



REPUBLIC OF KENYA

Ministry of Public Health & Sanitation



NATIONAL GUIDELINES FOR IDENTIFICATION & REFERRAL
OF CHILDREN WITH DISABILITIES AND SPECIAL NEEDS

APRIL 2010

TABLE OF CONTENTS

Acknowledgement	iv
Foreward	v
Abbreviations & Acronyms	vii
Introduction	1
a) Background.....	1
b) Child Health.....	1
c) Disability and special needs.....	2
1.0 Child growth and development	3
1.1 Early Child Development	4
1.2 Developmental milestones (from birth to 12 years).....	5
2.0 The Child with disability	6
2.1 Child development & disability.....	6
3.0 The disability concept	7
3.1 Defining disability.....	7
3.2 Measuring disability.....	7
3.3 Approaches used in defining disability	8
3.4 Defining disability for purposes of identification and referral of CWDs and special needs	8
3.5 The child with disability	9
3.6 Rehabilitation	9
3.7 Medical and social models of disability rehabilitation	9
3.8 Disability and special needs	10
4.0 Disability domains	10
4.1 Classification by domain	10
4.2 Mental disability.....	11
4.3 Physical disability	11
4.4 Emotional and behaviour disturbances.....	11
4.5 Sensory disability.....	11
4.5.1 Hearing disability	11
4.5.2 Visual impairment	12
4.6 Speech disability	12
4.7 Learning disability	12

5.0 Special interest disability types	15
5.1 Autism	15
5.2 Epilepsy	16
5.3 Down syndrome.....	16
5.4 Albinism.....	16
5.4.1 Causes	16
5.5 Cerebral palsy	17
5.5.1 Causes	17
5.6 Spina bifida	17
5.7 Visible infancy impairments & congenital malformations.....	17
5.8 Deaf blindness in children	17
5.8.1 Causes	17
5.9 Attention Deficit Disorder.....	18
6.0 Children with special needs	20
6.1 Children living in especially difficult circumstances	20
6.1.1 Orphans and vulnerable children	20
6.1.2 Child drug abusers	20
6.1.3 Physically abused children	21
6.1.4 Sexually abused children.....	21
6.1.5 Emotionally abused children.....	21
6.1.6 Situations that may lead to emotional abuse include	22
6.1.7 Child Soldiers	22
6.1.8 Child prisoners	22
6.2 Children with emotional and behavioural disturbances	22
6.3 Gifted and talented children.....	22
6.4 Disadvantaged children needing special attention	22
6.5 Children with chronic health condition or other health problem.....	22
6.6 Children with mental illness.....	23
7.0 Intersectoral collaboration	23
7.1 Collaboration, networking and referrals.....	23
7.2 Health sector.....	23
7.3 Education sector	23
7.4 Social services	24
7.5 National Council for Children's Services.....	24
7.6 Community support groups.....	24
7.7 NGOs and partners	24
7.8 CBOs and FBOs	24
7.9 Advocacy groups	24

7.10 Community leaders and resource persons	25
7.11 Care Givers / Assistants and Community Rehabilitation Workers (CRWs)	25
7.12 Parents, care givers / Assistant	25

List of Tables

Table 1 Developmental milestones	5
Table 2 Disability domains and their characteristics	13

Figures

Figure 1: Networking Systems between government and other stakeholders	26
---	-----------

ACKNOWLEDGEMENT

The Ministry of Public Health and Sanitation through the Division of Child and Adolescent Health recognises the efforts made by individuals, organizations and line ministries in developing this guideline. We would specifically like to appreciate the efforts of CPSK, Autism Society of Kenya, KMTC, ANPPCAN, and APDK who were a tremendous move towards the development of this document.

Our gratitude also goes to Downs Syndrome Society of Kenya, JHPIEGO Kenya, Child Welfare Society of Kenya, Kenya Association for the Welfare of Epileptics, Ministry Of Education through Educational Assessment and Resource Centre, KIE and KISE, Ministry of Planning (National Coordinating Agency for Population and Development), African Medical Research Foundation Kenya and City Council of Nairobi, NCCS, UNICEF and the World Health Organisation for their contributions without which these guidelines would not have come to be.

We acknowledge the work done by Kenyatta National Hospital, The Aga Khan Hospital, Nairobi Women's Hospital, Nairobi Hospital, Nairobi West Hospital, National Campaign Against Drug Abuse and Plan International Kenya. Their critique made us reach this far in the development of the document.

Finally special thanks to the Ministry of Public Health and Sanitation through the Division of Child and Adolescent Health for having put the agenda of children with disabilities and special needs as a right towards their survival in our midst.



Dr. Annah W. Wamae
Head Department of Family Health
Ministry of Public Health & Sanitation

FOREWARD

This document is coming up at a time when it has been recognised that there is a growing number of children with disabilities and special needs whose priorities are not being met due to lack of information.

There is a gap in service provision as far as identifying the particular disabilities and special needs that these children have, with the view to providing them with appropriate intervention measures which include but are not limited to the following:

- a) Medical interventions
 - Corrective surgery
 - Medical rehabilitation and therapy
- i. Screening and identification of disabilities
- ii. Physiotherapy services
- iii. Occupational therapy services
- iv. Speech therapy
- v. Outreach and home based care
- vi. Community based rehabilitation services
- vii. Counselling and support to parents support groups
- b) Provision of appropriate assistive supportive devices & services
- c) Educational referrals and interventions
 - Integrated school systems
 - Inclusive education system
 - Special schools
 - Informal schooling /training
 - Vocational training and sheltered workshops
- d) Social interventions
 - Social integration
 - Environmental and home adaptations
 - Economic empowerment
 - Parents community support groups

Families across Kenya are affected negatively by disabilities and special needs amongst their children. Identifying any possible developmental disorders as early as possible will be a critical milestone which will pave the way for effective and appropriate intervention to meet the needs of the children with disabilities and those with special needs.

Professionals, service providers, organisation of children with disabilities and those with special needs, NGOs and partners working for vulnerable children are called upon to play a greater role to ensure that these children are not neglected in our development systems.

These guidelines target health managers, social workers, special education teachers and rehabilitation workers who care for children with disabilities and special needs. These guidelines are also useful for students, lecturers in the health sector and teachers in learning and training institutions.



Dr. S.K. Sharif MBS, MBChB, M, Med. DLSHTM, MSc.
Director of Public Health and Sanitation

ABBREVIATIONS

ADD	-	Attention Deficit Disorder
ADHD	-	Attention Deficit Hyperactivity Disorder
AMREF	-	African Medical Research Foundation
AOP	-	Annual Operation Plan
ANPPCAN	-	African Network for the Prevention & Protection Against Child Abuse & Neglect.
APDK	-	Association for the Physically Disabled of Kenya
CBOs	-	Community Based Organizations
CBR	-	Community Based Rehabilitation
CCN	-	City Council of Nairobi
CDSGs	-	Community Disability Support Group
CPSK	-	Cerebral Palsy Society of Kenya
CP	-	Cerebral Palsy
CRWs	-	Community Rehabilitation Workers
CWDs	-	Children With Disabilities
CWDSGs	-	Children With Disability Support Groups
CWSK	-	Child Welfare Society of Kenya
CWSNs	-	Children With Special Needs
CAHA	-	Division of Child and Adolescent Health
EARC	-	Educational Assessment and Resource Centre
FBOs	-	Faith Based Organizations
FTT	-	Failure To Thrive
HIV	-	Human Immuno-deficiency Virus
ICF	-	International Classification of Function Disability and Health
ICIDH	-	International Classification in Disability and Health.
I.E.P	-	Individual Education Programme
IMCI	-	Integrated Management of Childhood Illnesses
KAWA	-	Kenya Association for the Welfare of Epileptics
KDA	-	Kenya Disability Act
KIE	-	Kenya Institute of Education
KISE	-	Kenya Institute of Special Education
KMTC	-	Kenya Medical Training College
KNSPWDs	-	Kenya National Survey for Persons With Disabilities
KNH	-	Kenyatta National Hospital
NACADA	-	National Campaign Against Drug Abuse
MOE	-	Ministry Of Education
NGOs	-	Non Governmental Organizations
NCAPD	-	National Co-ordinating Agency for Population & Development
NCCS	-	National Council for Childrens Services
NHSSP	-	National Health Sector Strategic Plan
TS	-	Tourettes Syndrome

OCD	-	Obsessive Compulsive Disorder
OVCs	-	Orphans and Vulnerable Children
PSGs	-	Parents Support Groups
UN	-	United Nations
UNCRC	-	United Nations Convention on The Rights of the Child.
WHO	-	World Health Organization

INTRODUCTION

Background

The development of any country depends on children being able to achieve their optimal physical growth and psychological development. Poor child health negatively affects the country's development through resources diverted to the treatment of illnesses and management of disabilities that could have been prevented or managed early. The effects of children's poor health, nutritional status and dependence caused by various disabilities and special needs prevent them from reaching their genetically pre-determined capacity in society.

Child Health

Good health is an inherent right of the child as stipulated in the United Nations Convention on the Rights of the Child (UNCRC) and the Kenya Children Act 2001. In this regard the Division of Child and Adolescent Health (DCAH) will strive to alleviate discrimination in health provision to vulnerable children particularly children with disabilities (CWDs) and those with special needs (CWSNs).

The Division of Child and Adolescent Health through the Integrated Management of Childhood Illnesses focuses on the well-being of all children without discrimination. The IMCI strategy aims to reduce death, illness and disability and to promote improved growth and development among children under 5 years of age. The IMCI includes both preventive and curative elements that are implemented by families and communities as well as health facilities.

Inline with the IMCI strategy this guideline is intended to enhance:

- a) Early identification of disabilities and handicapping situations in our communities and institutions of service provision
- b) Ensures appropriate combined interventions through referral in the management of all major illnesses, disabilities and handicapping situations affecting vulnerable children.
- c) Promote appropriate care-seeking behaviours, improved health and preventive care, and the correct implementation of prescribed care as well as the rehabilitation of children with disabilities and those with special needs in community settings.

Disability and Special needs

Disability and special needs is a great concern to any society. Disability is a public health burden to Kenyans due to the ignorance, cost of the technical intervention and management that go along with it. This is over and above the normal basic needs and requirements in rehabilitation. Children with disabilities and special needs put an enormous financial strain on their families. In this regard there is need for proper screening for early identification and appropriate intervention.

These guidelines are targeted for use during sensitisation & in screening of children with disabilities and special needs from birth to 18 years. It is however understood that some children due to their disability or specific needs may have a lower mental age as opposed to their genetic or chronological age. This will thus necessitate that their needs are addressed as per their mental age as opposed to the genetic or physical age.

The guideline will be used by stakeholders and service providers working with children with disabilities and special needs. This group will comprise but not limited to:

- a) Organisation of, and for children with disabilities / special needs
- b) Service providers in schools for children with special needs
- c) Institutions for disadvantaged children and those living in extremely difficult circumstances
- d) Health service providers and managers
- e) CBOs and FBOs working with CWDs & special needs.
- f) NGOs and partners providing services to CWDs and special needs
- g) Both public and private health facilities - Providing services for children with disabilities.

Statistics of studies done across the country show that there are quite a number of children with disabilities and special needs whose care and needs are partially met. The recent Kenya National Survey for Persons with Disability 2007 – (KNSPWDs) indicated that 4.6% of the Kenyan population comprises of PWDs which would translate to approximately 1.6 million Kenyans. Amongst the persons who were identified as having a disability, 2.4% were children aged between 0-14 years old. At the same time only 20.4% of the said number of children were using some form of assistive or supportive device. It is thus evident from the survey that 92.4% of the children aged 0-14 years lack assistive or supportive devices. The survey also indicated that 80.9% of children aged between 0-14 years were aware of the available health services (through proxy), 77% needed health services and only 52.4 received the services. 10.6% and 11.3% of people's attitudes was perceived as a problem to children with disabilities on a daily and monthly basis respectively. The above information indicates the actual status of CWDs.

The development of this guideline has been necessitated by the fact that there is a grow-

ing need for early identification, referral and intervention for the management of children with disabilities and special needs. The health issues of children with disabilities and special needs also forms part of the National Health Sector Strategic Plan (NHSSP) 2005 to 2010 .

In this guideline, the ICF system will also be adopted for easy and crosscutting method of identifying disabilities. It also considers both the medical and social models of disability, rehabilitation and social interventions.

This National Guidelines on the Identification of CWDSN is intended to provide guidance to health workers, stakeholders and communities on the important factors for consideration during screening, identification of disabilities and special needs in Kenya. The guideline will provide the stakeholders and those around them with up-to-date evidence based methods of screening and identification of children with disabilities and special needs. It will also give an insight on the role of partners and stakeholders regarding the services that they provide. The guidelines cover disabilities in children, certain aspects of rare disabilities commonly found in our communities and institutions of learning.

It is hoped that with the availability of these guidelines the care for these children with disabilities and special needs will be greatly enhanced through improvement and scaling up of the services by all stakeholders at all levels of service provision.

1.0 CHILD GROWTH AND DEVELOPMENT: (0-5, 5-10, 11-18 YEARS)

Over the last few decades, the relationships between health, physical growth, psychological development and parental care giving have become clearer. Combined growth and development interventions that help families practice “responsive parenting” have the potential to promote better psychological development, as well as physical growth.

Child growth and development in these guidelines will be referring to maturity in terms of physical, cognitive, language, social-emotional, temperament, or fine and gross motor skills development. In this regard it is important to understand and recognise the following stages in the development of all children:

- 1) Neonatal and infant development (0-5 years)
- 2) Child development (5 – 10 years)
- 3) Adolescent development (11 – 18 years)

1.1 Early Child Development

Brain and biological development during the first years of life depends on the quality and amount of stimulation in the infant's family and social environment. Early child development, in turn is a life long determinant of health, wellbeing, and learning skills. These facts make early child development a social determinant of health.

Addressing early child development means creating the conditions for children from pre-natal to 8 years to thrive equally in their physical, social/emotional, and language/cognitive development.

Children require stimulating, supportive and nurturing care even when their parents are not available. High quality childcare and early childhood education can improve children's chances for success in later life. In order to improve the state of early child development, governments and communities need to continuously improve the conditions for families to nurture their children by addressing economic security, flexible work, information and support, health, quality childcare needs and child rights issues.

Among all the social determinants of health, early child development is the easiest for communities and stakeholders to understand. This is because improved early child development means better health, a more productive labour force and reductions in other strains on the social safety net.

Early child development is a cornerstone of human development and should be central to how we measure the state of children's health and development.

Success in the area of early child development requires a partnership, not only among international, national, and local agencies but, also, with the world's families.

1.2 Developmental Milestones: (from birth to - 12 Years)

The table below shows the milestones at the different developmental stages in a child's development from 0 to 12 years.

Developmental Milestones

Table 1

Age	Cardinal Milestone	Other milestones
0 – 4 Weeks	Able to breast feed appropriately	
Age	Cardinal Milestone	Other milestones
4 - 6 weeks	Social smile	
1 – 3 Months	Head holding / control	<ul style="list-style-type: none"> • Following objects with the eyes
2 – 4 Months	Extends hand to grasp toy/ objects	<ul style="list-style-type: none"> • Can turn from back to front • Turns towards the origin of sound • Tosses about hand & feet while lying on back
5 – 9 Months	Sitting	<ul style="list-style-type: none"> • Starts crawling • Starts laughing
7 – 13 Months	Standing	<ul style="list-style-type: none"> • Says b-ba, m-ma • Understands being cautioned or refused something • Can recognize anger or happiness
12 – 18 Months	Walking	<ul style="list-style-type: none"> • Says baba, mama • Begins to differentiate dangerous and friendly environments • Can identify different family members
9 – 24 Months	Talking	<ul style="list-style-type: none"> • plays with other children • Can speak one word or more • Repeats what people say • Feeds self
24 Months to 60 Months	Feeds self using spoon, plate, cup,	<ul style="list-style-type: none"> • Comfortably repeats what people say • Has feeling for self and others • Communicates needs not crying • Tries to help in household activity
6 – 12 years	Able to communicate appropriately	<ul style="list-style-type: none"> • Reasoning power more advanced • Ready to learn other languages • Can perform more complex arithmetic • Can identify self with different people depending on interest
NB: Refer for assessment and intervention if a milestone delays beyond the average (normal) age limit		

2.0 THE CHILD WITH DISABILITY

2.1 Child development and disability

A pregnant woman who suffers an illness or stressful situation especially in first three months of pregnancy is likely to give birth to a child with a developmental problem and thus it (child) should be keenly followed up.

Immediately child is born

The child may present with:

- Abnormal or poor postures
- Not crying immediately after birth
- Pale looking
- Un proportional body parts

Soon after birth up to 2 weeks

- Yellowing of the eyes
- Lack of or partially developed limbs
- Frail limbs or limb
- Inability to carry own weight for some seconds when held in standing position.

2 months to 1 year

- Unable to turn, sit or crawl.
- Does not extend hands, grasp, explore or explores poorly with fingers and eyes
- Cannot say 'baba', 'mama'
- Remains aloof or plays with self only.

1 year to 3 years

- Not able to walk
- Does not imitate simple household activities
- Speech not developed
- Does not relate appropriately with people
- Still and unable to feed self

4 years to 6 years

- Not yet toilet trained
- Can not play interactively with other children
- May not have acquired some movement skills e.g. walking
- Not yet ready for school

7 years to 12 years

- Cannot appropriately communicate a need
- Not able to cope in school
- May not have acquired self care skills

13 years to 18 years

- Interpersonal relationships not developed
- Excessive fear of certain people, places and things
- Poor communication skills
- Excessive secretiveness
- Poor school performance
- Imbalance between physical development and mental development

3.0 THE DISABILITY CONCEPT

3.1 Definition of disability

The World Health Organisation describes disability as: "any restriction or lack (resulting from impairment) of ability to perform an activity in a manner or range that is considered normal for a human being." (WHO 1994).

3.2 Measuring disability

People intending to measure the extent and nature of a disability are normally faced with two major obstacles.

- A reliable definition for disability.
- An "instrument" to measure the different aspects of disability or handicapping situations.

There is no standard definition of disability. There is also no, standard test for disability

that is constant from one population or society to another (WHO 1994, ICDF I and II 2001).

During the period 1996 to 2001, in several surveys supported by World Health Organisation (WHO), disability was defined as any limitation in activity resulting from a long-term condition or health problem. The focus was, therefore, not on identifying the nature of the disorder or disabling condition, but rather the limitation resulting from it.

In these guidelines if one is using an assistive device such as a hearing or visual devices e.g. spectacles which completely eliminates their limitation then they will be considered not to have a disability. A concept of time was also added as an additional filter; the disability must have lasted or be expected to last for six months or more.

3.3 Approaches used to define disability

The International Classification of Function Disability and Health (ICF) has replaced the International Classification in Disability and Health as the international reference framework for the definition of disability. As with the ICIDH, use of the ICF in the measurement of disability helps to change the "culture" of measuring disability from the perspective of the medical model which tends to suit only the health workers primarily because of the interventions that follow there after. Use of the ICF concepts in disability measurement may also help change the social perception of disability and its stigmatization hence its appropriateness.

This new WHO disability classification was finalised in 2001 as the "International Classification of Functioning, Disability and Health (ICF)". This was not used for the 2001 surveys because the decision on which classification to use was made in 2000, before the new classification was finalised. The decision to use the same disability classification as was used in the 1996–1997 surveys was made in consultation with agencies from the disability community and government sectors where the surveys took place.

3.4 Defining disability for purposes of identification and referral of cwds and special needs

Defining disability in Kenya has also been as varied as the many organization and government line ministries which support as well as provide disability services. For the agencies and line ministries this will be determined by their organization policies, objectives and goal.

The Kenya National Disability Act 2003 (KDA 2003) defines disability as "a physical, sensory, mental, or other impairment, including a visual, hearing or physical disability,

which has a substantial long term adverse effect on a person's ability to carry out usual day to day activities".

Environmental designs are the major barriers to participation to those who have disabilities.

3.5 The child with disability and special needs

A child with disability (CWD) / special needs in this guideline is regarded as "that child with a physical, mental, emotional or other health condition or limitation which limits or prevents her/him from participating in the activities of daily living, recreation, school or community inclusion, mobility or self care.

3.6 Rehabilitation

Early identification and intervention is important for all children with disabilities and special needs since it facilitates their rehabilitation process, referral and integration in society.

Rehabilitation in this guideline is viewed as an integral part of the general management of children with disabilities, impairment, handicap or special needs.

The rehabilitation of CWDs and special needs is aimed at enabling them reach their optimal development maturity in terms of physical, cognitive, language, social-emotional, temperament, or fine and gross motor skills development. This in turn provides them with the skills to achieve maximum degree of self reliance or a higher level of self reliance.

3.7 Medical and Social models of rehabilitation

The medical model tended to view disability as a problem of the person, directly caused by disease, trauma or a health condition which requires medical intervention. This intervention is provided in the form of individual treatment and rehabilitative management by a health professional.

The social model of rehabilitation on the other hand sees the issue as socially constructed problem and basically as a matter of full integration or inclusion of individuals into society.

In this guideline, the identification of CWDs and special needs, the immediate interventions and rehabilitation will be viewed as an attribute of both the environmental social constructs and medical rehabilitation intervention needs thereafter.

child's functioning; disability or special needs in the guideline should be conceived as a dynamic interaction between:

Health conditions (disease, disorder, injuries, traumas etc.) and contextual factors.

Contextual factors include personal, social and environmental factors that surround the child at all times. In this regard it is also important to understand the differences between disability, impairment, handicap and children living in extremely difficult circumstances.

8 Disabilities and Special needs

Children with disabilities (CWDs) and special needs have a right to proper upbringing. Disability is one of the major impediments to normal development. Normal development and effective learning, social inclusion and integration for children in any society only takes place if there is a conducive atmosphere provided for the child to maximize their potential. Where this is interfered with, it affects the child's survival and growth by weakening their capacity to cope with biologically challenging conditions. Subsequently CWDs and those with special needs may tend to be isolated from the mainstream of society because of inability to cope with these challenging social dynamics that they come across in their day to day life.

In the guideline there are two main categories of children who need special consideration regards to identification, referral and intervention; They are:

Children with disabilities (CWDs)

Children with Special Needs (CWSNs)

10 DISABILITY DOMAINS

1 Classification by domain:

For purposes of this guideline children's disabilities will be classified into the following disability domains:

Mental disability (includes learning and developmental delay).

Physical disability (difficulty in moving one or more body parts)

Emotional and behaviour disturbances

Sensory disability (seeing and hearing difficulties)

Speech disability (difficulties in oral or spoken communication)

Seizure disorder (also referred to as epilepsy)

Congenital disorder (Those that one is born with)

Multiple disability (More than one of the above disabilities)

4.2 Mental disability

Mental disabilities refer to a variety of disorders that affect the acquisition, retention, understanding, organization or use of verbal and/or non-verbal information. This type of disability affects all or some aspects of a child's development. These could be cognitive, psychological, physical and developmental milestones, social, and communication development. It is almost impossible to list the all developmental disorders, however only a few have been discussed under special types of disabilities. Developmental delay is also under this category of disabilities.

4.3 Physical disabilities

Physical – includes children with mobility and/or agility difficulties.

Mobility difficulties – includes difficulty in walking or moving one or more parts of the body.

Agility difficulties – includes difficulties with more movements that help to improve co-ordination, speed, power and specific skills like to bend over to pick something up off the floor; dress or undress themselves; cut their own toe-nails; grasp or handle small objects like scissors; reach in any direction; cut their own food; or get themselves in or out of bed. This will include children on or around ages 8 years and above.

4.4 Emotional and behaviour disturbances

Psychiatric / Psychological – includes children who, because of a long-term emotional, psychological or psychiatric condition, have difficulty with or are stopped from doing everyday activities that people their age can usually do, including communicating, mixing with others or socialising.

4.5 Sensory Disabilities

Sensory disability– includes children with hearing and / or seeing disabilities.

4.5.1 Hearing Disability

Includes children who are deaf or have difficulty hearing that is not corrected by hearing aids or grommets. Hearing impairment is a general term indicating a hearing problem that may vary in severity from mild to profound. Hearing impairment is usually classified as:

- Conductive

-
- Sensori neural
 - Mixed

Conductive Hearing loss occurs when there is a problem in the outer or middle ear preventing sound from being conducted normally into the inner ear and auditory nerve.

Sensorineural Hearing loss occurs when there is damage to the inner ear or auditory (hearing) nerve itself. The impairment ranges from mild to profound, based on the threshold (the minimum loudness) of sounds that the child hears.

Mixed Hearing loss in which both the systems are affected (conductive and sensorineural).

A child not responding to any other sounds could be having complete deafness.

4.5.2 Visual Impairment

This is a general term referring to any damage or loss in the structure and/or functioning of the eye which may range from partial loss of sight to total blindness. It includes children who have difficulty seeing or cannot see ordinary newsprint and/or the face of someone from across a room, even when wearing corrective lenses. Children who are blind or have difficulty with seeing that is not corrected by glasses, spectacles or contact lenses will also be in this category.

4.6 Speech Disabilities

Speaking disabilities – will comprise children who have difficulty speaking or being understood because of a long-term condition or health problem.

4.7 Learning Disabilities

Learning disabilities refers to a variety of disorders that affect the acquisition, retention, understanding, organization or use of verbal and/or non-verbal information. Intellectual disability is one such form of disability which is rarely recognised by most people including some parents. It affects the general intellectual functioning of a child and presents with deficits in adaptive behaviour and manifests during the developmental period of the child.

The table below shows the main disability domains against the common characteristics.

Table 2

DISABILITY DOMAIN		Common Characteristics	EXAMPLES
1	Mental Disability	<ul style="list-style-type: none"> • Doesn't internalise things easily. • Has difficulty comparing things or classifying and sorting items according to a specific criteria • Time concepts present difficulty, before, after, tomorrow, last week etc. • Often slow to respond • Difficult time predicting what may happen next, or answering comprehension type questions • Does not answer questions appropriately • Difficulty thinking in a logical or sequential manner • Difficulty with number concepts • Often requires a great deal of clarification and one to one support 	<ul style="list-style-type: none"> • Dyslexia • Dysgraphia • Dyscalculia
	Developmental Delay	<p>This is a group of disabilities that affect all or some aspects of a child's development. These could be cognitive, psychological, physical and developmental milestones, social, and communication development.</p>	<p>Will be experienced also in learning and mental disabilities</p>
2	Physical Disability	<ul style="list-style-type: none"> • Difficulty in moving one or more parts of the body • Stiffness of joints and limbs • Stiffness of the spinal column • Muscle weakness 	<ul style="list-style-type: none"> • Paralysis / weakness of one both legs • Paralysis / weakness of one or both arms • Stiffness of limb joints • Stiffness of the spinal column • Weakness of trunk muscles
3	Emotional & behaviour disturbance	<p>Children who have :</p> <ul style="list-style-type: none"> • Communication difficulties • Difficulties mixing with others • Difficulties socialising 	

4	Sensory Disability	<p>Hearing – See if he/she :</p> <ul style="list-style-type: none"> • does not respond to any verbal communication • or struggles by tilting his/her head in certain positions in order to hear. • ay fail to acquire speech • Cupping the ear in the direction of sound • Stares at speakers face, seemingly reading lips <p>Seeing –includes children who have difficulty seeing even when wearing corrective lenses. Usually the eye has the following:</p> <ul style="list-style-type: none"> • The white part of the eye is red with or without discharge • Squint – one eye is not aligned with the other • Poor eye sight or complete Loss of sight • Swollen eye with or without pain • Excessive watery eyes without discharge • protecting eyes from the light (brightness) • squeezing of the eyes 	<p>Hearing difficulty – includes children who have difficulty hearing or cannot hear what is said in a conversation with one other persons and/ or a conversation with at least three other people.</p> <p>Seeing –These children can easily be identified by the parents/caretaker as the child will not respond to anything being handed to him/ her or shown, although in some cases they may fail to identify it in the well disguised ones.</p>
5	Learning Disability	<p>General characteristics</p> <ul style="list-style-type: none"> • Has difficulty comparing things or classifying and sorting items according to a specific criteria • Time memory impairment • Creativity and imagination is usually limited • Often slow to respond • Comments are often off track • Difficulty thinking in a logical or sequential manner • Often requires a great deal of clarification and one to one support <p>In children</p> <ul style="list-style-type: none"> • Delay in usual development e.g. sitting, walking, toilet training • Difficulty managing school work as well as other children because of learning disabilities • Behaviour problems <p>In Adolescence</p> <ul style="list-style-type: none"> • Difficulty with peers leading to social isolation • Inappropriate sexual behaviour • Difficulty making a transition to adulthood • Time memory impairment • Difficulties in social adjustment 	<p>DYSLEXIA - Specific learning difficulty present at birth and often remains through out life. It affects learning skills and reflects itself by reduced working speed, poor information processing.</p> <p>DYSGRAPHIA - A learning difficulty that reflects itself in poor hand writing, poor arrangement of letters and even having some letters facing opposite side.</p> <p>DYSCALCULIA - Difficulty in solving even the simplest mathematical problems.</p>

6	Intellectual Disability	<ul style="list-style-type: none"> Does not comprehend things like other children of similar age or age group. 	Another form of learning disability
7	Epilepsy / Seizures	<ul style="list-style-type: none"> Jerky movement of limbs followed by calmness and relaxation while some may have frothing at the mouth and passing urine. Lose of consciousness lasting for seconds to several minutes Some may just be seen momentarily un alert and grinding teeth 	Also known as "seizures"
8	Congenital Disabilities	These are disabilities that one is born with	Spina -bifida, cleft lip & pallet, Down Syndrome, Albinism, Autism, cerebra palsy etc

5.0 SPECIAL INTEREST DISABILITY TYPES (SIDTs)

These are disabilities and impairments which have not been discussed earlier amongst the main disability domains in this guideline. This is because of their special or rare nature in occurrence and how they impact on children and their families in society and institutions where these children live. For purposes of this guideline and our Kenyan situation we shall only deal with the following disability types or conditions:

- a. Autism
- b. Epilepsy
- c. Downs syndrome
- d. Albinism
- e. Cerebral Palsy
- f. Visible infancy impairments and congenital disabilities – (cleft, lip, cleft pallet, congenital talipes equinovarus, spina bifida) etc.
- g. Deaf blindness in children
- h. Attention deficit disorder

5.1 Autism

Autism can be defined as a neurobiological disorder affecting areas of social interaction, social communication and imagination. The main cause being genetic predisposition, environmental and other factors like;

- a) Maternal rubella
- b) Lack of adequate oxygen during birth
- c) Environmental pollution and toxins

However the exact cause of autism is still not clear or scientifically proven to most

ple.

2 Epilepsy (Seizures)

Epilepsy is a neurological disorder that may cause physical convulsions, minor physical convulsions, or uncontrolled jerky movements or thought disturbances depending on type.

3 Down Syndrome

Down syndrome is a common and readily identifiable chromosomal condition associated with developmental delays and learning difficulties leading to intellectual impairment. However, the effects and the extent of these impairments on each individual child will usually vary widely amongst the affected children.

Down syndrome can occur in any family regardless of their colour, race, social class, age, geographic region or religion.

4 Albinism

Albinism is an inherited condition present at birth, characterized by lack of pigment that normally gives colour to the skin, hair, and eyes. Many types of albinism exist, all of which involve lack of pigment in varying degrees. The condition, which is found in all races, may be accompanied by eye problems and the skin may develop cancer later in life.

The most common form of the condition is known as "oculocutaneous albinism" which affects the eyes, hair and skin. Every one with oculocutaneous albinism experiences abnormal flickering eye movements (nystagmus) and sensitivity to bright light. Other problems experienced may be poor vision and crossed eyes (strabismus).

The second most common form of the condition is "ocular albinism", in which only the eyes lack colour while the skin and hair are normal.

4.1 Causes

Albinism is an inherited condition caused by alteration in one or more of the genes that are responsible for directing the eyes and skin to produce or distribute melanin which is a protective pigment that absorbs ultra violet rays preventing the skin from being damaged. Albinism is an autosomal recessive condition which means you must have two copies of the defective gene from each parent to develop the condition. It may not be easy to diagnose the exact type of albinism one has.

5.5 Cerebral Palsy

Cerebral palsy is a term used to describe a group of conditions characterised by a disorder of posture and movement resulting from a non-progressive lesion of the brain resulting from brain injury in the early years of life (during pregnancy, at birth or after birth). The injury does not get worse but the physical condition of the child will change according to the kind of intervention offered.

5.5.1 Causes

- Prolonged labour
- Mother's illness during pregnancy
- Delivery problems
- Illness of child especially in first few years of life

5.6 Spina-bifida

This refers to a condition in which the vertebral column does not fuse in the midline during the formation of the foetus resulting in bony cleft through which the spinal cord tissue can protrude. At birth you may notice a hairy patch, lump or a dimple, sac, exposed neural tube.

5.7 Visible infancy impairments and congenital disabilities

These are impairments and disabilities that a child is born with or are noticed immediately after birth. The causes are normally unknown or genetic in nature.

5.8 Deaf-blindness in children

The degree of severe hearing loss and vision loss in an individual, a combination of which makes communication very difficult/complex

5.8.1 Causes

Direct causes could be Congenital German Measles (Rubella), Untreated Complications at /during birth/delivery. Ushers Syndrome, Meningitis, Measles, Malaria, Mumps, Accidents, Malnutrition, and cerebral palsy. Possibly the following: Lack of awareness, poverty, malnutrition, absence of preventive appropriate vaccination services, ignorance.

Attention deficit hyperactivity disorder (ADHD)

Attention deficit hyperactivity disorder (ADHD) is defined by two broad groups of behavioral problems: inattentiveness, and a combination of hyperactivity and impulsiveness.

Common symptoms within these groups include a short attention span, restlessness, being easily distracted, and constant fidgeting. Symptoms of ADHD tend to start at an early age, and they may become more noticeable when a child's circumstances change, such as starting school.

Many people with ADHD also have additional problems, such as sleep disorders, low self-esteem, and learning difficulties. However, ADHD has no effect on intelligence.

There are several criteria that must be met for a child to be diagnosed with ADHD. Adults find it harder to diagnose because there is no definitive set of age-appropriate symptoms.

There is no cure for ADHD, but it can be managed using medication. There are several medical treatments for ADHD, all of which should be accompanied by psychological, educational and social therapies.

Table 3

The table below shows disability types against common characteristics.

DISABILITY TYPE	COMMON CHARACTERISTICS	EXAMPLES if any
Autism	<ul style="list-style-type: none"> Finger flicking Arranging objects in lines Performing complicated rituals before entering a room or going to bed and sitting down to eat etc. Reporting standard words, phrases continuously (echolalia) Repeating questions and demanding standard answers thus incorporating other people into their rituals Non-responsive to others (Aloofness) Temper tantrums 	
Epilepsy	<ul style="list-style-type: none"> Loss of consciousness lasting for seconds to several minutes Some may just be seen momentarily un alert and grinding teeth Jerky movement of limbs followed by calmness and relaxation while some may have frothing at the mouth and passing urine 	
Downs syndrome	<ul style="list-style-type: none"> Flat Nasal bridge Epicanthal folds- (Slanting eyes with skin folds at the inner corners of the eye) Hyper flexibility- (excessive ability to extend the joints): Muscular Hypotonia – (Low muscle tone) Short broad hands with a single crease across the palm on the hand. Short fifth finger usually an in-curved finger Broad feet with a gap between the first and second toes. Ear abnormalities(low set ears, folded or short) Short neck with loose skin on the nape of the Neck: Small oral cavity with a slightly protruding tongue. 	<ul style="list-style-type: none"> Trisomy 21 Down syndrome Mosaic Down syndrome Translocation Down syndrome.
Albinism	<ul style="list-style-type: none"> Foresighted or near sightedness Constant involuntary movement of the eye ball Difficulty in co-coordinating the eyes in fixing and tracking objects Eyes may be very sensitive to light(Photophobia) Lack of skin pigment Their skin easily gets damaged by the sun if not protected Holding reading materials close to the eyes in order to see Occasionally being mistreated by their peers because they look or appear different 	<ul style="list-style-type: none"> Occulocutaneous albinism Ocular albinism
Cerebral Palsy	<p>There are four types of CP which presents with the following:</p> <ul style="list-style-type: none"> Spastic-characterized by stiffness of the muscle Floppy-characterized by low muscle tone Athetoid-muscle tone changes between high and low Ataxic- presents with difficulty in balance and movement 	
Deaf blindness	<p>The child presents with inability to hear or see</p>	
Visible infancy impairments and congenital disabilities	<ul style="list-style-type: none"> Club feet-feet rotated internally to face each other Cleft lip/palate-presents with lack of continuity of upper lip Extra or jointed finger-More fingers or toes Incomplete limbs-portion of a limb not completely developed Severe knock knees-one or both knees bent towards the other Also a child whose trunk height is not proportional to lower limbs height has got a form of dwarfism-FTT-A situation in which despite feeding, a child's physical stature falls 	
Spina Bifida	<ul style="list-style-type: none"> Defect is most common in the lumbar-sacral area as a protrusion Paralysis of the lower limbs may occur Lack of control of the bowel and bladder Hydrocephaly in severe cases. 	
Multiple complex disorder	<ul style="list-style-type: none"> Intense generalized anxiety Irritability Recurrent panic episodes 	There is also high frequency of idiosyncratic anxiety reactions

6.0 CHILDREN WITH SPECIAL NEEDS

This refers to a child who by their health status is unable to reach the highest possible developmental potential of life due to physical, biological, or other environmental circumstance. Children in these categories are classified as follows:

- a) Children living in especially difficult circumstances
- b) Children with emotional and behaviour disturbances
- c) Children who are gifted and talented
- d) Disadvantaged children needing special attention
- e) Children with chronic health problems (Lasting over 6 months)
- f) Children with mental illness

6.1 Children living in especially difficult circumstances

This is a group of special needs which have arisen due to psychological and social factors which have had/are having a negative impact on a child's development. The risk factors which contribute to abuse and neglect include:

- a) Lack of compassion from parents
- b) Hostile, lack of / poor bonding between child and caregiver
- c) Death of one or both parents
- d) Family crisis (alcoholism, separation or divorce of parents)
- e) Undesirable characteristics of the child's mental disability, handicaps, hyperactivity, and "wrong sex" of the child)
- f) Background of parent(s) or care giver: (a person who was abused as a child may also grow up to be an abuser).

Children living in especially difficult circumstances are divided into the following categories:

6.1.1 Orphans and vulnerable children

Orphans and vulnerable children (OVC) face a number of challenges, including finding money for school fees, food, clothing, and access to basic healthcare. Their desperation makes them more vulnerable to abuse and exploitation, ultimately making them more susceptible to contracting HIV and other diseases

6.1.2 Child drug abusers

Drug abuse treatment can help many child drug abusing offenders change their attitudes,

beliefs, and behaviours towards drug abuse, avoid relapse, and successfully remove themselves from a life of substance abuse and crime.

Drug abuse is implicated in at least three types of drug related offences: (1) offenses defined by drug possession or sales, (2) offences directly related to drug abuse (e.g., stealing to get money for drugs), and (3) offences related to a lifestyle that predisposes the drug abuser to engage in illegal activity (e.g., through association with other offenders or with illicit markets)

6.1.3 Physically abused children

Normally occurs as a result of cruelty to children. The following would be some of the commonest features noted:

- Bruises on children- how to differentiate accidental from non-accidental bruises.
- Fractures in children - Examines the relationship between fractures and physical abuse
- Head injuries in children
- Oral injuries and bites on children
- Thermal injuries on children.

6.1.4 Sexually abused children

Child sexual abuse (CSA) is a grave and complex sociological, psychological and physical problem that produces devastating consequences and occurs in epidemic proportions worldwide. However, it is important to note that any form of child abuse causes negative emotional feeling.

6.1.5 Emotionally abused children

It is psychological in nature and has an adverse effect on the behaviour perceptions or emotional development of a child.

Neglect - Is the failure of the parent or guardian, caregiver, institution or other persons charged with responsibility over a child to provide him/her with the basic necessities of life such as food, shelter, clothing, medical care and education. Neglect may also happen where a child is denied love and emotional support that are necessary for effective socialisation.

6.1.6 Situations that may lead to emotional abuse include:

Humiliation, verbal insults, use of derogatory language, unattainable demands by parents, guardians and teachers, confinement, displacement, abduction and abandonment.

6.1.7 Child soldiers

In times of war, a heightened demand for soldiers encourages the exploitation of children. Also, becoming a soldier may be the only option for survival in a war-torn vacuum of family, social and economic structures.

6.1.8 Child Prisoners

Children staying /living with parents (mother / care giver) in prison. These situations may arise when a child is born while its/his /her mother is already serving a prison sentence or the mother was sentenced while she had an infant.

6.2 Children with Emotional and Behavioural Disorders

These are children who deviate from appropriate behaviour at a given age which significantly interferes with their own development, learning and or that of others. Young people with this type of disorder usually have little concern for others and repeatedly violate the basic rights of others and the rules of society. Such offences may include lying, theft, aggression, truancy, the setting of fires, and vandalism.

6.3 Gifted and talented children

Gifted and talented refers to those with outstanding abilities, who are capable of high performance and who require differentiated educational programmes in order to realize their contribution to self and society.

6.4 Disadvantaged children needing special attention

Most children with disabilities and those with special needs would normally fall under this category. Twins or underweight babies. Children who are not breast-fed or those whose parents are often away for various reasons. They include autism, hyperactivity, attention deficit disorders, learning difficulties or eating disorders

6.5 Children with Chronic condition or health problem

Chronic condition or health problem – includes children who have a chronic condition,

such as severe asthma, lung condition or disease (not including mild asthma or bronchitis), heart condition or disease (not including heart murmurs), kidney condition or disease, cancer, diabetes, epilepsy, long-term chronic gastro-intestinal condition, or growth failure or failure to thrive.

6.6 Children with Mental illness

State of mental ill health which interferes with a person's ability to think clearly, distinguish reality from fantasy make decisions and relate to others. The major cause is usually genetic fragility and inadequate environmental coping abilities accompanied with occasional delusions and hallucinations.

7.0 INTERSECTORAL COLLABORATION

7.1 Collaboration, networking and referrals

Collaboration networking in disability rehabilitation and identification of children with disability and special needs will take place amongst the various stakeholders. This will depend on the client being referred, level and role of each organisation, agency or the individual involved in the rehabilitation process.

7.2 Health Sector

The health sector is charged with the provision of preventive, promotive, curative and rehabilitative health services. This will include but not limited to:

- i. Disability prevention
- ii. Early identification, screening and assessment of disabilities
- iii. Provisions of:
 - a. Institution based disability services
 - b. Out reach disability services
 - c. Community based rehabilitation services (CBR)
 - d. Provision of assistive and supportive devices as appropriate
- v. Organise referrals to other service providers as deemed appropriate.
- vi. Networking and collaboration.

7.3 Education sector

Organise and conduct the assessment of children with disabilities and special needs in the EARCS with an aim of ensuring appropriate school placement, integration and inclusion. Ensuring that the education of CWDs takes place in an inclusive environment as deemed appropriate.

7.4 Social services

Through the department of culture and social services, parents support groups and children with disabilities would be registered, appropriate referral and some social welfare needs met as need be.

7.5 National Council for Children Services

Coordinates the activities of the government, non-governmental organizations, faith and community based organizations, bilateral and multi-lateral organizations as well as private sectors providing various services to all children in Kenya with regards to children's rights.

7.6 Community Support Groups (CSGs)

This will be in form of Parents Support Groups (PSGs) or Children With Disabilities Support Groups (CWDSGs) offering different services ranging from identification of CWDs and referral services, and rehabilitative health services, social integration, advocacy for the children, funding for children's activities and socio-economic sustenance programmes.

7.7 NGOs and Partners

The main role of most NGOs and partners at various levels will be to solicit for funding for various services towards the welfare of children with disabilities and special needs. Some NGOs will provide direct services while some will be purely funding agencies through local NGOs and Faith Based organisations (FBOs). Some NGOs work hand in hand with the government.

7.8 Community Based Organisations (CBOs) and Faith Based Organisations (FBOs)

Some CBOs and FBOs will be directly involved in provision of service for a certain selective disability. In some circumstances they will also offer advocacy as well as assistive and supportive devices whenever appropriate.

7.9 Advocacy Groups

This ensures that children with disabilities and special needs receive their rightful services. These groups which are found at all levels of service provision are involved purely in advocacy and sensitisation on disability rights issues.

7.10 Community leaders and resource persons

These are persons at community level who have been identified for purposes of linking CWDs to the systems which provide certain services in disability. Normally they are also connected to other community development systems within their catchment areas. They also play a critical role in advocacy & sensitization on disability issues.

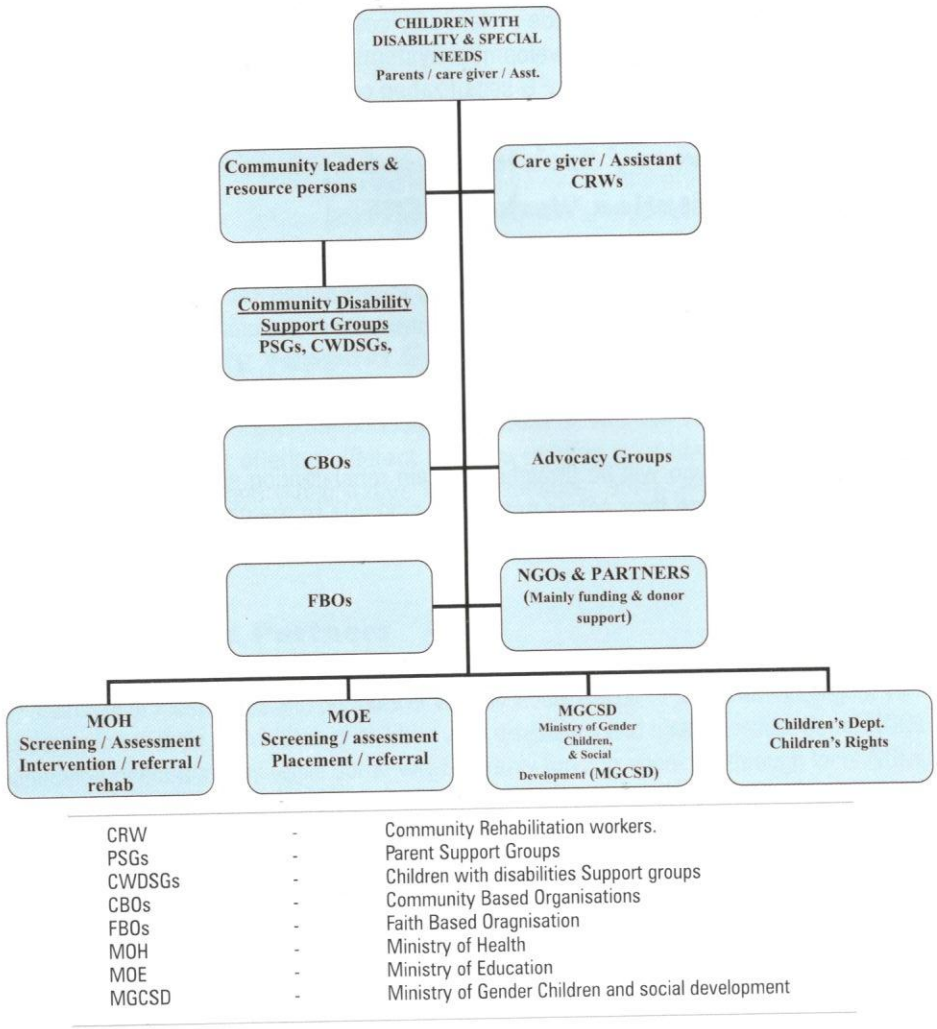
7.11 Care Givers / Assistants and Community Rehabilitation Workers (CRWs)

These are persons who will be providing basic rehabilitation services as well as act as the link persons between the care givers /assistant the community & the CWDs & SNs.

7.12 Parents, care givers / Assistant

These are persons who will be providing certain rehabilitation services to the children while at the same time they act as personal assistants to the children particularly with severe or multiple disabilities. They also care for and support these children emotionally as parents.

Fig 1 : Networking Systems Between Government and Other Stakeholders



The above organogram shows the various stakeholders and their key roles towards CWDS & SNs

