366

Saied, H. (2006). *Stress, coping, social support and adjustment among families of children in picu after heart surgery.* Unpublished Doctoral Dissertation, Case Western Reserve University.

Saloviita, T., Itälinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a Double ABCX Model. *Journal of Intellectual Disabilities Research.* May-Jun; *47*(Pt 4-5), 300-312.

Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation, 111,* 155–169.

Terre des Hommes (2007) Netherland: Special Needs, Equal Rights, Education for Children with Disabilities in East Africa.

Tomoka et al . (2012). professional caregivers view on Mental Health in parents of children with developmental disabilities : A nationalwide study of institutions and consultation centres.in Japan . *ISRN Pediatr* .

United Press International. (2008). *14 percent of U.S. kids with special needs.* Retrieved Sep 9, 2010, from http://www.upi.com/Health_News/2008/03/05/14-percent-of-US-kids-with-special-needs/UPI-93651204755296/

Yeh, C. H. (2002). Gender differences of parental distress in children with cancer. *Journal of Advanced Nursing, 38* (6), 598-606.

Yildirim et al . (2010). Depression among mothers of children and adults with Intellectual Disabilities in Turkey . *int j nurs pract* , 53. Abidin, R. R.(1992)Determinants of parenting behavior. *Journal of Clinical Child Psychology, 21,* 407-412.

APPENDICES

Appendix 1: Participant's informed consent form explaination.

Dear participant,

My name is Mercy Njeri Githara, a Master of Science in Clinical Psychology student, in the Department of Psychiatry, University of Nairobi. Your permission is being requested to participate in a study entitled "**PREVALENCE OF DEPRESSIVE SYMPTOMS AND LEVEL OF STIGMATIZATION AMONG PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITIES"** that will be conducted in public primary special schools in Nairobi.

It is important for you to understand the following

1. Your participation is voluntary
2. You may withdraw at any time
3. If you refuse to participate none of the benefits will be denied to you nor will you lose any rights that you may have.
4. Feel free to ask questions and only participate when you are ready.

Purpose of the study

The aim of the study is to provide information whether parents of children with intellectual disabilities experience depressive symptoms and if they also experience there is any stigmatization. By understanding these, it will enable key stakeholders provide psychological help to reduce the symptoms and create awareness so as to reduce stigmatization.

Procedure

You will be asked to read this consent explanation document. You will be given time to ask the researcher questions that you may have. When you have understood and are willing to participate you will be asked to sign the consent form attached to this document. Signing the consent form indicates that you have agreed to participate in the study. After which you will be requested to fill out a questionnaire that will take about 30 to 45 minutes. No name will appear on the questionnaire. Your responses will be strictly confidential and there will be no linkage of the data by name.

Risks

There are no anticipated physical risks in participating in this study. However the questionnaire may trigger anxiety that you experience in the process of parenting your child.

Benefits

There is no direct compensation for participation in this study. However the results of the study may draw the attention of stakeholders and other institutions on the magnitude of intellectual disability in schools and utilize the same to offer help to the parents of children with intellectual disabilities. Referral to an appropriate counselor may be done if emotional distress arises from answering sensitive questions in the questionnaire. No payments would be forthcoming in agreeing to participate in the study.

Thank you for your assistance

Mercy Njeri Githara

MSc. Clinical Psychology Student

Department of Psychiatry

University of Nairobi

Tel: 0720890258.

You may also forward any concerns to The Secretary, KNH/UON- Ethics and Research Committee- (Tel: 726300-9 or P.O. Box 20773, Nairobi.)

Kwa mpendwa mshiriki

Jina langu ni Mercy N. Githara, mwanafunzi wa uzamili wa Kliniki ya Kisaikologia kwa idara la psychiatry chuo kikuu cha Nairobi. Ruhusu yako inahitajika katika wa **"PREVALENCE OF DEPRESSIVE SYMPTOMS AND LEVEL OF STIGMATIZATION AMONG PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITIES"**ambao utafanyika katika shule za Msingi za umma katika kitengo ya kipekee katika mji wa Nairobi.

Ni muhimu kuelewa yafuatayo:

1. Kushiriki kwako ni kujitolea
2. Unaweza kukoma kishiriki
3. Usiposhiriki hakuna utakachopoteza wala kunyimwa haki zinazokuhusu
4. Kuwa huru kuuliza maswali na kushiriki uapo tayari

Kusudi la utafiti

Lengo la utafiti ni kufahamu kama kuwa wazazi wa watoto walemavu kiakili wana dalili za kuzuni kwa kuelewa hawa ,wanahusika wataweza kutoa usaidizi wa kisaikolojia utakaopunguza ishara za huzuni na kueneza ujumbe utakao punguza ubaguzi wa ulemavu wa akili.

Taratibu

Utahitajika kusoma nakala hii na utapewa muda wa kuuliza mtafiti maswali.ukielewa na uwe tayari kushiriki utaulizwa kutia sahihi katika nakala utakayopewa . utiaji wa sahihi unaonyesha ya kwamba umekubali kushiriki katika utafiti huu. Baadaye utahitahitajika kujibu maswali yatakayochukua muda wa dakika thelathini hadi arobaini na tano. Usiandike majina yoyote na majibu yako yatakua siri na hatajuzwa yeyote.

Hatari

Maisha ya mshiriki hayajahatarishwa. lakini maswali yanaweza kuleta hisia za wasiwasi kutokana na ulezi wa mtoto wako.

Faida

Hakuna malipo kwa kushiriki kwa utafiti ,lakini matokeo ya utafiti yanaweza kuwavuta washika dao wengine kusaidia wazazi wa watoto walemavu akili. Kupendekezwa kwa nwanasaikolojia kunaweza fanyika kama matatizo ya kihisia yakiibuka kutokana na kujibu maswali.

Asante kwa muda wako,

Mercy Njeri Githara

Mwanafunzi wa Kliniki ya Saikolojia

Numberi ya simu: 0720890258

Pia unaweza utatuma hoja au mapendekezo yako kwa katibu mkuu wa kamati ya KNH/UON ERC

Nambari ya simu : 726300-9 or Sanduku la Posta 20773, Nairobi.)

Appendix II: Participants Consent Form

I ……………… (Code number) hereby give consent to voluntarily participate in the research study entitled:

The prevalence of depressive symptoms and level of stigmatization among parents of children with intellectual disabilities in public primary special schools in Nairobi

It has been explained to me that the project is in partial fulfillment of a Master of Psychology Degree in the Department of Psychiatry at the University of Nairobi. The purpose of this research has been explained to me and I understand that I have the right to withdraw from participating in the research study at any time, without redress.

I understand that my identity will be kept anonymous at all times. I understand that after the project has been written; all the materials used in data collection will be safely kept under key and lock to ensure confidentiality at all times.

I am aware that the researcher can assist by referring me to an appropriate counselor if sensitive information spoken during the study causes me to feel emotionally distressed.

Signature: Participant …………………………………. Date: …………………

Signature: Researcher …………………………………. Date: ……………

Mimi …………………………………….. (namba ya usajiri) najitoa katika ushiriki katika utafiti. Nimeelezwa na kupata kuelewa kuwa utafiti huu ni wa kutosheleza na kuleta ukamilifu katika idara ya Psychiaty katika Chuo Kikuu cha Nairobi.

Nimepata kufahamu kusudi la utafiti na basi naweza kujiuzulu wakati wowote. Naelewa kuwa sitapata kujitambulisha au kutambulika na yeyote. Makala yote yaliyotumika katika utafiti yatahifadhiwa vyema bila kumjuza yeyote.

Naelewa ya kwamba mtafiti anaweza nisaidia kwa kunielekeza kwa mwanasaikolojia iwapo ujumbe nitaoeleza utanifanya nitatizike kimawazo.

Sahihi (Mshiriki)………………. Tarehe ………………………

Sahihi(Mtafiti)…………………. Tarehe …………………………

Appendix 11I: Social Demographic Questionnaire part I:

Gender M F Date [ ] Serial Number [ ]

1. What age range do you fall into?

   - ☐ 18-25
   - ☐ 26-35
   - ☐ 36-45
   - ☐ 46-55
   - ☐ 56-65
   - ☐ 66 and above

2. What is your current marital status?

   - ☐ Single (never married)
   - ☐ Married
   - ☐ Remarried
   - ☐ Separated
   - ☐ Divorced
   - ☐ Cohabiting

3. What is your current employment status?

   - ☐ Unemployed
   - ☐ Working Part-time
   - ☐ Working Full-time
   - ☐ Self-Employed
   - ☐ Volunteering
   - ☐ Type of business: ____

4. What is your highest level of education?

   - ☐ No formal education
   - ☐ Primary
   - ☐ Secondary
   - ☐ Vocational Training
   - ☐ College/University
   - ☐ Post Graduate

5. What income range do you fall into?

   - ☐ Ksh 5000 and below
   - ☐ Ksh 5001-10000
   - ☐ Ksh 10001-15000
   - ☐ Ksh 15001-20000
   - ☐ Ksh 20001- 30000
   - ☐ Other income: ____

6. What is your religion?

   - ☐ Christian
   - ☐ Islam
   - ☐ Hindu
   - ☐ Other: ____

7. How many biological children do you have?

   ____

8. How many of these children have Intellectual disabilities?

8. When did you first learn about the disability?

[ ]

9. What is the age of child/children with intellectual disability?

- ☐ 1-3 years
- ☐ 4-6 years
- ☐ 7-9 years
- ☐ 10-13 years
- ☐ Other: [ ]

10. How many people are living with you?

- ☐ 1-3
- ☐ 4-6
- ☐ 7-9
- ☐ 10-12
- ☐ Other: [ ]

Socio demographic questionnaire part II: Associated factors to parental stress, depression and stigma

Depressed mood

11. Have you been unwell physically or has someone close to you been unwell that it has made you very sad? If yes, is it yourself or someone close to you, if latter how is he/she related to you?

○ Yes ◉ No

12. Has someone very dear/close to you died in last 0-12months? If yes, who was it and when?

○ Yes ○ No

Marital Satisfaction

13. Has your relationship deteriorated since the knowledge of your child's disability?

○ Yes

○ Somewhat yes

○ Mostly no

○ No

If yes state how?

○ Yes

○ No

14. Have you been happy in your relationship/marriage from the beginning?

Stigma and Discrimination

15. Do you feel ashamed of having a child with ID?

☐ All the time

☐ Mostly

☐ Occasionally

☐ Never

16. What does your community say about children with intellectual disability?

17. Do you blame yourself for having a child with ID?

☐ All the time

☐ Mostly

☐ Occasionally

☐ Never

18. Does the community blame you for having a child with ID?

☐ All the time

☐ Mostly

☐ Occasionally

☐ Never

Stress and Burden of Care giving

19. Has your child experienced discrimination (isolation, not receiving your rights, made to feel inferior or outcaste)? Yes No

If yes, state how?

○ Yes

○ No

20. Do you feel much burdened with care of your child with intellectual disabilities?

Yes

No

Kiswahili version

1.Kati ya umri hizi mbalimbali gani unaweza kuangukia?

- ☐ 18-25
- ☐ 26-35
- ☐ 36-45
- ☐ 46-55
- ☐ 56-65
- ☐ 66 na zaidi

2. Jinsia

- ☐ kiume
- ☐ kike

3. Je, ni ipi hali yako ya sasa ya ndoa?

- ☐ Bado sijaoa/sijaoleka
- ☐ Kwenye Ndoa
- ☐ Tumeachana na Mke/mume
- ☐ Talaka
- ☐ Tunaishi pamoja lakini hatujaoana

4. Hali yako ya kazi ni ipi kwa sasa?

- ☐ Sina ajira
- ☐ Nafanya sehemu wakati
- ☐ Nafanya muda kamili
- ☐ kazi ya kibinafsi
- ☐ nimejitolea bila mapato
- ☐ Aina ya biashara..

5. Ipi ngazi yako ya juu ya elimu?

- ☐ Option 1
- ☐ shule ya msingi
- ☐ shule ya upili
- ☐ ufundi mbalilmbali
- ☐ chuo kikuu/shahada
- ☐ uzamili wa shahada

6. Mapato yako ni yapi kati ya haya?

- ☐ shilingi elfu tano na chini
- ☐ kati ya shilingi 5001 na 10000
- ☐ kati ya shilingi 10001 na 15000
- ☐ kati ya shilingi 15001-20000
- ☐ kati ya shilingi 20000-30000
- ☐ zaidi ya shilingi 30000

7. Dini yako ni gani?

- ☐ mkiristo
- ☐ muisilamu
- ☐ mhindi
- ☐ Nyingine.....................

8. Je una watoto wangapi wa kibiolojia?

- ☐ kuna wengine ?

9. Watoto wangapi wana ulemavu wa akili?

☐

10. Mara yako ya kwanza kujua kuelewa kuhusu ulemavu huu ulikua lini?

☐

11. Eleza umri wa watoto/mtoto aliye na ulemavu wa akili?

12. Watu wangapi wanaishi na wewe?

- ☐ 1-3
- ☐ 4-6
- ☐ 7-9
- ☐ 10-12
- ☐ Zaidi ya 12 eleza idadi

13. **Je, umekuwa na maumivu ya kimwili ama kuna yeyote wa familia ambaye amekuwa na shida ya mwili ambayo imekuletea huzuni sana. kama ndio ni wewe ama ni mtu wa karibu na mnauhusiano gani?**

- ☐ Ndio
- ☐ La

14. **Je, kuna mtu wa uhusiano wa karibu sana na wewe ambaye ameaga kati ya miezi 0-12 .kama ndio ni nani na ilikuwa lini?**

- ☐ Ndio
- ☐ La

15. **Je, uhusiano wako umeshuka tangu upate maarifa ya ulemavu wa mtoto wako?**

- ☐ Ndio
- ☐ La

16. **Je umekua na furaha katika uhusiano wako /ndoa yangu mwanzo?**

- ☐ Ndio
- ☐ Labda ndio
- ☐ Kwa kawaida la
- ☐ La

17. **Je, unaona aibu kwa kuwa na mtoto mwenye ulemavu wa akili?**

- ☐ kila wakati
- ☐ sanasana
- ☐ mara kwa mara
- ☐ la hasha

18. **Je , wajilaumu kwa kuwa na mtoto mwenye ulemavu wa akili?**

- ☐ kila wakati
- ☐ sanasana
- ☐ mara kwa mara
- ☐ la hasha

19. **Jamaa inakulaumu kwa kuwa na mtoto mwenye ulemavu wa akili?**

- ☐ Kila wakati
- ☐ sanasana
- ☐ mara kwa mara
- ☐ la hasha

20. **Je, mtoto wako amekua na uzoefu wa ubaguzi (kutengwa,kutopokea haki zako, kupuuzwa au kudunishwa**

- ☐ ndio
- ☐ la

21. **Je wewe hujiskia na mzigo sana kwa huduma ya mtoto wako aliye na ulemavu wa akili?**

- ○ ☐ Ndio
- ○ ☐ la

Appendix IV: Beck's Depression Inventory

On this questionnaire there are groups of statements. Please read each of the statements carefully, then pick out the one statement in each group which best describes the way that you have been feeling the past week, including today

Circle the number besides the statements in each group before making your choice

1.

0. I do not feel sad
1. I feel sad
2. I am sad all the time and I can't snap of it
3. I am sad, unhappy that I can't stand it

0. I feel discouraged about the future
1. I feel I have nothing to look forward to
2. I feel that the future is hopeless and that things cannot improve
3. I am not particularly discouraged about the future

3

0. I do not feel like a failure
1. I feel that I have failed more than the average (normal) person
2. As I look back on my life, all I can see is a lot of failures
3. I feel I am a complete failure as a person

4.

0. I am not particularly discouraged about the future
1. I feel discouraged about the future
2. I feel I have nothing to look forward to
3. I feel that the future is hopeless and that things cannot improve

5.

6.

0. I get much satisfaction out of things as I used to
1. 0. I don't enjoy things the way I used to
2. I am dissatisfied or bored with everything
3. I don't get real satisfaction out of anything anymore

0. I don't feel particularly guilty
1. I feel guilty a good part of the time
2. I feel guilty most of the time
3. I feel guilty all the time

7.

0. I don't feel I am being punished
1. I feel I may be punished
2. I expect to be punished
3. I feel I am being punished

8.

0. I don't feel I am any worse than anybody else
1. I am critical of myself for my weaknesses or mistakes
2. I blame myself all the time for my faults
3. I blame myself for everything bad that happens

9.

0. I don't have thoughts of killing myself
1. I have thoughts of killing myself, but I would not carry them out
2. Would like to kill myself
3. I would kill myself if I had the chance

10.

0. I don't cry any more than unusual
1. I cry more now than I used to
2. I cry all the time

3. I used to be able to cry, but now I can't even though I want to

11

0. I am no more irritated now than I ever was
1. I get annoyed or irritated more easily than I used to
2. I feel irritated all the time now
3. I don't get irritated at all by the things that used to irritate me

12

0. I have not lost interest in other people
1. I am less interested in other people than I used to be
2. I have lost most of my interest in other people
3. I have lost all of my interest in other people

13.

0. I make decisions about as well as I ever could
1. I put off making decisions more than I used to
2. I have greater difficulty in making decisions more than I used to
3. I can't make decisions at all any more

14.

0. I don't feel I look any worse than I used to
1. I am worried that I am old or unattractive
2. I feel that there are permanent changes in my appearances that make me look unattractive
3. I believe that I look ugly

15.

16.

0. I can work about as well as before
1. It takes an extra effort to get started at doing something
2. I have to push myself very hard to do anything
3. I can't do any work at all

0. I can sleep as well as usual
1. I don't sleep as well as I used to
2. I get tired from doing almost anything
3. I am too tired to do anything

17.

0. I don't get more tired than usual
1. I get tired more easily than I used to
2. I get tired from doing almost anything
3. I am too tired to do anything

18.

0. My appetite is no worse than usual
1. My appetite is not as good as it used to be
2. My appetite is much worse now
3. I have no appetite at all anymore

19.

0. I haven't lost much weight, if any, lately
1. I have lost more than five pounds
2. I have lost more than ten pounds
3. I have lost more than fifteen pounds

20.

0. I am no more worried about my health than usual
1. I am very worried about my physical problems such as aches and pains; or upsets stomach; or constipation

2. I am very worried about my physical problems and it's hard to think of much else
3. I am worried about my physical problems that I cannot think about anything else

21

0. I have not noticed any recent change in my interest in sex
1. I am less interested in sex than before
2. I am less interested in sex now
3. I have no interest in sex completely

Kiswahili BDI

1.

0. Sina huzuni

1. Nina huzuni

2. Nina huzuni wakati wote na siwezi kijiondoa katika hali hii ya huzuni

3. Nina huzuni sana mpaka siwezi kustahimili/kuvumilia

2. 0. Sijavunjika moyo hasa na siku zusoni

1. Nahisi nimevunjika moyo na siku za usoni

2. Nahisi sina ninalo tarajia siku za usoni

3. Nahisi nimekata tamaa ya siku za usoni, na naona mambo hayawezi kuwa bora zaidi

3.

0. Sijihisi kama nimeanguka maishani
1. Nahisi nimeanguka maishani zaidi ya mtu wa kawaida
2. Nkiangalia maisha yangu yaliopita naona nimeanguka sana
3. Nahisi nimeanguka kabisa maishani

4.

0. Naridhika na mambo kama ilivyo kawaida yangu
1. Sija furahi mambo kama nilivyokuwa nikifurahia
2. Sitosheki tena kikamilifu na jambo lolote
3. Sitosheki wala sichangamshwi na chochote tena

5.

0. Sihisi hasa kama nina hatia fulani
1. Nahisi nina hatia wakati mwingine
2. Nahisi nina hatia wakati mwingi
3. Nahisi nina hatia wakati wote

6

0. Sihisi kama nina adhibiwa
1. Nahisi kama naweza kuadhibiwa
2. Natarajia kuadhibiwa
3. Nahisi nina adhibiwa

7.

0. Sihisi kama nimeikasirikia nafsi yangu
1. Nimeikasirikia nafsi yangu
2. Najidharau
3. Najichukia

8.

0. Sihisi kama mimi ni mbaya zaidi ya mtu yeyote yule
1. Najisuta (kujitoa makosa) sana katika makosa yangu ama udhaifu wangu
2. Najilaumu wakati wote kwa makosa yangu

3. Najilaumu kwa ovu lolote linalo tendeka

9.

0. Sina wazo lolote kujiua
1. Nina wazo la kujiua
2. Ningetaka kujiua
3. Nitajiua nikipata nafasi

10.

0. Silii siku hizi zaidi ya vile ilivyo kawaida yangu
1. Nalia siku hizi zaidi ya ilivyokuwa kawaida yangu
2. Nalia wakati wote siku hizi
3. Nilikuwa nikiweza kulia, lakini sasa hata nikitaka kulia siwezi

11

0. Sikasirishwi kwa urahisi siku hizi zaidi ya ilivyo kawaida yangu
1. Nakasirishwa kwa urahisi zaidi ya ilivyokuwa kawaida yangu
2. Nahisi nimekasirishwa wakati wote siku hizi
3. Sikasirishwi kamwe na mambo ambayo yalikuwa yakinikasirisha

12

0. Sijapoteza hamu ya kujihusisha au kujumuika na watu
1. Hamu yangu ya kujihusisha na watu imepungua zaidi ya ilivyokuwa
2. Nimepoteza sana hamu yangu ya kujihusisha na watu
3. Nimepoteza hamu yangu yote ya kujihusisha na watu

13

0. Ninafanya uamuzi kuhusu jambo lolote kama kawaida
1. Ninahairisha kufanya uamuzi zaidi ya vile nilivyokuwa nikifanya

2. Nina uzito mkubwa wa kufanya uamuzi kuliko hapo awaki
3. Siwezi tena kufanya uamuzi wa jambo lolote lile

0. Sihisi kuwa naonekana vibaya zaidi ya nilivyokuwa

14.

1. Nina wasi wasi kuwa naonekana sivutii
2. Ninahisi kuwa kuna mabadiliko yasio ondoka kwenye umbo langu yanayofanya nisivutie
3. Nina amini kuwa nina sura mbaya

15

0. Naweza kufanya kazi kama vile ilivyokuwa hapo awali
1. Nilazima nifinye bidii, ndipo nianze kufanya jambo lolote
2. Inabidi nijilazimishe sana ili niweze kufanya jambo lolote
3. Sitaweza kabisa kufanya kazi yoyote

16.

0. Ninalala kama kawaida yangu
1. Silali vyema kama nilivyo kuwa nikilala hapo awali
2. Naamka mapema kwa saa limoja au masaa mawili, ambayo sio kawaida yangu, halafu ni vigumu kupata usingizi tena
3. Naamka mapema zaidi ya masaa mawili, ambayo sio kawaida yangu, halafu siwezi kupata usingizi tena

17

0. Sichoki zaidi ya nilivyokuwa nikichoka hapo awali
1. Nachoka kwa urahisi zaidi ya kawaida yangu
2. Nachoshwa (Nachokeshwa), karibu na kila jambo ninalofanya
3. Ninachoka sana hata siwezi kufanya lolote

18.

0.Hamu yangu ya chakula sio mbaya zaidi ya vile ilivyokuwa hapo awali

1. Hamu yangu ya chakula sio mbaya zaidi kama vile ilivyokuwa hapo awali

2. Hamu yangu ya chakula ni mbaya zaidi siku hizi

3. Sina tena hamu ya chakula hata kidogo

19

0. Sijapunguza uzito wa mwili wa kuonekana hivi karibuni
1. Nimepunguza uzito wa mwili zaidi ya kilo mbili
2. Nimepunguza uzito wa mwili zaidi ya kilo tano
3. Nimepunguza uzito wa mwili zaidi ya kilo saba

20

0. Sina wasiwasi usio wa kawaida kuhusu haki yangu ya afya
1. Nina wasiwasi kuhusu shuda za mwili kama vile maumivu hapa na pale; au shida ya tumbo,au kufunga choo
2. Nina wasiwasi kuhusu matatizo ya mwili mpaka inakuwa ni vigumu kuwaza jambo lengine lolote
3. Nina wasiwasi kuhusu matatizo ya mwili mpaka siwezi kuwaza jambo lengine lolote

21

0. Sijaona mabadiliko yoyote hivi karibuni kuhusu hamu yangu ya kufanya mapenzi
1. Hamu yangu ya kufanya mapenzi imepungua zaidi ya vile ilivyokuwa
2. Hamu yangu ya kufanya mapenzi imepungua sana siku hizi
3. Nimepoteza kabisa hamu yangu ya kufanya mapenzi

Discrimination and stigma scale (DISC-12)

Please choose **one** answer for each question”					
1.	Have you been treated unfairly in making or keeping friends?	Not at all	A little	Moderately	A lot
Give an example:					
2.	Have you been treated unfairly by the people in your neighborhood? Not applicable	Not at all	A little	Moderately	A lot
Give an example;					
3.	Have you been treated unfairly in dating or intimate relationships?	Not at all	A little	Moderately	A lot
Give an example:					
4.	Have you been treated unfairly in housing?	Not at all	A little	Moderately	A lot
Give an example:					

5.	Have you been treated unfairly in your education	Not at all	A little	Moderately	A lot
Give an example:					

6.	Have you been treated unfairly in marriage or divorce?	Not at all	A little	Moderately	A lot
Give an example:					
7.	Have you been treated unfairly by your family?	No t at	A little	Moderately	A lot
Give an example:					
8.	Have you been treated unfairly in finding a job?	Not at	A little	Moderately	A lot
Give an example:					
9.	Have you been treated unfairly in keeping a job?	No t at	A little	Moderately	A lot
Give an example:					
10.	Have you been treated unfairly when using public transport?	No t at	A little	Moderately	A lot
Give an example:					

11.	Have you been treated unfairly in getting welfare benefits or disability?	Not at all	A little	Moderately	A lot
Give an example:					
12.	Have you been treated unfairly in your religious practices?	Not at all	A little	Moderately	A lot
Give an example:					
13.	Have you been treated unfairly in your social life?	Not at all	A little	Moderately	A lot
Give an example:					
14.	Have you been treated unfairly by the police?	Not at all	A little	Moderately	A lot
Give an example:					
15.	Have you been treated unfairly when getting help for physical health problems	Not at all	A little	Moderately	A lot
Give an example:					

		Not at all	A little	Moderately	A lot
16.	Have you been treated unfairly by mental health staff?				
Give an example:					
17.	Have you been treated unfairly in your levels of privacy?	Not at all	A little	Moderately	A lot
Give an example:					
18.	Have you been treated unfairly in your personal safety and security	Not at all	A little	Moderately	A lot
Give an example:					
19.	Have you been treated unfairly in starting a family or having children?	Not at all	A little	Moderately	A lot
Give an example:					
20.	Have you been treated unfairly in your role as a parent to your children?	Not at all	A little	Moderately	A lot
Give an example:					
21.	Have you been avoided or shunned by people who know that you have a mental health problem?	Not at all	A little	Moderately	A lot

Give an example:

22.	Have you been treated unfairly in any other areas of life?	Not at all	A little	Moderately	A lot

23.	Have you stopped yourself from applying for work?	Not at all	A little	Moderately	A lot

Give an example:

24.	Have you stopped yourself from applying for education or training courses?	Not at all	A little	Moderately	A lot

Give an example:

25.	Have you stopped yourself from having a close personal relationship?	Not at all	A little	Moderately	A lot

Give an example:

26.	Have you concealed or hidden your mental health problem from others?	Not at all	A little	Moderately	A lot

27.	Have you made friends with people who don't use mental health services?	Not at all	A little	Moderately	A lot

Give an example:					
28.	Have you been able to use your personal skills or abilities in coping with stigma and discrimination?	Not at all	A little	Moderately	A lot

31.	Have you been treated more positively in housing?	Not at all	A little	Moderately	A lot
Give an example:					
32.	Have you been treated more positively in your religious activities?	Not at all	A little	Moderately	A lot
Give an example:					
33.	Have you been treated more positively in employment	Not at all	A little	Moderately	A lot
Give an example:					
34.	Have you been treated more positively in any other areas of life?	Not at all	A little	Moderately	A lot
Give an example:					

1.	Je, umenyanyaswa kwa kutafuta na kudumisha marafiki?	Sio wakati wote	kidogo	Kiasi	sana
Toa mfano:					
2.	Je, umenyanyaswa na watu walio katika mazingira yako/ maeneo unayoishi?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
3.	Je, umenyanyaswa katika uhusiano wa karibu ama kutafuta mchumba/kuchumbiana	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
4.	Je, umenyanyaswa katika utafiti wa makao?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
	Je, umenyanyaswa katika utafiti wa elimu?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
6	Je, umenyanyaswa katika ndoa au talaka?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					

No.	Swali	Sio wakati wote	kidogo	kiasi	sana
7	Je umenyanyaswa na familia au Jamii?				
Toa mfano:					
8.	Je, umenyanyaswa katika utafiti wa kazi au ajira ?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
9.	Je umenyanyaswa katika uhifadhi wa kazi yako?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
10.	Je, umenyanyaswa katika usafiri wa magari ya umma?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
11	Je,umenyanyaswa katika kufaidika na kupata mapato ya walemavu?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
12	Je, umenyanyaswa katika shughuli zako za kidini?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					

13	Je, umenyanyaswa katika maisha ya kijamii?	Sio wakati wote	kidogo	kiasi	sana
14	Je, umenyanyaswa na polisi?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					

15	Je umenyanyaswa katika kutafuta msaada wa shida za kimwili?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
16	Je, umenyanyaswa na wafanyikazi wa ulemavu wa akili?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
17	Je, umenyanyaswa katika maisha yako ya kindani?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano					
18	Je, umenyanyaswa kaitika ulinzi wa maisha yako ya kibinafsi?	Sio wakati wote	kidogo	kiasi	sana

Toa mfano					
19	Je umenyanyaswa katika kuanza familia au kupata watoto?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
20	Je, umenyanyaswa katika kutekeleza jukumu lako kama mzazi?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					

21.	Je umetengwa ama kubaguliwa na watu wanaofahamu kuwa una shida za ulemavu wa akili?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
22.	Je umenyanyswa katika ngazi zingine za maisha?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano					
23.	Je, umekoma kutafuta kazi/ajira?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
24.	Je umekoma kujiendeleza kielimu ama	Sio wakati	kidogo	kiasi	sana

	kujiunga na vyuo mbalimbali?	wote			
Toa mfano:					
25.	Je, umekoma kuwa na uhusiano wa karibu /kibinafsi?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
26.	Je umeficha ama kuifanya hali ya ulemavu wa akili kuwa siri?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					

.27	Je umefanya urafiki na watu wasio tumia huduma za ulemavu wa akili	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
28	Je umeweza kutumia uwezo wako na ujuzi katika uzoefu wa unyapaa na ubaguzi wa ulemavu wa akili?	Sio wakati wote	kidogo	kiasi	sana

Toa mfano:					
29.	Familia yako imeweza kukubali hali yako?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
30	Je, umepokea vyema katika kufaidika na mapato ya walemavu?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
31	Je, umepokelewa vyema katika makaazi yako?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
32	Je, umepokelewa vyema katika shighuli za kidini?	Sio wakati wote	kidogo	kiasi	sana
Toa mfano:					
33	Je , umepokelewa vyema katika kuajiriwa?	Sio wakati wote	kidogo	kiasi	sana

<table>
<tr><td colspan="6">Toa mfano:</td></tr>
<tr><td rowspan="2">34</td><td rowspan="2">Je, umepokelewa vyema katika viwango mbalimbali za maisha?</td><td>Sio wakati wote</td><td>kidogo</td><td>kiasi</td><td>sana</td></tr>
<tr><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="6"></td></tr>
</table>

Appendix VI: Letter of Approval from Ethics and Research Committee

Appendix VII: Proposed Work Plan- Flow Chart

TIME SCHEDULE

Development of proposal	December 2014- February 2015
Approval of proposal	February 2015 -March 2015
Ethics committee	March 2015- June 2015
Data collection	January- March, 2016
Data analysis and reporting	March- June , 2015
Presentation	June, 2016

Completion of the work and binding of the book.

Appendix VII: Budget

Financial implications of the study will be:

Proposal preparation

Typing and printing	4000
Photocopies	8000
KNH/UON/ERC	1000
Internet/ communication	5000

Stationery

Foolscaps 1 ream	400
A4 printing papers	600
1 dozen Pencils	240
5 Rubbers	250
Pens 1dozen	250
2 Rulers	100
Pins (1 pack)	250
Paper punch	1000

Storage devices

Flash disc (2GB)	500

Travelling/lunch expenses

From the house to the schools for 12 working days @ 500 per day -6,000(researcher)

Data processing

Coding and entry	20000
Analysis	15000
Book binding	10,000
Sub Total	**72,590**
Contingency 15% of total =	**10,888.50**
Total =	83,478.50

The proposal is not sponsored by anyone so I will meet all the expenses

TOTAL amount required to complete the research is therefore ksh.**83, 500**