THE REPUBLIC OF UGANDA

TORORO DISTICT LOCAL GOVERNMENT

-Over View of Disability in Uganda with focus on Tororo: Prevalence, Causes, Preventions and Management.

-Disability and Human Rights: the Current Provisions for Disability in Uganda

A Planned Radio Talk Show on Rock Mambo in Collaboration with Plan-Tororo

By

Moiza Moses
Ag. Senior Community Development Officer-Elderly & Disability-English

District Health Officer-English
One CDO at Sub County and Aluka Akisoferi Osinde-for Jopadhola
2 Councilors for PWDs
Alamai Susan, Ag. PSWO-for Ateso
Ikileng Simon, Reminar Okoth, CBR Volunteers-Ateso

&
Plan Focal Person

September 2008

RADIO TALK SHOWS ON DISABILTY

Lead Questions for Discussion

1. **What is Disability?**

2. **Who are People with Disabilities?**

3. **When addressing Disability, Environmental factors are emphasized. What are these environmental Barriers to People with Disability?**

4. **What are Common Disabilities in Uganda and Tororo in Particular?**

5. **What is the National prevalence (Data) of Disability in Uganda and Tororo as a District?**

6. **You mentioned about intellectual Disability but much Attention has been paid to Physical Disabilities, Visual and Hearing impairments, what do you have to share with the public about intellectual Disabilities?**

7. **Why are issues of intellectual Disability less addressed both by Government and NGOs (District and Plan)?**

8. **What is the Way forward on handling issues of Intellectual Disability?**

THEME I: OVER VIEW OF DISABILITY IN UGANDA

Objectives to the Discussion:

Listeners should be able to:

- ✓ Under Impairment, Disability and Hand carp
- ✓ Know the various types of Disability in Uganda-Tororo in particular
- ✓ Know the Statistical situation of Disability in Uganda-Tororo in particular
- ✓ Know the Plans and challenges of handling PWIDs

Introduction to key Concepts

WHO defines **impairment** as any lose or abnormality in Psychological, physiological or anatomical function of any body part.

Impairment: Refers to loss of, injuries to, deviation from the normal psychological, physiological, or biological functions of the body. (User to citizen, NOU 2001:22-Norwegian)

The People with Disability Act, 2006 refers to disability as "**a substantial functional limitation of daily life activities** caused by physical, mental or sensory impairment and **environmental barriers** resulting in **limited participation"**

According to the National Policy on Disability in Uganda, 2006, "Disability is a **permanent** and **substantial functional limitation of daily life activities** caused by physical, mental or sensory impairments and **environmental barriers** resulting in limited **participation**".

People with Disabilities: -Refers to people whose practical living is limited due to discrepancy or gaps between their impairments and the demands of the society/ environment.(User to citizen, NOU 2001:22-Norwegian)

The People with Disability Act, 2006 refers to a person with disability as "a person having physical intellectual, sensory or mental impairment which substantially limits one or more of the major life activities of that person."

Note I: All persons with Disabilities are impaired but not all impaired persons are disabled.

Note II: It is the environment that disables persons with impairments. Removal of environment barriers equally removes disabilities from all those impaired. Barriers manifest in: Attitudes, accessibility, sign language limitation, Braille…
Handicap: A situation of disadvantage expressed towards PWDs.

Disability in Uganda

Disability in Uganda is wide spread. It cuts across all social settings. It therefore requires a combined effort to meet the needs of all persons with Disabilities.
General observations indicate more mental disabilities being associated with urban areas while physical disabilities are more associated with the rural settings. The living standards in both settings and activities could partly explain the differences.

WHO estimates 10% of the world population is of PWDs. This puts the number of PWDs in Uganda to about 3 million according to the current population projection of 30 million.

Common Disabilities in Uganda
National Policy on Disability in Uganda (2006) indicates the following disabilities/impairments:

No.	Impairment/Disability Type	% Population
1.	Loss and limited use of limbs-CP, club foot, Polio, Spinal Bifida, hydrocephalus/Metacephalus, cleft plate…	35.3
2.	Difficulty in hearing – Deaf, hard of hearing…	15.1
3.	Difficulty in Seeing –Blind, Partial sightedness…	6.7
4.	Difficulty in speech and conveying messages	3.9
5.	Mental retardation and Illness	3.6
6.	Others –Covering intellectual Disabilities	9.6

Regional Disability Prevalence in Uganda
According to the Uganda Population and Housing Census Report (2002) at least 4 out of every 25 persons in Uganda is with a disability (Current estimate of about 4.8m PWDs). It was also indicated that the prevalence rate was higher than 1.1% obtained in the 1991 Census. The prevalence rate increase with age where among children below 18 years was 2% and 18% among the older persons.

The Northern region experiences the highest disability prevalence rate at 4.4% followed by the East at 3.6%. Central region experiences 3.1% while the Western Region experiences the least rate of prevalence at 2.9%

Factor to explain the differences may include among others:

- Internal conflicts
- Cultures
- Development of infrastructures e.g. Health Centres, Roads, Education systems among others

Case Study on Distribution of Disability in Uganda:

Tororo District Summary for Persons with disabilities 2006

District *TORORO*

Sub-county	See	H	S	M	L	Fits	SB	LSF	Others	Male	Female	Total
EASTERN DIVISION	12	10	14	26	16	9	10	2	1	49	51	100
WESTERN DIVISION	16	9	8	41	4	8	6	0	2	52	42	94
IYOLWA	91	78	58	201	25	43	52	23	44	301	314	615
KIREWA	58	44	29	200	1	7	32	44	3	234	184	418
KISOKO	16	6	12	54	6	20	8	0	8	75	55	130
KWAPA	22	39	35	165	5	58	18	4	5	237	114	351
MELLA	27	14	16	125	8	16	9	14	10	140	99	239
MERIKIT	137	95	43	162	19	31	9	17	52	321	244	565
MOLO	154	74	54	141	10	13	9	15	43	328	185	513
MUKUJU	72	92	48	218	6	61	32	26	12	305	262	567
MULANDA	43	26	17	57	4	13	6	6	15			187

										84	103	
NABUYOGA	84	59	56	252	3	35	31	17	14	330	221	551
NAGONGERA	114	107	65	279	48	36	52	13	39	438	315	753
OSUKURU	56	43	39	160	24	59	26	9	11	192	235	427
PAYA	73	54	36	234	21	37	30	26	24	227	308	535
PETTA	38	26	33	73	5	16	14	0	14	134	85	219
RUBONGI	97	114	49	288	7	65	26	24	35	429	276	705
Total	**1,110**	**890**	**612**	**2,676**	**212**	**527**	**370**	**240**	**332**	**4,539**	**2,430**	**6969**

Total difficult **6,969**

H-Hearing
S-Speech
M-Movement
SB-Strange Behavior
LSF-Loss of Skin Feeling
MD-Multiple Difficulties/Disabilities
L-Learning

Intellectual Disability:
This is a type of Disability associated with the intellect. It is a limitation in mental processing of information. It's one of those disabilities with no particular statistics and some times left out due to the difficult in meeting the needs for PWIDs. Their needs call for life support.

The Various Intellectual Disabilities include:

- Mental illness(Schizophrenia)
- Down syndrome
- Autism
- Asparagus syndrome
- Mental retardation
- Epilepsy
- Some types of cerebral palsy
- Severe cases of Hydrocephalus

Characteristics of Persons with Intellectual Disability (PWIDs)

- Slow learners
- Some are hyper actors
- Some are so withdrawn
- Un-controllable movements
- Experiences of un-coordinated speeches
- Some are very selective in their life style
- Tendency to persistent behaviors and resistance to changes
- To some extend they become aggressive when dealing with issues affecting them.
- Common failure to take quick decision/choice on any issue
- Cognitive difficulty –Memory failures
- Slow Physical growth/un-proportionate growth-Facial appearance, young or old for age**.**

Limitation in addressing issues of persons with intellectual Disability

- Missing data on Intellectual Disabilities both at National and at District levels
- Limited resource personnel to deliver services like Psychiatric specialists, SNE to teach in Inclusive setting.
- Limited resources to meet the special needs of PWIDs-Drugs, building rehabilitation Centres.
- Unable to demand for services. Limitations in services causes' demand driven service delivery which is impossible to PWIDs-Do it through the Councilors, Parents and Community Leaders…
- Life time support for PWIDs. There is no graduation from the support. Can on improve but not heal.
- NGOs-Programmes are Result Oriented and time bound. Some consider this none-comfort zone.
- Donor directed Programmes at times have limitations on coverage, target population and time frame.
- Limited employment opportunities

Way forward on Handling Issues of Intellectual Disability

- Establish the data at the District Level including the type, level and location.
- Build the capacity of CDOs and local leaders (Councilors for PWDs), CBR Volunteers to include issues of PWIDs in CBR activities
- Conduct a participatory planning strategy to come with a project to address issues of intellectual Disabilities.
- Raise awareness on issues of intellectual Disabilities in the community.
- Advocate for Skills Training Centre for PWIDs
- Train PWIDs in employable skills

THEME II: CAUSES, MANAGEMENT AND PREVENTION OF DISABILTY

Objectives to the Discussion:

Listeners should be able to:

- ✓ Understand the Scientific Causes of Disability
- ✓ Have skills in the Management/Prevention Existing disabilities
- ✓ Appreciate the role of NGOs in disability movement.

Lead Questions for Discussion

1. **Last time we discussed a lot about disabilities including various types and the statistics both at National and District level. What are the causes of Disability?**

2. **Why should the public know about the causes of Disability?**

3. **How can we prevent disabilities in the community?**

4. **How can the community and families manage the existing Disabilities?**
5. **What is the role of Gov't, NGOs (focus on Plan) and parents in the Disability Management**

6. **Epilepsy is one of the lead disabilities in the District, how can the community manage the issues of epilepsy?**

The Causes of Disability may include the following:

- **Disease**-Malaria, measles, trachoma,
- **Drug Abuse**-Opium, cocaine, alcohols…
- **Genetic factors**-Mental Disabilities
- **Accidents**
- Domestic Violence
- Underlying causes include: poverty, environment factors eg. Pollution.

Note:

- Emphasis should be placed on the abilities of the people rather the disabilities.
- Causes of Disability are discussed for prevention purposes.
- User friendly terms should be used when referring to PWDs

General Prevention Measures

1. Disease Control: Diseases may be classified as:

-Congenital diseases-inheritable Sick cells anemia, Epilepsy, Dawn-syndrome

-Chronic diseases e.g. Pressure, asthma, anemia, diabetic

-Infectious diseases e.g. malaria, HIV/AIDS, TB, STDs etc

-Communicable diseases – measles, poliomyelitis

- **Immunization**-against the killer diseases like Polio against poliomyelitis, TB, Measles-BCG dose at 9 months.
- Gene screening-hereditary diseases like Sick cells anemia, Epilepsy, Dawn- syndrome
- Proper hygiene- water and sanitation (latrines, beddings, Housing-Ventilation-TB)
- Regular medical care/check up.

2. injuries/Trauma Related Disabilities

- Observe Road rules (Traffic)
- Clean the compound and remove sharp objects
- Avoid tree climbing
- Stable political environment

3. Drug abuse related disabilities: They are mainly mental illness e.g. Schizophrenia, anxiety, depression, insomnia, sex mania…

- limit the alcohol consumption
- Correct use of drugs to avoid injection paralysis
- Counseling

4. Ageing: Old age comes with a number of impairments ranging from physical to mental**.**

One should prepare for ageing by:

- Investing savings

- Proper health care practices-exercises, enough rest (1-2 hrs during day and 6-8 hrs @ night)
- Proper nutrition
- Housing
- Community participation

LEVELS OF PREVENTION OF DISABILITIES

1. Primary level

- Primary Health Care (PHC) –Message: covering Health Education like sanitation and hygiene, diet and nutrition.
- Family planning produces manageable number of children to reduce the poverty.
  At this level, one is preventing occurrences of impairments

2. Secondary Level: (When Impairment has occurred)-Reducing its effects on the individual and family.

- Early identification/Detection of an impairment
- Assessment of the effects of the impairments on the person.
- Appropriate referrals like Health, Education and Vocational
- Home Based Care Programmes: They are rehabilitation accordingly
- Hygiene and Health to avoid secondary disabilities
- Nutrition patterns
- Care and support to PWDs/CWDs in the home
- Provision of assistive devices
- Construction of local appliances

3. Tertiary Level - Good interpersonal relationship in the family and institutional handling

Involves reduction of negative attitudes and information barriers
Attitude

Management with Focus on Epilepsy:

Introduction

World wide Epilepsy is said to affecting 0.5% of the population. There are over 500 PWE in Tororo District.

Epilepsy was greatly feared in the African Tradition because was considered a supernatural happening-Controlled by the gods. It was commonly viewed as a witch craft, demon possession, curses or punishments for sins and highly contagious. As such persons with Epilepsy were always shunned and avoided. They were seen as unfortunate, unlucky and socially unfit.

When early identified and managed, some children out live the condition while others live with it fir life.

NB: a person with Epilepsy is -not mentally ill.

-Not possessed
-Can't pass on epilepsy to another person.

Definition: Epilepsy is a falling sickness or neurological disorder characterized with brain discharge, occurs suddenly, disappears spontaneously and has a tendency to reoccur.

It's a brain disorder characterized with **fits** or **attacks of loss of consciousness, body rigidity and violent body movement.**

Types of Epilepsy:

S/N	Type	Characteristics/Symptoms
1.	Grand-mal(Generalized)	-Suddenly attack, -loud noise -Violent/uncontrolled movement/jerking stiffness of the body parts -Eye roll back -Loss of consciousness, -Deep sleep -flow of saliva - urinating/defecating -Tongue biting -stoppage of breathing -last 3-5 minutes
2.	Petit mal (absence/black spell)	-Common in Children 3-15 yrs. -Sudden stoppage of any activity -Does not fall -Eyes may flutter -Rapid breathing or deep breathing
3.	Jacksonian (Focal Epilepsy)	-Affect a particular part of the body e.g. thumb, leg. -only the body part controlled by the particular body part of the brain will be affected. -the seizure may spread to other parts of the body and is generalized.
4.	Temporal lobe (Psychomotor)	-loss of memory -mood variation -strange behaviour- e.g. hearing strange voices and un-coordinated movements, -Strange smell
5.	Status Epileptic (Continuous epileptics)	-It has all characterized of grand mal -Follow each other in succession - Consciousness is rarely gained - May end up in death more often if not attend to immediately

No Conclusive research has established the causes of epilepsy. However the following are pointed out:

- Heredity
- Head injuries-accidents
- Birth trauma- injury at birth
- Brain tumor/growth in the brain
- Infections e.g. Cerebral malaria, HIV/AIDS
- Drug abuse

Management:

Before falling:

- Identify the symptoms like:
- Sickly
- Shaking gently and steady increase
- Un comfort
- Some one stops active participation
- Some one stops doing an activity was doing

Action

- Remove sharp objects
- Dress person to prevent head damage or other parts likely to get problems
- Lay her/him down

When is attached or has fallen down

- Comfort lying
- Loosen tight dressing
- Removing sharp objects
- Monitoring the situation
- Open windows, doors to allow more oxygen
- Changing lying position

Don’ts

- Running away
- Stopping the jerking
- Giving drinks or eats

After

- Let somebody sit up
- Engage him/her in conversation
- Let person continue
- Counseling /Re- assure the person of life

THEME III: DISABILITY AND HUMAN RIGHTS: CURRENT PROVISIONS FOR DISABILITY IN UGANDA:

Objectives:
Listeners should be able to:

- ✓ Tell what is a right
- ✓ Understand what the constitutional mandate on Rights of PWDs.
- ✓ Know other specific legal provision on Disability in Uganda.
- ✓ Serve PWDs based on Human rights-emphasis on Justice for all
- ✓ Understand Implication of the laws provided on Disability.
- ✓ Responsibilities of all persons in relations to the legal provisions
- ✓ Know the contributions of development partners in protection of Rights of PWDs.

Lead Questions for Discussion

1. **There is a lot talked about peoples rights. What is a right in reference to People with Disability?**

2. **Why are there legal provisions on the Rights of Persons with Disabilities?**

3. **What is the Constitutional Mandate on Rights of persons with Disability?**

4. **Are there specific Legal Provisions on Disability in Uganda?**

5. **How is the implementation of these legal provisions on Disability in Uganda and Tororo District?**

6. **What is the Contribution of Development Partners in the advancement of Rights of PWDs?**

Rights:

- These are people's entitlement in life.
- The Human Rights approach to disability demands that all people are equal; deserve equal opportunities, respect and dignity.
- Services rendered to PWDs are not privileges but rights to which they deserve and have rights to demand.
- There is always a need for protection and deriving mechanisms to ensure equal service delivery to PWDs.

Based on the above the laws on Disability in Place are mainly made to:

- ✓ Provide legal protection of PWDs

- ✓ Encourage the people and all sectors of government and community recognize, respect and accept difference and disability as part of humanity and human diversity.
- ✓ Eliminate all forms of Discriminations against PWDs
- ✓ To enhance empowerment, participation and protection of the rights of PWDs
- ✓ To guide and inform on Programme implementation, monitoring and evaluation of activities of PWDs at all levels.

Three-layered structure of right protection

- **System advocacy** (Institutional right protection）

Court, Police, Council for Disability, government departments like Probation and Social Welfare, Elderly and Disability Office, the adult guardian system

- **Individual advocacy**（Right protection by individuals/Right advocacy organizations）

Safety net in the community-Organizations like TODIPU, TOCINET, Plan Tororo, and Mifumi advocate for the rights of PWDs.

- **Self-advocacy** Self-protection)

Here PWDs lead the struggle against discriminations. They speak for themselves.

The Constitution of Uganda gives power for subsidiary legislation to address specific Rights/needs of different categories of persons and issues including Disability.

Chapter four of the Constitution: This is the basis for Community Development. All power for community development is enshrined in this chapter. However, Community development is diverse and hence interacts with all the constitutional provisions and all other Acts of Parliament in place.

- Rights are naturally given. ***Article 20 (1) Fundamental rights and freedoms of the individual are inherent and not granted by the state.***
- All people have equal fundamental Rights to life, privacy, speech, liberty, freedom or ownership of property…
- Persons with Disabilities have same rights like able bodied persons
- Where an offence is presumably committed by any person (with or without Disabilities), the suspect is subjected to the **Principles of Natural Justice.** ***This is enshrined in Article 28 of the Constitution.***
  –Right to be heard and impartiality in administering justice.
  (Personal presence in court or representation, notification, presenting

of witnesses/cross examining the witnesses, No one is a judge in his own case, Justice must not be only done but be seen done…)

- Where a person's Rights conflicts with another person, Justice must be sought

Provisions on Disability in Uganda:

The UN Conventions on Rights of People with Disability is the International Basic for protection of PWDs. Although Uganda is a signatory to the UN Conventions, it has not ratified the Convections on the Rights of PWDs. Ratification would mean adjusting Uganda's laws to fit the International Law on Disability.

The Constitution of the Republic of Uganda Provides for:

- ✓ Discrimination (Article21)
- ✓ Respect and Dignity of PWDs (Article35)
- ✓ Legislation of Laws on disability (Article 35 clause2)
- ✓ Participation of PWDs in Elections (Article 59)

Existing Specific Laws/Policies on Disability in Uganda include:

The People with Disability Act 2006 which provides for:

- ✓ Rights of PWDs to Quality Education and medical care-*Section 5-11*
  -inclusive education,

  - Commitment of 10% for SNE

  - None Expulsions of CWDs from School

  -Sign language and sign language interpreters in public places

  -brailing of drug labels.

- ✓ Employment- *Section 12-18*
  -Inclusive Advertisement
  -modification of premises to fit the needs of employees with Disability
  -Tax Reduction of 15% for employers with at least 10 PWDs

- ✓ Accessibility- *Section 19-24*
  -Provision of ramps, mobility demarcations,
  -Accessibility to information- brails and use of sign language interpreter during TV news
  -Signals for crossing the road for the blind
  -denial of driving permit

- ✓ Discrimination against PWDs-*Section 25-31*
  -Refusal to give services to PWDs which are given to others
  -assistive devices
  -Sports for PWDs

- ✓ Other Social Rights-Section 32-38
  -Affirmative Action
  -Right to Privacy
  -Right to family
  -participation including in cultural life

- ✓ Exemptions(Acts done under statutory authority*)- Section 39*
- ✓ Offences and penalties- *Section 43*
- ✓ Disability coding-*First schedule*

National Council for Disability Act 2003 provides:

- ✓ Formation of National Council, District and Sub county Councils for Disability
- ✓ Promotion of Equalization of opportunities for PWDs
- ✓ Monitoring of Programmes for PWDs
- ✓ Intervening in the violations of rights of PWDs-*Section 41 of the PWDs Act 2006.*

National Policy on Disability in Uganda 2006 provides for:

- ✓ Accessibility
- ✓ Participation of PWDs at all levels
- ✓ Capacity building
- ✓ Awareness raising on disability
- ✓ Prevention and management of Disabilities
- ✓ Basic care and Support of PWDs by caregivers/Parents
- ✓ Research
- ✓ Use of sign language

Circumstances when rights are denied/your responsibility:

- When responsibility is not taken by the right's bearer e.g. parents failing to take the children to school, seeking medication, legal redress when violated, reporting issues to relevant authorities like police, probation office, Council for Disability, Local leaders, related NGOs like Mifumi...)
- When one violates another person's right e.g. abusing some one in the name of freedom of speech.
- For National and International security e.g. right to own property does include having weapons.

Challenges in the implementation of the legal provisions on Disability

- ✓ Ignorance of existing laws on Disability-Especially by PWDs***(Not that ignorance of the law is no defense)***

- ✓ UN Convention on the Rights of PWDs is not ratified by Uganda Government

- ✓ Regulations giving effect to the implementation of the People with Disability Act, 2006 are not yet finalized (Section 44)
- ✓ Limited resources to handle the legal battles against the offenders e.g. Payment of Lawyers.

Implementation Strategy

Despite the above challenges Government is committed to address the issues of Disability by:

- Establishing a special Ministry to address issues of Disability-(Minister Hon. Sulaiman Kyebakoze Madada), department in the Ministry of GLSD and at all District levels.
- Established Councils for Disabilities
- Implementation of CBR as a community Strategy to respond to the needs of PWDs
- Establishment of SNE Centres like UNISE-Now under Kyambogo University.
- One special school for CWDs per region.
- Mainstreaming of Disability issues in all sector plans-Bonna bagagawale, NAADS, PMA, FAL…
- Construction of accessible facilities on all public buildings

Conclusion

- People with disabilities have rights like any other person.
- The potentials of PWDs need to be protected against exploitation especially in areas of marriage, employment and service delivery
- Existing gaps can not be used to defeat justice for people with Disability
- A good environment for PWDs is a better environment for all.
- Planning with and for the marginalized (PWDs) is planning for ALL.
- Services to PWDs should not be considered as charity but rather as rights for empowerment. PWDs need same services as those without.

TORORO DISTRICT LOCAL GOVERNMENT

DEPARTMENT OF COMMUNITY BASED SERVICES,
SECTION OF ELDERLY AND DISABILITY,
P.O BOX 1,
TORORO

IN COLLABORATION WITH PLAN UGANDA TORORO

Radio Programme for Sensitization on Disability Issues

Week	English Presenters –Mondays	Ateso Presenters-Wednesdays	Jophadola Presenters-Fridays
One	Moiza Moses (CDO-E/D), Kanamugire Mike(Disability Focal Person-Health Dept), Hon. Okea(District councilor for PWD)	Alamai Susan (Ag. PSWO),Ikileng Simon-PWD & CBR Volunteer	Odoi Patrick-CDO & Aluka Akisoferi-TODIPU-C/man
Two	Moiza Moses (CDO-E/D), Kanamugire Mike(Disability Focal Person-Health Dept), Hon. Christrine(district councilor for PWD)	Alamai Susan (Ag. PSWO), Remina Okoth (Parent of CWD & loca leader)	Odoi Patrick-CDO & Aluka Akisoferi-TODIPU-C/man
Three	Moiza Moses (CDO-E/D), Kanamugire Mike(Disability Focal Person-Health Dept)	Alamai Susan (Ag. PSWO),Ikileng Simon-PWD & CBR Volunteer	Odoi Patrick-CDO & Hon A.Christine
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Five	Moiza Moses, and Hon. Okea John & Alamai Susan (Ag. PSWO)	**Alamai Susan(Ag. PSWO) & Ikileng Simon(representative for PWD**	Odoi Patrick-CDO & Aluka Akisoferi-TODIPU-C/man
Six	Moiza Moses, Alamai Susan and Hon. A.Christine. Mr. Aluka Akisoferi-TODIPU-C/man	Alamai Susan (Ag. PSWO), Remina Okoth (Parent of CWD & loca leader)	Odoi Patrick-CDO & Hon. Okea Joh

INTELLECTUAL DISABILITY

- Presentation to the National Training of Community Development Officers At DATIC, Tororo District

By

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28th-29th October 2008

Coverage of the Presentation

- Disability Concepts
- What is Intellectual Disability?
- Types and causes
- Case Studies of Intellectual disabilities
- Challenges/Limitation in service delivery to PWIDs
- Possible suggestions to the limitations

Disability Concepts

Its important to note the following keys concepts that relate to Disability:

Impairment: WHO defines as any lose or abnormality in Psychological, physiological or anatomical function of any body part.

Impairment

- **Impairment**: Refers to loss of, injuries to, deviation from the normal psychological, physiological, or biological functions of the body. (User to citizen, NOU 2001:22- Norwegian)
-

Impairment

- The People with Disability Act, 2006 refers to **disability** as "**a substantial functional limitation of daily life activities** caused by physical, mental or sensory impairment and **environmental barriers** resulting in **limited participation"**

Disability

- According to the National Policy on Disability in Uganda, 2006, “Disability is a **permanent** and **substantial functional limitation of daily life activities** caused by physical, mental or sensory impairments and **environmental barriers** resulting in limited **participation**”.
- **People with Disabilities**: -Refers to people whose practical living is limited due to discrepancy or gaps between their impairments and the demands of the society/ environment. User to citizen, NOU 2001:22-Norwegian)

People with Disability

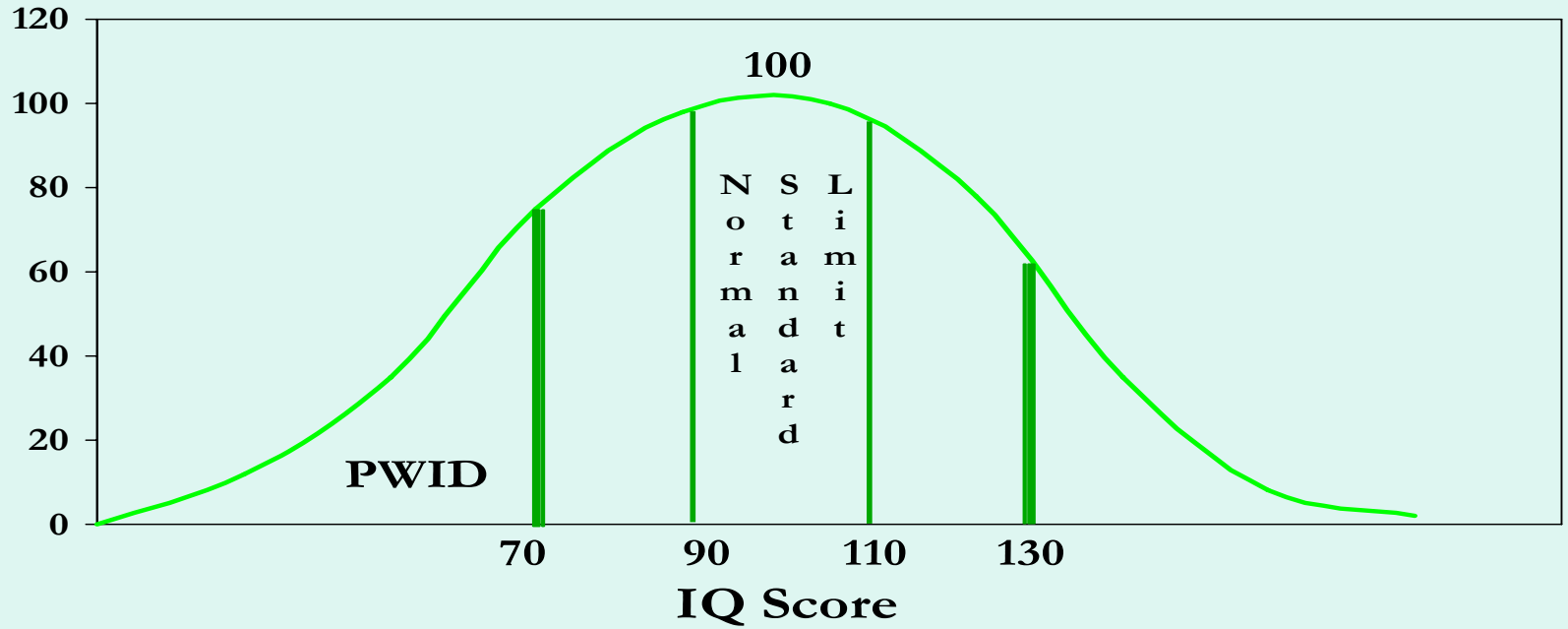
- The People with Disability Act, 2006 refers to a person with disability as “a person having physical intellectual, sensory or mental impairment which substantially limits one or more of the major life activities of that person.”
- **Note I:** All persons with Disabilities are impaired but not all impaired persons are disabled.
- **Note II:** It is the environment that disables persons with impairments. Removal of environment barriers equally removes disabilities from all those impaired. Barriers manifest in: Attitudes, accessibility, sign language limitation, Braille…
- **Handicap**: A situation of disadvantage expressed towards PWDs.

INTELLECTUAL DISABILITY

- **Intellectual Disability:**
- This is a type of Disability associated with the intellect. It is a limitation in mental processing of information. It's one of those disabilities with no particular statistics and some times left out due to the difficult in meeting the needs for PWIDs. Their needs call for life support.
- The most common Cause of intellectual disabilities is genetic and birth defects.

Intelligence Quotient for PWIDs

- IQ Grading
- Lowest IQ For MR-70-75



The Various Intellectual Disabilities

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- Un-controllable movements
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Characteristics cont…

- To some extend they become aggressive when dealing with issues affecting them.
- Common failure to take quick decision/choice on any issue
- Cognitive difficulty –Memory failures
- Slow Physical growth/un-proportionate growth-Facial appearance, young or old for age.

CASE STUDY I

DOWN SYNDROME

Occurrences

It is estimated at 1 per 800 to 1 per 1000 births.

At maternal age:

20 to 24 …… 1/1562

35 to 39 …… 1/214

Above age 45 …… 1/19

Occurrences

Although the probability increases with maternal age, 80% of children with Down syndrome are born to women under the age of 35 reflecting the overall fertility of that age group.

Paternal age, especially beyond 42, also increases the risk of Down Syndrome

There has been no evidence that it is due to parental behavior or environmental factors.

What is Down syndrome?

- **Down syndrome** or **trisomy 21** is a chromosomal disorder caused by the presence of all or part of an extra 21st chromosome. It is named after John Langdon Down, the British doctor who described the syndrome in 1866.

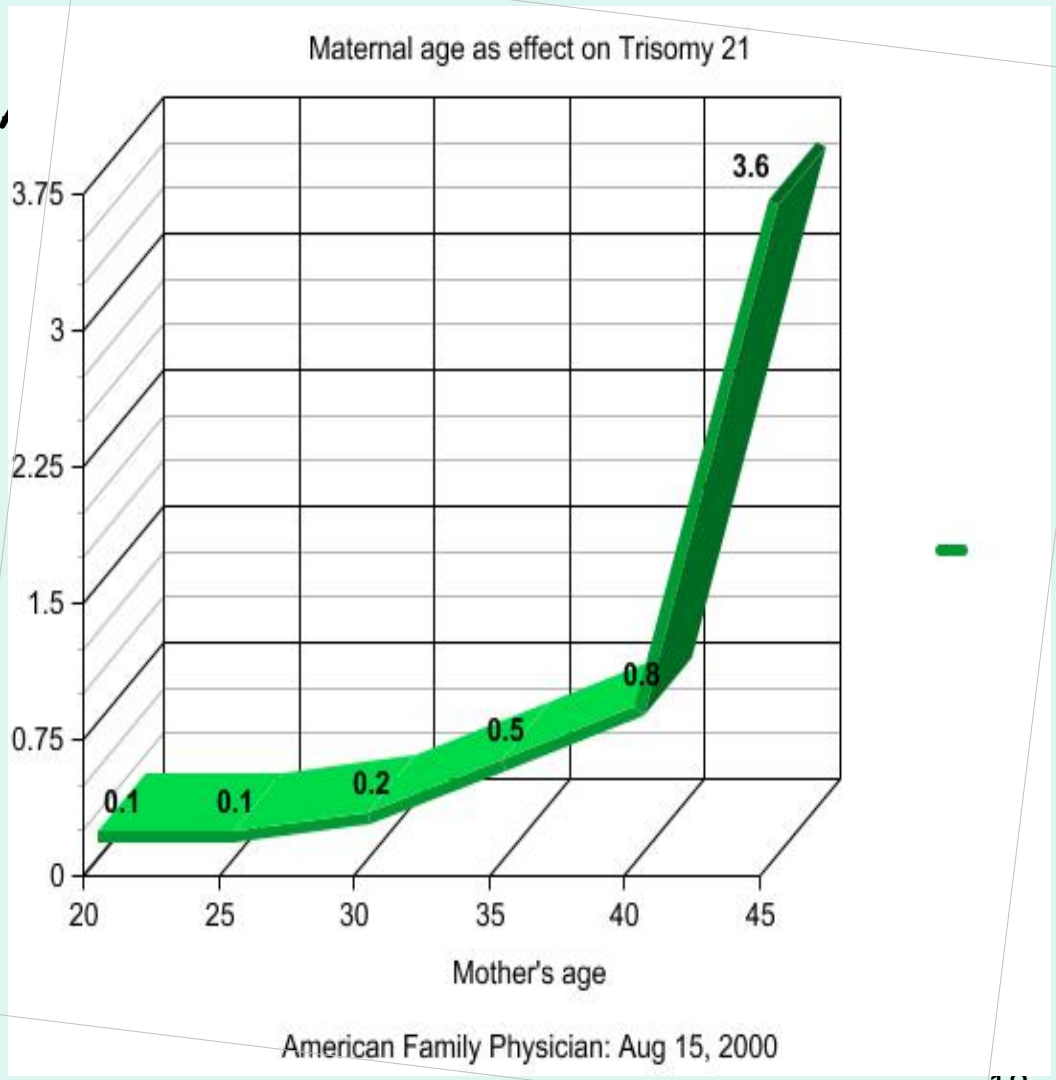
- It is the result of a chromosomal anomaly by which the nuclei of cells in the human body has 47 chromosomes instead of 46, belonging the extra chromosome to the pair 21.

Associated with:

- Cognitive disability
- Slow physical growth
- Facial appearance.

MATERNAL AGE AS EFFECT ON TRISOMY 21

Center of desease control U.S.A



Physical and Medical Characteristics

- The back of the head is often flattened
- The eyelids may be slightly slanted,
- Small skin folds at the inner corners of the eye
- The nasal bridge is slightly depressed
- Nose and ears are usually somewhat smaller
- In the newborn there is often an excess of skin at the back of the neck.
- The hands and feet are small and the fingerprints are often different from chromosomally “normal” children.

Physical and Medical Characters...

- Loose ligaments
- About one-third of children with Down syndrome have congenital heart disease.
- Blockage in the bowels and cataracts
- Hearing deficits
- Visual problems
- Thyroid dysfunction-obesity
- Intestinal abnormalities
- Respiratory problems
- Increased susceptibility to infection
- Higher risk of childhood leukemia.

Many of these conditions are treatable.

There are some common elements in their way of being and acting...

- Character and Personality:
  - Little Initiative
  - Less ability to inhibit behaviors
  - Tendency to persistent behaviors and resistance to changes.
  - Low responsiveness to environmental factors
  - Constancy and punctuality.
- Sociability
- Memory
- Attention
- Intelligence
- Cognitive aspects
- Language –Slow devepment

Motricity

MEMORY

- Difficulty in retaining information, both by limitations to receive and process (short-term memory) and to consolidate it and retrieve it (long-term memory).
- Operational and procedural memory, is well developed, so they can perform tasks accurately sequenced.
- Significant deficiencies with the explicit or declarative memory that's why they can perform complex behaviors that are unable to explain or describe.
- Difficulties following more than three follow instructions given in sequential order.
- His ability to capture and retain visual information is greater than the one that is receive by hearing.

  Do not know how to use or develop strategies to improve their memory ability.

Sociability

- Traditionally they are considered to be very "loving“ persons, the truth is that without a systematic intervention, their level of spontaneous social interaction is low.
- In general they reached a good level of social adaptation.
- They tend to be friendly and show themselves as collaborators, affectionate and sociable.
- In children often occurs heavy reliance on adults, something that can be seen both at school and at home.
- Usually prefer to play with younger children.

Dev’t of language

- They present a significant delay in the emergence of language and language skills, with great variability between them.
- Difficulty with verbal responses, giving better motor responses.
- Difficulty capturing spoken information, but noted that have better level of understanding that expressive language.
- Trouble communicating their ideas and in many cases they know what to say but can not find how to say it. Hence relied on gestures .
- Their difficulties often associated stereotyped answers as "not know", "I do not remember",

CASE STUDY II

- Autism: Defined as behavioral syndrome
- Behavior tends to persist although it can be improved over time.
- Commonly congenital in nature

Diagnostic Criteria of Childhood Autism

- Qualitative impairments in reciprocal interaction
- Qualitative impairments in communication
- Restricted, repetitive, and stereotyped patterns of behavior, interests and activities
- Developmental abnormalities must have been present in the first 3 years for the diagnosis to be made
- (ICD-10 WHO , 1994; DSM-IV-TR APA, 2000)

Abnormal Behaviors frequently associated with Autism

In Childhood

hyperactivity, sleep disturbance, oversensitivity to sounds, abnormalities in eating etc

After Adolescence

inertia, obsessive-compulsive disorder (OCD) like behavior, catatonia,

mood disorders (depression, bipolar disorders, “mood swings” self-injurious behavior SIB),

aggressive behaviors,

Intelligence and cognition

- Since autism is a behavior syndrome, each autistic child has different intelligence
- Cognitive skills

are usually uneven

- Intelligence

develops with age

Major Findings on Standard Psychological Tests

1. autistic children reject tasks not due to "autistic shell", but due to difficulty of tasks
2. Wechsler tests show a characteristic profile
3. relatively few autistic children obtain IQ scores within normal range, and most function at a severely retarded level
4. IQ scores are remarkably stable, regardless clinical changes in behavior
5. obtained IQ scores are predictive of later adjustment

(Dr. Othta-Japan,2008)

Modern Principles of Psycho-educational Approaches

- Developmental perspective
- Difficult to facilitate learning under free situations
- Appropriate tasks and structured settings
- Programs reducing abnormal behavior must combine with those enhancing adaptive behaviors
- Non-aversive approach
- To make entirely programs under consideration of three dimensions; 1. to facilitate development of basic cognition including emotion, 2. to facilitate adaptive behaviors, 3. to reduce or control abnormal behaviors

Treatment of Autism

Environment modulation (indirect treatment)

- to stimulate various sensations & to integrate between sensations
- to differentiate means and goals
- to foster basic communication abilities
- to facilitate abilities to understand that everything has a name

Direct treatment: Psychopharmacological treatment

Psychopharmacologic agents

- Anti-psychotics
- sedative hypnotics
- stimulants
- Anti-anxiety drugs
- mood stabilizers
- antidepressants
- anticonvulsants
- others

Limitation/Challenges in addressing issues of persons with intellectual Disability

- Missing aggregated data on Intellectual Disabilities both at National and at District levels
- Limited resource personnel to deliver services like Psychiatric specialists, SNE to teach in Inclusive setting.
- Limited resources to meet the special needs of PWIDs-Drugs, building rehabilitation Centres.

Limitation Cont…

- Unable to demand for services. Limitations in services causes' demand driven service delivery which is impossible to PWIDs-Do it through the Councilors, Parents and Community Leaders...
- Life time support for PWIDs. There is no graduation from the support. Can on improve but not heal.

Challenges cont…

- NGOs-Programmes are Result Oriented and time bound. Some consider this none-comfort zone.
- Donor directed Programmes at times have limitations on coverage, target population and time frame.
- Limited employment opportunities

Way forward in Handling Issues of Intellectual Disability

- Establish the data at the District Level including the type, level and location.
- Build the capacity of CDOs and local leaders (District & Sub county Councilors), CBR Volunteers to include issues of PWIDs in CBR activities
- Conduct a participatory planning strategy to come with a project to address issues of intellectual Disabilities.
- Raise awareness on issues of intellectual Disabilities in the community.
- Advocate for Skills Training Centre for PWIDs
- Train PWIDs in employable skills
- Development of one Shop-stop Centre for PWDs

Source of information

- National Policy on Disability in Uganda, 2006
- People with Disability Act 2006
- User to citizen, NOU 2001:22-Norwegian
- Class notes from Training Materials from Japan (Intellectual Disability in community Activity class 2008).
- Field experiences drawn from Japan, Norway, Bangladesh and Uganda

Thanks

- *“Your participation in Intellectual Disability Issue is an investment for independent living of Persons with Intellectual Disabilities.”*