



Mental Illness and Exclusion:

Putting Mental Health on the Development Agenda in Uganda

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Mental health in Uganda

Mental health is more than the absence of disease or disorder. It is a state of complete mental wellbeing including social, cognitive, spiritual and emotional aspects. Mental wellbeing is part of an individual's capacity to lead a fulfilling life, which includes the ability to study, engage in gainful work or pursue leisure interest, and to make day-to-day personal or household decisions and choices. On the other hand, mental disorders relate to symptoms that affect thinking and emotions, as well as those that relate to the relationships of individuals with family and society, often resulting in an inability to cope with the ordinary demands of life. Disturbances to one's mental wellbeing therefore compromise one's capacities in a fundamental and enduring manner. Because of its close link to poverty (and economic wellbeing), it is imperative that mental health is given as much weight or even more as a development issue as it is given medically; and that appropriate programs are designed to address socioeconomic challenges resulting from mental disorders.

In Uganda there exists a close association between mental health and chronic poverty. Although statistics on mental health in the country are scanty, anecdotal qualitative research evidence suggests an increase in the incidence of mental disorders. According to the Uganda Bureau of Statistics (2006), for example, basing on the UNHS 2005/06 Qualitative Module Report, of all households with disabled members (an estimated 7% of households in the country), 58% had at least one person with a mental disorder.¹ Similarly, physical and psychological war-related trauma accounts for major depressive disorders among 71% of refugees and Internally Displaced Persons. The proportions of common mental disorders among the general population are PTSD (9%), common depression (20%), manic depression (3%), anxiety (4%), Epilepsy (3%) and Schizophrenia (1%); and these account for 20-30% of all hospital outpatient attendance.². At least one in five people (approximately 23%) with mental health problems has "suicidal tendencies" and nearly one in four (18%) engage in substance abuse;³ In absolute terms, an estimated 35% of Ugandans (approximately 9,574,915 people)⁴ suffer from some form of psychiatric (mental) disorders; at least 15% of which require treatment.5

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Mentally ill persons and their care-givers line up for monthly treatment at a remote health centre in Hoima District

The Global Picture of Mental Health

There is very little data / literature globally on the prevalence of mental disorders and their effects. Analyses by the World Health Organisation suggest that approximately 10% of adults suffer from mental disorders, and that during their entire lifetime, more than 25% of individuals develop one or more mental disorders. Also, 20% of all patients seen by Public Health Care workers have at least one Mental Disorder. It is estimated that one in four families has at least one member currently suffering from a mental disorder. Mental disorders accounted for 10.5% of the global burden of disease in 1990, they increased to 12% in 2000, and are expected to reach 15% by 2020 (WHO, 2001)

 ¹ Uganda Bureau of Statistics(2006) UNHS 2005 / 06: Qualitative Module Report
 ² Ministry of Health – Uganda (2005). Draft Mental Health Policy
 ³ Musisi S (2005) War and Mental Health in Africa. In: Njenga FG, Acuda W, Patel V., editors Essentials of Clinical Psychiatry for sub-Saharan Africa. Milan:Masson; 2005

- ⁴ UBOS: The projected population figure for Uganda in 2006 is 27,356,900
 ⁵ Basangwa D (2004) Mental Health Care in Uganda: Emerging Challenges of HIV/AIDS and
- Civil Strife ⁶ Bird K (2004). Fracture Points in Social Policies for Chronic Poverty Reduction
- ^o Bird K (2004). Fracture Points in Social Policies for Chronic Poverty Reduct ⁷ ibid

Policy and Practice

The Uganda National Health Policy and Draft Mental Health Policy (2000 – 2005) commit to prioritise mental disorders because they are major contributors to the country's disease burden. This commitment is expected to lead to greater allocation of the government budget to health spending, through the Uganda National Minimum Health Care Package (UNMHCP). Despite this commitment, Uganda still spends less than 1% (0.07%) of its health budget on mental health⁶. Also, while the emerging policies recognise the relationship between mental health and poverty, they do not make practical proposals or suggestions on how to deal with the socio-economic effects of mental disorders on the population. Besides, dominant poverty discourses continue to identify people with mental disorders as being less deserving of help than other categories of the poor.⁷ Not surprisingly, therefore, there is a lack of community level mechanisms to cater for the needs of people with mental disorders, and initiatives to support households affected by mental illness to cope with the socio-economic challenges they face are limited to self-help.

Mental Health and Chronic Poverty in Uganda:

An intricate link exists between the incidence of mental disorders and chronic poverty in Uganda. The two are linked in a vicious cycle of exclusion, poor access to services, low productivity, diminished livelihoods and assets depletion, as well as failure of affected individuals and families to be economically active (UNHS 2005/2006). Individuals with mental disorders may be too weak from treatment, or so disoriented that they may not always be able to engage in livelihood activities. Household members on the other hand may have to spend a lot of time looking after the affected person; limiting the time they have available to invest in livelihood activities.

Stigma and discrimination:

People with mental disorders in Uganda experience some of the worst forms of stigma and discrimination, linked to lack of awareness, misinformation and stereotyping about their condition. Consequently, they are denied the chance to participate fully in community activities or enjoy basic social services. They are also commonly excluded from development programmes, membership of self help groups and government welfare schemes, and they find it difficult to find work. Even when they are willing to work, the rest of the community may be unwilling to offer them even casual work. A belief that mental illness is contagious exacerbates and intensifies stigma and exclusion.

During the time my daughter Miriam was very ill, she was violent and destructive so I gave up working and devoted most of my time to tending to her and ensuring that she did not run away. This put a strain on our wellbeing as we no longer had any form of income. When all our assets were depleted, I gave up treatment and decided to keep her at home tied up so she wouldn't destroy property and harm herself."

Jane, a mother of a mentally ill girl of a remote rural village in Sembabule District, Uganda.

Adapted from a life story written by DRT for BasicNeeds UK in Uganda

⁸ Uganda Bureau of Statistics (2006). UNHS 2005 / 06: Report on the Socioeconomic Module

⁹ BasicNeeds UK in Uganda (2004). Baseline Study on Mental Health in Sembabule, Masaka, Hoima, Masindi and Kampala districts

Exploitation:

Adverse incorporation is the other challenge which most people with mental disorders face. Many suffer labour exploitation, working for low pay, payment in "kind" or none at all for labour intensive menial jobs including collecting water and firewood or cleaning homes and public places in their community.

When I have some strength, I do odd jobs for people, expecting payment. Most of them pay "in kind" by giving me food. A few pay in cash. Either way, I receive much less than I should. I know they cheat me because I am 'mad'! I feel exploited but then I just have to take what they give because I badly need it!

Sperito, a mentally ill youth in a rural trading centre of Kalegero in Masaka District

Access to services:

Limited access to specialist services, like mental hospitals and special education facilities, is the order of the day, mainly due to the low level of priority given to mental health. For instance, the UNHS 2005 / 06 showed that in Uganda, 66.6% of people with mental disorders aged between six and twenty four years had their school attendance either fully or partially negatively affected by their situation, while 80.7% of people with mental disorders aged between 14 and 16 years have their work / employment negatively affected.⁸ In addition, mental disorders require long term treatment which is expensive for the individual, their families and the nation. Costs of medical treatment range from Ushs. 20,000 (\$13) to Ushs. 100,000 (\$63) per person per month, and traditional treatments (which are preferred by many) on average cost between Ushs. 20,000 (\$13) and Ushs. 70,000 (\$44) per visit. Most traditional practitioners also demand in-kind payments in the form of cattle, goats, chicken, cowry shells, or cloth.⁹ This reduces households' ability to afford food, education and to meet other health needs; implying a loss of future livelihood opportunities.

We were unfortunate because unlike other children, our father was mentally ill. Because of this, my siblings and I could not go to school as we always lacked fees. The problem became persistent as my father's health deteriorated. He became destructive, burnt our crops and household items as well as those of our neighbours. We have basically lived a life of perpetual need.

Lamentations of a young man in Hoima District, in Uganda, whose father is mentally ill.

Adapted from a newsletter article written by DRT for BasicNeeds UK in Uganda

Because lower level health centres in Uganda do not offer mental health services, people with mental disorders have to travel long distances, at least 10kms, to find treatment, often incurring additional costs.¹⁰ Also, because of stigma, those consulting traditional healers about mental disorders prefer to travel away from the prying eyes of their own communities.

The cost of treatment:

The high costs of accessing mental health treatment often affect household

¹⁰ ibid ¹¹ PubMed Central (2002). Table 1: World Psychiatry. 2002 February; 1(1): 32 – 35 income and result in considerable additional expenditure. Many affected families eventually sell their assets in a bid to meet these costs. However, even such distress sales do not necessarily generate all the resources which are required to meet total treatment costs. As such families are, after sale of assets, often left in the triple dilemma of "assetlessness", inability to complete a treatment regime, and inability to meet basic needs.

Impact on social capital:

Mental disorders negatively affect social capital of the affected and their families; yet this is a key asset for the poor and is an important element of sustainable poverty reduction. Some people with mental disorders become destructive, which often leads to strained relationships with neighbours and the need to spend money on dispute resolution at local courts; which further encroaches on their meagre resources. Thus those who see their social capital eroded may face long-term, persistent and recurrent poverty.

What are the constraints to improving services for people with mental disorders?

There are many challenges to implementation of effective services for those affected by mental disorders in Uganda. We outline some of these in the following paragraphs.

Criminal exploitation:

According to a recent Ugandan newspaper report (Sunday Monitor, July 22nd, 2007), mental illness was also being "criminally used" (or abused) by unscrupulous elements in Ugandan society. These use the false pretext of "a person being of un-sound mind" as an excuse to grab their property, settle scores, or even ensure speedy divorce settlements. Innocent and "un-ill" civil servants were similarly reported to be threatened with dismissal from their jobs. Reports spoke of cases of innocent people being herded into the national mental hospital in Butabika for mental health tests to be carried out. By declaring one of unsound mind the affected people are made "eligible for dismissal from the public service". Cheating relatives also proceed to either gain powers of administration over properties of those who are declared to be mentally ill, or to speedily process divorce papers (in the case of estranged spouses). The Director of Uganda's main mental rehabilitation hospital at Butabika Dr. Fred Kigozi was reported as saying: "we have seen several cases where some people are brought here (Butabika) because individuals want to take advantage of them. Mental illness is used as an escape route"

Lack of a reliable mental health information system, capable of providing data on prevalence and magnitude of the problem; social disadvantages associated with mental disorders; relationships between mental disorders and socioeconomic indicators, and their importance to national development; cost-benefit analysis of treating Mental disorders; economic cost of the mental disorders to individuals, families and the nation; and, efficiency and effectiveness of various interventions being tried currently.

Insufficient human and financial resources for the sector, including shortage of drugs and specialised personnel at national, regional and Public Health Care levels. Despite having a population of 22 million, Uganda has only 9 psychiatrists, 5 psychologists, 400 psychiatric nurses and 450 psychiatric hospital beds (2002)¹.

Contradictory or conflicting treatment regimes:

Some traditional healers provide conflicting and often antiquated explanations



A mentally ill mother of twins in a remote village of Sembabule District in Uganda struggles to feed her babies

for the cause of the disorders. Despite this, there is no policy that health and development practitioners can use to challenge the excesses of traditional healers.

Delayed treatment:

Individuals with mental disorders and their families may delay seeking professional help because they do not realise their condition can be treated; may not afford treatment; or fear being labelled and stigmatised.

Competing (and sometimes incorrect) national priorities:

Despite inclusion of mental health in the Uganda National Minimum Health Care Package, mental health issues have not been included among the core priorities of national, district and lower local government plans, budgets or programs. This is aggravated by lack of information for appropriate decision making and a multitude of development issues competing for the meagre government resources. Moreover, there is a limited social or political movement in support of a stronger focus on mental health in Uganda.

Lack of rational Mental Health policies and legislation:

Uganda currently has an outmoded Mental Treatment Act 2000 and a draft Mental Health Policy that has taken a very long time to be debated and later translated into actionable processes in favour of people with mental illness.

Priority Actions to promote Mental Health in Uganda

Recognise Mental Health as an important development issue:

Recognising mental illness as a health issue is not sufficient. Breaking the mental health – poverty cycle will necessitate addressing mental health as a broader development issue; dealing with the dysfunctions; and recognising that this will lead to increased productivity of those who are on one hand treated and on the other included in the mainstream of development. In part this will require increased mental health expenditure both by government and its development partners, including civil society, and further expenditure in education, production and social welfare sectors.

Create awareness on mental health:

Knowledge is required on the causes of mental disorders; the link between these and chronic poverty, and to change negative perceptions among the public and policy makers and promote the rights of the affected individuals and families.

Adopting an integrated and multi-sector approach:

Mental Health stakeholders should consider cross sectoral service provision and coordination of policies and institutions, including health, education, agriculture, social welfare, law and order (e.g. the Police). the legislature and the judiciary. The linking of local and national efforts will be crucial. Local initiatives such as building local movements and grassroots strengths will generate local resources for therapy and management of mental disorders, information for decision making, and give people with mental disorders voice. This will in turn raise the status of people with mental illness as well as reshape and enhance community health and social programs in their favour. It addition it will help ensure consistency between policy and practice. Creativity will equally be needed to help build programs that link local resources and professional knowledge, and learning from existing models will be necessary for the design of new initiatives.

Providing targeted social support:

Social networks of, and social protection to, people with mental disorders (and their families) should be supported through group processes which may be

GLOSARY OF TERMS

Anxiety

A state of feeling tense, worried or fearful

Chronic Poverty

Clinical Depression

A state of depression so severe as to require clinical intervention by a health care professional.

Depression

A state of sadness, despair or loss of interest in daily life.

Epilepsy

A condition in which seizures occur repeatedly.

Manic Depression

Is a condition in which people have mood swings that are far beyond what most people experience in the course of their lives. These mood swings may be low, as in depression, or high, as in periods when we might feel very elated.

Mental Disorders

Any clinically significant behavioural or psychological syndrome characterized by the presence of distressing symptoms, impairment of functioning, or significantly increased risk of suffering death, pain, disability, or loss of freedom

Mental Health

Mental Health is a state of complete mental wellbeing including social, cognitive, spiritual and emotional aspects

used to raise consciousness and renegotiate changed attitudes and structures regarding mental health.

Improve Policy and Legislation:

Apart from specifically addressing treatment of mental health disorders, policy and legislation should be improved to address sufferers' overall empowerment, particularly, their need for equitable employment, health and education services, as well as social and economic development.

Investing in Action Research:

Research into key areas of mental disorders and chronic poverty is needed, and should explore the causes, prevalence and consequences of mental health disorders; and evidence of efficiency, effectiveness, appropriateness and sustainability of mental health care strategies. Information arising from such research should be able to improve policy decisions.

Post traumatic stress Disorders

A condition of mental distress occurring in a person who has had a life threatening experience

Psychological Trauma

Psychological trauma is a type of damage to the psyche that occurs as a result of a traumatic event

Schizophrenia

A type of irrational fear which often lasts many years

Somatisation

Somatisation is when physical symptoms develop through stress or emotional problems

Substance Abuse

It is a substance use disorder characterised by the use of a mood or behaviour-altering substance in a maladaptive or un suitable pattern resulting in significant impairment or distress, such as failure to fulfil social or occupational obligations or recurrent use in situations in which it is physically dangerous to do so or which end in legal problems, but without fulfilling the criteria for substance dependence

Suicidal Behaviours

Suicidal behaviour is an unmistakable signal that a person has feelings of desperation and hopelessness which include attempted suicide

Uganda National Minimum Health Care Package

It is national health policy that clearly defines the priority program known as the Uganda National Minimum Health Care Package (UNMHCP) to ascertain medical care to all.

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