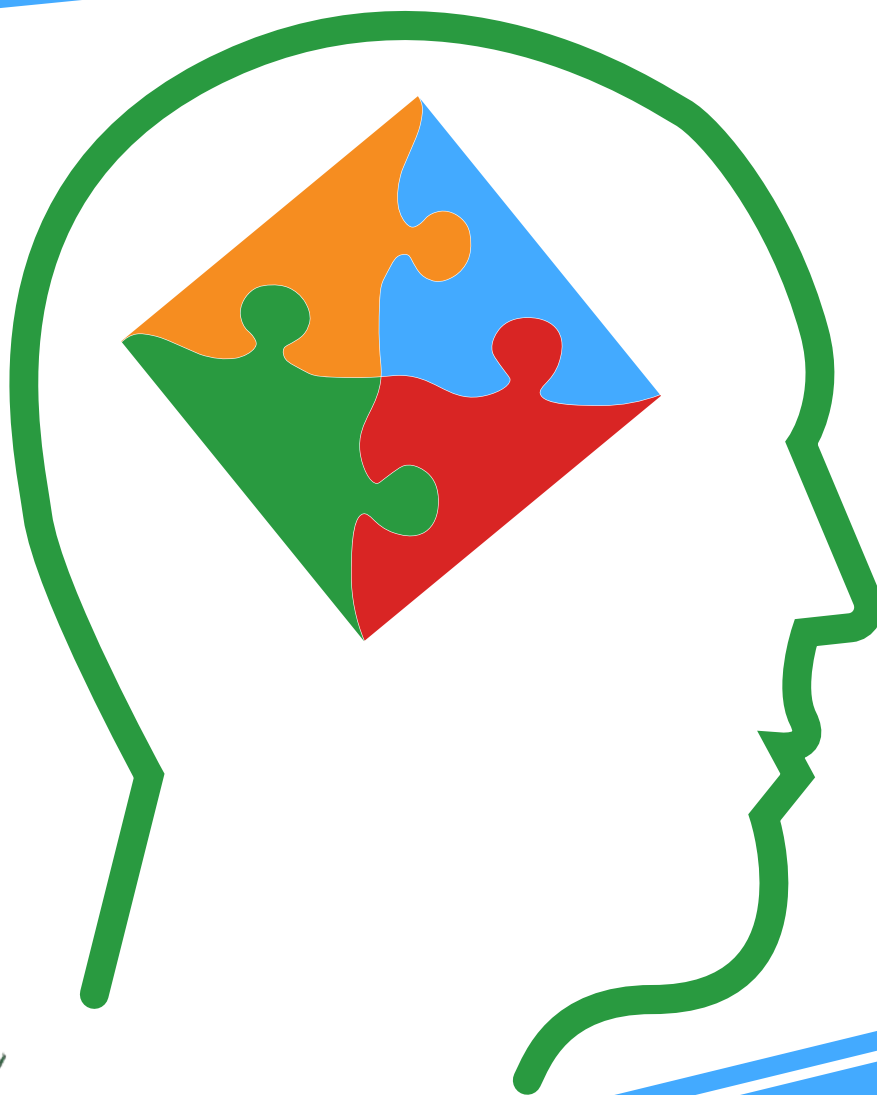




NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES (NCPWD)



ANALYTICAL MONOGRAPH ON AUTISM

SPECTRUM DISORDERS AND RELATED
DEVELOPMENTAL DISABILITIES



Vision

**“A barrier free society for
Persons with Disabilities”**



Mission

**“To promote and protect
equalization of opportu-
nities and realization of
human rights for persons
with disabilities to live
decent livelihoods”**



Core values

**Non-discriminative
Commitment
Protection
Willingness
Disciplined
Sustainable**

FOREWORD



STATEMENT BY THE CABINET SECRETARY, MINISTRY OF LABOUR AND SOCIAL PROTECTION

The complexities underpinning Autism Spectrum Disorders (ASD) and other related developmental disabilities make it difficult to be detected and understood. The lack of understanding and recognition has led to stigmatization, discrimination and isolation of affected persons. The main objective of this monograph was to provide the Government and relevant stakeholders with essential information for evaluating policies and easing planning and budgeting processes.

The monograph is imperative to the realization of the Bottom-up Economic Transformation Agenda (BeTA), the Council's Strategic Plan of 2023-2027, the universal health coverage agenda and the Sustainable Development Goals (SDGs). The report not only enhances knowledge on this subject but also serves as a basis for assessment, reporting and eventually monitoring inclusion of issues affecting Persons with ASD & other related developmental disabilities and their caregivers in the Government plans and programmes at the national and county levels.

Generally, the analysis reveals that extra costs were incurred by the caregivers towards therapy and in incontinence management supplies. These costs vary from one developmental disability to another. Specifically, the evidence is expected to contribute immensely towards measuring and monitoring the attainment of Goal 3 of the Sustainable Development Goals on Good Health and Well-being; Goal Number 4 on Quality Education and; Goal 10 on Reduced Inequalities that have special association to persons with ASD and related developmental disabilities.

On behalf of the Government, I wish to thank the Management and Board of Directors of the National Council for Persons with Disabilities as well as stakeholders who have made contributions towards the preparation of this report.

Hon. Florence Bore
Cabinet Secretary,
Ministry of Labour and Social
Protection

CONTENTS

FOREWORD	3
ABBREVIATIONS	6
OPERATIONAL DEFINITIONS OF KEY TERMS	7
01 INTRODUCTION	8
1.1 Background and Context of the Assessment	8
1.2 Purpose, Goal and Objectives of the study	9
1.3 Specific Objectives:	9
1.4 Research Questions	9
1.5 Scope of the and Study	10
1.6 Assumptions of the Study	10
1.7 Limitations of the Study	10
1.8 Rationale for the Study	10
1.9 Conceptual Framework	10
02 SITUATION ANALYSIS	12
2.1 Disability in Kenya	12
2.2 National and International Legal frameworks and Policies on ASD & RDD	14
2.2.1 National Instruments	14
Table 2.1: Statutes that Protect the Rights of PWDs	14
Table 2.2: Policies that Protect the Rights of PWDs	15
2.2.2 International Legal Instruments	15
2.2.3 Gaps in the Laws	17
Table 2.3: Gaps in the law	17
03 RESEARCH METHODOLOGY	18
3.1 Research Design	18
Figure 3.1: Overview of the Methodology	19
3.2 The phased-in approach to the development of the monograph	19
3.2.1 Phase I: Pre-field data collection steps	19
Figure 3.2: Overview of the phased in approach	20
3.3 Study Population	20
3.4 Sample and Sampling Techniques	20
Table 3.1: Sample Frame	20
3.5 Instruments of Data Collection	20
3.5.1 Quantitative Data collection instruments	20
3.5.2 Qualitative Data Collection Techniques	21
3.6 Eligibility criteria for inclusion/exclusion in the study	21
3.7 Validity and Reliability of the Research Instruments	21
3.7.1 Validity of the Research Instruments	21
3.8 Procedure of data collection	21
3.9 Data Analysis	22
3.9 Ethical considerations	22
04 KEY FINDINGS AND DISCUSSIONS	23
4.1 Socio-demographic characteristics of respondents	23
4.1.1 Response rate	23
Table 4.1: Distribution of respondents by County and gender	24
4.1.2 Response Rate Per Region	24
Figure 4.1: Response Rate Per County	24
4.2.1: Category of Respondents	25

Table 4.2: Category of respondents by gender	25
4.2.2: Age of Respondents in Years	25
Figure 4.2.1: Age of Respondents in Years	25
4.2.3 Highest Level of Education Attained by Respondents	25
Figure 4.2.2: Level of education	26
Figure 4.2.3: Marital Status of Respondents	26
Figure 4.2.4: Autism and Related Developmental Disabilities	26
Figure 4.2.5: Occupation of Respondents	26
Figure 4.2.6: Respondents Monthly Income	27
4.3 Disability category	27
4.4 Analysis of Findings	29
Figure 4.4.1: Extent to which challenges faced by persons with ASD and RDD affect them	29
Figure 4.4.2: Figure Effects of ASD and RDD	30
4.5 Challenges, Current needs, priorities and resources required by persons with Autism and RDD	30
4.6 Opportunities and Gaps in the existing Legal Frameworks, policies and regulations for ASD and RDD	33
 05 RECOMMENDATION ON PROGRAMME DESIGN	 34
5.1 A: SPECIFIC OBJECTIVE I – EARLY IDENTIFICATION, DIAGNOSIS, MANAGEMENT AND CARE	34
5.1.1 Activity: -Map Health & Social Care Service Providers	34
5.1.2 Activity: Develop Guidelines for Management & Care of ASD & RDD	35
5.1.3 Activity: - Training & sensitization of health & social care workers on the guidelines for management & care of ASD & related developmental disabilities	35
5.1.4 Activity: - Develop collaboration agreements between the Council & selected health and social care facilities	35
5.2 SPECIFIC OBJECTIVE II – ACCESS TO HEALTH AND SOCIAL CARE SERVICES	35
5.2.1 Activity: - Map and Enrol beneficiaries	35
5.2.2 Activity: - Increase access of health care services to persons with ASD and related developmental disabilities	35
5.2.3 Activity: - Negotiate & enter into an agreement with NHIF to provide a comprehensive cover to persons with ASD and related developmental disabilities.	35
5.2.4 Activity: - Enrol programme beneficiaries to NHIF cover	36
5.2.5 Activity: - Awareness and sensitization on health & social care services	36
5.2.6 Activity: - Procurement of products and services	36
5.3 SPECIFIC OBJECTIVE II – SOCIO-ECONOMIC EMPOWERMENT	36
5.3.1 Activity: Advocate for Inclusive Employment Opportunities for persons with ASD and RDD	36
5.3.2 Activity: Build the capacity of persons with ASD and RDD to venture into entrepreneurship	36
5.3.3 Activity Mobilize parents and carers to form support groups	36
5.4 SPECIFIC OBJECTIVE III – INCLUSIVE EDUCATION	37
5.4.1 Activity: Champion the Alignment of Sector Policy for Learners and Trainees with Disabilities with the CBC	37
5.4.2 Activity: Liaise with partners to allocate a quota for learners with ASD and RDD	37
 06 REFERENCES	 39

ABBREVIATIONS

ASD	Autism Spectrum Disorder
A& RDDs	Autism and Related Developmental Disabilities
CATI	Computer Assisted Telephone Interview
COVID	Corona Virus Disease
EARCs	Education, Assessment and Resource Centres
FGDs	Focus Group Discussions
II	In-depth Interviews
IRB	Institutional Review Board
KIIs	Key Informant Interviews
KISE	Kenya Institute of Special Education
NACOSTI	National Council for Science and technology
NCPWD	National Council for Persons with Disabilities
ODK	Open Data Kit
PWDs	Person With Disabilities
SOPs	Standard Operating Procedures
RDDs	Related Developmental Disabilities
SoW	Scope of Work
SPSS	Statistical Package for Social Sciences
ToR	Terms of Reference
WHO	World Health Organization
USNIMH	United States National Institute of Mental Health

OPERATIONAL DEFINITIONS OF KEY TERMS

Key Term	Definition
Autistic Spectrum Disorders	A range of neurological disorders that most markedly involve some degree of difficulty with communication, interpersonal relationships, obsessions and repetitive behaviours.
Related Developmental Disabilities	Disorders associated with autism that can take the form of cerebral palsy, down syndrome, epilepsy, mental and intellectual disabilities which may occur singularly or as multiple disabilities.
Legal Capacity	The right to access the civil and juridical system and the legal independence to speak on one's own behalf.
Early Intervention Measures	Methods and techniques used to address the problems a learner may be having early enough to help prevent or reduce the effect of the disability in life. They include; Restructured Environment, Picture Exchange Communication System, Use of Sign Language and Use of social media.
Restructured Environment	A modified physical classroom environment that aids in meeting the behavioural and educational needs of children with autism spectrum disorders. Reasonable adjustments made to this classroom environment help to reduce barriers to learning.
Social Interaction	Social Interaction is the gradual gaining of skills, relationships and attitudes that enable a person to interact in the society.

01

INTRODUCTION

1.1 Background and Context of the Assessment

The National Council for Persons with Disabilities (NCPWD) was established by the Persons with Disabilities Act No. 14 of 2003 on 31st December, 2003 and came into effect by Legal Notice Number 64 of 16th June, 2004. The Council is a State Corporation under the Ministry of Labour and Social Protection with Statutory mandate to champion for the rights and equalization of opportunities for Persons with Disabilities (PWDs) nationally, regionally and internationally, as well as the interface between the three. The National Council for Persons with Disabilities has for a long time fully depended on exchequer resources to fund its recurrent and development operations. These annual budgetary allocations have not been sufficient for the efficient execution of the Council's mandate.

The World Health Organization (WHO) estimates that one out of 59 children are born with Autism and Related Developmental Disabilities which includes, Cerebral Palsy, Down Syndrome, Epilepsy and Intellectual Disabilities. The complexities underpinning Autism and Other Related Developmental Disabilities make it difficult to be detected and understood. The lack of understanding and recognition has led to stigmatization, discrimination and isolation of affected persons.

Persons with Autism and Other Related Developmental Disabilities are concealed by families, sometimes in degrading conditions. Lack of proper and early detection has led to many Persons with Autism and Other Related Developmental Disabilities being misdiagnosed as psychiatric cases and condemned to mental institutions in breach of Article 27, Article 28 and Article 54 of the Constitution.

The Council is coming up with a programme that seeks to support at least 6,000 Persons with Autism and Other Related Developmental Disabilities annually to cover interventions such as early identification and management, including

referral care; provision of therapy i.e., diet therapy, occupational therapy, speech therapy, essential drugs and supplies; and provision of adult diapers for those with severe disabilities.

This monograph, therefore, seeks to enable the Council to prioritize its efforts to areas of greatest impact for persons with Autism and related developmental disabilities. These include health and social care priority areas, resource needs, identification, and mapping and aligning stakeholders' goals to the overall vision and mission of the organization.

1.2 Purpose, Goal and Objectives of the study

The purpose of this consultancy is to develop a monograph for persons with Autism and related developmental disabilities will inform designing interventions that address challenges and create the greatest impact for persons with autism. These include health and social care priority areas, resource needs, identification, and mapping and aligning stakeholders' goals to the overall vision and mission of the organization.

This assignment provides an opportunity for a detailed study that is in line with the growing demands of services along with the emerging needs, and will ensure that persons with Autism and related developmental disabilities priorities are aligned with the objectives of the Council. Further this detailed study will provide insight on the existing policies and legislations that will guide the development of guidelines for management and care of persons with Autism and related developmental disabilities. The study will inform the Council on access of health and social care services that are in existence, and also make recommendations on the legislative proposals that could be pursued to realise these benefits for the target group.

The goal of is to have a complete understanding of the current status of persons with Autism and related developmental disabilities, which will inform the direction of future programmes and initiatives

of the Council.

1.3 Specific Objectives:

- a. Conduct a comprehensive analysis on the current status of persons with autism spectrum disorders and other related developmental disabilities (ASD & RDD).
- b. Engage caregivers of ASD & RDD with a view of establishing challenges, current needs, priorities and resources required.
- c. Develop a criteria and tools for identification of programme beneficiaries based on the needs identified.
- d. Identify and analyse gaps and opportunities in the existing legal frameworks (National and International), policies and regulations on ASD & RDD.
- e. Identify existing structures for early identification, management and care of ASD & RDD and provide recommendations on the best implementation support mechanisms
- f. Determine gaps in the existing support structures and provide clear solutions to address these gaps
- g. Establish the findings on an effective monitoring and evaluation mechanism on the programme
- h. Develop a detailed Report on the findings, present it to the Council and key stakeholders for validation.

1.4 Research Questions

The study will be guided by the following research questions:

- a. What is the current status of persons with ASD & RDD? (In terms of demographics on persons with ASD & RDD, access to services (specify the services) and the current support received, and challenges, current needs, priorities and resources required.
- b. What are the challenges, current needs, priorities and resources required for persons with ASDs and RDDs?
- c. Which criteria and tools would you develop for identification of programme beneficiaries based on the needs identified?
- d. What recommendations would you provide for the programme to develop tools and improve on SOPs for persons

with ASDs and RDDs?

e. what are the gaps and opportunities in the existing legal frameworks (National and International), policies and regulations on ASD & RDD?

f. How would you identify the existing structures for early identification, management and care of ASD & RDD? (And what are the gaps in the existing support structures? provide clear solutions to address these gaps in the support structures of ASD & RDDs? What are the key findings on an effective monitoring and evaluation mechanism on the programme?

g. What are the key recommendations on the best implementation support mechanisms for ASD and RDDs?

1.5 Scope of the and Study

The geographical scope of the monograph study covered least 24 Counties randomly selected from the 9 regions of Kenya specifically identified to provide convenience and logistic cost-effectiveness in the execution of the study. The participants will be persons from both genders who are persons with ASD and related disabilities and their service providers that represent the face of Kenya in terms of geo-political and socio-economic diversity.

The study focused on determining key areas that affect persons with ASDs and RDDs in Kenya specifically collecting 24 counties.

1.6 Assumptions of the Study

This study assumes that:

1. Persons with ASD have social challenges that subject them to negligence by both caregivers and society.
2. The respondents provide valid, honest and objective information that is a true reflection of their issues so as to achieve reliable and valid results.
3. It also assumes that the NCPWDS provides resources and support to all persons with ASD and RDD and their families.

1.7 Limitations of the Study

The following are study limitations:

1. Use of questionnaire with closed ended items might lead to ceiling and floor effects as some respondents might tick false responses to please the researchers. This will be minimized using both opened ended questions, focused group discussions and interviews.

2. High expectations from respondents that especially from the research team and the confusion that arose where the research team were perceived to be NCPWD staff. As such, most found a chance to vent their frustrations accessing some of the services.

1.8 Rationale for the Study

The study will be significant to persons with ASD and RDD, families, community, NCPWD, policy makers, researchers, government of Kenya across the ministries through provision of information necessary in understanding ASD and RDD.

The study will enhance service provision for persons with autism, understand the current status of persons with ASD and RDD, in terms of demographics, accessibility to services, current trends, priorities, and resources needed for persons with ASD and RDD, enhance development of relevant policies to protect persons and families with Autism and related developmental disabilities.

By identifying the existing structures for early identification, management and care for persons with ASD and RDD, and the necessary support mechanisms needed for ASD and RDDs, the study will provide clear recommendations to address the gaps identified.

Finally, the study recommends a wide range of measure that improves the well-being of persons with ASD and RDDs through continuous monitoring and evaluating the support systems and services of ASD and RDD programmes.

1.9 Conceptual Framework

The study was guided by the conceptual framework as follows:

For an effective service and support systems for ASD and RDD its important

NCPWDs identify and address the difficulties facing persons with ASD and RDD, identify priorities and resources required. Then there is need for early identification, early intervention and management of ASD. For effective service delivery, the NCPWD will need to work closely with relevant parliamentary committees to legislate relevant laws that support service delivery and uphold rights of persons with ASD and RDD at home, community, schools and learning institutions, in employment and at all levels for holistic service delivery.

The Council needs to identify relevant stakeholders to collaborate with in terms of service provision such as occupational therapists, speech and language therapists, social workers, parents and families, community, relevant government ministries, NGOs and CBOs for ASD and RDD, nutritionists.

The Council will need to benchmark with developed nations the best practices in protecting, supporting and upholding rights of persons with ASD and RDD. This will assist in improving the support systems and mechanisms in service provision of the needs of persons with ASD and RDD.

Lastly, the framework proposes need to continuously monitor and evaluate service delivery and support mechanisms for ASD and RDD on quarterly basis.

¹ 1. Coast region; 2. Eastern Region; 3. North Eastern Region; 4. Nairobi Region; 5. Central region; 6. South Rift Region; 7. North Rift Region; 8. Western Region; and 9. Nyanza Region

02

SITUATION ANALYSIS

This section provides the context of disability in Kenya and in specific, the situation of persons with ASD and RDD. It also covers the legal and policy environment underpinning ASD and RDD and a summary on the various actors – stakeholders – involved in enabling a life of dignity for this constituency.

2.1 Disability in Kenya

According to the World Health Organisation (WHO), 16% of the world population currently have a disability. This shows an increase from the international body's earlier estimates of 10 – 15%. It also shows that one in six people have a form of disability. When this is projected to the latest official Kenyan population data of 47,564,296 as per the Kenya National Bureau of Statistics (KNBS), this represents about 7.6 million Kenyans.

According to Kenya Population Housing Census 2019, Kenya had 918,270 people aged 5 years and above living with a disability. More females than males had disabilities. The common types of disability found in the country during the census were mobility (385,417) and visual impairment (333,520). A total of 9,729 persons had some form of albinism. Experts and players in the disability sector contend that this was a markedly low figure based on the mode of administration of the Census data tools and classification of disability.

The United States National Institute of Mental Health (USNIMH) defines autism spectrum disorder (ASD) as a Neurological and Developmental Disorder that affects how people interact with others, communicate, learn, and behave ((USNIMH, 2023). Although autism can be diagnosed at any age, it is described as a “developmental disorder” because symptoms generally appear in the first 2 years of life.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), people with ASD often have: difficulty with communication and interaction with

other people; restricted interests and repetitive behaviours; Symptoms that affect their ability to function in school, work, and other areas of life (U.S NIMH, 2023)

Globally, it is estimated that nearly **75 million people** have autism spectrum disorder, which represents 1% of the world's population. The World Health Organization (WHO) estimates that one out of 59 children are born with Autism and Related Developmental Disabilities which includes, Cerebral Palsy, Down Syndrome, Epilepsy and Intellectual Disabilities. Available data show that autism prevalence increased to 178% since 2000, with boys being more likely to have autism spectrum disorder (ASD) than girls.

An analysis of autism rate by country rank Kenya at number 46 with an estimated 402.57 per 100, 000 having autism . The complexities underpinning Autism and Other Related Developmental Disabilities make it difficult to be detected and understood. The lack of understanding and recognition has led to stigmatisation, discrimination and isolation of affected persons. Persons with Autism and Other Related Developmental Disabilities (A&RDDs) are concealed by families, sometimes in degrading conditions.

ASD and RDDs has various effects on the life of the individual such as functional and financial impact on those affected and their families (Knapp, Romeo and Beecham, 2009). This results in high health expenditure and out of pocket payments for non-covered health services o low employment prospects of the person, poor mental and physical health, anxiety, frustrations, and general wellbeing problems (Howlin, Goode and Hutton, 2004).

Social Interaction refers to the gaining of relationship, skills and attitudes

gradually hence enabling a person to effectively interact with other people in the society (Nagent and Pam, 2013). Active socialisation with others helps these children build a sense of self-realisation and increases awareness of their expectations. They are able to actively respond to both positive and negative influences around them and play active role in creating and shaping their desired relationships (Hartup, 2014).

To help children with autism develop socially, early intervention measures must be taken right at school level to enable them acquire social skills for both social interaction and social communication, which eventually may enhance behaviour relation (Tracey, S. et al 2021).

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), people with ASD often have: difficulty with communication and interaction with other people; restricted interests and repetitive behaviours; Symptoms that affect their ability to function in school, work, and other areas of life (U.S NIMH, 2023).

Early intervention measures refer to a variety of childcare, educational and family support specially designed in order to minimise disability effect or rather prevent future occurrence of developmental and learning difficulties in the child's life presumed to be at risk of such problems (Cusack, et.al,2016).

Early intervention measures can be both in the classroom and home-based programmes providing compensatory services for children assumed to be at risk for future behaviour and learning problems as well as provision of related services for already encountered difficulties or problems (Garguilo, 2016). Early intervention measures include restructured

² World Health Organisation, 2023 <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>

³ Kenya Population and Housing Census 2019

⁴ See: <https://www.udpkenya.or.ke/blog/persons-with-disabilities-and-data-inclusion/>

⁵ <https://wisevoter.com/country-rankings/autism-rates-by-country/>

environment, picture exchange communication system and sign language among others, (Khasakhala, 2018).

2.2 National and International Legal frameworks and Policies on ASD & RDD

2.2.1 National Instruments

Various national legal instruments protect the rights of persons with disabilities. Article 54 of the Constitution of Kenya expressly provides for various rights that persons with disabilities are entitled to including access to all places, public transport and information, access to educational institutions and facilities, access to assistive devices to enhance the person's mobility or communication, among others.

There are other articles in the Constitution that protect persons with disabilities as espoused in the Bill of Rights such as non-discrimination (Article 27), Access to Information (Article 35), Political Rights (Article 38), Equality and Human Dignity (Article 28).

Other rights are espoused in Article 43 that recognises economic and social rights including; highest attainable standard of health, housing, sanitation, freedom from hunger, clean and safe water, social security, education and emergency treatment as well as Children's Rights (Article 53). Articles 97, 98 and 100 espouse the rights of persons with disabilities to be nominated to National Assembly, Senate and County Assemblies respectively.

Kenya has also enacted the Persons with Disability Act of 2003 which provides a legislative framework for access to services and inclusion of Persons with disabilities in all facets of life. It expressly calls for equalisation to opportunities by protecting persons with disabilities from discrimination in employment, education and health among others.

There are other laws that expressly mention the rights of persons with disabilities as follows:

Some Select Statutes that Protect the Rights of Persons With Disabilities

Table 2.1: Statutes that Protect the Rights of PWDs

Act	Purpose
Employment Act, 2007	Prohibits the discrimination of persons with disabilities in employment in public and private Sectors (Section 5).
National Employment Authority Act	Makes a case for inclusion of minorities such as youth and persons with disabilities in employment.
Public Procurement and Asset Disposal Act, 2015	Provides for reserved procurement opportunities for youth, women and persons with disabilities.
Social Assistance Act	Provides for the right to social assistance to persons with severe mental or physical disabilities, whose disability renders them incapable of catering for their basic needs.
Mental Health Act	Enshrine the rights of persons with *mental disorders to protection of their estates in succession matters. More inclusive language should have been used in the Act.

Some Select Policies that Protect the Rights of Persons With Disabilities

Table 2.2: Policies that Protect the Rights of PWDs

Policy	Purpose
Kenya Health Policy	Espouses the right of persons with disabilities to reasonable access to health facilities and materials. Makes a case for accommodations in health care provision.
The Kenya National Social Protection Policy, 2011	Prohibits non-discrimination of persons with disabilities and prioritises their social protection needs
Sector Policy for Learners and Trainees with Disabilities, 2018	An elaborate policy that prioritises the provision of education and training for learners and trainees with disabilities – making a case for inclusive education
National Adolescent Sexual and Reproductive Health Policy, 2015	Expressly states that adolescents with disabilities are entitled to sexual reproductive health rights

2.2.2 International Legal Instruments

Kenya has signed several international treaties that protect and promote the rights of persons with disabilities. These treaties have their legal underpinning in Article 2 (5) and (6) of the Constitution of Kenya which expressly states that international laws that Kenya has signed are sources of our laws.

The Convention on the Rights of Persons With Disabilities was signed and ratified by Kenya in 2007 and 2008 respectively. The purpose of the Convention as enshrined in Article 1 is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. When it comes to the rights of persons with ASD and RDD, the Convention is a very important instrument in many ways. To mention but a few, the Convention in its purpose mentions expressly the rights of ALL persons with disabilities. In addition, it describes persons with disabilities in the most comprehensive sense:

Persons with disabilities include those who have long-term physical, **mental, intellectual or sensory impairments** which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. The comprehensiveness of the definition of a person with disabilities recognise persons with ASD and RDD.

Thirdly, the Convention provides a paradigm shift from the medical and charity model of disability to social model and human rights model. It views disability in social dimension as an interaction between persons with impairment and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. This is important in viewing persons with ASD and RDD within the society.

On May 30, 2014 the WHO passed **the first ever global Autism Resolution** dubbed the “Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorder.” The resolution was cosponsored by 50 states and received the support of all of the 194 member countries at the annual assembly of the WHO. Kenya therefore adopted this important instrument.

⁶ Constitution of Kenya

The Resolution called on countries to eliminate stigmas surrounding developmental disorders so that they can be addressed effectively, rather than ignored. The resolution has designed policies and procedures that will help countries work toward attainable goals and make life better for those with autism.

At the Continental level, Kenya is a signatory of Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa.

Other International Conventions that protect the rights of persons with disabilities and specifically those with ASD and RDD include: United Nations Convention on the Rights of the Child (1989); United Nations Standard Rules on Equalisation of Opportunities for Persons with Disabilities (1993); Salamanca Statement and Framework for Action (1994). rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. When it comes to the rights of persons with ASD and RDD, the Convention is a very important instrument in many ways. To mention but a few, the Convention in its purpose mentions expressly the rights of ALL persons with disabilities. In addition, it describes persons with disabilities in the most comprehensive sense:

Persons with disabilities include those who have long-term physical, **mental, intellectual or sensory impairments** which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. The comprehensiveness of the definition of a person with disabilities recognise persons with ASD and RDD.

Thirdly, the Convention provides a paradigm shift from the medical and charity model of disability to social model and human rights model. It views disability in social dimension as an interaction between persons with impairment and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. This is important in viewing persons with ASD and RDD within the society.

On May 30, 2014 the WHO passed **the first ever global Autism Resolution** dubbed the "Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorder." The resolution was cosponsored by 50 states and received the support of all of the 194 member countries at the annual assembly of the WHO. Kenya therefore adopted this important instrument.

The Resolution called on countries to eliminate stigmas surrounding developmental disorders so that they can be addressed effectively, rather than ignored. The resolution has designed policies and procedures that will help countries work toward attainable goals and make life better for those with autism.

At the Continental level, Kenya is a signatory of Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa.

Other International Conventions that protect the rights of persons with disabilities and specifically those with ASD and RDD include: United Nations Convention on the Rights of the Child (1989); United Nations Standard Rules on Equalisation of Opportunities for Persons with Disabilities (1993); Salamanca Statement and Framework for Action (1994).

⁷<https://www.borgenmagazine.com/makes-history-global-autism-resolution/>

2.2.3 Gaps in the Laws

There are several gaps in the law that hinder the full enjoyment of rights of persons with ASD and RDD and indeed persons with disabilities in general as follows:

Table 2.3: Gaps in the law

Law	Gap
Legal Capacity	Legal capacity gives the right to access the civil and juridical system and the legal independence to speak on one's own behalf. Any Article of the Constitution and Statute that presumes that persons with ASD and RDD have 'unsound minds' and cannot therefore have a say in voting or be elected is an affront to the very principle of Legal Capacity. Examples are provided in a number of Statutes below.
Persons With Disabilities Act 2003	Failure to align the Persons With Disabilities Act 2003 with the Constitution and the Convention on the Rights of Persons With Disabilities. This has affected implementation of rights of persons with disabilities starting with the very definition of persons with disabilities. That is why Persons With Disabilities Bill 2023 that seeks to repeal the Persons With Disabilities Act 2003 should be fast-tracked.
The Marriage Act	Limits the rights of persons with mental health conditions to get married
Penal Code	Creates the offence of "rape of an imbecile" presumes that any person with a mental health condition cannot consent to sex
Mental Health Act	Allows guardianship laws to strip persons with disabilities of their rights to make decisions amongst other laws
The Law of Succession	Limits the rights of persons with disabilities to inheritance
Criminal Procedure Code	Allows courts to sentence persons with mental disabilities to serve sentences at the President's pleasure
Article 83 (1) (c) Constitution of Kenya	This Articles states that a person qualifies to be registered as a voter if, among other things, he or she is not declared to be of unsound mind.
Article 99(2) (e) of the Constitution of Kenya	This Article states that a person of unsound mind is ineligible for election to Parliament.

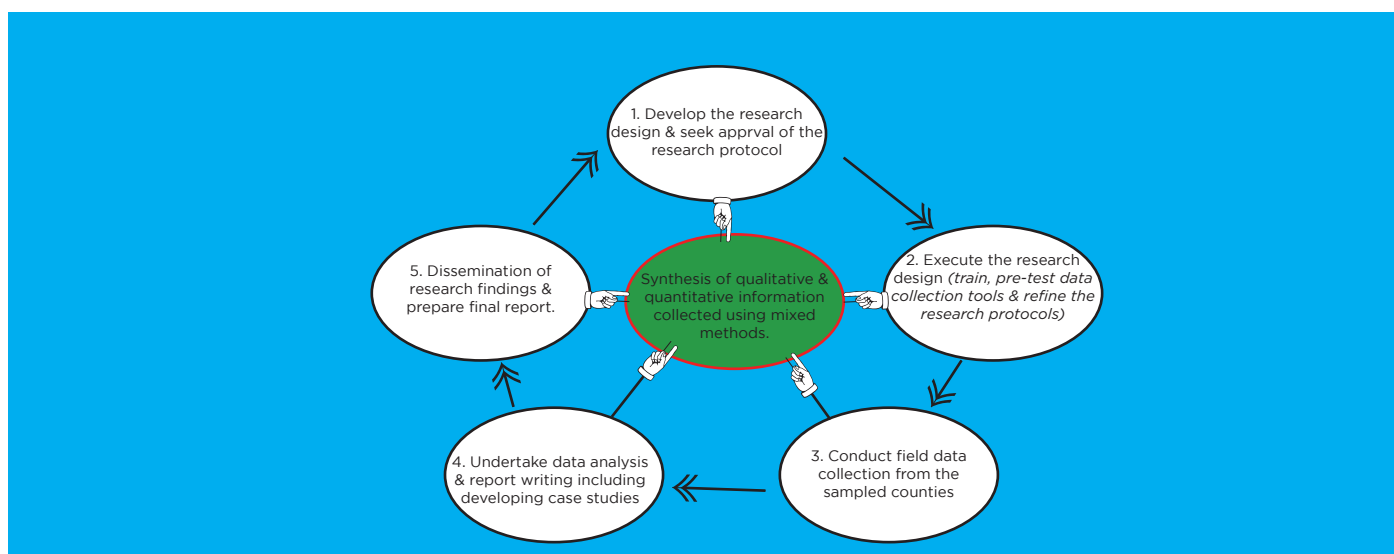
03

RESEARCH METHODOLOGY

3.1 Research Design

The study employed a mixed methods approach that involved the application of qualitative and quantitative data collection approaches and collect primary and secondary data from respondents using techniques outlined below.

Figure 3.1: Overview of the Methodology



A descriptive survey mixed method research design was used in this study to allow for data triangulation and corroboration of information from multiple sources and respondents and secondly to facilitate the blending of approaches that were more empowering to different categories of respondents.

Approaches used involved; firstly, mining relevant data from existing secondary sources/literature including project documents and secondly, generating primary data using well designed data collection tools based on the objectives and specific research questions to be answered.

The following phased in steps guided the process:

3.2 The phased-in approach to the development of the monograph

The research adopted a phased in approached summarized on figure 3.1. These phases are:

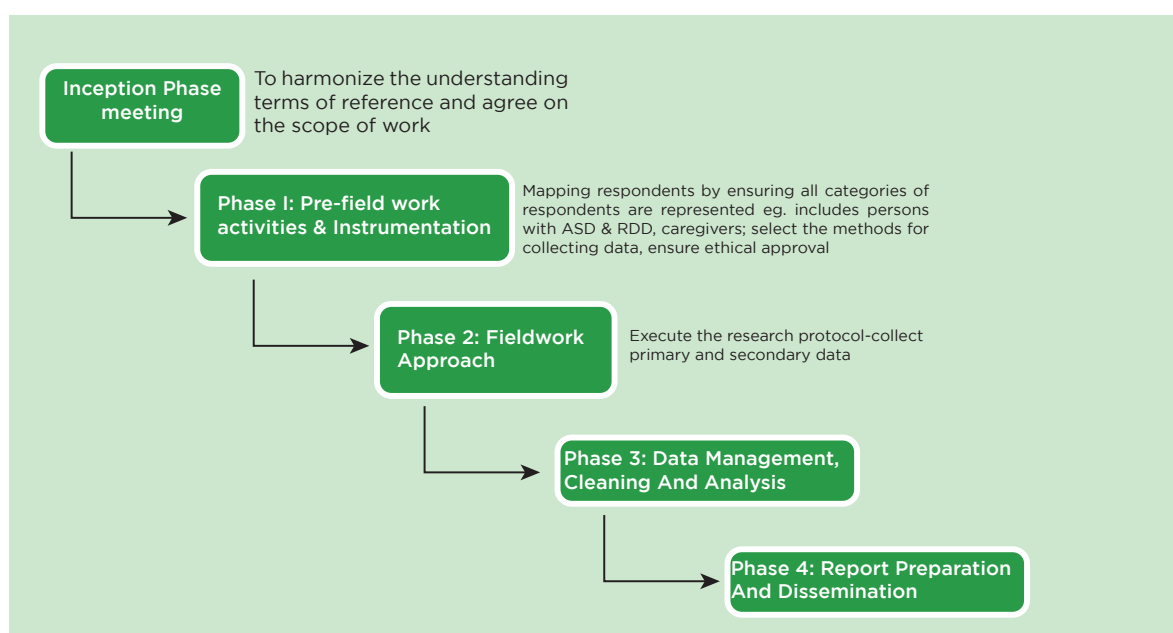
- i. The inception phase and pre-field work activities
- ii. Field work (data collection phase)
- iii. Data Management (cleaning and analysis phase)
- iv. Report writing and dissemination phase

3.2.1 Phase I: Pre-field data collection steps

Phase one involved development of the inception report and a comprehensive framework of the assessment methodology. The research team was fully involved in the inception phase to ensure a solid and an all-inclusive approach, which was relevant to the study and acceptable to NCPWD team and all stakeholders involved in the implementation. The inception report provided details about the study methodology and indicators that will be used to measure the program success and how data collected will be used.

The consultants used the indicators as outlined in the project document to inform execution of the study and specifically the refinement of the methodology and data collection tools

Figure 3.2: Overview of the phased in approach



3.3 Study Population

The study population involved 1,224 persons with ASD and RDD and/or caregivers who were interviewed on behalf of persons of ASDs and RDDs; 150 Key informants and Focus group discussants.

3.4 Sample and Sampling Techniques

Using simple random sampling, 350 persons with ASD and care-givers and 150 key informants were sampled for the study. The size is indicated in table 1 below.

Table 3.1: Sample Frame

Respondent	N	n	%
Persons with ASD and RDD and/or Care-givers for ASD and RDD	1224	350	33.3
Key informants (teachers, EARC, professionals working with ASD)	150	50	33.3

Key: N- Population

n- Sample size

% - percentage

3.5 Instruments of Data Collection

Quantitative data was collected using semi-structured questionnaire for persons with ASD and RDD and care-givers. Qualitative data was collected using focused group discussions for persons with ASD and RDD, and key informant interview schedule.

3.5.1 Quantitative Data collection instruments

A semi-structured questionnaire to respondents particularly persons with Autism and/or their immediate family members and caregivers was used to collect quantitative data. Quantitative data will also be extracted from secondary sources. Primary data from respondents was collected smart using an online data collection software application will ODK/Enketo ONA software applications which can work offline and Computer Assisted Telephone Interviews (CATI) techniques or any other that may be preferred by the NCPWD.

Semi-structured questionnaires with both closed and open-ended questions were used

to collect data from persons with ASDs and RDDs and/or caregivers. The questionnaire was divided into sections based on the objectives of the study monograph.

3.5.2 Qualitative Data Collection Techniques

Qualitative techniques were used to capture data that cannot be quantified by facilitating respondents to facilitate discussions that describe how the persons with autism and other related developmental disabilities are treated, perceptions, practices, policies and legislations that exist and how these affect them etc. The qualitative methods will thus help to interpret and achieve deeper understanding of any information gained through the application of quantitative methods. Qualitative data collection methods comprised of the following:

a. Key informant Interviews (KIIs):

These were sampled purposively in consultation with the NCPWD team.

b. In-Depth Interviews (IIs): were conducted by expert with in-depth knowledge on inclusive management practices, policies and working with persons with ASD and RDD selected through snow-balling approach. The interview focused on the key areas of each objective.

c. Focus Group Discussions (FGDs):

These were carried out on the sites using FGD guides developed by the consultants, pre-tested, and extensively discussed with NCPWD staff. These were administered to a group of individuals each comprising 6-8 people with common characteristics (homogeneous group) respondents conducted in at least 15 of the sampled counties. Respondents included persons with ASD and RDD, caregivers, household and support group members.

3.6 Eligibility criteria for inclusion/exclusion in the study

Inclusion criteria: To enter the study, an individual must meet all of the following conditions to be included:

- a. Person with autism and related developmental disabilities or a caregiver living with persons with autism.
- b. Currently or previously worked with OPDs that support persons with autism and autism related developmental disabilities.
- c. Participating in interventions targeting persons with autism at the local community, sub-county, county, regional, national or international level.
- d. Be aged 18 years or older and able to provide written informed consent.

Exclusion criteria:

- a. Are unwilling to give either verbal or written informed consent.
- b. Unwilling to participate in the autism related developmental disabilities research activities.
- c. Those individuals -including caregivers and persons without persons with autism and RDDs.

3.7 Validity and Reliability of the Research Instruments

3.7.1 Validity of the Research Instruments

Validity refers to the accuracy and meaningfulness of inferences made based on results obtained. It is asking a relevant question framed in the least way (White, 2005). It is the agreement between the researcher's conclusion and the actual reality.

For the purposes of this study, the researcher adopted content validity to measure the validity of the instruments that were used. Mugenda and Mugenda, (2015) explains that Content validity enables data being collected to be reliable in representing the specific content of a particular concept.

3.8 Procedure of data collection

Before collecting data, the researcher sought an introductory letter from NCPWD, to request for a research approval from MUSERC, Maseno University and research permit from the National Commission for Science, Technology and

Before collecting data, the researcher sought an introductory letter from NCPWD, to request for a research approval from MUSERC, Maseno University and research permit from the National Commission for Science, Technology and innovations (NACOSTI). The permit was used to seek permission from the school authorities and county education officials to collect data.

All data quality control measures were adhered to during the study. Relevant approvals were sought from Maseno University Ethics Review Committee and approved Institutional Review Board (IRB the National Council for Science Technology Innovation (NACOSTI).

3.9 Data Analysis

Data was collected from the field using questionnaires, interview schedules and observation checklists, sorted, coded and entered into the computer for analysis using the Statistical Package for Social Sciences (SPSS) version 21.0 for windows.

Data was analysed by use of both qualitative and quantitative techniques. Quantitative data from the questionnaire were analysed using frequency counts, percentages and mean. Qualitative data was transcribed, organised and categorised and analysed using thematic analysis. The thematic analysis was classified and reported into as themes and sub-themes. The reporting was done in verbatim form and interpreted based on the study objectives.

3.9 Ethical considerations

The study took note of the fact that there were certain risks associated with community-based research, both on the researchers and research subjects. To minimise such risks and ensure ethical compliance, the following set of ethical considerations and measures were followed in conducting the study:

1. Informed consent, voluntary participation and right to withdraw: Participants in the study, whether in interviews or focus group discussions were informed

informed about the purpose of the “event”, how they were selected to participate, that their participation was voluntary and that they were free to withdraw their participation at any time or decline the answer to any questions.

2. Confidentiality and anonymity in relation to data and participants’ identity in survey interviews was ensured by the consultants. Commitment was made to ensure that no identifying information was released and such information can only be accessed by those directly involved in the study.

3. Considering the sensitive nature of human rights issues, and the rights of persons with disabilities the team ensured sensitivity to the participants and community culture and practices, sensitivity to gender and rights and doing no harm was observed at all times. The Team was specifically briefed on these principles and commit to uphold them.

4. The consultancy team and participants did no risk nor harm as a result of their participation in the study. The research team ensured that the members were not exposed to risk and were only be sent to the field during safe times and only to safe locations. In case either the researchers or the participants felt that they may be at risk of psychological harm as a result of addressing a traumatic event, they were referred to one of the psychosocial services operating in the area.

04

KEY FINDINGS AND DISCUSSIONS

This Chapter provides the findings of the study in line with the situation analysis, questionnaires, key informants responses as well as focused group discussions.

The introductory parts of the findings capture the demographic details of the respondents.

4.1 Socio-demographic characteristics of respondents

4.1.1 Response rate

Data on response rate was analysed and presented in table 4.1.

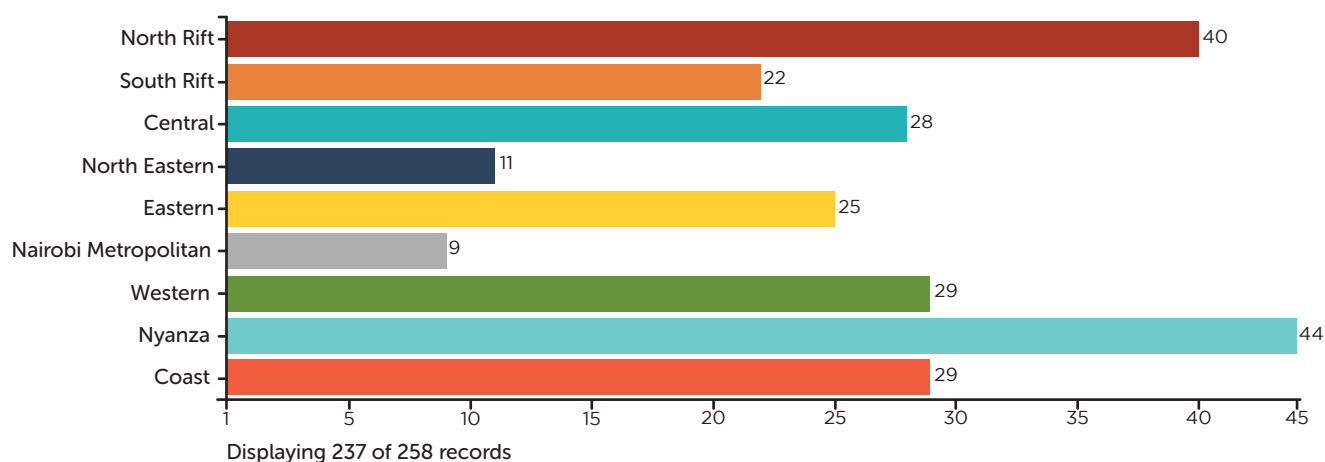
Table 4.1: Distribution of respondents by County and gender

County	Gender				Grand Total	
	Female	%	Male	%	Total	%
Mombasa	5	2%		0%	5	2%
Nyeri	7	3%		0%	7	3%
Laikipia	20	8%		0%	20	8%
Isiolo	7	3%	3	1%	10	4%
Mandera		0%	1	0%	1	0%
Turkana	6	2%	4	2%	10	4%
Trans_Nzoia	10	4%	2	1%	12	5%
Uasin_Gishu	5	2%	4	2%	9	3%
Nandi	7	3%	2	1%	9	3%
Nakuru	6	2%	2	1%	8	3%
Kwale	9	3%	3	1%	12	5%
Bomet	5	2%	5	2%	10	4%
Kisii	16	6%	6	2%	22	9%
Homa Bay	10	4%	3	1%	13	5%
Kisumu	6	2%	6	2%	12	5%
Kakamega	12	5%	7	3%	19	7%
Nairobi	6	2%	3	1%	9	3%
Bungoma	12	5%		0%	12	5%
Kilifi	10	4%	2	1%	12	5%
Makueni	6	2%	6	2%	12	5%
Machakos	11	4%	2	1%	13	5%
Kiambu	6	2%	5	2%	11	4%
Embu	8	3%	2	1%	10	4%
Grand Total	190	74%	68	26%	258	100%

4.1.2 Response Rate Per Region

Data on response rate per county was analysed and presented in figure 4.2.

Figure 4.1: Response Rate Per County



Results on response rate per region indicated that the highest response rate of questionnaires came from Nyanza (44), followed by North Rift (40), Western (29), Coast (29), Central (28), Eastern region (25), North Eastern (11) and Nairobi (9). Further interrogation from the team leaders indicates the highest were due to proper mobilisation.

4.2.1: Category of Respondents

Data from the respondents was analysed and presented and reported in table four below.

Table 4.2: Category of respondents by gender

Count of Category of respondents	Gender				Grand Total	
	Female		Male			
	Count	%	Count	%	Count	%
Caregiver	158	61%	50	19%	208	81%
Others	6	2%	2	1%	8	3%
Person with ASD & RDD	5	2%	9	3%	14	5%
Regular Teacher	21	8%	7	3%	28	11%
Grand Total	190	74%	68	26%	258	100%

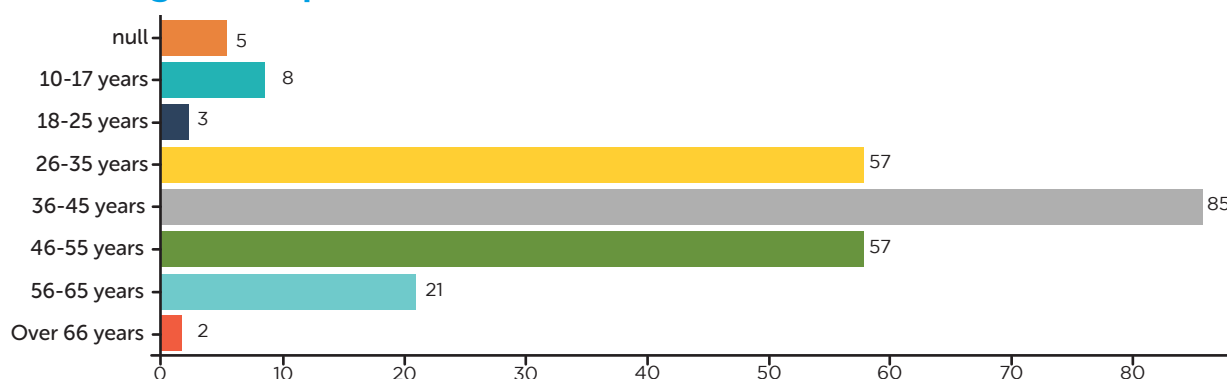
Results from table 4 indicated that most respondents were caregivers (81%), followed by regular teachers for learners with autism and RDD (11%), persons with autism and RDD (5%) and the least were other practitioners such as occupational therapists, speech therapists, EARC and DPOs leaders (3%).

Majority of the respondents were **female (190, 74%)**, and **male respondents accounted for 68 (26%)**. This huge variation is due to high number of caregivers which accounted for female (158, 61%) and male 50 (19%). This implied that persons with ASD and RDD are mostly taken care and provided for by female care-givers. This was clearly brought during focused group discussion where a significant segment of mothers of Persons with ASD and RDD across the country explained they had been abandoned by the fathers of the children due to disability.

4.2.2: Age of Respondents in Years

Data on age of respondents was analysed using ONA package and represented in figure 4.2.1.

Figure 4.2.1: Age of Respondents in Years

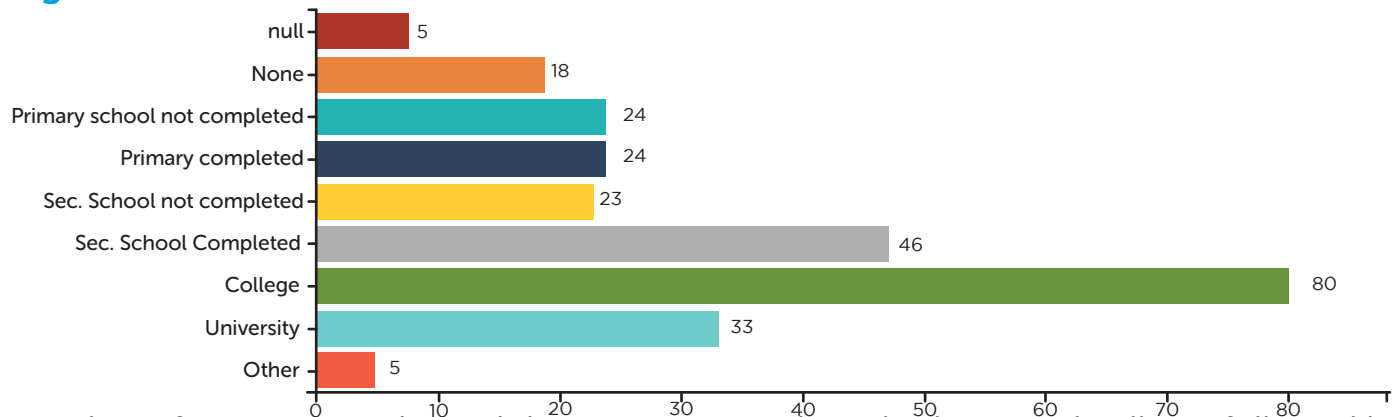


Results from figure 3 indicates that most respondents who participated in the research were aged between **35 to 45 years (85%)**, followed by 25-35 years (57%), 46-55 years (57%), 56-65 years (21), 10-17 years (8), 18-25 years (3) and the least were aged over 66 years (2). It is worth noting that most caregivers, and practitioners for persons with Autism and RDD were aged **35 to 45 years**.

4.2.3 Highest Level of Education Attained by Respondents

Data on level of education of both caregivers and service providers was analysed using ONA and presented in figure 4.3 below.

Figure 4.2.2: Level of education



Results in figure 4.2.2 indicated that most respondents had attained college, followed by secondary schools and universities

Figure 4.2.3: Marital Status of Respondents

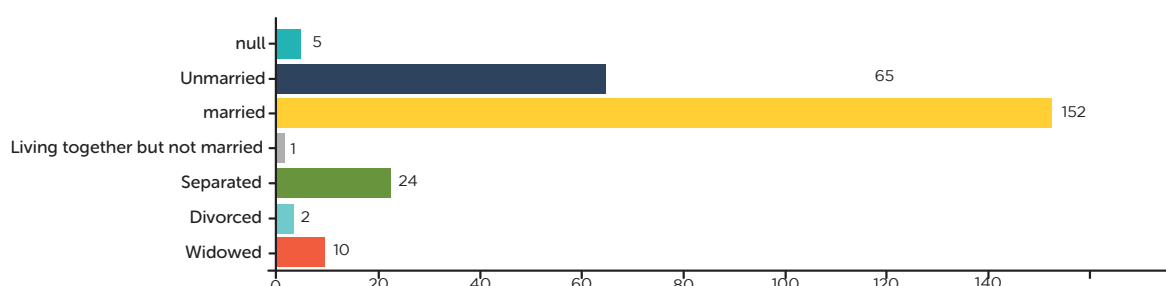


Figure 4.2.4: Autism and Related Developmental Disabilities

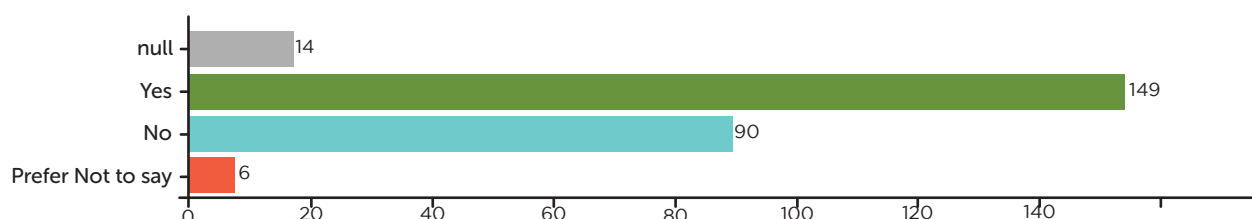


Figure 4.2.5: Occupation of Respondents

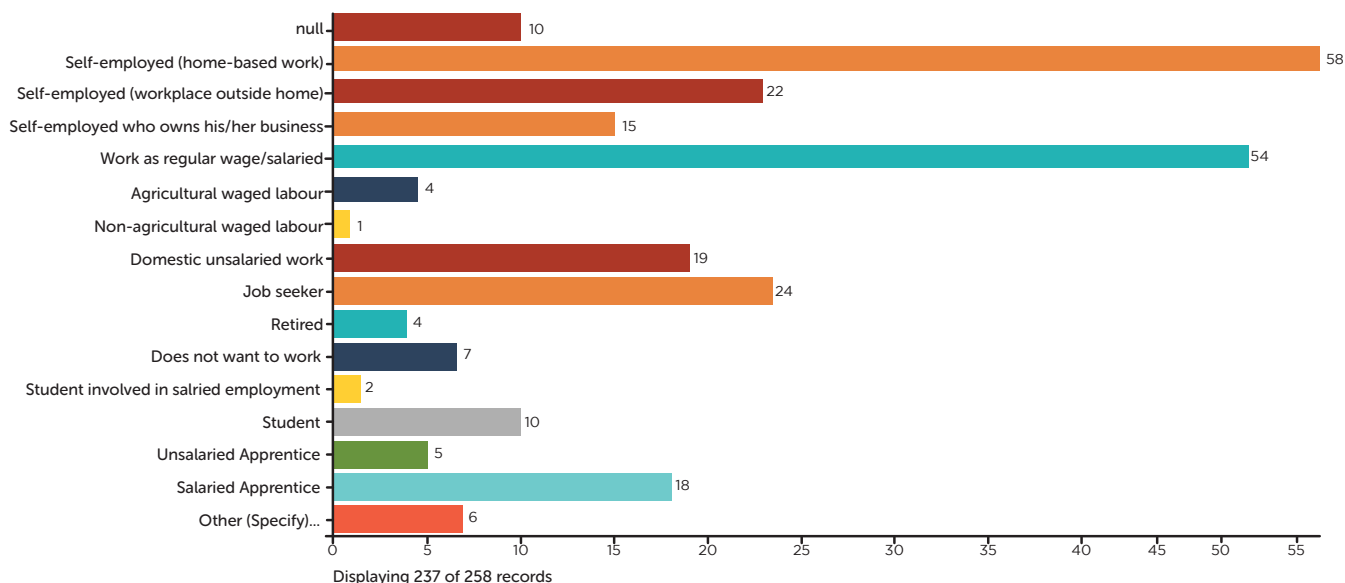
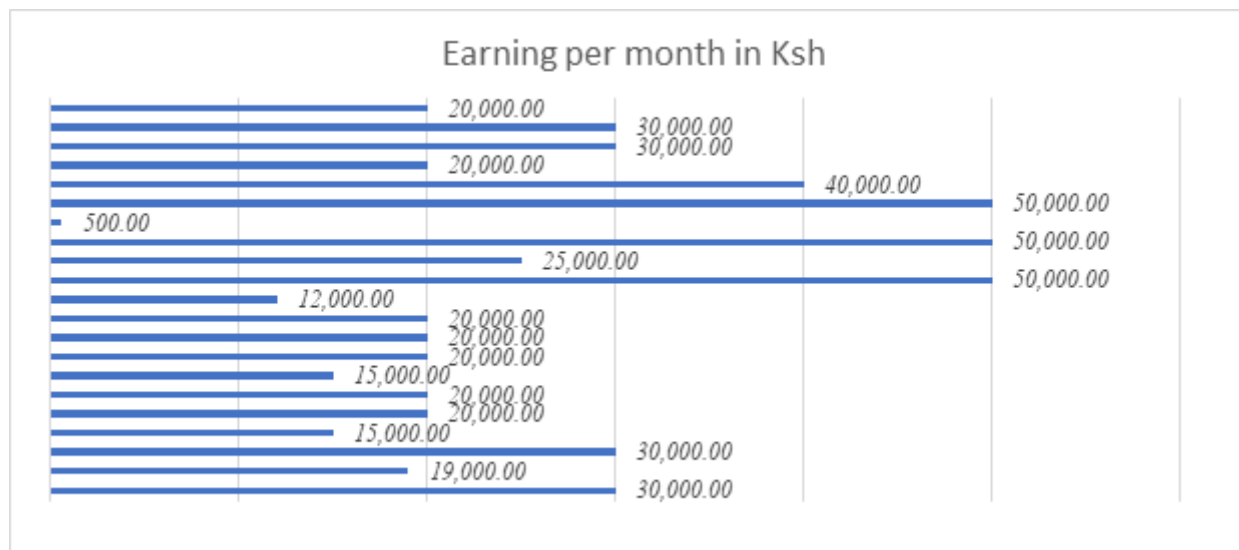


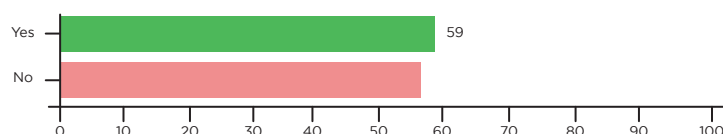
Figure 4.2.6: Respondents Monthly Income



4.3 Disability category

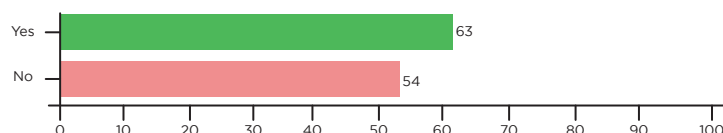
This question sought to find out the disability characteristics of each person with Autism and RDD. This section is also very important in bringing out the comorbidities.

Upper body mobility problems



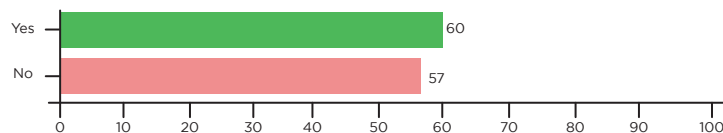
Findings of the study indicated that 59 respondents had upper mobility problems out of the total 104 that were administered with the questionnaire.

Lower body mobility problems



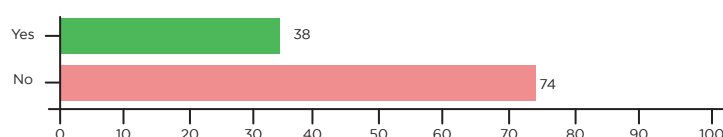
Sixty-three respondents had lower mobility problems. This was likely the case for a person with cerebral palsy.

Hearing and speech impairment

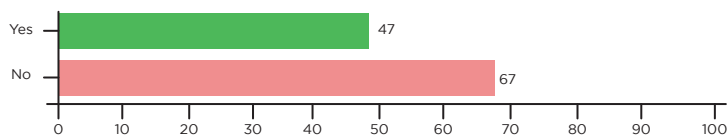


Results from the chart on hearing and speech impairment indicated that 60 respondents agreed they had hearing and speech impairment. Due to these characteristics, persons with autism and RDD agreed they experienced communication difficulties that really affected their quality of life.

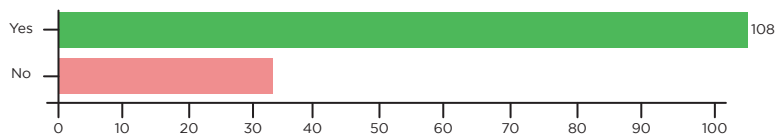
Visual impairment



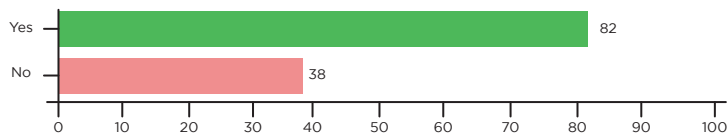
Hearing impairment



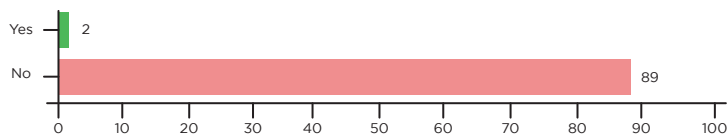
Speech impairment



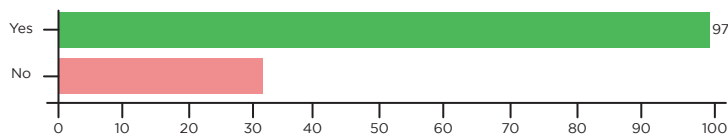
Self-care



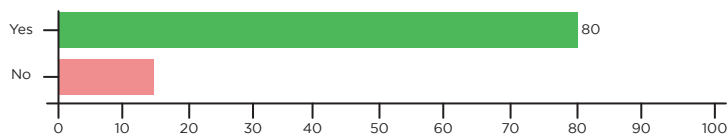
Albinism



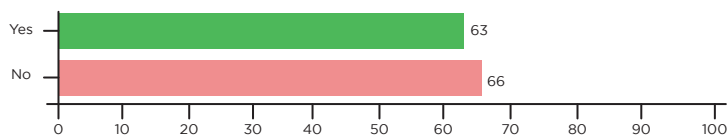
Psychosocial



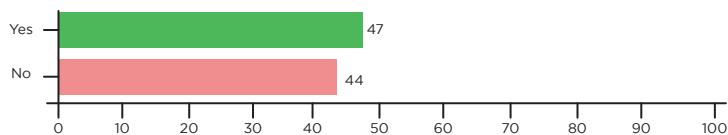
Autism



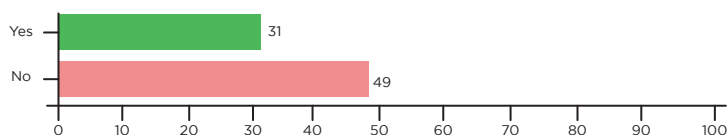
Epilepsy



Cerebral Palsy

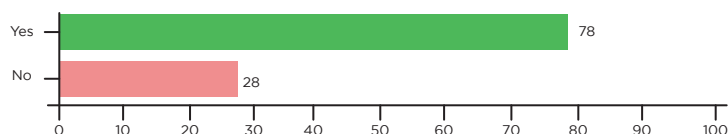


Down Syndrome



Respondents across the county previous figure indicates that out of the possible 258 respondents, 31 had down syndrome which affected their learning and social interaction.

Developmental



Note: Severity of disability was a subjective factor

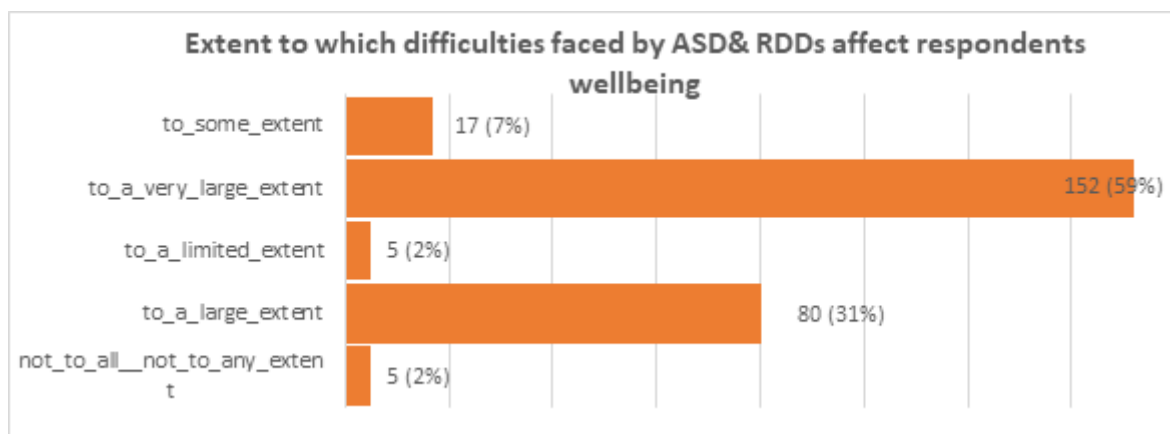
4.4 Analysis of Findings

Data on status of persons with Autism and RDD was analysed and presented in figure below.

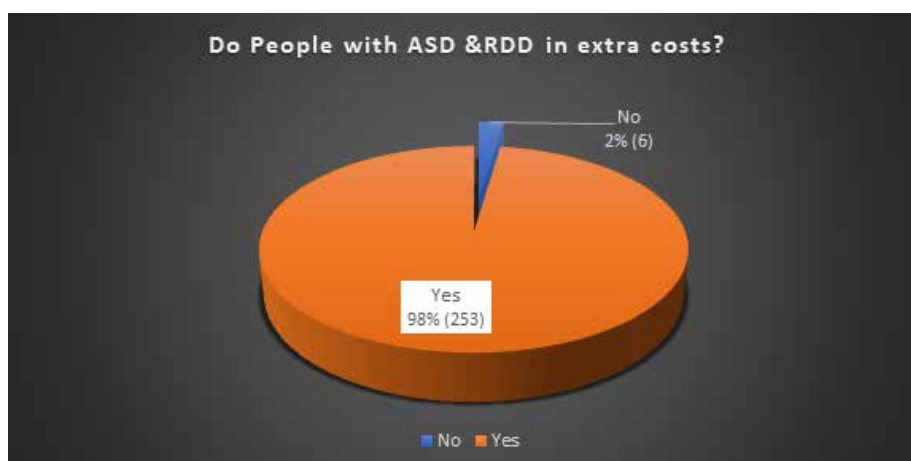
Data on the extent to which the difficulties faced by persons with Autism and RDD affected respondents was analysed and presented in the figure below.

QUESTION 1: To what Extent do the Difficulties Faceb by Persons With ASD and RDD Affect them?

Figure 4.4.1: Extent to which challenges faced by persons with ASD and RDD affect them



The results above show that Persons with ASD & RDDs have varied needs and incur additional costs due to their disabilities. These costs vary from one disability to another. From the graph its clear most respondents were affected to a very large extent by the difficulties (59%), followed by to a large extent (31%), to some extent (7%), limited extent (2%) and the least was not to any extent (2%).

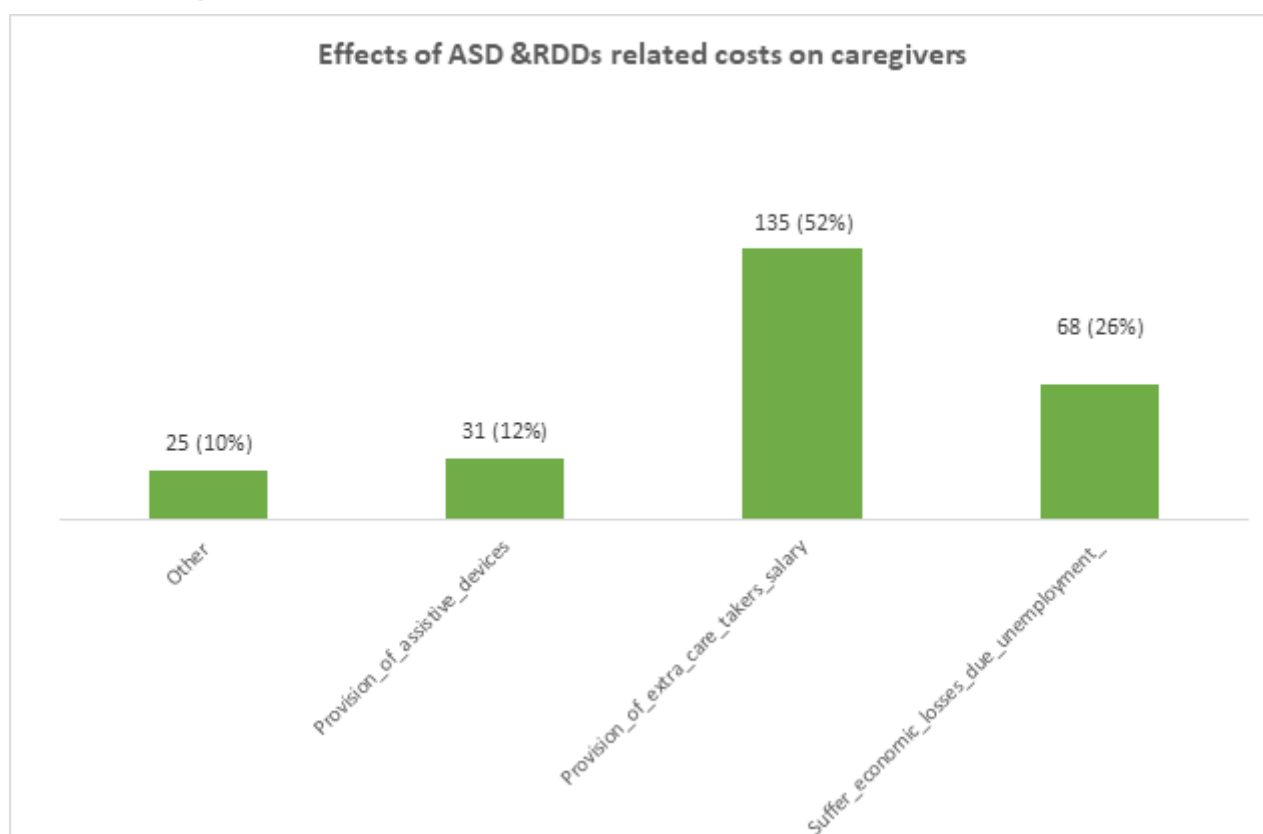


Results from the chart above indicate that persons with autism and RDD incur extra costs as a result of their disability (253 respondents) 98 percent. While a few indicated they do not incur extra costs as a result of disability 2% (6 respondents).

Further probing the responses showed that the extra cost ranges from buying of assistive technologies, drugs, paying for occupational therapy, speech therapy and a dietary intervention, provision of communication boards, PECs.

Results on effects of autism and RDD related costs on caregivers were analysed and presented in figure below.

Figure 4.4.2: Figure Effects of ASD and RDD



Results indicated that the extra costs were incurred by the caregivers. 52% of the respondents reported that most of their income went towards caregivers' support and therapy.

4.5 Challenges, Current needs, priorities and resources required by persons with Autism and RDD

QUESTION 2: What are the Main Difficulties Faced by Persons with ASD and RDD?

When persons with ASD and RDD and their families were asked the main difficulties that they faced due to their conditions, they listed the following in descending order:

1. Management and Care of ASD and RDD
2. Stigma
3. Financial challenges as a result of difficulties in getting into economic activities such as work
4. Lack of education and transition opportunities for persons with ASD and RDD
5. Exclusion in societal activities such as political participation, social issues, among others

QUESTION 3: What are the Main priorities for Persons with Autism and RDD and Caregivers and stakeholders?

The following are the main priorities that were identified in the studies for Persons With ASD and RDD:

1. Lack of Early Diagnosis and Identification, Management and Care of ASD and RDD

This was noted as a foundational challenge that persons with ASD and RDD face. Earlier identification and diagnosis of ASD and RDD can help improve opportunities for children to benefit from interventions and lessen the challenges faced by parents and caregivers. While there is no known single cause of autism spectrum disorder, early diagnosis helps individuals receive resources that can support the choices and opportunities needed to live a well-rounded life.

From key informants' interviews and focused group discussions with persons with ASD and RDD and caregivers, it emerged that challenge is exacerbated by four main factors:

1. When parents have poor awareness of the early symptoms of ASD and RDD or when they may not be the main caregivers; for instance, when working parents rely on the support of domestic helpers.
2. Cases of mis-diagnosis in assessment centres
3. Denial by parents of persons with ASD and RDD
4. Lack of standard guidelines for early identification, care and management of ASD and RDD.

Another challenge that came out was inadequate practitioners with requisite skills to manage ASD and RDD such as speech therapists, occupational therapists, social workers, special teachers, learner supports, among others. Related to this was lack of therapy centres with requisite equipment for managing ASD and RDD. In the northern region of the country, these services were found to be totally unavailable. The few instances of limited management of such cases were found in small centres operated by faith-based organisations such as the Catholic Church.

Caregivers were also found to be lacking in skills to manage persons with ASD and RDD. In other cases, schools were found to be poorly equipped with knowledge to manage cases of epilepsy amongst pupils and students. Proper first aid skills which are pivotal in the early minutes of epilepsy episodes were found to be markedly lacking in Kenyan schools.

2. Ignorance and Stigma Related to ASD and RDD

Respondents reported that they had experienced entrenched stigma related to Autism Spectrum Disorder (ASD). Stigma had a retrogressive impact on persons with ASD and RDD, as well as their families. For instance, it emerged that in some communities, ASD and RDD conditions were thought to be associated with curses and punishment to parents or their clans. A study conducted in Kilifi on the prevalence of epilepsy showed that communities in the counties believed that epilepsy was associated with 'majini' – traditional spirits.

The main contributing factor to stigma on persons with ASD and RDD is ignorance or lack of awareness that exacerbate taboos and stereotypes. Many respondents reported that they had been subjected to labelling in some places having derogatory terms such as wajinga (idiots), among other epithets. This is no different from the use of the term 'of unsound mind' in the Constitution of Kenya and statutes such as the Criminal Procedure

Code, Marriage Act 2014, Penal Code, Elections Act 2011, among others.

Lack of awareness and ignorance also contribute to exclusion of persons with ASD and RDD from societal and political activities. A study conducted by the Kenya Association of the Intellectually Handicapped (KAIH) on stigma in 2022- 2023 faced by persons with intellectual disabilities showed that most of them were barred from voting as they were told 'they had no ability to decide.'

It also emerged that parents of children with ASD and RDD experienced labelling from the society. A total of 15 mothers reported to have been left by their husbands in various counties when they got a child with the condition.

3. Challenges Accessing Education Opportunities and Transition Gap

Individuals with Autism Spectrum Disorder (ASD) and RDD encounter diverse challenges in the education system. For instance, when differentiated curriculum is not provided, many of them have functioning difficulties planning, and time management therefore limiting their ability to complete assignments and tasks independently.

Many children with ASD and RDD also lack individualised attention and support. Many schools don't have modifications to accommodate their unique learning styles. Many of our teachers are lack training and awareness about ASD and they therefore lack strategies for modified and adaptive teaching.

"The lack of support services, such as speech therapy, occupational therapy, and behavioural interventions, can hinder the progress of individuals with ASD and RDD in the education system" – Sylvia Mochabo, founder Andyspeaks, parent of children with neurodiverse disabilities and a Board Member at the National Council for Persons With Disabilities.

"There is need to provide a supportive and inclusive learning environment that offers individualised accommodations – Fatma Wangare, Executive Director, Kenya Association of the Intellectually Handicapped (KAIH).

"Kenya has a serious gap in figuring out transition of persons with ASD and RDD. Many go through the school system without earning a certificate. This country has not figured out how to absorb learners with ASD and RDD into vocational training programmes," Alice Mundia, Differently Talented Society of Kenya (DTSK).

4. Limited Socio-Economic Opportunities for Persons With ASD and RDD and their Families

Persons with ASD and RDD and their families reported that they faced various socio-economic challenges that affect their quality of life and dignity.

(a) Limited Employment Opportunities:

Adults with ASD and RDD reported that they faced challenges in securing and maintaining employment due to diverse factors such as: discrimination, ignorance and stigma on their conditions, social and communication difficulties and failure by employers to provide relevant accommodations.

⁸ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3672948/>

(b) Underemployment, Unemployment and Exploitation

Persons with ASD and RDD and their caregivers reported that in instances where they secured wage opportunities, they ended up being exploited. Some family members of persons with ASD and RDD from Kilifi County reported that their siblings with these conditions had been exploited by restaurants and were misused during water shortages when they had to fetch water from far-off distances at exploitative wages.

5. Challenges Accessing Justice

Persons with ASD and RDD reported that they faced diverse difficulties accessing justice in Kenya. Some of these challenges include:

(a) Communication Barriers

Individuals with ASD and RDD may experience difficulties in communication and understanding complex language.

(b) Difficulties Understanding Legal Procedures

Persons with ASD and RDD may find difficulties understanding the legal processes, language, and concepts or even what they need to do when they find themselves in courts and/or police stations.

(c) Lack of Intermediaries

Kenyan courts lack intermediaries such as communication aides and advocates who can enhance their ability to navigate legal proceedings – Kenya Association of the Intellectually Handicapped.

4.6 Opportunities and Gaps in the existing Legal Frameworks, policies and regulations for ASD and RDD

Most respondents indicated the only exiting legal framework they were aware of that had protected the rights of persons with ASD and RDD was the Constitution of Kenya. Some were aware of the Persons With Disabilities Act 2003 while very few especially in the rural areas were aware of the Convention on the Rights of Persons With Disabilities.

Qualitative data from the FGD and interviews noted that the current legal and policy frameworks such as the Constitution of Kenya (2010), Persons With Disabilities Act and other laws focus on disabilities in general. They called for specific laws – statutes and policies – that mention ASD and RDD.

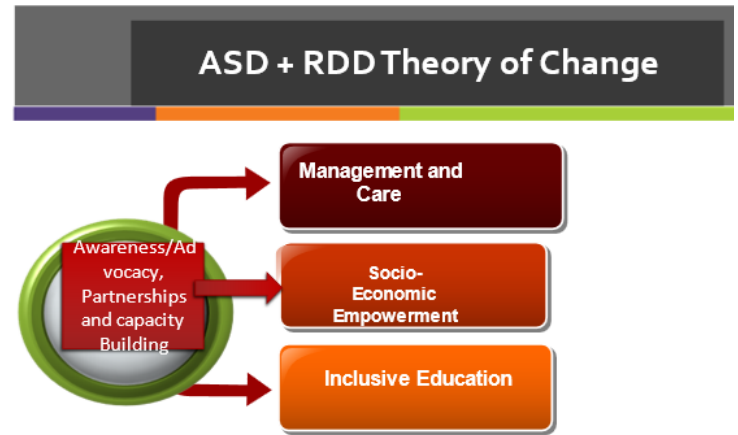
It is important to mention that the Persons With Disabilities Act 2003's definition of disability is not in line with the CRPD in two ways: the CRPD has a more comprehensive definition that takes care of persons with ASD and RDD since it includes the word **intellectual**. Secondly, the CRPD in its definition talks about barriers and how persons with disabilities interact with them in the society. This shows the transition from the medical to social to human rights model. The specific articles in the Convention such as Article 27 on Work and Employment.

A Key informant from Mandera county noted that:

“While the purpose of the Constitution of Kenya and the Persons With Disabilities Act 2003 is to protect the rights of persons with disabilities, there is a clear gap in implementation. For instance, many schools in our county don’t have the capacity to provide education to autistic children. The teachers are not well trained on inclusive education. Our children can only benefit in the big cities like Nairobi. Let’s be honest: how many can afford such? These pastoralists whose cow die every so often due to drought?”

05

RECOMMENDATION ON PROGRAMME DESIGN



ANCHOR PILLARS:

5.1 A: SPECIFIC OBJECTIVE I – EARLY IDENTIFICATION, DIAGNOSIS, MANAGEMENT AND CARE

Establish structures for early identification, management and care of ASD and RDD.

5.1.1 Activity: -Map Health & Social Care Service Providers

This is to determine the number of health and social care service providers, their locations and services offered up to the sub county level.

Procedure

- The Council to develop a mapping criterion with relevant stakeholders;
- The Council to derive a data collection tool from the criteria;
- The Council to brief the ED on the draft data collection tool & seek approval for pre-testing;
- The EDs office to officially communicate to the CoG on pre-testing & data collection exercise;
- The Council to conduct pre-testing of the mapping tool. Approval shall be required from the participating institutions;
- The Council to review & finalize the data collection tool;
- The Council to train County CDSOs on the data collection tool;
- The Council & CDSOs to conduct nation-wide data collection;
- The Council to analyse collected data & map facilities based on the mapping criteria;

- j) The Council to convene a stakeholder meeting to share the mapping report;
- k) The Council to Report, Monitor and learn.

5.1.2 Activity: Develop Guidelines for Management & Care of ASD & RDD

Develop guidelines for standardized provision of management and care services

Procedure

Engage a consultant in developing guidelines for management & care of ASD & related developmental disabilities.

5.1.3 Activity: - Training & sensitization of health & social care workers on the guidelines for management & care of ASD & related developmental disabilities

There's need to train & sensitize health & social care workers on the guidelines for management & care of ASD & related developmental disabilities

Procedure

Engage MOH and relevant stakeholders to review training manuals and facilitate the training.

5.1.4 Activity: - Develop collaboration agreements between the Council & selected health and social care facilities

This is to formalize collaborations by defining the roles & responsibilities of the parties.

Procedure

- a) Hold a consultative meeting to agree on the roles, responsibilities and area of collaboration with the intended partner(s);
- b) Disseminate the draft MOUs/service contracts for consensus;
- c) Negotiate on added or deducted areas on the draft MOUs/service contracts;
- d) Finalisation & signing of the MOUs/service contracts by the ED & Legal officer

5.2 SPECIFIC OBJECTIVE II – ACCESS TO HEALTH AND SOCIAL CARE SERVICES

Increase access to health and social care services to persons with ASD and RDD

5.2.1 Activity: - Map and Enrol beneficiaries

This helped in identifying & enrolling targeted beneficiaries of the programme

Procedure

- a) Develop/adopt a beneficiary mapping tool;
- b) On boarding the beneficiaries on to the MIS;
- c) Report, Monitor and learn.

5.2.2 Activity: - Increase access of health care services to persons with ASD and related developmental disabilities

This is to identify, engage health and social care facilities closest to the beneficiaries.

Procedure

- a) The Council to negotiate with Health and Social care facilities on cost, proximity to services and enhanced therapy services
- b) Disseminate the draft MOUs/service contracts and share with the facilities for consensus;
- c) Finalization & signing of the MOUs/service contracts by the ED & Legal officer of the council & the intended partner
- (d) The Council to Report, Monitor and learn

5.2.3 Activity: - Negotiate & enter into an agreement with NHIF to provide a comprehensive cover to persons with ASD and related developmental disabilities.

Majority of persons with ASD & related developmental disabilities have not been accessing health & care services due to: distance, affordability and availability. NHIF cover will improve access to the

service.

Procedure

- a) The Council to negotiate with NHIF on cost, proximity to services and an enhanced medical cover
- b) Disseminate the draft MOUs/service contracts and share with NHIF for consensus;
- c) Finalization & signing of the MOUs/service contracts by the ED & Legal officer of the council & NHIF
- d) The Council to Report, Monitor and learn

5.2.4 Activity: - Enrol programme beneficiaries to NHIF cover

This will help to improve ease of access to health care services.

Procedure

- a) The programmes Council to submit list of beneficiaries to NHIF as per the requirements
- b) NHIF to enrol beneficiaries to the system
- c) The Council to mobilize beneficiaries for biometric registration
- d) The Council to Report, Monitor and learn

5.2.5 Activity: - Awareness and sensitization on health & social care services

The majority of persons with ASD & related developmental disabilities, parents/carers play a primary role of ensuring access to services. Awareness & sensitization will ensure that they are well informed of key programme services, types of disabilities and disability etiquette.

Procedure

- a) The CDSOs to organize sensitization forums for parents/ carers with relevant stakeholders including but not limited to NHIF, Ministry of Health, Ministry of Education and social workers.
- b) CDSOs to Monitor and Report

5.2.6 Activity: - Procurement of products and services

This involves acquisition of diapers, medi-

cation and any other product and services according to the Public Procurement and Asset disposal Act 2015 and related regulations and, other government Circulars.

Procedure

- a) Procurement of products and services in will be informed by data on the Autism programme.
- b) Warehousing will be outsourced to a contracted agency.

5.3 SPECIFIC OBJECTIVE II - SOCIO-ECONOMIC EMPOWERMENT

Foster the socio-economic empowerment of persons With ASD and RDD and their families

5.3.1 Activity: Advocate for Inclusive Employment Opportunities for persons with ASD and RDD

Procedure

- a) Lobby private and public sector to employ persons with ASD and RDD
- b) Develop frameworks and guidelines for accommodations of persons with ASD and RDD

5.3.2 Activity: Build the capacity of persons with ASD and RDD to venture into entrepreneurship

Procedure

- a) Build the capacity of ASD and RDD into entrepreneurship – (borrowing from KAIH's model of self-advocates)
- b) Lobby for AGPO opportunities through the Kenya National Chamber of Commerce and Industry partnership

5.3.3 Activity Mobilize parents and carers to form support groups

Most parents and carers of persons with ASD & related developmental disabilities are not organized into groups where they can share experiences. Peer support can improve experiences and outcomes. It is easier to disseminate important information to groups rather than individuals.

Procedure

- The CDSOs to identify parents/carers of persons with ASD & related developmental disabilities who are in groups and those who are not
- The CDSOs to on-board those with groups onto the MIS
- The CDSOs to mobilize parents/ carers to form and register groups
- The CDSOs to Report, Monitor and learn

5.4 SPECIFIC OBJECTIVE III – INCLUSIVE EDUCATION

Through partnerships with OPDs and stakeholders in MOE, advocate for inclusive education for persons with ASD and RDD.

5.4.1 Activity: Champion the Alignment of Sector Policy for Learners and Trainees with Disabilities with the CBC

Procedure

- Propose revamp of the Sector Policy for Learners and Trainees with Disabilities in line with CBC
- Lobby for the implementation of the Sector Policy

5.4.2 Activity: Liaise with partners to allocate a quota for learners with ASD and RDD

Procedure

- Liaise with OPDs and parent support groups to establish the learners with ASD and RDD in schools
- Provides scholarships to learners with ASD and RDD

CROSS-CUTTING PILLARS:

PILLAR 1: AWARENESS AND ADVOCACY

PILLAR	INTERVENTIONS
AWARENESS	
IEC Materials	Merchandise e.g. lesos, T-shirts, skirts, etc. for awareness creation
On-ground activities/Forums	NCPWD activations in counties
Media engagement	Leverage on mainstream and community media stations, talk shows, etc.
Social media engagement	Run NCPWD TV for Explainers on ASD and RDD
OPDs support for awareness	Support OPDs through granting model – hinged on capacity assessment and capacity building
Convenings	Organise an annual ASD and RDD Dialogue to raise the profile of the conditions

PILLAR	INTERVENTIONS
ADVOCACY	
Laws with an impact on persons with ASD and RDD	Lobby for the passage of Persons With Disabilities Bill 2023, Learners With Disabilities Bill 2023 and Social Assistance (Amendment) Bill 2023 – on caregivers
Access to justice	Lobby for passage of clear access to justice guidelines encompassing the interests of persons with ASD and RDD in the whole criminal justice system: Judiciary, Police Service and ODPP
Amendment of Laws with Derogatory Clauses	Lobby for amendment of clauses in statutes e.g. Criminal Procedure Code and Penal Code with derogatory clauses against persons with ASD and RDD.

PILLAR 2: CAPACITY BUILDING

PILLAR	INTERVENTIONS
CAPACITY BUILDING	
- Spearhead the development of necessary frameworks and guidelines advancing the rights of persons with ASD and RDD e.g. caregivers' guidelines - Build the capacity of various actors across the three anchor pillars e.g. judiciary, media, care givers, etc.	

PILLAR 3: PARTNERSHIPS

PARTNER	TARGET
PARTNERSHIPS	
Media	Awareness creation and programme visibility
Judiciary and the whole criminal justice system	Access to Justice
Amendment of Laws with Derogatory Clauses	Lobby for amendment of clauses in statutes e.g. Criminal Procedure Code and Penal Code with derogatory clauses against persons with ASD and RDD.
OPDs	'On-ground' campaigns
Treasury	Increase funding to the programme
FAO/WFP/UNICEF	Malezi Bora programme and nutrition
Academia	Research
National Assembly Committees and Caucuses	Passage of laws advancing the rights of persons with ASD and RDD
Flying Doctors and St John Ambulance	First Aid packages on epilepsy management
County Governments	Co-funding of the programme – through absorption of some of the persons with ASD and RDD and their families e.g. parent support groups into their programmes
IEBC	Inclusive electoral process that will guarantee the participation of persons with ASD and RDD into elections

06

REFERENCES

1. Centre for the Advancement of Positive Behaviour Support(2014), BILDEnable SG. Services for Children with Special Needs (0-6 Years) [Accessed Jan 1, 2019]. Available at: <https://www.sgenable.sg/pages/content.aspx?path=/for-children/> Autism Resource Centre (Singapore) Autism Resource Centre Home Page. [Accessed Jan 1, 2019]. Available at: <https://www.autism.org.sg/>
2. Mannion A, Leader G. (2013). Comorbidity in Autism Spectrum Disorder: a literature review. Res Autism Spectrum Disorder. 2013;7:1595-616. [Google Scholar]
3. Monika, R. (2018). Autism and the right to education in the EU: Policy mapping and scoping review of the United Kingdom, France, Poland and Spain. National Library of Medicine, United Kingdom. retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6116926/> on May 12, 2023 at 8.15 a.m.
4. Lai M-C, Lombardo M V, Baron-Cohen S. Autism. Semin 896 www.thelancet.com. 2014;383. 10.1016/S0140-6736(13)61539-1 [CrossRef]
5. Rutter M. Incidence of autism spectrum disorders: Changes over time and their meaning *. Acta Peadriatica. 2005;94: 2-15. 10.1080/08035250410023124 [PubMed] [CrossRef] [Google Scholar]
6. Newschaffer CJ. Investigating Diagnostic Substitution and Autism Prevalence Trends. Pediatrics. 2006;117: 29-32. 10.1542/peds.2005-2834 [PubMed] [CrossRef] [Google Scholar]
7. Baron-Cohen S, Allen J, Gillberg C. Can Autism be Detected at 18 Months? The needle, the haystack, and the CHAT. Br J Psychiatry. 1992;161: 839-843. 10.1192/bjp.161.6.839 [PubMed] [CrossRef] [Google Scholar]
8. Elsabbagh M, Divan G, Koh Y-J, Kim YS, Kauchali S, Marcín C, et al. (2012). Global Prevalence of Autism and Other Pervasive Developmental Disorders.

Autism Res. 2012;5: 160–179. 10.1002/aur.239 [PMC free article] [PubMed] [CrossRef] [Google Scholar]

9. Brugha T, Cooper S, McManus S, Purdon S, Smith J, Scott F, et al. (2012). Estimating the prevalence of Autism Spectrum Conditions in adults: extending the 2007 adult psychiatric morbidity survey. The NHS Information Centre for Health and Social Care. 2012. [Google Scholar]

10. van Heijst B, Geurts H. Quality of life in autism across the lifespan: A meta-analysis. Autism. 2015;19: 158–167. 10.1177/1362361313517053 [PubMed] [CrossRef] [Google Scholar]

11. Knapp M, Romeo R, Beecham J. Economic cost of autism in the UK. Autism. 2009;13: 317–336. Available: <http://journals.sagepub.com/doi/pdf/10.1177/1362361309104246> 10.1177/1362361309104246 [PubMed] [CrossRef] [Google Scholar]

12. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. J Child Psychol Psychiatry. 2004;45: 212–229. Available: <http://onlinelibrary.wiley.com/doi/10.1111/j.1469-7610.2004.00215.x/abstract> [PubMed] [Google Scholar]

13. WHO. World Report on Disability. 2011.

14. Autism Europe. Autism and education. 2003.

15. ‘Social stories and comic strip conversations with students with Asperger syndrome and high-functioning autism’ (1998), Springer.

16. ‘Strategies and approaches’, The National Autistic Society

17. Malone, K. (2021). The Challenges Students with Autism Face. retrieved from <https://www.graduateprogram.org/2021/01/the-challenges-students-with-autism-face/> on Thursday May 11, 2023 at 9.40 a.m.

18. National Institute of Mental Health. (2023). Autism Spectrum Disorders. Researchers Develop Method to Study Brain Connectivity, Functionality [Press Release]. U.S. Department of Health and Human Services, National Institutes of Health. Retrieved January 11, 2023, from <https://www.nimh.nih.gov/news/science-news/2022/researchers-develop-method-to-study-brain-connectivity-functionality>

19. Unigwe, S. (2016). Autism- Plugging Gaps in service provision and improving the healthcare experiences. Retrieved from <https://socialcare.blog.gov.uk/2016/06/29/autism-plugging-gaps-in-service-provision-and-improving-the-healthcare-experience/> on Thursday, May 11 2023 at 10.18 a.m.

20. Palmisano, G. (2015). The Protection of People with Autism in the Framework of the Council of Europe and the European Union. In: Della Fina, V., Cera, R. (eds) Protecting the Rights of People with Autism in the Fields of Education and Employment. Springer, Cham. https://doi.org/10.1007/978-3-319-13791-9_2



NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES (NCPWD)



P.O. BOX 66577 – 00800,
Nairobi



0709107000



info@ncpwd.go.ke



0202314621 /
2375994



@Ncpwds



www.ncpwd.go.ke



National Council for Persons
with Disabilities (NCPWD)