



**MULONGO DIASPORA
FOUNDATION**
SERVING COMMUNITIES


THE STATE OF MENTAL HEALTH IN UGANDA:

A Case Study of
Inclusion of
People Living
with Down
Syndrome
in Uganda.



**MULONGO
DIASPORA
FOUNDATION
MAGAZINE**

Issue 1







First published in 2023

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DOWN SYNDROME

This is a genetic condition caused by having an extra chromosome 21 in some or all of the body cells that leads to multiple abnormalities such as, recurrent respiratory infections and a heart defect.



MENTAL HEALTH

This is defined as a state of well-being that enables people to cope with the stress of life, realize their abilities, contribute to their communities, learn well and work well.

INCLUSION

This is known as the practice or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalized such as, those who have physical or intellectual disabilities.





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Prevalence of Mental Health in Uganda.

14 million people out of
the 43.7 million
Ugandans live with
mental illness.



Common Physical Features of People with Down Syndrome.

- A flattened face especially the nose bridge.
- Almond-shaped eyes that slant up.
- A short neck;
- Small ears.
- A tongue that tends to stick out of the mouth.
- Tiny white spots on the iris (colored part) of the eye.
- Small hands and feet.
- A single line across the palm of the hand (palmar crease).
- Small pinky fingers that sometimes curve toward the thumb.
- Poor muscle tone or loose joints.
- Shorter in height as children and adults.



The Number of People Living with Down Syndrome in Uganda.

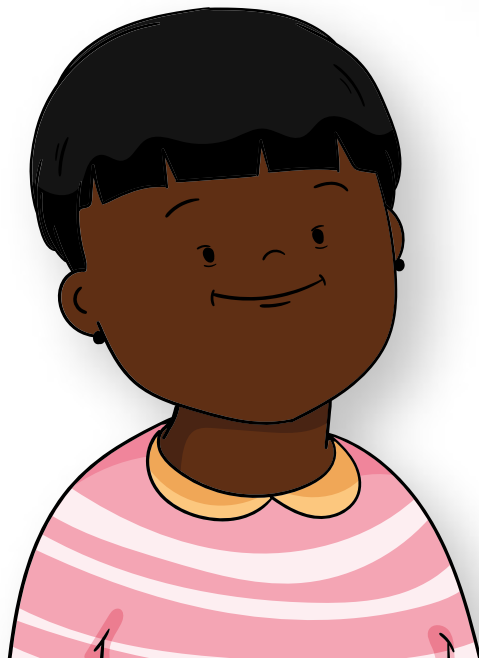
It is estimated that 5,000 Ugandans have Down Syndrome. However, there is no statistic on the number of people with Down Syndrome who are suffering from mental disorders.



TYPES OF DOWN SYNDROME

TRISOMY DOWN SYNDROME

This is where each cell in the body has 3 separate copies of chromosome 21 instead of the usual 2 copies.



TRANSLOCATION DOWN SYNDROME

This occurs when an extra part or a whole extra chromosome 21 is present but it is attached or “trans-located” to a different chromosome rather than being a separate chromosome 21.

MOSAIC DOWN SYNDROME

This is where some cells of people with Down syndrome have 3 copies of chromosome 21, but other cells have the typical two copies of chromosome 21.



COMMON MENTAL DISORDERS AMONG PEOPLE WITH DOWN SYNDROME

MOOD DISORDERS

These are categories of mental illnesses which primarily affect a person's persistent emotional state (their mood). It is symptomized by changes in mood, sleeping, eating behaviors, energy levels and thinking abilities.

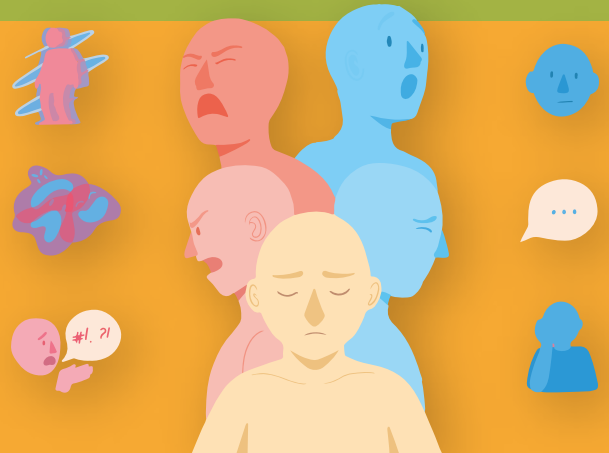


ANXIETY DISORDERS

This refers to a group of mental illnesses involving persistent and excessive worry that interferes with daily activities. It is characterized by restlessness, being easily fatigued, having headaches, muscle aches, stomach aches and having sleep problems.

SCHIZOPHRENIA

This is a serious mental illness that affects how a person thinks, feels, and behaves. It is characterized by delusions, hallucinations, disorganized speech, trouble with thinking and lack of motivation.



PERSONALITY DISORDERS

These are mental health conditions that involve long-lasting, all-encompassing, disruptive patterns of thinking, behavior, mood and relating to others. They are illustrated by inflexible and atypical patterns of thinking, feeling, and behaving.



PSEUDOBULBAR AFFECT

This is a neurological condition that causes outbursts of uncontrolled or inappropriate laughing or crying.



DEMENTIA

This is a term for several diseases that affect memory, thinking and the ability to perform daily activities. It is symptomized by memory loss, poor judgment, confusion, reading and writing, difficulty in speaking, understanding and expressing thoughts and repeating questions.



OPPOSITIONAL BEHAVIORS

This is a childhood behavioral problem symptomized by hostility, frequent temper tantrums, over arguing, questioning rules and refusing to do tasks, annoying people or upsetting others and blame shifting.



TIC DISORDER

This refers to a class of childhood-onset neuropsychiatric disorders characterized by involuntary motor and vocal tics like blinking, jerking, banging objects, clicking fingers, uncontrolled touching of items, coughing, throat clearing, grunting, repeating words or phrases, nose twitching and eye darting.



IMPULSE CONTROL DISORDERS

They refer to a group of mental health disorders which make a person unable to control or ignore impulses to engage in certain behaviors. They are characterized by starting fires, sudden explosive anger or acts of violence, hair pulling, participating in risky sexual behaviors, stealing, impulsive lying, poor social skills, isolating oneself from family and friends.



CONDUCT DISORDER

This refers to a group of repetitive and persistent behavioral and emotional problems in youngsters. It is demonstrated by lying, breaking and entering, bullying, stealing and forgery.

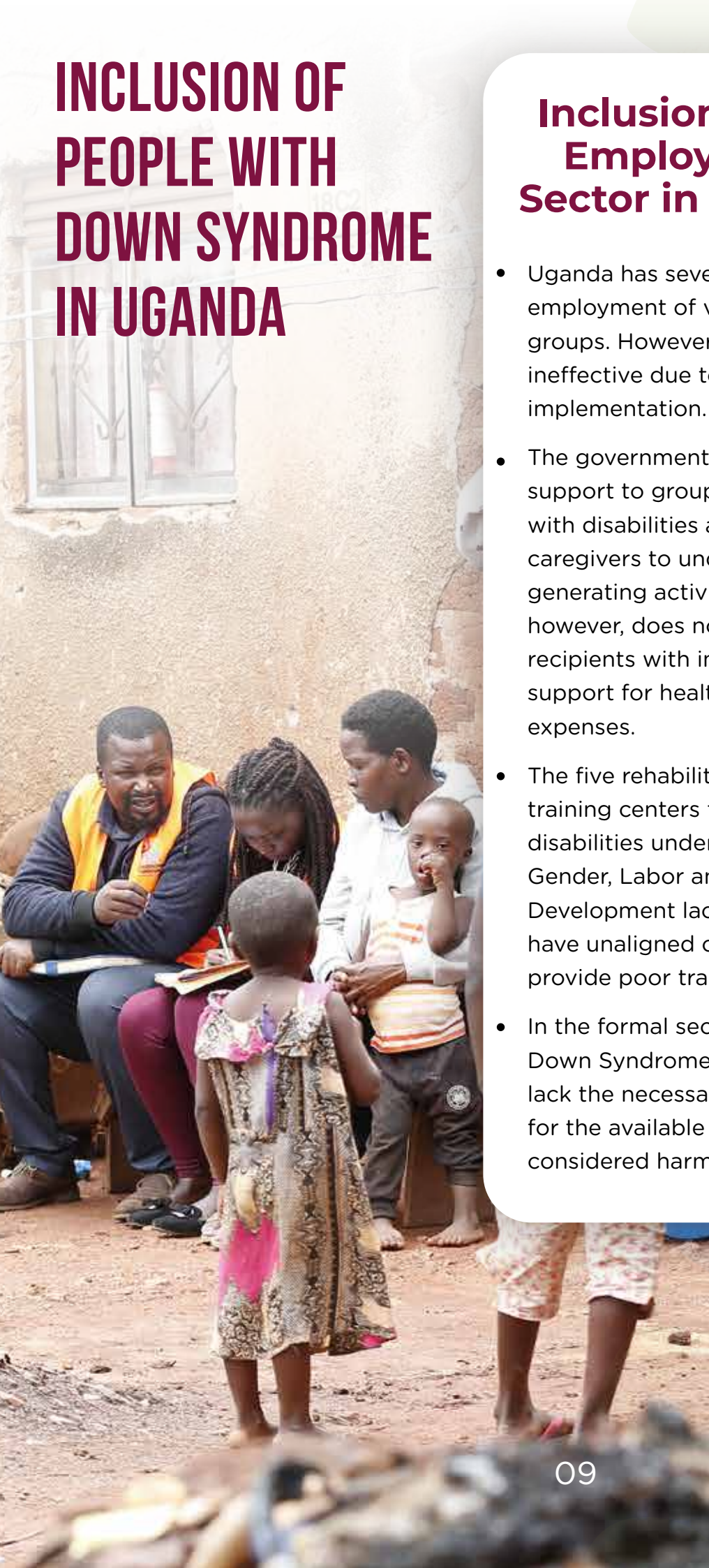


Causes of Mental Health Disorders Among People with Down Syndrome.

- Hardship in accessing health services, education and transport.
- Stigmatization.
- Bullying.
- Discrimination.
- Attitudinal biases.
- Low expectations.
- Limited access to meaningful work and social activities.



INCLUSION OF PEOPLE WITH DOWN SYNDROME IN UGANDA



Inclusion in the Employment Sector in Uganda

- Uganda has several policies on employment of vulnerable groups. However, they are ineffective due to poor implementation.
- The government provides support to groups of persons with disabilities and their caregivers to undertake income generating activities. This project however, does not provide the recipients with immediate support for health or education expenses.
- The five rehabilitation and training centers for people with disabilities under the Ministry of Gender, Labor and Social Development lack resources, have unaligned curricula and provide poor training.
- In the formal sector, people with Down Syndrome are perceived to lack the necessary qualifications for the available jobs and are considered harmful.

A STORY ON INCLUSION IN THE EMPLOYMENT SECTOR



Name: Acaa Joyce

Age: 19 years

Acaa Joyce was born with Down Syndrome, her parents however, learnt that she had Down Syndrome when she was three months old.

She is currently living with her single mother and studies from Kireka School of Children with Special Needs.

According to her teachers, Acaa has a low concentration level and as such, her syllabus involves vocational trainings only.

During the research, her mother stated that among other things, Acaa can make mats which she normally sells at 10,000 Ugandan shillings each.

She added that Acaa is still dependent on her because of limited job opportunities for people with Down Syndrome in addition to lack of start-up capital as well as her inability to manage and calculate her finances.



Inclusion in Education

Most of the children with Down Syndrome in Uganda study from regular schools. However, a few attend schools for children with special needs which are few and very expensive with limited resources to provide all the necessary educational services for children with Down Syndrome.

Further, there is high rate of school dropout among children with Down Syndrome due to discrimination, stigmatization, unfavorable curricula and lack of funds to finance their education.

A STORY ON INCLUSION IN EDUCATION

Name: Acen Catharine

Age: 19 years

Acen Catharine was born with Down Syndrome. Her mother learnt that she had Down Syndrome when she was 5 years old.

According to Acen's mother, Acen experienced discrimination and stigmatization while she was studying at a regular school. She further stated that the children at the school disassociated themselves from Acen while in class and outside class. She also narrated that on one occasion, Acen was badly beaten by her fellow pupils because of her distinctive appearance. As a result, Acen's eyes were operated and she stopped schooling for fear of being beaten.

Further, she stated that she later took Acen to a school for children with special needs.

However, due to the long distance and lack of school fees she dropped out.



Social Inclusion in Uganda

People living with Down Syndrome in Uganda and their care givers are still facing discrimination and stigmatization in public places and communities due to lack of awareness and barbaric cultural beliefs.

A STORY ON SOCIAL INCLUSION

Name: Peduni Immaculate

Age: 25 years

Peduni Immaculate is a single mother of a child with Down Syndrome.

Immaculate stated that when the father of her child found out that he had Down Syndrome, he chased her and the child away from his home because he believed that the child was a curse. To her dismay, her relatives also rejected her for the same reason leaving her homeless.

Immaculate added that on one occasion, her child's father beat her to the extent that her clothes tore because she asked for child support.

According to Immaculate, the stigmatization and discrimination she faced caused her to pray for her child's death so that she could be free.

Up to date, Immaculate is still struggling without any support from the father of her child and her relatives.



Inclusion in Health Care

According to the Ministry of Health (Uganda), there are no special medical programs which are specifically tailored towards people with Down Syndrome in addition to lack of skills and tools to diagnose Down Syndrome.

FACTS ABOUT INCLUSION IN HEALTH CARE

Name: Dr. Okiror Micheal

Title: Country Director of Uganda Down Syndrome Association

According to Dr Okiror, half of the children with Down syndrome in Uganda have holes in their hearts. He added that each of those children needs approximately 20 million Ugandan shillings to under go a heart surgery.

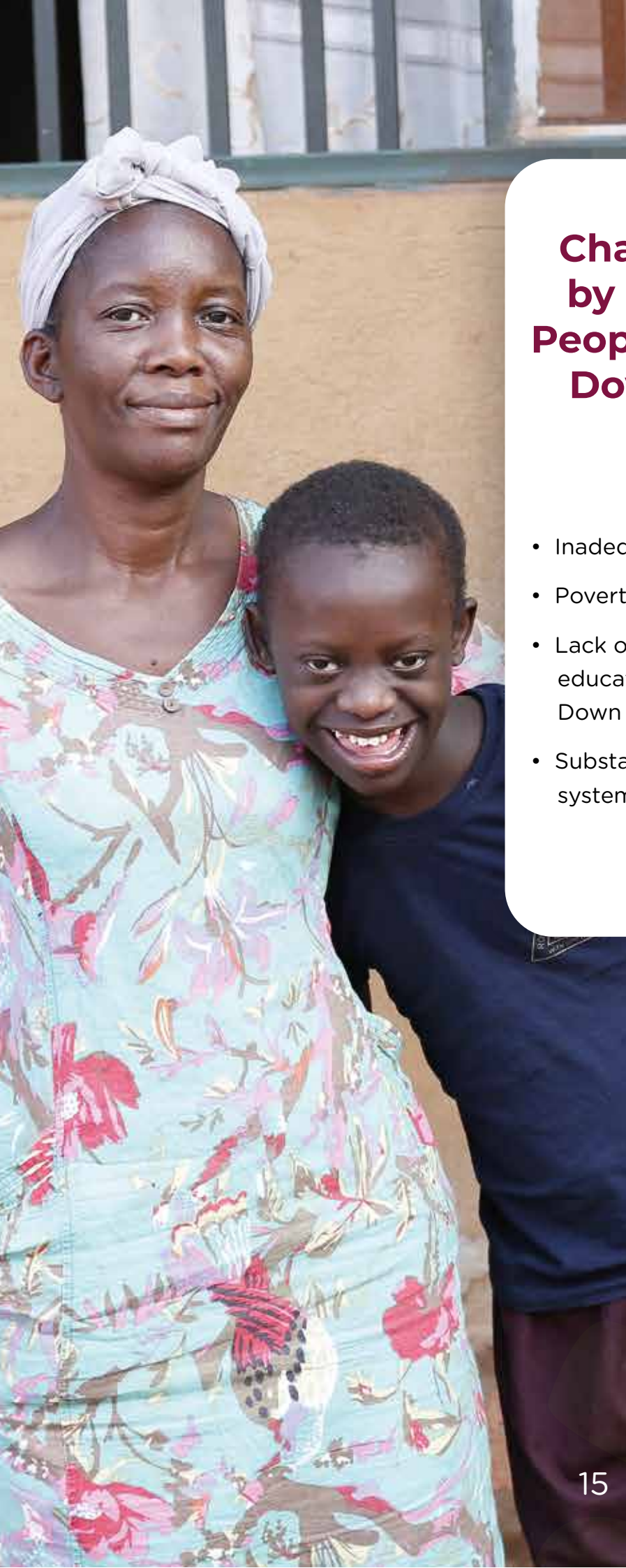
Dr. Okiror however, stated that the surgery is very expensive for most of the parents of children with Down Syndrome in Uganda and that his endeavor to lobby for the subsidization of the cost of the heart surgeries by the government has been in vain.

He concluded that at the time of recording the story the Association had 7 children who were in need of heart surgeries and were at the verge of dying if not treated immediately.

Barriers to Inclusion of People with Down Syndrome in Uganda

- Discriminative cultural beliefs.
- Lack of awareness about Down Syndrome among the communities.
- Lack of medical care for people with Down Syndrome.
- Unaligned curricula to meet the special educational needs of children with Down Syndrome.
- Inability to detect and record children with Down Syndrome at birth.





Challenges faced by Care Givers of People Living with Down Syndrome in Uganda

- Inadequate food.
- Poverty.
- Lack of free and specialized education for people with Down Syndrome.
- Substandard health care systems.



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How to Promote Mental Health among People with Down Syndrome.

- Promoting access to health services and education for people with Down Syndrome.
- Creating awareness and sensitization about Down Syndrome.
- Funding education and health services for people with Down Syndrome.
- Creation of employment opportunities for people with Down Syndrome.
- Putting into place disability health insurance.
- Building a center for people with Down Syndrome.
- Offering vocational courses, life skills and talent building of people with Down Syndrome.
- Promoting inclusion of people with Down Syndrome.
- Lobbying for the subsidization of the cost of heart surgeries.
- Training teachers to provide specialized education to people with Down Syndrome.





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