



NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES (NCPWD)



ANALYTICAL MONOGRAPH ON AUTISM

SPECTRUM DISORDERS AND RELATED
DEVELOPMENTAL DISABILITIES



2024



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

STATEMENT FROM THE CHAIRPERSON, BOARD OF DIRECTORS



The challenge of Autism Spectrum Disorders and Related Developmental Disabilities in Kenya is complex, but it is not insurmountable. There are high costs borne by persons with ASD and RDD and their families in managing the conditions. Others grapple with discrimination, stigma, stereotyping and labelling. Others struggle to access services such as education and therapy and many others encounter difficulties with our justice system.

The process of development of this monograph was strategically guided by the Board of NCPWD. With their rich knowledge and experience, Board Members provided insights and feedback that enriched the research. I want to thank all of them for creating time and offering their wisdom.

I also appreciate the Secretariat led by the Executive Director for spearheading the process of development of this monograph. This study will provide in-depth knowledge on ASD and RDD in Kenya. This will inform programming and interventions by various actors. It will also inform the legislative agenda as the national and sub-national level.

The report shows that the cost of managing these conditions is astronomically high. It is this background that I request actors in the disability and human rights space as well as donors, well-wishers and philanthropists to collaborate to address this challenge.

With collective effort and dedication, we can transform the lives of persons with ASD and RDD and their families and build an inclusive future where every individual is given the opportunity to reach their full potential.

Mrs. Elizabeth Chesang
Chairperson,
National Council for Persons With
Disabilities

STATEMENT BY THE EXECUTIVE DIRECTOR



Across the country, many persons with Autism Spectrum Disorder and Related Developmental Disorders and their families have faced stigmatisation and labelling. Others remain hidden and denied a life of dignity. Many other families have faced the high costs associated with care and management of these conditions. ASD and RDD have specific contours that demand our collaboration and indeed focused attention.

For the first time, Kenya now has a nationwide study on ASD and RDD. Capturing the views from all regions of the country, the monograph captures the challenges faced by persons with ASD and RDD and their families in areas such as education, socio-economic challenges, access to justice, stigma, among others. It also captures various recommendations to inform the now robust ASD and RDD programme at the NCPWD.

This study would not have been possible without the support of our mother ministry – Labour and Social Protection – that has provided technical support and guidance to the Council over the years. We also recognise the ministry of National Treasury and Economic Planning for providing financial resources and guidance in programmes execution and funds utilisation.

The monograph provides a major reference point for the Council and any other agency or organisation keen to undertake interventions such as direct service delivery, advocacy and resource mobilisation.

The stigma that persons with ASD and RDD have faced has its roots in the nascent levels of awareness and understanding of autism in the country. There are entrenched beliefs and misconceptions in many Kenyan communities as the study shows on the causes of ASD and RDD. This not only breeds discrimination but also impedes timely diagnosis and interventions.

I call on all actors involved in the disability sector to collaborate with the Council to undertake interventions that will give persons with ASD and RDD a life of dignity. Advocacy is about power in numbers. In this regard, I call on persons with ASD and RDD and their representative organisations to work together to build a robust movement of actors championing the rights of this constituency.

Harun Maalim Hassan, EBS
Executive Director
National Council for Persons With
Disabilities

PREFACE AND ACKNOWLEDGMENT

This Monograph was developed following extensive consultation with diverse stakeholders that NCPWD acknowledges.

The Council appreciates the support received from the Ministry of Labour and Social Protection – its parent ministry – for the support and guidance in the development of the Monograph. We also appreciate the Ministry of Treasury and Planning for providing resources to implement the ASD and RDD programme and indeed other interventions by the

We appreciate the Board of Directors of NCPWD for their strategic guidance and counsel in the development of the report. Their input helped enrich the report with actionable recommendations.

The Council also appreciates the Executive Director for his guidance in the development of the Monograph. We also appreciate the Management and Staff of the Council for their participation in various consultative meetings.

We also thank the Planning Department for its valued coordination of the process. Special mention goes to the Council's ASD and RDD Programme Lead Winfred Mbugua for overseeing the process of research and indeed quality control.

The Council appreciates the Research Team Members, namely: Simon Wachira (Team Leader), Kennedy Okumu (Lead Researcher), Dr Joel Okutoyi (Lead Researcher) and Paul Kamau (Principal Researcher). The Team was supported by: Mumbiko King'ori, Angela Kibagendi, Kelvin Gusimba and Florence Mwazemba.

For several years, organisations working in the space of ASD and RDD lobbied, engaged Parliament and Senior officials at the Ministries of Labour and Social Protection, Treasury and Health. This network of committed disability champions formed a robust network that was very instrumental in the design of the NCPWD ASD and RDD programme and indeed in the development of this Monograph. We thank them for this role. We also appreciate the stakeholders from organisations of persons with disabilities that took part in the validation process of the Monograph.

Lastly, the Council appreciates its funding partners that complement its resources ranging from private sector organisations, public sector organisations, Embassies, Foundations and bilateral organisations.

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ABBREVIATIONS

ASD	Autism Spectrum Disorder
ASD & RDD	Autism Spectrum Disorder and Related Developmental Disabilities
CATI	Computer Assisted Telephone Interview
CDSOs	County Disability Service Officers
COVID	Corona Virus Disease
CP	Cerebral Palsy
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
WHO	World Health Organization
USNIMH	United States National Institute of Mental Health

OPERATIONAL DEFINITIONS OF KEY TERMS

Key Term	Definition
Autism 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 capability and power under law of a person to occupy a particular status or relationship with another or to engage in a particular undertaking or transaction.
Early Intervention Measures	Methods and techniques used to address the problems persons with developmental disabilities may be having early enough to help prevent or reduce the effect of the disability in life. They include; Therapy services, assistive devices, Restructured Environment, Picture Exchange Communication System, Use of Sign Language and Use of social media e.t.c.
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 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 came up with a programme to support 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., Nutrition support, occupational therapy, speech therapy, essential drugs and supplies; and provision of adult diapers for those with severe disabilities.

This monograph, therefore, will 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

This monograph will guide the process of designing interventions that address challenges and create the 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.

The monograph informs the Council's interventions in addressing 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 provides insight on the existing policies and legislations that inform guidelines for management and care of persons with Autism and related developmental disabilities. The study will inform the Council on 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 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

The detailed study was informed by the need to:

- 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

1.4 Research Questions

The study was 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) 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? 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 9 clustered regions of Kenya specifically identified to provide convenience and logistic cost-effectiveness in the execution of the study.

The participants were persons from both genders who had ASD and Related Developmental Disabilities as well as their families, teachers and caregivers. The participants mirrored 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 in the 24 counties.

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

1.6 Assumptions of the Study

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

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 offers great insights 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.

Through the study, service providers and caregivers for persons with ASD and RDD will understand the current status of persons with ASD and RDD, in terms of demographics, accessibility to services, current trends, priorities and resources needed. This will enhance the development of relevant policies to protect persons and families with ASD and RDD.

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 provides clear recommendations to address the gaps identified.

Finally, the study recommends a wide range of measure that improves the well-being of persons of 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.

1.10 Background on Autism Spectrum Disorders and Related Developmental Disabilities

Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) refer to a range of neurodevelopmental conditions characterised by difficulties with socialisation, communication, and repetitive or restrictive behaviours. The term “spectrum” in ASD highlights that these disorders vary widely in their severity and symptoms and can affect individuals differently.

The 67th World Health Assembly held in May 2014 noted that, globally, an increasing number of children are being diagnosed with ASD and RDD and the Assembly recommended appropriate recognition and actions to address these conditions.

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-- (WHA67.8) “ calling on countries to eliminate stigmas surrounding developmental disorders so that they can be addressed effectively, rather than ignored.

Characteristics of ASD

1. Social Communication and Interaction Difficulties

- a. Difficulty in understanding and responding to social cues like body language, tone of voice, and facial expressions.
- b. Preference for solitary play or lack of interest in social interactions.

2. Repetitive Behaviours

- (a) Strict adherence to routines and discomfort when changes are made.

(b) Intense, focused interests in specific topics.

(c) Sensory sensitivities, such as aversion to certain sounds, lights, or textures.

3. Variability in Skills and Abilities:

(a) Uneven development of cognitive skills; strengths in some areas and challenges in others.

(b) Some individuals may have significant intellectual or cognitive difficulties

(c) Co-occurring conditions such as ADHD, anxiety, depression, or learning disabilities are common.

Need for Early Diagnosis and Interventions

ASD can often be reliably diagnosed by age 2, but many children may not receive a final diagnosis until older. Early intervention has been shown to improve therapy and interactions later in life.

Management of ASD

There is no cure for ASD, but various therapies can help manage symptoms and improve quality of life. These include:

1. Behavioural Therapies: These can help improve social, communication, and learning skills.

Dietary Interventions: Dietary support has shown consistent positive results in the management of ASD.

2. Speech Therapy: Helps improve communication skills.

3. Occupational Therapy: Focuses on improving activities of daily living skills and sensory integration.

It is important to note that the Ministry of Health in 2010 developed National Guidelines and Manual for identification and referral of children with disabilities. The Ministry In 2013 also launched a Training Manual for Health Workers on Prevention, Early Identification and Interventions for

Disability. OPDs note that the effectiveness of such guidelines will be greatly enhanced by the addition of clinical guidelines that are specific for the management of conditions in the spectrum for instance, Clinical Guidelines for the Management of Down syndrome.

Down Syndrome

Down syndrome is a genetic condition where a person is born with an extra copy of chromosome 21. This means that they have a total of 47 chromosomes instead of 46. The condition is named after John Langdon Down, the British doctor who first fully described the syndrome in 1866.

Who Does it Affect?

Down syndrome can affect anyone. It's a genetic condition. A majority of Down syndrome cases happen randomly.

Characteristics and Symptoms

1. Physical Features: Persons with the condition has distinct facial features such as a wide face, small head, short neck, protruding tongue, upward slanting eye lids (palpebral fissures), unusually shaped or small ears and weak muscle tone.

2. Cognitive Difficulties: Persons with down syndrome have varying degrees of intellectual disability which could be mild or moderate. They may also experience delayed cognitive and language development. In addition, they may have difficulties walking and moving (gross and motor skills), learning difficulties, play (social and emotional skills), among others.

3. Mobility and Co-ordination: Due to some of these cognitive difficulties, children with Down syndrome may have difficulties in toilet training, speaking their first words, taking their first steps and eating food independently.

4. Growth Delays: Persons with Down syndrome experience slower growth and development. This may lead to shorter

than average size in adulthood.

5. Health Difficulties: Persons with down syndrome are at an increased risk of congenital heart defects, respiratory difficulties including obstructive sleep apnea, hearing difficulties, vision difficulties or eye diseases. However, not every individual with Down syndrome will experience all these health issues.

6. Behavioural Difficulties: persons with Down syndrome may exhibit behavioural difficulties usually when unable to communicate their needs to their parents, guardians or caregivers. These difficulties may include difficulties paying attention, obsessive or compulsive behaviours.

Causes and Diagnosis

1. Trisomy 21: The most common form of Down syndrome, where there is an extra copy of chromosome 21 in all cells. This is caused by nondisjunction, an error in cell division.

2. Translocation Down Syndrome: A portion of chromosome 21 attaches to another chromosome, usually chromosome 14. The total number of chromosomes in the cells remains 46, but the presence of extra material from chromosome 21 causes Down syndrome characteristics.

3. Mosaicism: A mixture of two types of cells, some with the usual 46 chromosomes and others with 47. These individuals may have fewer characteristics of Down syndrome due to the presence of some (or many) cells with a typical number of chromosomes.

4. Prenatal Testing: Down syndrome can often be diagnosed before birth through screening and diagnostic tests.

Management and Support

1. Early Intervention: Therapies starting in infancy can significantly help in development. These may include speech, occupational, and physical therapy.

2. Education and Support: Educational programs, along with social and family support, are key in aiding individuals with Down syndrome to develop skills and live fulfilling lives.

3. Regular Health Check-ups: Monitoring and managing the associated health issues are important for maintaining the health and well-being of individuals with Down syndrome.

Inclusive Considerations

(i) Inclusive Society

Persons with Down syndrome have a right to live in an inclusive society. They have a right to education, employment and economic opportunities such as entrepreneurship as well as participation in societal affairs such as civic processes: elections, public participation, among others.

(ii) Inclusive Education

According to the International Guidelines for the Education of Learners with Down Syndrome, there are three key human rights concepts identified in Article 24 of the UNCPRD of relevance to the education of learners with Down syndrome namely: Inclusive Education, Lifelong Learning and Equal Opportunity. Learners with Down syndrome are individuals with a variety of strengths and challenges and have the capacity to learn and continue to do so throughout their lives. Because of their varied strengths, learners with Down syndrome require different form of supports and accommodations that would work in an inclusive learning environment. Some experience difficulties with vision, hearing and indeed speech, language and communication therefore necessitating tailored support.

Cerebral Palsy

Cerebral Palsy (CP) is a condition that affects the motor part of the brain hence making movement and posture difficult or unattainable at all. It is formed by two words, cerebral relating to or concerning the brain and palsy which entails movement. Palsy comes from Greek paralysis, which literally means “loosen” or loss of the ability to move a body part.

Important to note, CP is an umbrella term that encompasses a wide variety of disorders that affect a person’s ability to move. In this regard, it is a group of neurological conditions that affect a person’s ability to move and maintain balance and posture. It is the most common motor disability in childhood.

Cerebral palsy is caused by abnormal development or damage to the parts of the brain that control movement, balance, and posture. This damage can occur before, during, or shortly after birth, and the symptoms and severity can vary greatly among individuals. This can be caused by injury to the brain, before, during and after birth.

Globally, cerebral palsy affects around 1.5 and 4 out of every 1,000 live births. There are no official statistics on the prevalence of the condition in Kenya, but some experts estimate that about three in every 100 children in the country currently live with the condition – showing a higher prevalence than the global estimates.

Characteristics and Symptoms

1. Motor Difficulties: These can range from mild to severe and may include muscle stiffness (spasticity), weakness, poor coordination, tremors, or involuntary movements.

²Faragher, R., Robertson, P., & Bird, G. (2020). International guidelines for the education of learners with Down syndrome. Teddington, UK: DSI

³Ibid

2. Variability: The condition can affect one limb, one side of the body, or the entire body. The lower limbs are often more affected than the upper limbs.

3. Associated Conditions: Many individuals with CP may also experience epilepsy, intellectual disabilities, vision or hearing difficulties as well as speech and language disorders.

4. Developmental Delays: Delays in reaching motor skill milestones such as sitting, crawling, feeding, toileting, or walking are common.

5. Gait Disturbances: A variety of gait patterns can be observed, often characterised by an unusual walk, including asymmetrical steps.

Causes

1. Prenatal Disruptions: Most CP cases are believed to result from issues that occur during pregnancy which affect normal brain development.

2. Perinatal and Postnatal Factors: Problems during labour and delivery, as well as infections, head injuries, or jaundice shortly after birth, can contribute to developing CP.

3. Risk Factors: Premature birth, low birth weight and infections during pregnancy are known risk factors.

Diagnosis

1. Early Signs: Usually noticed before a child reaches three years of age. Parents or doctors might notice delays in development and growth milestones.

2. Medical Evaluation: Includes neurological exams and possibly brain imaging techniques like MRI to assess brain damage or abnormalities.

Types of Cerebral Palsy

1. Spastic Cerebral Palsy: Character-

ised by increased muscle tone, resulting in stiff and jerky movements. It's the most common type.

2. Dyskinetic Cerebral Palsy (Athetoid): Involves fluctuations in muscle tone, leading to uncontrolled or involuntary movements.

3. Ataxic Cerebral Palsy: Affects balance and depth perception, leading to unsteady or shaky movements and difficulty with fine motor tasks.

4. Mixed Cerebral Palsy: Some individuals have symptoms of more than one type of CP.

Management and Treatment

a. Rehabilitation Therapies: Physical, occupational, and speech therapies are key components of managing CP.

b. Medications: Used to manage symptoms like muscle spasticity and seizures.

c. Surgical Interventions: In some cases, surgery may be necessary to manage orthopedic difficulties or severe spasticity.

d. Assistive Technologies: Such as communication aids or mobility aids such as walkers or wheelchairs can greatly improve quality of life.

e. Regular Medical Care: Regular assessments by a healthcare team are important to address the changing needs of persons with CP.

Inclusive Considerations:

(a) Inclusive Education – Like other persons with disabilities, persons with CP do well in inclusive learning environment. A study on inclusive needs of persons with cerebral palsy noted that:

Children with Cerebral Palsy needs effective support and optimal care along with

education. They need regular lovable interaction. Optimal care may involve interaction by physical therapist, occupational therapist, speech-language therapist, special education teacher, adaptive sports therapist, nutritionist and other related supporters.

(b) Socio-Economic Empowerment: Persons with CP need to grow in inclusive societies that enable their participation in social, economic and political affairs. With necessary supports and accommodations, they can work, run businesses and play a role in civic processes such as voting, vying for positions, public participation, among others. Across the world, various leaders with CP have emerged through nominative and elective opportunities.

Epilepsy

Epilepsy is a central nervous system (neurological) disorder in which brain activity becomes abnormal, causing seizures or periods of unusual behaviour, sensations, and sometimes loss of awareness.

Seizures may be short or long – lasting between seconds (short seizures) to minutes (long seizures). Persons with epilepsy experience the condition in varied ways.

Characteristics and Symptoms

1. Seizures: Persons with epilepsy experience recurrent seizures that can occur in various ways such as convulsions and loss of consciousness to confusion, staring spells or uncontrolled jerking movements.

2. Types of Seizures: Seizures are generally classified into two categories:

- o **Focal Seizures:** These originate in a specific part of the brain and can occur with or without loss of consciousness.

Symptoms may include alterations in smell, taste, hearing, vision, or emotional state.

- o **Generalised Seizures:** These involve all areas of the brain. Common types include absence seizures – this is brief loss of awareness and this is largely seen in children. Other persons with epilepsy experience tonic-clonic seizures (convulsions, muscle rigidity, and loss of consciousness), among others.

3. Triggers: Certain factors can trigger seizures in people with epilepsy, such as stress, flashing lights, lack of sleep, or alcohol consumption.

What Causes Epilepsy?

The cause of epilepsy is often unknown, but it can be attributed to various factors, including:

a. Genetic Factors: Some types of epilepsy are genetic, where the condition runs in families or is linked to specific genes.

b. Head Trauma: Such as injuries sustained in accidents.

c. Brain Conditions: Brain tumours or strokes can cause epilepsy. Strokes are a leading cause of epilepsy in adults over the age of 35.

d. Infectious Diseases: Such as meningitis and HIV/Aids.

e. Prenatal Injury: Babies are susceptible to brain damage before birth due to several factors such as an infection in the mother, poor nutrition, or oxygen deficiencies, which can result in epilepsy.

f. Developmental Disorders: Epilepsy can sometimes be associated with

developmental disorders such as autism.

Diagnosis

1. Neurological Examination: To test behaviour, motor abilities, mental function, and other areas to diagnose epilepsy and determine the type of seizures.

2. Blood Tests: To check for signs of infections, genetic conditions, or other conditions that may be associated with seizures.

3. Electroencephalogram (EEG): The most common test used in diagnosing epilepsy, which records the electrical activity of the brain.

4. Brain Scans: Such as MRI or CT scans, to look for abnormalities in the brain.

Treatment

a. Medications: Anti-epileptic drugs (AEDs) help a lot in controlling seizures in many patients.

b. Surgical Procedures: Surgery may be an option for those whose seizures aren't controlled by medications, typically involving removing the area of the brain where seizures begin.

c. Neurostimulation Devices: Devices like Vagus nerve stimulators or responsive neurostimulation systems can help control seizures.

d. Dietary Therapies: Such as the ketogenic diet, have been effective, especially in children, in controlling seizures.

Emerging Issues in Epilepsy Management and Care

In November 2020, the 73rd World Health Assembly (WHA) adopted resolution WHA 73.10 on Global actions on epilepsy

and other neurological disorders to develop an ***Intersectoral global action plan on epilepsy and other neurological disorders (IGAP)*** in consultation with Member States. The action plan will address the challenges and gaps in providing care and services for people with epilepsy and other neurological disorders that exist worldwide and ensure a comprehensive, coordinated response across sectors.

To meet the global targets, IGAP includes proposed actions for WHO Member States, the WHO Secretariat, and national and international partners in the following areas:

(i) Access to services for epilepsy – Approximately 70% of people with epilepsy can be seizure-free if provided with treatment. There are, however, gaps in treatment. The current treatment gap estimate is 75% in lower-income countries and is substantially higher in rural areas.

(ii) Engagement and support for people with epilepsy – Persons with epilepsy and their families are stigmatised as a result of the misconceptions and negative attitudes on the condition. In many communities in Kenya, epilepsy is seen as a curse or a spell. In Kilifi for instance, a study showed that communities in the region associate the condition with traditional spells (majini).

(iii) Epilepsy as an entry point for other neurological disorders – Epilepsy can be secondary to other neurological conditions, such as stroke or traumatic brain injury. It also can occur along with other conditions; for example, 19% of people with epilepsy also have migraine, and about 26% of adults with epilepsy also have intellectual disability.

Building on this WHO resolution, the International League Against Epilepsy has developed a 90-80-70 action plan that addresses challenges and gaps in

⁵ International League Against Epilepsy

providing care and services for People with Epilepsy and other neurological disorders and ensuring a comprehensive coordinated response across sectors.

The aims of the action are that by 2031:

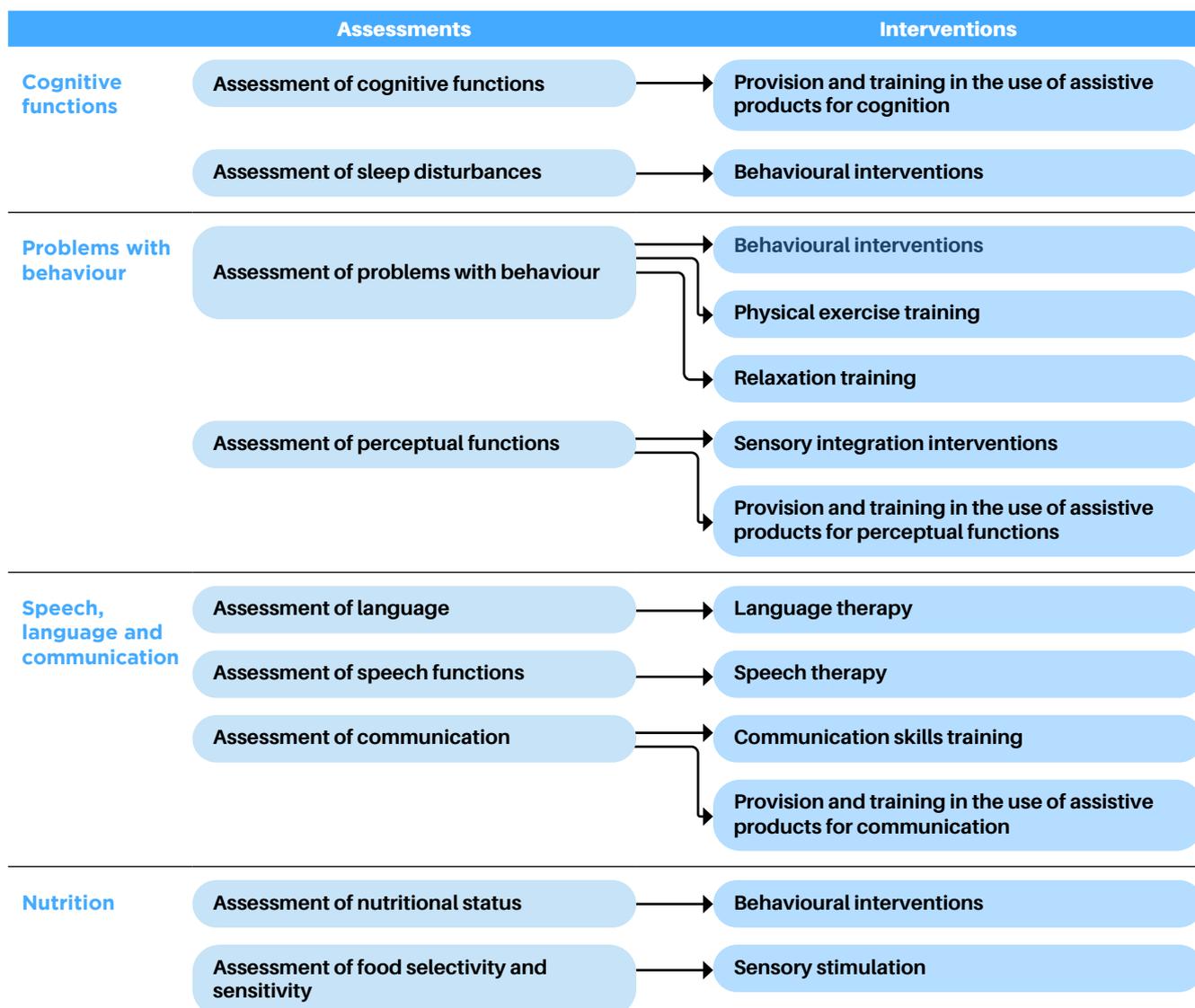
- 90% of people with epilepsy are aware of their diagnosis as a treatable brain disorder
- 80% of people with epilepsy have access to affordable, appropriate, safe anti-seizure medication
- 70% of people with epilepsy receiving treatment achieve adequate seizure control

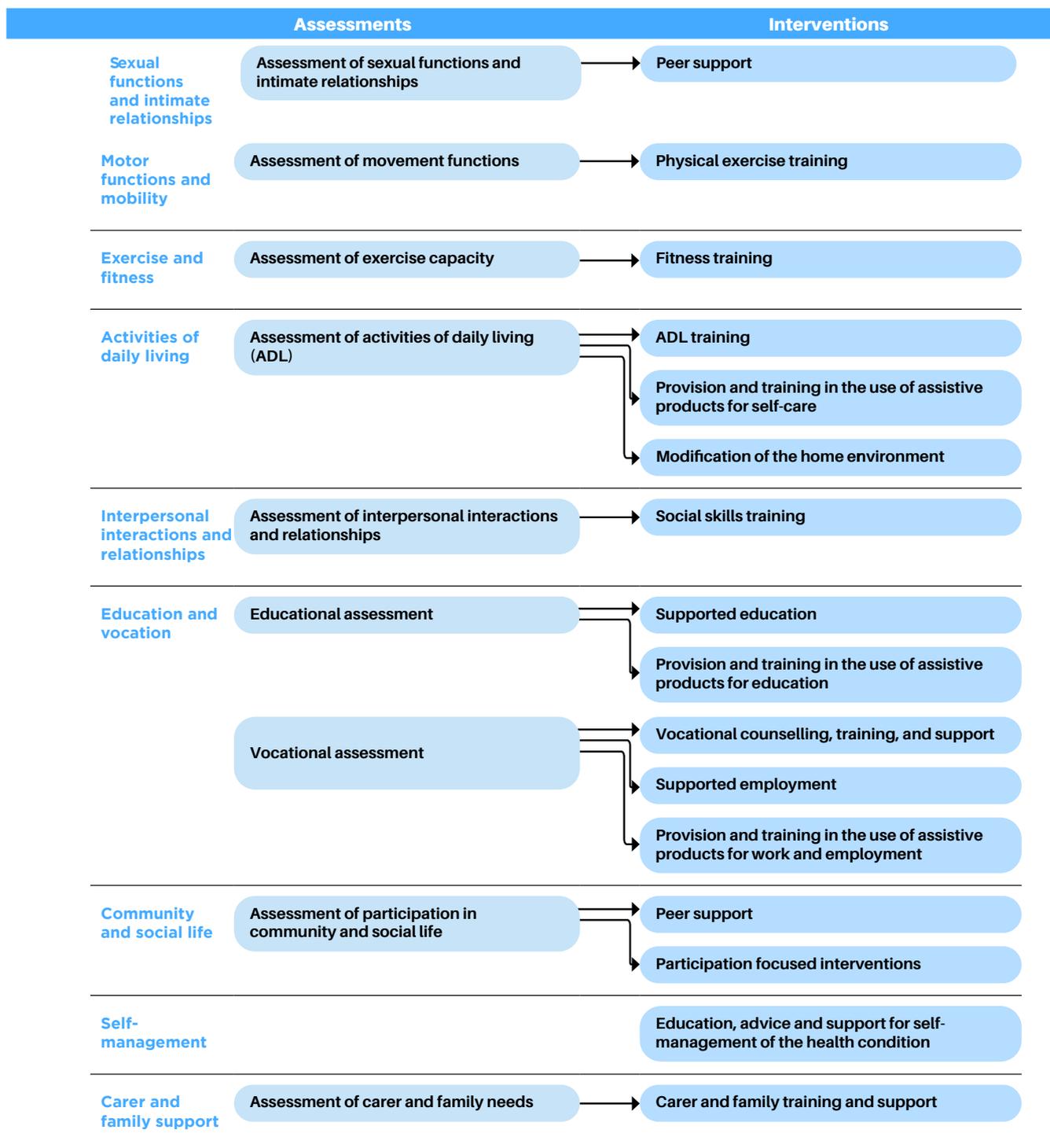
National Guidelines for the Management of Epilepsy

In 2014, Kenya launched the National Guidelines for the Management of Epilepsy. The rationale behind the guidelines was to ensure that the country has a standardized framework for the management of epilepsy and indeed empower patients to self-manage their condition and indeed address stigma.

Overview of the interventions for rehabilitation in Autism Spectrum Disorders

Functioning interventions





Interventions for the prevention and treatment of secondary conditions related to autism spectrum disorder

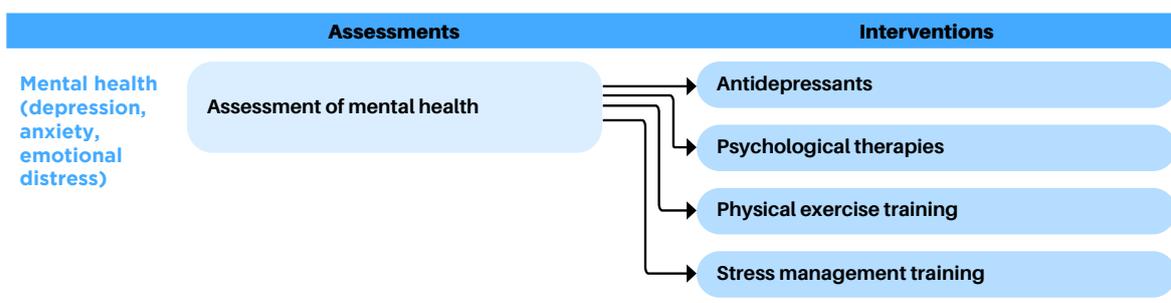


Image adopted from WHO Rehabilitation Interventions for Developmental Disabilities.

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 78% 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

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

2.2 Legal frameworks and Policies on ASD & RDD

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

⁶ World Health Organisation, 2023 <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>

⁷ Kenya Population and Housing Census 2019

⁸ See: <https://www.udpkenya.or.ke/blog/persons-with-disabilities-and-data-inclusion/>

⁹ <https://wisevoter.com/country-rankings/autism-rates-by-country/>

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 No. 11 of 2007	Prohibits the discrimination of persons with disabilities in employment in public and private Sectors (Section 5).
National Employment Authority Act No. 3 of 2016	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 No. 24 Act 2013	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 No. 27 of 2022	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 2014 - 2030	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

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.

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).

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:

¹⁰Constitution of Kenya

Table 2.3: Gaps in the law

Law	Gap
Legal Capacity	Legal capacity gives a person the capability and power by law to occupy a particular status or relationship with another or to engage in a particular undertaking or transaction. 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 No. 14 of 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 No. 4 of 2014	Limits the rights of persons with mental health conditions to get married
Penal Code CAP 63 No.20 of 2020	Creates the offence of "rape of an imbecile" presumes that any person with a mental health condition cannot consent to sex
Mental Health Act No. 27 of 2022	Allows guardianship laws to strip persons with disabilities of their rights to make decisions amongst other laws
The Law of Succession CAP 160 No. 11 of 2021	Limits the rights of persons with disabilities to inheritance
Criminal Procedure Code CAP 75 No. 18 of 2018	Allows courts to sentence persons with mental disabilities to serve sentences at the President's pleasure
Article 83 (1) (c) Constitution of Kenya	This Article 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.

¹¹<https://www.borgenmagazine.com/makes-history-global-autism-resolution/>

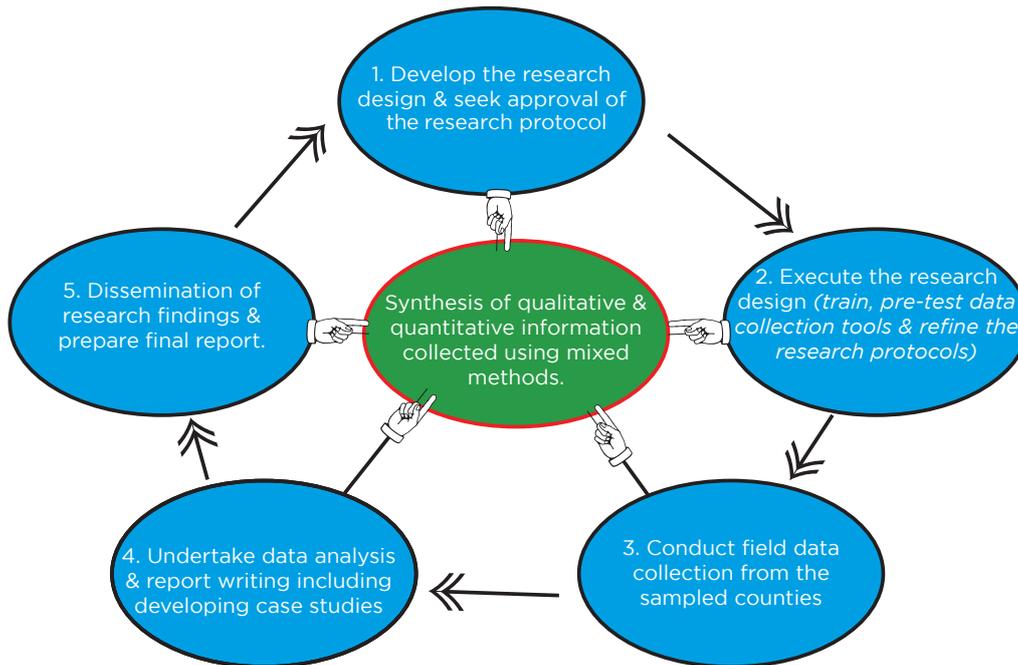
03

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

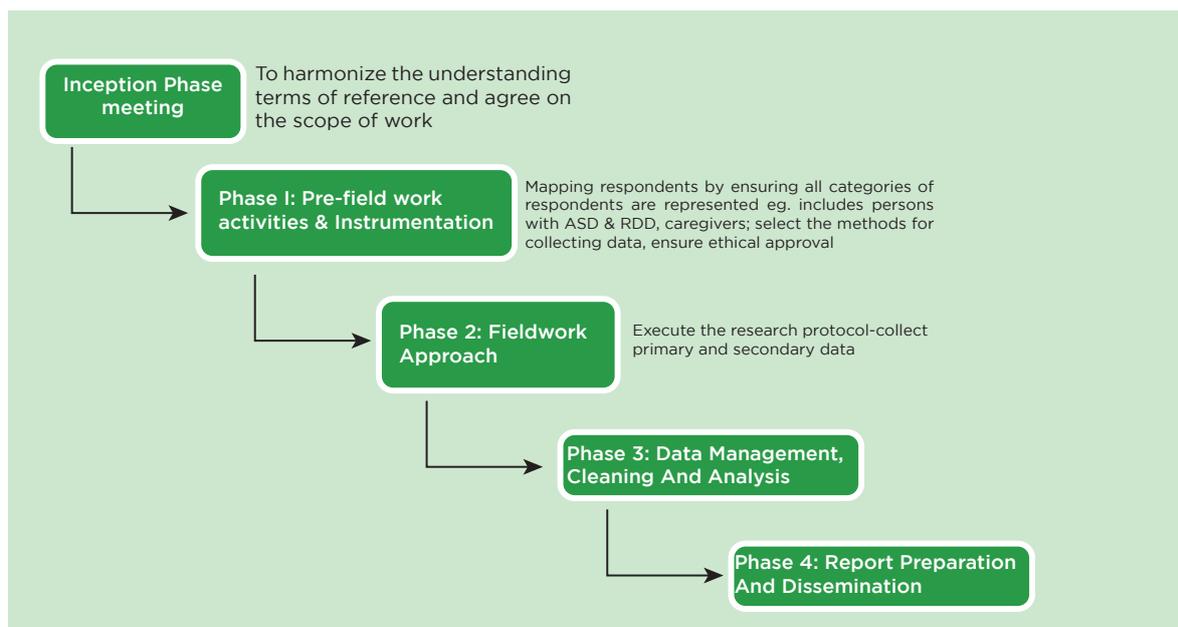
Phase I: Pre-field data collection steps

Phase one involved development of the inception report and a comprehensive frame

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.

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.

Qualitative Data Collection Techniques

Qualitative techniques were be 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

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 Innovation (NACOSTI). 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 Innovation (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.

3.10 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

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.



PARTNERSHIP FOR GOALS: Enabling a life of dignity for Persons with ASD and RDD will be hinged on the power of partnership of diverse actors

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 Per County

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

Table 4.1.1: Distribution of respondents by County and gender

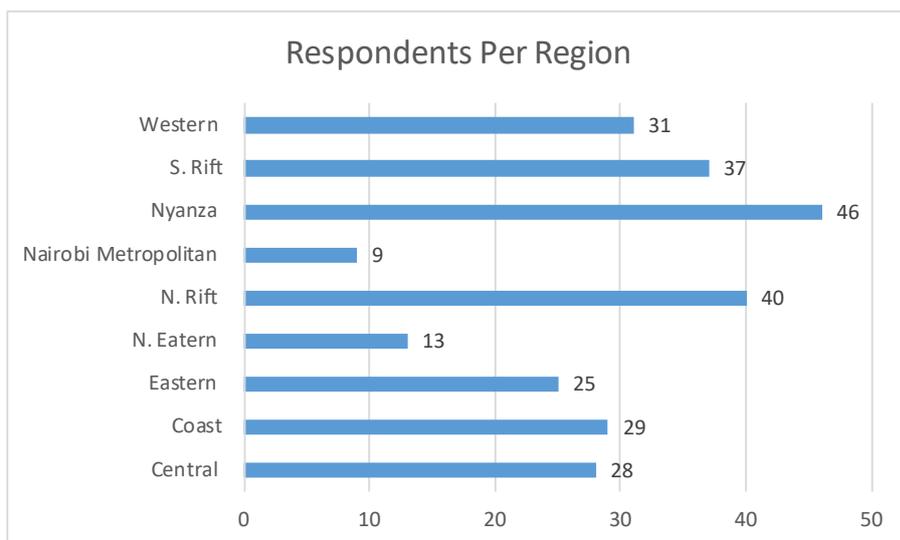
County	Gender				Grand Total	
	Female	%	Male	%	Total	%
Mombasa	5	2%	0	0%	5	2%
Nyeri	7	3%	0	0%	7	2%
Laikipia	19	8%	0	0%	19	8%
Isiolo	7	3%	3	1%	10	4%
Garissa	1	1%	1	0%	2	0%
Mandera	0	0%	1	0%	1	0%
Turkana	6	2%	4	1%	10	4%
Trans_Nzoia	10	4%	2	1%	12	5%
Uasin_Gishu	5	2%	4	2%	9	3%
Nandi	7	3%	2	1%	9	3%
Nakuru	6	2%	2	1%	8	3%
Kwale	9	3%	3	1%	12	5%
Bomet	5	2%	5	2%	10	4%
Kisii	16	6%	5	2%	21	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	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 4.1.2: Response Rate Per County

Region	Respondents Per Region
Central	28
Coast	29
Eastern	25
N. Eastern	13
N. Rift	40
Nairobi Metropolitan	9
Nyanza	46
S. Rift	37
Western	31



Results on response rate per region indicated that the highest response rate of questionnaires came from Nyanza (46), followed by North Rift (40), South Rift (37), Western (31), Coast (29), Central (28), Eastern region (25), North Eastern (13) and Nairobi (9). Further interrogation from the team leaders indicates the highest were due to proper mobilisation.

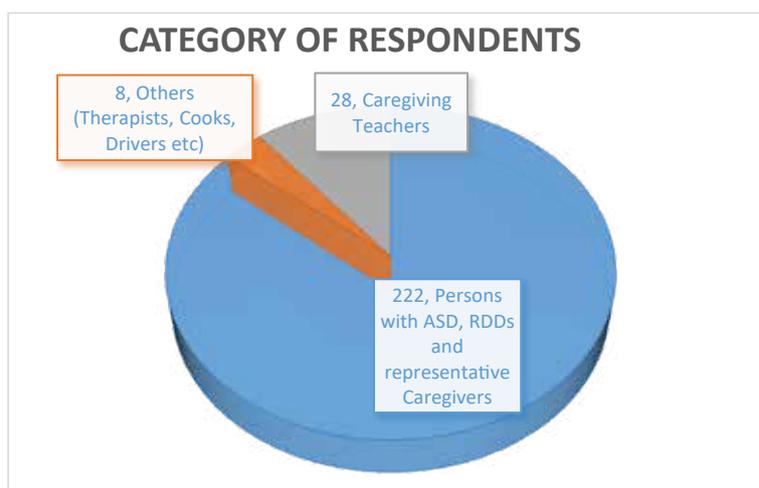
4.2 Category of Respondents

Data from the respondents was analysed and presented and reported in table 4.2 below.

Table 4.2.1: Category of respondents by gender

Count of Category of respondents	Gender				Grand Total	
	Female		Male		Count	%
	Count	%	Count	%		
Persons with ASD, RDDs and representative Caregivers	163	63%	59	22%	222	86%
Others (Therapists, Cooks, Drivers etc)	6	2%	2	1%	8	3%
Caregiving Teacher	21	8%	7	3%	28	11%
Grand Total	190	74%	68	26%	258	100%

Figure 4.2.1: Category of Respondents



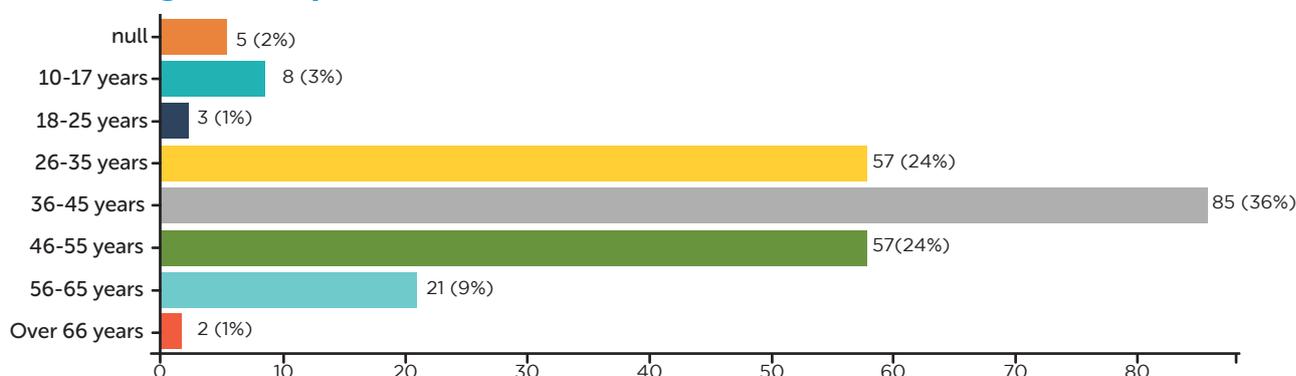
Results from table 4.2 indicated that most respondents were caregivers (81%), followed by regular teachers for learners with autism and RDD (11%), persons with autism and RDD (5%) and the least were other practitioners such as occupational therapists, speech therapists, EARC and DPOs leaders (3%).

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.

4.1.3 Age of Respondents in Years

Data on age of respondents was analysed using ONA package and represented in figure 4.2.2.

Figure 4.2.2: Age of Respondents in Years

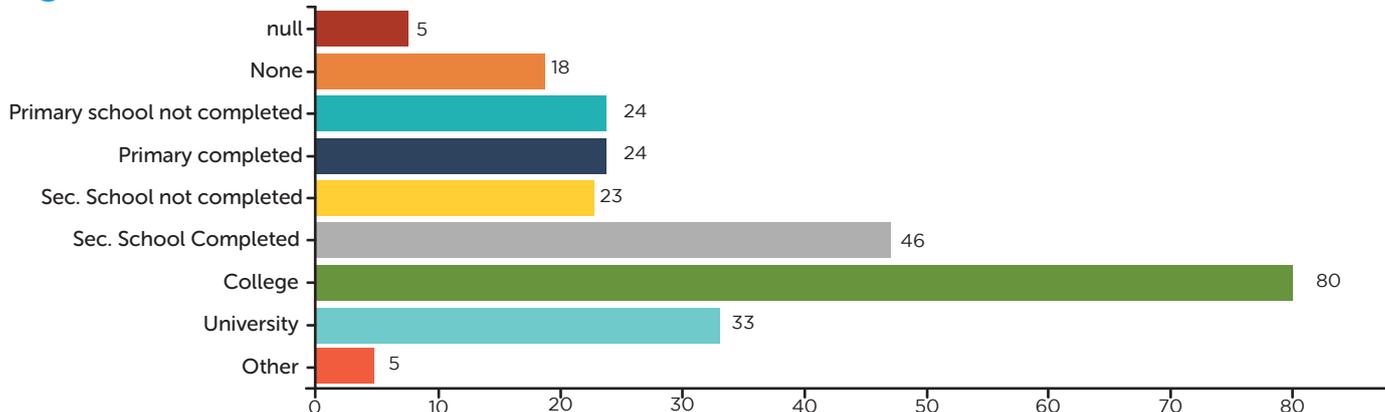


Results from figure 3 indicates that most respondents who participated in the research were aged between **36 to 45 years (36%)**, followed by 26-35 years (24%), 46-55 years (24%), 56-65 years (9%), 10-17 years (3%), 18-25 years (1%) and the least were aged over 66 years (1%). It is worth noting that 36% - most of whom were caregivers were aged 36 to 45 years showing that raising family members with ASD and RDD take up the productive age and time of most caregivers.

4.1.4 Highest Level of Education Attained by Respondents

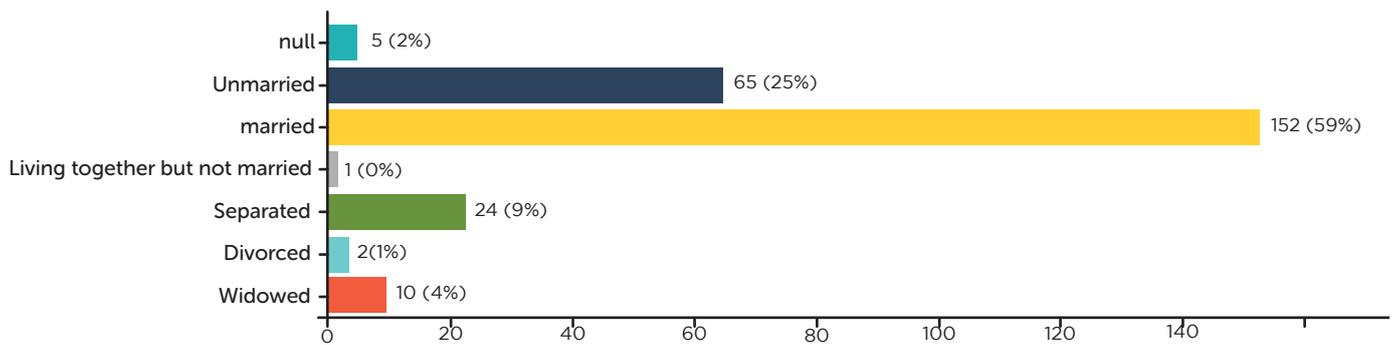
Data on level of education of both caregivers and service providers was analysed using ONA and presented in figure 4.2.3 below.

Figure 4.2.3: Level of education



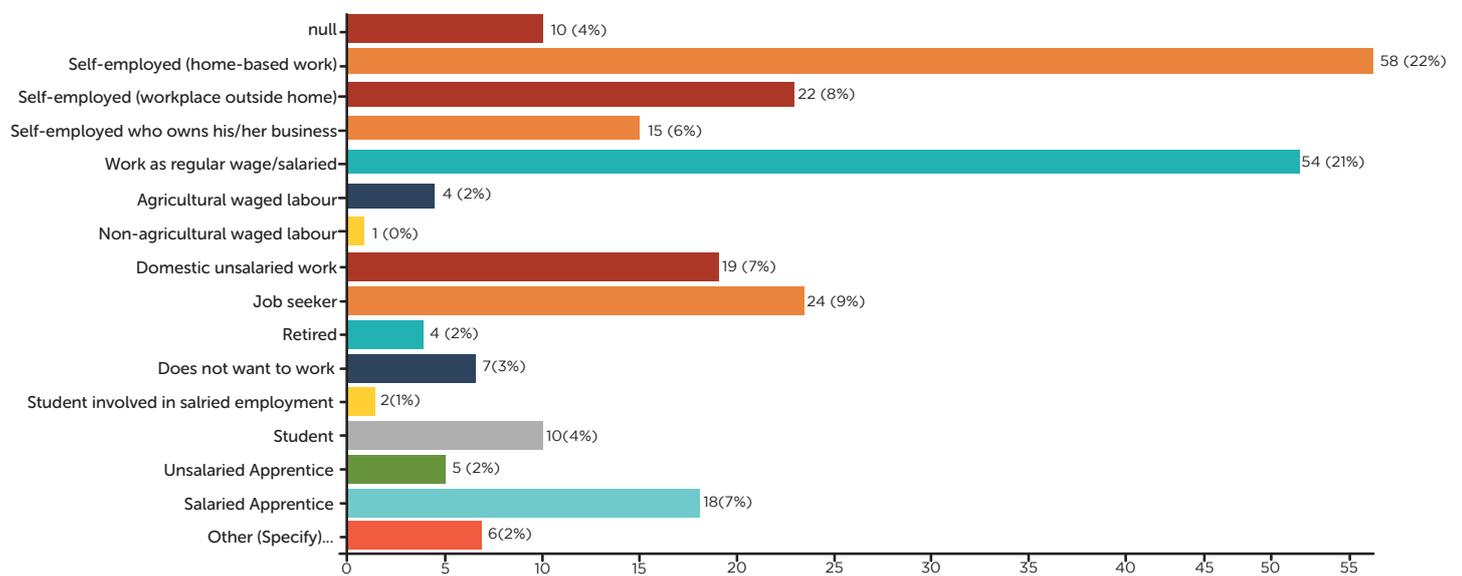
Results in figure 4.2.3 indicated that most respondents had attained college, followed by secondary schools and universities

Figure 4.2.4: Marital Status of Respondents



10% of the respondents reported that after giving birth to a child with ASDs and RDDs, they were accused of being cursed and their children as bad omen. The stigma brought about led them to either divorce (1%) and/or separation (9%).

Figure 4.2.5: Occupation of Respondents



Majority of the respondents (22%) reported that they undertook home based work because those of their family members with ASDs & RDDs needed total care and they did not have the finances to employ caregivers. Some others mentioned that caregivers were not willing to attend to persons with ASDs & RDDs and that even those who took up the jobs resigned shortly after.

Table 4.2.2: Respondents Income Range

Income Range (Kshs)	Respondents
0-20,000	126
20,001 - 30,000	42
30,001 - 40,000	24
40,001 - 50,000	12
Over 50,000	18

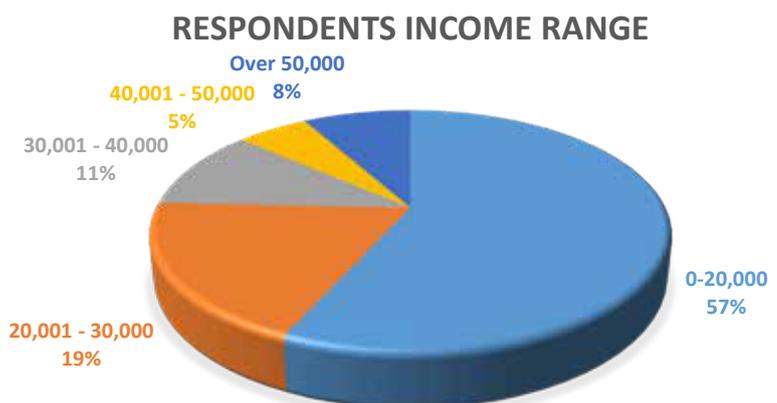


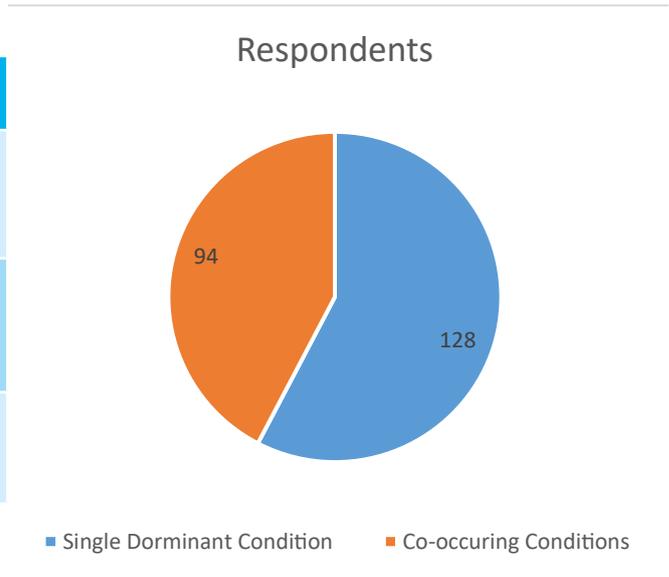
Figure 4.2.6: Respondents Income Range

4.3 Distribution of Respondents by Broad Conditions

Table 4.3.1: Distribution of Respondents by Broad Condition

Figure 4.3.1: Distribution of Respondents by Broad Condition

Condition	Respondents
Single Dorminant Condi-tion	128
Co-occurring Conditions	94
Total	222



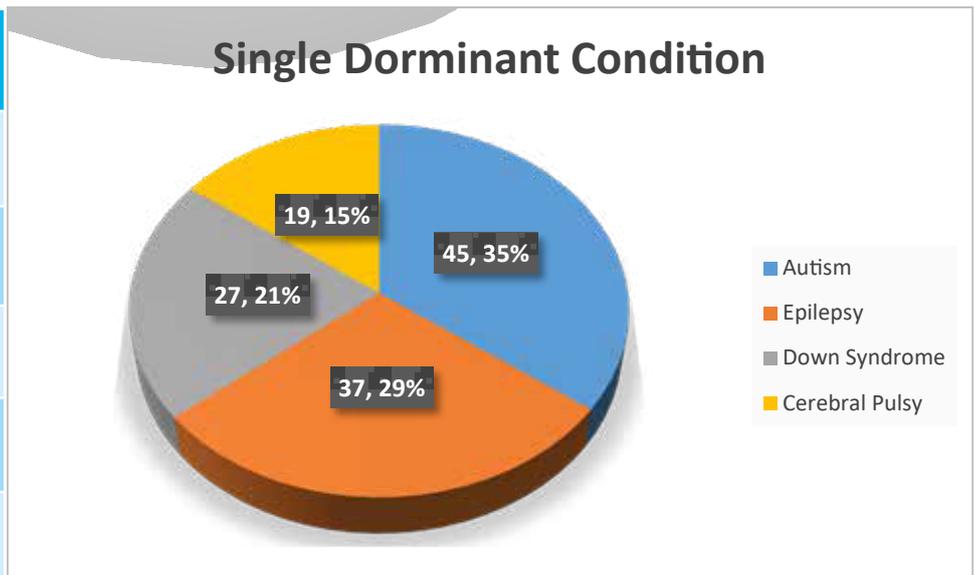
An analysis of data from the respondents show that 58% of persons with ASD and RDD (or their care-givers) were only aware of one dominant condition that they had. It is important to acknowledge that lack of awareness amongst the respondents could have contributed to this. More robust awareness and capacity building are needed especially in rural and frontier counties.

4.4 Breakdown of ASD and RDD Further by Occurence

Table 4.4.1: Distribution of Respondents by Single Dorminant Condition

Figure 4.4.1: Distribution of Respondents by Single Dorminant Condition

Condition	Respond-ents
Autism	45
Epilepsy	37
Down Syn-drome	27
Cerebral Palsy	19
Total	128



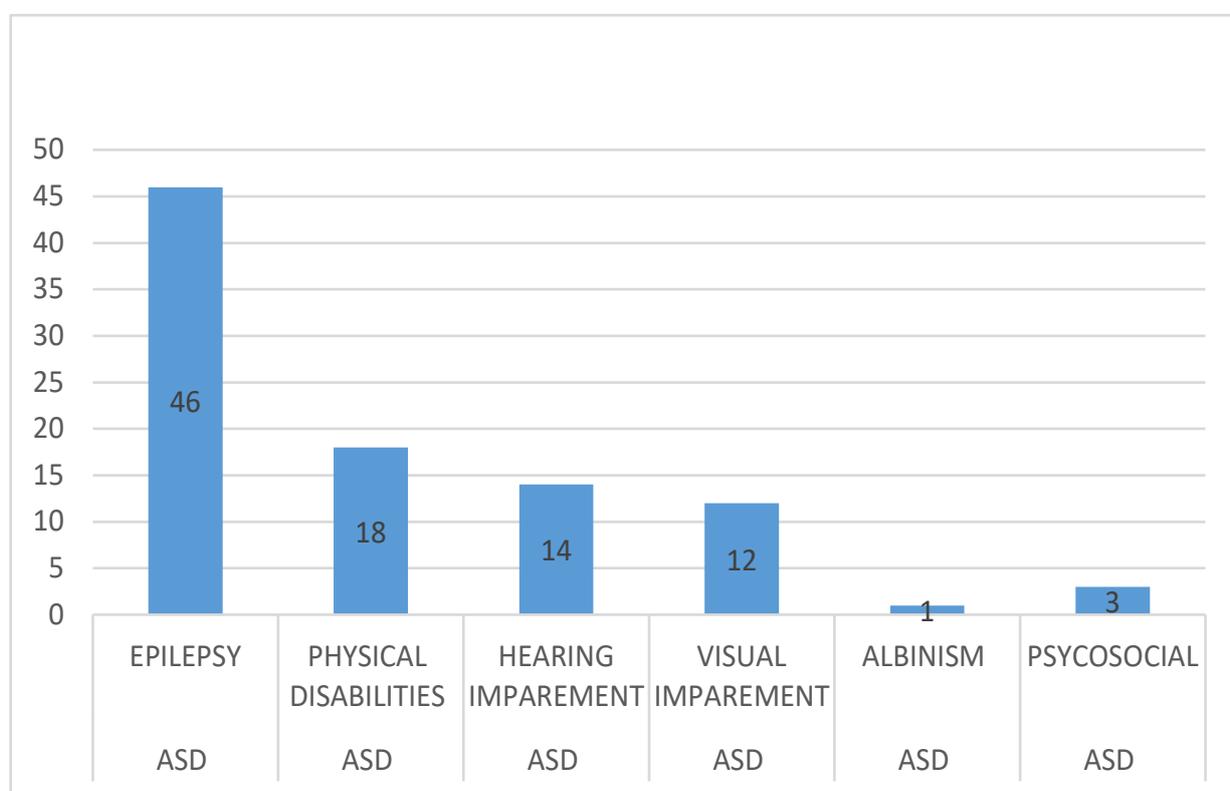
Out of the persons with ASD and RDD who said that they had one dominant condition, ASD emerged as the most occurring condition at 45%. It was followed by Epilepsy, Down Syndrome and Cerebral Palsy in that order.

4.5 Analysis of ASD and Co-Occuring Conditions

Table 4.5.1: Distribution of Respondents with Co-Occuring Condition

Dorminant Condition	Co-occurring Condition	Respondents
ASD	Epilepsy	46
ASD	Physical Disabilities	18
ASD	Hearing Difficulties	14
ASD	Visual Impairment	12
ASD	Albinism	1
ASD	Psychosocial Disabilities	3

Figure 4.5.1: Distribution of Respondents with Co-Occuring Condition



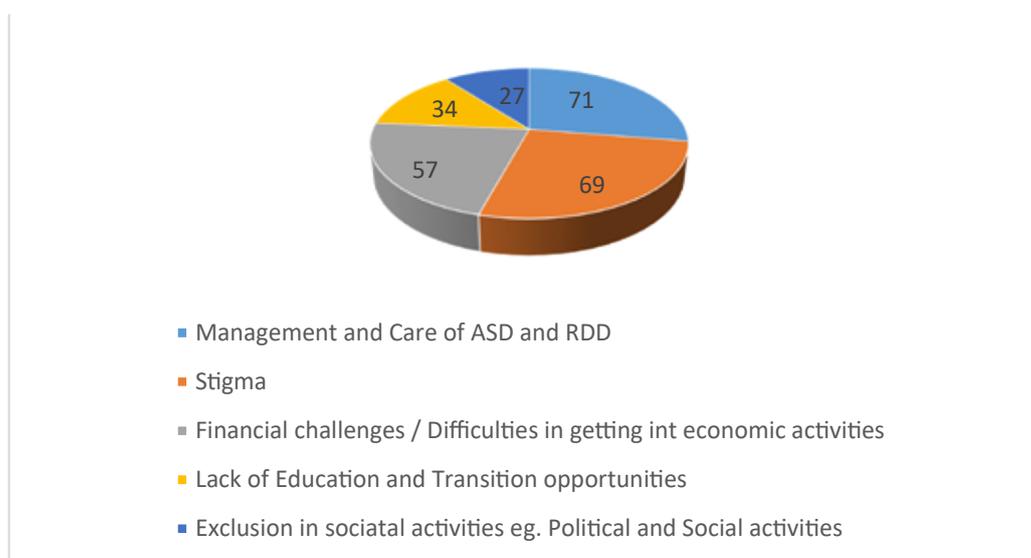
An analysis of ASD and Co-occurring conditions, out of the respondents who said that they had such, shows that there were more cases of ASD co-occurring with epilepsy at 49%. This was followed by a co-occurrence of ASD with physical disabilities. Caregivers across the regions where the research was undertaken lacked in-depth knowledge on ASD and RDD. They may, for instance, not be aware of psychosocial disabilities that their sons or daughters, kins, e.t.c may have -apart from ASD and RDD. Some of the feedback of the caregivers was largely not informed by medical assessment but observable characteristics.

4.6 Main Difficulties Faced by Persons With ASDs and RDDs

Table 4.6.1: Main Difficulties Faced by Persons With ASDs and RDDs

MAIN DIFFICULTIES FACED BY PERSONS WITH ASDs and RDDs	
Management and Care of ASD and RDD	71
Stigma	69
Financial challenges / Difficulties in getting int economic activities	57
Lack of Education and Transition opportunities	34
Exclusion in sociatal activities eg. Political and Social activities	27
Total	258

Figure 4.6.1: Main Difficulties Faced by Persons With ASDs and RDDs



When respondents were asked the main challenges that persons with ASD and RDD faced, Management and Care of ASD and RDD emerged as the biggest challenge at 28%. Under this, most care-givers, service providers and teachers mentioned that the cost and unavailability of therapy, in some cases especially in the rural areas and informal settlements was a big challenge.

During the focus group discussions, a majority of the respondents reported that they committed at least a quarter (25%) of their income or wages to the Management and Care of family members with ASD and RDD. The main costs mentioned were: therapy services, care and medication (where necessary), education, nutrition(special diet), assistive devices and incontinence products such as diapers, pads, among others.

Stigma faced by persons with ASD and RDD and their families was named the second biggest challenge at 27%. From focused group discussions, persons with ASD and RDD and caregivers attributed lack of awareness on these conditions as one of the main contributors of stigma that they face in the society.

The other challenges that were mentioned were financial difficulties, lack of inclusive education and transition opportunities for the persons with ASD and RDD. The last major issue raised was exclusion from social activities such as political affairs for instance voting, public participation among others.

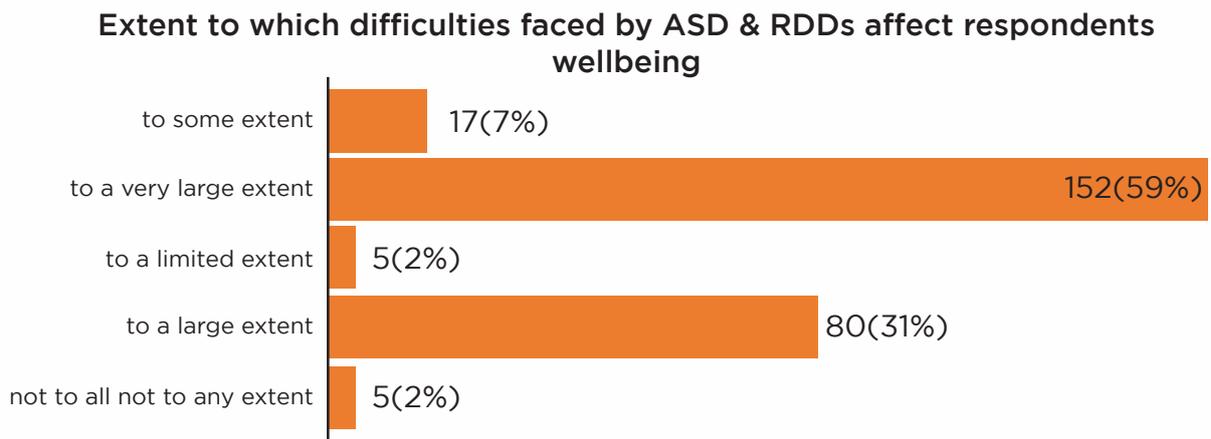
4.7 Analysis of Findings

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?

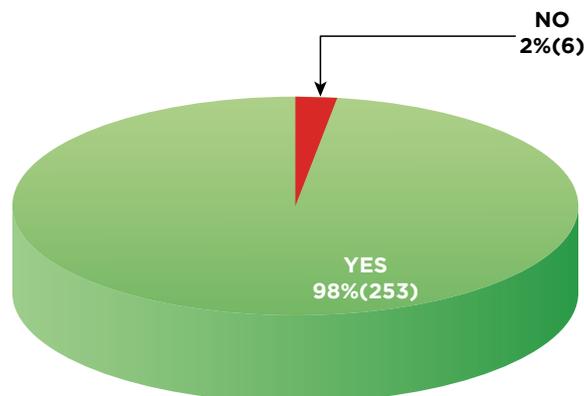
Figure 4.7.1: Extent to which challenges faced by persons with ASD and RDD affect them



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%).

Figure 4.7.2: Extra Costs incurred as a result of ASDs and RDDs condition

Do people with ASD & RDD incur extra costs?

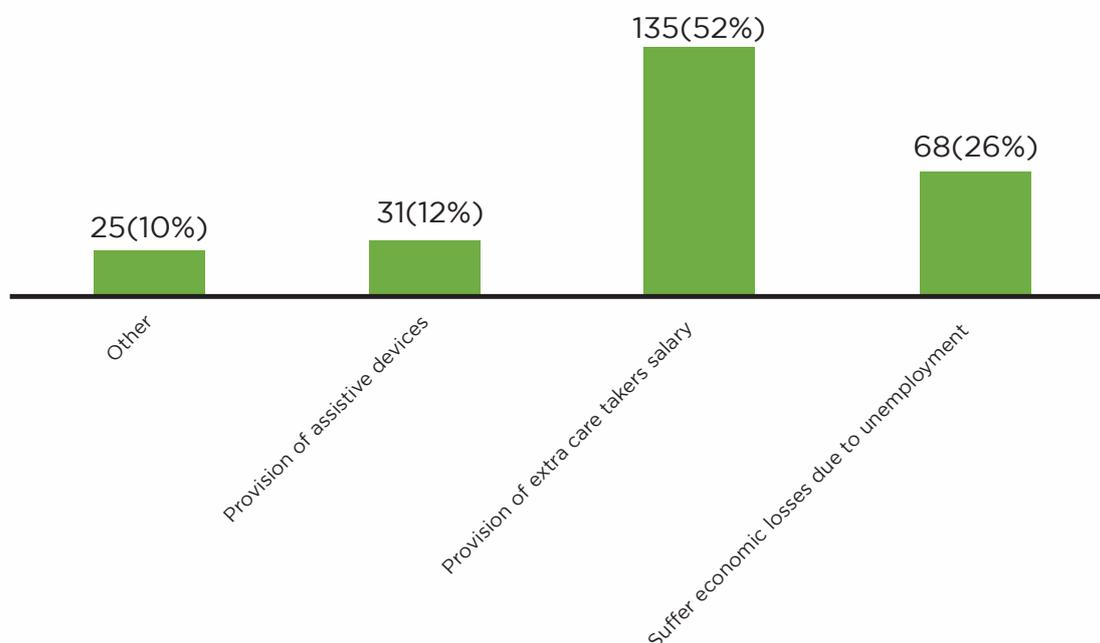


Results from the chart above indicate that persons with autism and RDD incur extra costs as a result of their disability (253 respondents) 98 percent. While a few indicated they do not incur extra costs as a result of disability 2% (6 respondents).

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 4.7.3: ASD & RDDs related costs on caregivers



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.

4.8 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

Inclusive education—which fully engages all students, including pupils and students with disabilities or other learning difficulties, in quality education—has proven particularly effective in helping all students learn. Inclusive education for individuals with Autism Spectrum Disorders (ASD) and related developmental disabilities ensures that they learn in inclusive education settings through a supportive, accommodating, and collaborative environment. This approach ensures that the diverse needs of all pupils and students are met.

Key Components of Inclusive Education for ASD and Developmental Disabilities:

1. Individualised Attention: This ensures that each pupil or student with ASD and RDD has education tailored to their specific needs, strengths, and challenges.

Some of the critical components of this include clarity in specific learning objectives, appropriate accommodations, and support services. It is, therefore, critical that Kenya ensures that the CBC aligns with the individualised needs of persons with ASD and RDD.

2. Individualised Services: This ensures access to individualised instruction and therapies, such as speech therapy, occupational therapy, and behavioural interventions.

3. Training for Educators and Staff: Teachers and school staff should receive training on ASD and developmental disabilities, including understanding different behaviors and learning styles, effective communication strategies, and ways to foster social inclusion.

4. Classroom Accommodations and Supports: Modifications in teaching methods and classroom environment, such as visual aids, sensory breaks, structured routines, and assistive technology, can significantly enhance learning and participation.

5. Peer Education and Support: Educating peers about ASD and encouraging a culture of acceptance and support can promote positive interactions and friendships between all students and pupils.

6. Participation of Families and Care Givers: Engaging families in the educational process is vital. Parents and guardians can provide valuable insights into the child's needs and behaviors and should be active partners in developing and implementing IEPs.

7. Social Skills Development: Programs focusing on social skills training are important for pupils and students with ASD to help them navigate social interactions and build relationships.

¹² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3672948/>

8. Transition Planning: As students with ASD progress through school and prepare for adulthood. In this regard, schools should provide guidance and resources for transition planning, including post-secondary education and employment opportunities. Transition is big lacuna that Kenya has not implemented. As a result of this, persons with ASD and RDD and their families reported that pupils and students with ASD and RDD go through school without clarity of their next course of action. They end up not getting certificates to prove that they were in school.

9. Inclusive Curriculum Design: The curriculum should be adaptable to accommodate diverse learning needs and styles, ensuring that all students, including those with ASD, can access and engage with the material. Learning materials should be in 'easy-to-read' to read versions. Devices and learning programmes that are now become common in Kenya should cater for the individualised needs of the pupils and students with ASD and RDD.

10. Safe and Supportive Environment: Creating a school environment that is physically and emotionally safe and supportive for students with ASD is critical. This includes addressing bullying and promoting a culture of understanding and respect.

Important Considerations

Inclusion Versus Specialized Settings – The Reality: While inclusion is beneficial, it's also important to appreciate that some students with ASD and RDD may thrive better in specialised settings. Decisions should be based on individual needs. This reality is appreciated in the Kenyan Sector Policy for Learners and Trainees with Disabilities.

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 of 'Andy Speaks 4 Special Needs Persons Africa', 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).

¹³[Sector Policy for Learners and Trainees with Disabilities, Ministry of Education, 2018](#)

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.

(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 Autism Spectrum Disorders and Related Developmental Disabilities as well as their families reported that they have faced barriers accessing justice. These were the identified broad challenges in access to justice.

Challenges Faced by Individuals with ASD in the Legal System

- 1. Communication Difficulties:** Persons with ASD and RDD have difficulties with verbal and non-verbal communication, which can hinder their ability to report crimes, testify in court, or interact with legal professionals.
- 2. Sensory Sensitivities:** Courtrooms and legal settings can be overwhelming due to sensory sensitivities common in individuals with ASD and RDD.
- 3. Misinterpretation of Behaviour:** Behaviors associated with ASD and RDD such as avoiding eye contact can be misinterpreted by law enforcement and legal professionals as signs of guilt or dishonesty.
- 4. Lack of Understanding:** There is often a lack of awareness and understanding of ASD and RDD among legal professionals, leading to misjudgments and unfair treatment.
- 5. Vulnerability to Manipulation:** Individuals with ASD may be more susceptible to pressure or coercion, increasing the risk of false confessions or exploitation.

6. Strategies for Improving Access to Justice

- 1. Training for Legal Professionals:** The Kenyan judiciary should collaborate with NCPWD, Organisations of Persons With Disabilities and learning institutions to build the capacity of judges, lawyers, police officers, and other legal professionals about ASD and RDD. This will ensure that they dispense justice equitably and cognizant of the individualised needs of persons with ASD and RDD.
- 2. Individualised Legal Advocacy:** There is room for the Kenyan judiciary, OPDs,

organisations such as Kituo Cha Sheria and the Law Society of Kenya to provide advocates who understand the needs of persons with ASD and RDD. This will also ensure that they provide pro bono legal services.

3. Communication Aids and Supports: Using communication tools (like picture boards or speech-generating devices) and allowing the presence of support persons and intermediaries during legal proceedings can help individuals with ASD express themselves more effectively.

4. Tailored Legal Procedures: Adapting legal procedures to accommodate the individualised needs of persons with ASD and RDD, such as allowing breaks during testimony, using plain language, or providing a quiet waiting area, can help reduce stress and sensory difficulties.

5. Awareness and Sensitivity Training for Law Enforcement: Police officers and other first responders, the officers in the Office of Director of Public Prosecutions should receive training on how to recognise and interact with individuals with ASD and RDD.

6. Community Education: Educating the community about ASD and RDD and developmental disabilities can foster a more understanding and supportive environment for individuals with these conditions.

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

Most respondents indicated the only existing 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.

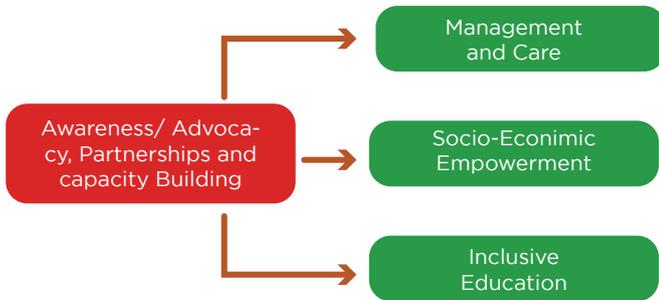
Qualitative data from the FGD and interviews noted that the current legal and policy frameworks such as the Constitution of Kenya (2010), Persons With Disabilities Act and other laws focus on disabilities in general. They called for specific laws – statutes and policies – that mention ASD and RDD.

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?”

ASD + RDD Theory of Change

**ANCHOR PILLARS:****5.1 SPECIFIC OBJECTIVE I – EARLY IDENTIFICATION, DIAGNOSIS, MANAGEMENT AND CARE**

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

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

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.

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.

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.

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

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.

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

Activity: - Negotiate & enter into an agreement with SHIF 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

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

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

Activity: - Procurement of products and services

This involves acquisition of diapers, medication 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

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

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

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

- a) The CDSOs to identify parents/carers of persons with ASD & related developmental disabilities who are in groups and those who are not
- b) The CDSOs to on-board those with groups onto the MIS
- c) The CDSOs to mobilize parents/ carers to form and register groups
- d) 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.

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

Procedure

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

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

Procedure

- a) Liaise with OPDs and parent support groups to establish the learners with ASD and RDD in schools
- b) 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
	<ul style="list-style-type: none"> 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
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

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