



SOUTHERN AFRICAN INSTITUTE  
*for* POLICY AND RESEARCH

## Occasional Papers Series

Discrimination and Stigmatisation of People with Epilepsy in  
Zambia: The Need for Integration of Social, Healthcare, and Policy  
Reform

Amy Allen<sup>1</sup> and Ethan Green<sup>2</sup>

19 August 2013

Occasional Paper #2013/01

---

<sup>1</sup> aja76@cornell.edu

<sup>2</sup> erg53@cornell.edu

## **Abstract**

Epilepsy is the most common neurological disease in sub-Saharan Africa with a high burden on low- and middle-income countries worldwide. The economic and medical impacts of its social stigmatisation are readily apparent in Zambia, and a study of its healthcare system and resulting association with mental disorders is reflective of a broader problem. Both past and present legislation violate international declarations of the rights of the disabled, and only recently have mental health advocates been successful in implementing changes to government policy. While many government and non-government advocates have made substantial progress in public education surrounding and treatment of people with epilepsy, significant challenges remain. Lack of funding to decentralise healthcare away from stigmatised mental health centres and to train clinical officers in rural areas poses a major hurdle to proper care and treatment. Human rights, social, and medical perspectives must be included in policies drafted by the Zambian legislature going forward in order to adequately address these issues.

This research explored the state of epilepsy in Zambia by describing the types of discrimination and stigmatisation faced by PWE, treatment options for epileptics in rural and urban settings, the policies and organisations active in the system of epilepsy care and finally summarises how the system of treatment can be improved. The content of this paper is comprised of a review of existing literature and semi-structured interviews with a diverse set of stakeholders in fields ranging from governmental to medical in Lusaka, Zambia.

## Abbreviations

EAZ	Epilepsy Association of Zambia
MCDMCH	Ministry of Community Development, Mother and Child Health
MHUNZA	Mental Health Users Network of Zambia
MOE	Ministry of Education
MOH	Ministry of Health
PWE	People with Epilepsy
UTH	University Teaching Hospital
WHO	World Health Organisation
WWE	Women with Epilepsy

## Background

In Zambia, as in much of the developing world, people with epilepsy (PWE) face discrimination and stigmatisation as a result of their condition on a day-to-day basis. Epilepsy is the most common neurologically based non-communicable disease, with over 85% of the global burden of disease occurring in low and middle-income countries (WHO, 2004). This large burden of disease can be attributed to social, economic, and health issues. While many people are born with epilepsy, others can become epileptic due to secondary causes, such as poor nutrition or perinatal complications. Those that are most prone to these types of health issues are often the same people who cannot afford or access treatment. This is especially true in rural areas, where the incidence of epilepsy is highest and where it is estimated that two-thirds to three-quarters of people do not have access to health care (WHO, 2004; Birbeck & Baskind, 2005). This lack of access may be due to long distances to health clinics, high user fees, or high travel costs.

Lack of treatment for PWE is not exclusive to rural areas. Even those who do have access to treatment may not know that there are viable treatment options available. This lack of knowledge may stem from general unawareness of epilepsy or may be the result of commonly held misconceptions about the disorder. Stigma affecting PWE and their families may also deter patients from seeking effective treatment. In urban areas, PWE face discrimination and stigmatisation due to the association of epilepsy with mental illness. The mental health system in Lusaka, Zambia's capital, is indicative of the structural origination of stigma for epileptic patients. While epilepsy is a medical issue, treated by pharmacological means and to be counselled accordingly, patients are almost universally

treated in mental health institutions. In some cases, association with the mental hospital may be enough to discourage PWE from seeking treatment (Kapungwe et al., 2010).

Due to the strong association between epilepsy and mental illness, PWE are highly affected by the mental health policies, disability laws, and government involvement. Mental illness was not one of the top ten focus areas in the current national development plan and it has continually received insufficient funding and attention. Due to the structural nature of the referral system in Zambia, widespread treatment and resources for PWE and the mentally ill have been severely restricted. The large amount of referrals to high-level hospitals has created a centralised system for epilepsy treatment that is difficult for PWE to access at the primary care level (Atkinson et al., 1999; Mwape, 2010).

The consequences of uncontrolled epilepsy in Zambia can affect every aspect of life. PWE often face open discrimination on account of the lack of understanding and knowledge about epilepsy among peers, family, teachers, or employers. This ubiquitous stigma often socially and economically disadvantages PWE in both rural and urban settings. The violent nature and loss of control during seizures has led many to associate seizures with demonic possession or witchcraft, both of which are extremely stigmatised and often thought to occur when a victim or family member has done something immoral. In this way, it may be presumed that PWE and their families have brought seizures onto themselves. Misconceptions of epilepsy go beyond association with bewitchment and mental illness, as there is also a pervasive fear that epilepsy is contagious. This common misconception may prevent people from assisting a person who is having an attack and can be extremely detrimental to social relationships.

The enormous treatment gap for epilepsy in Zambia (>90%) reflects the structural, social, and economic difficulties facing PWE who try to access treatment (WHO, 2004; Birbeck, 2007). This treatment gap is in spite of the fact that phenobarbital, one of the most inexpensive and widely available anti-seizure medications, only costs US\$5 per person per year. Nowhere in the world is epilepsy more stigmatised than in sub-Saharan Africa and, in Zambia, access to reliable treatment raises concerns about the efficacy of existing policy, the structure of mental healthcare, and ethical issues surrounding the right to widespread treatment. Although extensive literature can be found on stigma-associated epilepsy in Zambia, little effort has been made to provide a comprehensive assessment of the efforts made to confront this stigma. This paper seeks to highlight the resources that are being made available for people with epilepsy and describe the current issues facing PWE in Zambia.

## **Methods**

This research explored the state of epilepsy in Zambia by describing the types of discrimination and stigmatisation faced by PWE, treatment options for epileptics in rural and urban settings, the policies and organisations active in the system of epilepsy care and finally summarises how the system of treatment can be improved. The content of this paper is comprised of a review of existing literature and semi-structured interviews with a diverse set of stakeholders in fields ranging from governmental to medical in Lusaka, Zambia.

Stakeholders were contacted through collaboration with the Southern African Institute of Policy and Research (SAIPAR) and the Zambian Governance Foundation (ZGF). The

interviews were conducted with nine stakeholders including representatives from the Ministry of Health, the Epilepsy Association of Zambia, the Mental Health Users Network, physicians at the University Teaching Hospital (UTH) and individual researchers.

Interviews were conducted from June to August 2013.

## **Discrimination and Injustice**

The consequences of stigma affect every facet of life for PWE. In Zambia, stigmatisation of epilepsy is largely due to misconceptions of the origin and nature of seizures. In many cases, this lack of understanding has led to fear and propagation of misconceptions that affect daily life. Fear and stigmatisation has led to discrimination that significantly disadvantages PWE socially and economically in a manner that violates basic human rights.

Some of the most obvious examples of this discrimination are the disproportionate rates of unemployment and the education discrepancy between PWE and the rest of the population. One study conducted in Zambia in 2007 by Gretchen Birbeck, a physician and professor at Michigan State University who is an expert on epilepsy in Zambia, examined the education and employment statuses of people with epilepsy in comparison to people of similar age, sex, and location who had other non-stigmatised chronic medical conditions. The study found that people with epilepsy had significantly less education (7.1 vs. 9.4 years;  $p=0.0001$ ) and lower rates of employment ( $p=0.001$ ). People with epilepsy also reported lower food security, poorer living conditions, and higher rates of abuse. Of the women enrolled in the study, 20% of PWE reported having been raped as opposed to just 3% of the control group (Birbeck et al., 2007).

These findings are not surprising when one considers that attitudes towards stigmatising conditions are held by all members of society, including employers, policy makers, and teachers. In some cases, PWE report being kicked out of school by teachers after having a seizure in the classroom. One study done in Zambia, which was also headed by Birbeck, examined the knowledge and attitudes of teachers towards PWE. The study found that many teachers did not have a better understanding of epilepsy than the general population. Of the respondents, witchcraft (16.8%) and spirit possession (17.3%) were commonly attributed as the causes of epilepsy and contagion was also noted as a possible cause (28.2%). Although 74.7% of the respondents said that they would allow a child with epilepsy into their classroom if he/she had never had a seizure in school, only 61.2% said that they would allow a child to stay in the class after a seizure in school (Birbeck, 2006).

In addition to children seeking education, women with epilepsy (WWE) are doubly disadvantaged as both a PWE and as members of a vulnerable social group. WWE are particularly vulnerable to rape, domestic violence, and abandonment. A woman's inability to fulfil the domestic and child-rearing responsibilities expected of a wife and mother may heighten tensions between the woman and her family. One study conducted with epileptic women describes the heart-breaking, but common, stories of women whose lives have been destroyed by uncontrolled epilepsy. The women reported feeling unsafe because of no family support, being fearful of having a seizure in public, and being worried about their ability to perform as a wife and mother. One woman described the constant stigma that she felt after having a seizure in public saying, "because of my epilepsy, people won't sit next to me. Even my family has rejected me" (Birbeck, 2008).



PWE may also face excessive discrimination within the justice system itself. Law enforcement officers in Zambia, who are usually the first on the scene to respond to seizures that occur in public, are not specifically trained to deal with PWE and may hold misconceptions about seizures that negatively affect their response. In a survey conducted among police officers in Lusaka, 23% of respondents said that they would arrest, isolate, or restrain a person who was brought into the police station for having convulsions. Among the officers, fear of contagion and association with supernatural causes were common misconceptions about epilepsy (Mbewe, 2007).

Discrimination and injustice are common occurrences for PWE in Zambia. The large disparities between PWE and the rest of the population suggest that epilepsy-associated stigma pervades all aspects of life in both urban and rural settings. It suggests a deeply ingrained prejudice that can only be adequately addressed by a multifaceted approach to stigma reduction through educational campaigns, policy reform, and healthcare reform.

### **Treatment Options for PWE in Zambia: The Role of Health Care Structures in Stigmatisation of Epilepsy**

Discrimination against PWE is largely a result of misconceptions and stigmatisation of epilepsy. Interestingly, the Zambian health care system is intimately connected to this stigmatisation and has the potential to significantly alter how the disorder is perceived by the general public. In the informal health care sector, treatment from traditional healers contributes greatly to social perception of the disorder. In the formalised health care system, the categorisation and treatment of epilepsy as a mental health issue perpetuates the misconception that epilepsy is a mental illness.

### *Traditional Healers*

In rural areas, where access to formalised healthcare may be non-existent, many PWE and their families consult traditional healers. In Zambia, traditional healers commonly associate epilepsy with witchcraft and maintain that the bodily fluids of an epileptic can transmit seizures to those who come in contact with them. Although there is no standard treatment, many healers believe that epilepsy can be treated by giving the patient a concoction comprising of the ingredients used to create the original witchcraft. Generally, this includes products from animals that exhibit convulsive behaviour.

Although traditional healers do not receive any official medical training, their role in the epilepsy treatment should not be understated as they are able to give their patients both the social and cultural support that is absent in most modern day health facilities. In this sense, traditional healers can play a key role in stigma reduction or propagation.

Traditional healers may offer a relief from social stigma or lessen the anxiety felt by the patient or his/her caretakers by providing contextualised treatments that address sources of fear. For example, although it might seem that traditional healers' misguided claim that epilepsy is contagious may negatively affect the lives of PWE, it is also beneficial to consider that these healers can prescribe remedies to family members to prevent perceived transmission. When family, caretakers, or friends are able to feel comfortable around PWE, felt stigma can drastically decrease.

Despite the potential benefits of traditional medicine, there may also be negative consequences if a patient is unable to control his/her seizures. The cost of treatment from a traditional healer may deplete a family's scarce financial resources and further deter them from seeking modern treatment. Prejudice against western medicine and misconceptions

perpetuated by traditional healers also have the potential to increase stigma surrounding a patient and some methods of treatment employed by traditional healers may be actively harmful to the health of the patient (Baskind & Birbeck, 2005).

### *Formalised Health Care: Referral System and Centralisation of Care*

The treatment of epilepsy in formalised health care settings is often seen as a source of stigma itself. Zambian hospitals operate on a referral system that involves the interaction between multiple levels of healthcare. The system operates by encouraging patients to seek treatment at primary care facilities that are located around the country and that are supported by larger health centres and hospitals. When a condition is beyond the abilities of the primary health care provider the patient is referred to the appropriate health facility. In theory, this system is primary care focused and allows the majority of medical conditions to be treated at low-level clinics, which are generally more accessible to the average Zambian than Lusaka hospitals, and allows higher-level centres to focus on serious conditions that are beyond the capacity of primary care.

The structure of the referral system assumes strong communication and collaboration between lower and higher-level treatment centres that often does not exist in most developing nations. In practice, the necessary emphasis is not placed on primary care and patients often bypass primary care facilities, are referred to higher-level clinics for conditions that could be treated at lower-level clinics, or are not referred back to primary care facilities after receiving treatment at higher-level clinics. The end result is overcrowded high-level clinics that are caring for patients who could be treated at lower-level clinics (Atkinson et al., 1999).

Such is the case with epilepsy. In Zambia, epilepsy has not been adequately incorporated into primary care. Although epilepsy is a neurological disorder, not a mental illness, it is categorized and treated under mental health institutions and most PWE are referred to the neurology or psychiatry departments at the University Teaching Hospital (UTH), the main government-run general hospital in Lusaka, or to Chainama Hills Hospital, the only mental health institution in Zambia.

Because of its association with mental health and its treatment by mental health professionals, the issues facing incorporation of mental health at the primary care level are also applicable to the issues facing epilepsy at the primary care level. Primary health care centres are both disorganised and understaffed in terms of mental health treatment despite the capacity for mental health treatment at the primary care level. This centralisation of epilepsy care at Chainama and UTH is further exacerbated by the hospitals themselves, as there are few referrals back to primary care centres, and patients are often encouraged to continue seeking treatment at the high-level hospitals (Mwape, 2010).

Besides overcrowding high-level hospitals and disadvantaging patients in rural areas with limited access to Lusaka, the centralisation of care at Chainama and the association of epilepsy with mental health have perpetuated the common misconception that epilepsy is a mental illness. This perception has many consequences as stigma surrounding mental health treatment is also then attributed to epilepsy. Similar to stigma surrounding epilepsy, stigma surrounding mental illness largely stems from a lack of knowledge and understanding about the causes and nature of mental illness. Because of an association of mental illness with alcoholism and drug abuse, many people believe that mental illness is self-inflicted. There is also a common perception that the mentally ill are incapable of

caring for themselves or making decisions and that they are not entitled to the same rights afforded to the general population. Even Chainama itself is enshrouded in stigma, with a common local derogatory term for a mentally ill person being a “Chainama case”.

Association of epilepsy with mental health introduces a broader dynamic of stigma, as the condition takes on misconceptions of seizures as well as misconceptions about mental illness. Recent efforts to distance epilepsy from mental health have been made, but treatment is still largely handled in the psychiatry department at UTH and at Chainama.

### **Legal Action: Dissecting Mental Health Policy in Zambia**

Discrimination and injustice cannot be adequately addressed simply by investing in large-scale awareness campaigns; it must also be systematically approached by comprehensive policy implementation. Because of the strong association between mental health care and epilepsy, epilepsy is most often grouped into the general body of laws concerning mental health and therefore subject to the critical failings and lack of attention attributed to such legislation.

Government intervention and legal advocacy are two major drivers of change in Zambia, and while there are still enormous policy gaps to be filled, disability and mental health law have steadily evolved since its independence. While 79.5% of African nations have some form of mental health laws, 70% had not been changed in 15 years or more. Although Zambia has made much recent headway powered by a variety of advocacy organisations, both specifically for epilepsy and mental health as a whole, there are still many measures yet to be taken to ensure the rights of PWE in Zambia (WHO, 2010).

Zambia's original mental health statute, the *Mental Disorders Act of 1951*, set out many basic principles of disability rights to care and treatment, yet failed to secure respect and the protection of human rights for persons with mental disability (Birbeck, 2008). While seemingly impressive in its clairvoyance at a very early point under the colonial government and later in the country's history, the initial legislation treated mental health patients as incapable of making their own decisions and the text is aimed more at protecting the population at large from persons of mental disability than at treating and aiding those persons themselves.

The opening language of the law defines a person with mental disabilities as someone "incapable of managing himself or his affairs, a danger to himself or others... and requires supervision, treatment or control" ("Mental Disorders," 2012). This definition, placed at the very outset of the legislation, depicts those with mental health as societal liabilities who need to be locked away in secluded treatment facilities, allotted few personal liberties, and who should be feared by society. This legislation, which was only recently repealed, reflects the harsh views of both policymakers and laypeople of those with mental health issues and reiterates the strong stigmatisation surrounding PWE and mental illness at large. Furthermore, the focus of the legislation on protecting citizens from mental health users, as opposed to a focus on protecting the users themselves, means that the policy did not attempt to rectify any of the structural or social issues that were keeping mental health users from accessing adequate care.

It has long been noted that the current mental health system does not promote wide access to mental health care services through primary care. This issue was finally addressed by policy in 2005, when significant progress was made with a new Mental

Health Policy issued by the Ministry of Health. This policy focused primarily on the need to integrate primary healthcare workers into the mental health system and decentralise its structure away from the current referral system (Mwape, 2010). It also signalled the addition of mental health to the National Health Services Strategic Plan, a dramatic increase in attention to the Ministry's agenda and a significant victory for mental health advocates. The Policy was initially hailed as a great stride forward in the mental health initiative, but the failure of parliament to repeal the initial Mental Disorders Act and very limited resources devoted by the government ultimately curtailed the Policy's impact.

After 50 years of detrimental impact on Zambian society and over a decade of debate and revisions, a new mental health bill was finally passed in 2012 that repealed the original Mental Disorders Act. The Zambian parliament passed a new disability law that makes major gains in providing for a human rights perspective, as opposed to purely a medical perspective, in helping to protect those with mental disability. However, even basic voting rights for those with epilepsy can come into question. Anecdotal evidence was provided by a Zambian with epilepsy who was admitted to Chainama hospital, for which she had to be accompanied by the police to and from the voting station in order to submit her ballot, a clear source of future stigma and public discomfort (Personal Communication, July 2013).

The continued drafting of a new Zambian constitution in 2013 provides additional opportunities to embed core human rights and international protection principles in the legal foundation of the country. While significant language is included in section 104 (2) of the draft constitution to "recognise the equal right[s] of persons with mental incapacity," the Mental Health Users Network of Zambia (MHUNZA) notes that the use of the word "incapacity" implies a more stigmatised connotation, and the use of the word "disability"

instead goes a long way to framing the political mind of the country in a protectionist viewpoint (“Mental Health,” 2010). If the rights of the mentally disabled are to be preserved, the technical committee writing the draft should be in a mind-set very different from those of the colonial government, with mental disability, and not incapacity, in their thoughts as they continue the formation of this essential legislative foundation.

The legal framework within which the mental healthcare system and mentally disabled operate shackles those with epilepsy to the civic and medical limitations of the past colonial system. While those same limitations have been in effect for over 50 years, the rise of mental health advocacy organisations and globalised human rights policies have helped form new legislation which greatly benefits the disabled. These pieces of legislation must make it through government ratification and the old laws must be repealed, however, in order for mental healthcare reform to be truly effective.

## **Addressing Epilepsy Stigma in Zambia: Key Players**

Zambia is in a unique position to combat stigma, as it has a variety of institutions in place that could be mobilised to prevent discrimination of PWE and mental health users. In 2004, the WHO published a report about epilepsy in the African region as a part of the Global Campaign against Epilepsy which aims to address inadequate access to treatment and stigma reduction for PWE. The report summarises the situation of stigmatisation and discrimination in Zambia while outlining interventions from specific organisations that are needed to reach their goal. The WHO report identifies the need for coordination between a country’s Ministry of Health, a dedicated epilepsy organisation, a national focal person and WHO offices (“Epilepsy,” 2004). This paper focuses on the activities of three of these



organisations in Zambia: the Ministry of Health (MOH), the Epilepsy Association of Zambia (EAZ), and the Mental Health Users Network of Zambia (MHUNZA).

### *Ministry of Health*

The MOH, as the Zambian government branch directly associated with maintaining and improving the structure of healthcare nationwide, is a crucial element in decreasing public stigma and increasing access to epilepsy treatment. The 2004 WHO guidelines view the role of the MOH as advocating for epilepsy at the country level, integrating epilepsy into primary care, collaborating with other ministries to reduce stigma, and allocating resources to epilepsy groups (“Epilepsy,” 2004).

In Zambia, the MOH does each of these tasks through the Mental Health Unit branch, whose mission is to improve access and human rights treatment for mental health users. This unit has identified a national focal person for epilepsy, the president of the Epilepsy Association, to coordinate between the MOH and epilepsy organisations. The decision was made to coordinate epilepsy and mental health efforts separately, with the intention of disassociating neurologically-based disorders from mental illnesses. Although this is a step in the right direction, the fact that epilepsy and mental health are both under the Mental Health Unit does not make this disassociation clear.

The MOH acknowledges the problems of centralised care at specialty centres like Chainama, which promote stigma and create long queues to see a doctor. There is a recognised need for decentralisation of mental health care, but the MOH does not currently have the resources to tackle the issue. Instead, the MOH works directly with the institutions where the few (three at last count) epilepsy specialists are located to develop

comprehensive treatment standard guidelines that can be used to train future medical professionals. There is also potential for collaboration with other Ministries, such as the Ministry of Education (MOE) and the Ministry of Community Development, Mother, and Child Health (MCDMCH). It has been recognised that collaboration between MOH and MOE to introduce an epilepsy unit into primary education would be valuable to stigma reduction, though no known effort has yet been made to this effect (Personal Communication, July 2013).

Despite the commitment of a Mental Health Unit, only 0.38% of healthcare funding is directed to improving mental health. This limited funding greatly constrains the impact that the Mental Health Unit is able to have, though there is hope for future increased funding. Mental Health Unit officials report that the field is seeing an increasing interest in investment, especially in light of recent legislation (Mwape, 2011).

### *Epilepsy Association of Zambia*

The Epilepsy Association of Zambia (EAZ) is Zambia's national organisation for epilepsy. EAZ is the official partner of the MOH in the desensitisation and treatment of epilepsy across the nation. Anthony Zimba, an epilepsy specialist and the focal person for epilepsy in the MOH, founded the organisation after recognizing the need for greater improvements in the way PWE were treated by the public and doctors back in 2001. He and his colleagues recognised that stigma surrounding treatment at Chainama was continuing to build and subsequently created a programme that included community education initiatives, a national epilepsy awareness day, and community-based rehabilitation programmes in rural districts, among other initiatives. As the Mental Health

Unit at the MOH began to recognise the impact of the stigma on the lives of PWE and the lack of adequate resources allocated to epilepsy, the MOH decided to take on EAZ as its chief epilepsy affiliate and shifted all tasks to the leadership of the Association. The Mental Health Unit also transfers a significant portion of its budget to EAZ programmes and missions.

Using these additional resources, the EAZ implements public desensitisation initiatives, clinical officer training programmes, and the rehabilitation infrastructure throughout Zambia. The Association also hosts a radio programme that seeks to dispel myths and fallacies commonly associated with epilepsy and organises two original public awareness holidays: National Epilepsy Day and Seizure-Free Day. On these days, PWE who have been treated share anecdotes of empowerment. Additionally, EAZ organises Purple Day, also known as international epilepsy day. Initiatives throughout the rural provinces of Zambia are also organised, with EAZ staff providing informational presentations for both clinical officers practicing in rural clinics and laypersons alike. Finally, the EAZ has been granted land in the Chainama Hills premises on which to run an epilepsy rehabilitation centre. This is an environment in which those with poorly controlled epilepsy can live and work, with the support of staff. However, although EAZ initiatives are designed to have widespread impact, their reach is often limited by lack of funding (Personal Communication, July 2013).

### *Mental Health Users Network of Zambia*

Founded by members of the Zambian community with a passion for and expertise in government policy advocacy and mental health, the Mental Health Users Network of Zambia (MHUNZA) consists of a small but active organisation working to promote

improvements in mental healthcare. Healthcare workers and laypeople alike began to realise the detriments that the Mental Disorders Act of 1951 was continuing to have on the public perception of the mentally disabled. As a result, the organisation was formed with the vision of creating a mental health system that meets the needs of the mentally disabled and protects their basic human rights.

The Network's primary goals are policy and legislation change, and its mission is to "provoke the government to repeal archaic law," which harms rather than helps the disabled (Personal Communication, July 2013). According to a member of the organisation, a major division in the way in which mental health is approached at a policy level in Zambia is the "medical/human rights divide (Personal Communication, July 2013)". Many members of the MOH and their medically trained advisors approach policy decisions from purely a treatment perspective, with a focus on providing funding to train mental health professionals and access to healthcare. Even these policies are severely constrained due to lack of funding and national attention and, as a result, little policy attention is paid to the effects of public stigma and human rights violations for the mentally disabled.

One of their primary criticisms of the original Mental Health Act and current policy aims is their lack of accordance with international human rights provisions, including the United Nations Convention of Persons with Disabilities. Under such conventions, the rights of the disabled should include "individual autonomy including the right to make one's own choices" and "full and effective participation and inclusion in society" (UN General Assembly, 2007). MHUNZA increasingly interfaces with the MOH on bilateral projects, including lobbying for legal reform and being asked to draft mental disability policy drafts.

## Potential for Change

Substantial stigma reduction can only occur through a multifaceted approach that involves social, health care, and policy reforms. With the proper coordination and resources, each of these organisations has the potential to better the lives of PWE in Zambia. One of the most necessary interventions to decrease stigma and increase access to treatment is the decentralisation of the mental healthcare system. This would involve the incorporation of mental health into the primary care package. In order to adequately implement such a large-scale programme, there would need to be collaboration and agreement between policy makers, advocacy groups, mental health specialists, and medical teaching institutions. Although the MOH is committed to integrating mental health into primary care, very little has been done to address this issue. Policy makers in the ministry of health must create a comprehensive and methodical approach to integration and implementation. Advocacy groups like MHUNZA must take charge of lobbying for the integration of primary care and must create awareness of the issue within the general public. Finally, medical organisations like EAZ must be given the appropriate resources to collaborate with teaching institutions to train primary care workers in mental health (Mwape, 2011).

Admittedly, this analysis is extremely oversimplified and there are many challenges that must be overcome if mental health is going to be incorporated into primary care. These challenges include but are not limited to education, political will, coordination between many different organisations, and widespread reach in rural areas. Perhaps the most limiting challenge is funding. In order to enact such a large healthcare reform, more than 1% of the MOH budget has to be appropriated to mental health. Surprisingly, the

estimated cost of epilepsy integration into primary care is not high. One study conducted in Zambia sought to determine the cost of delivering epilepsy care at the primary level. The model took into account the number of PWE seeking treatment, labour costs at all levels of health care, diagnostic tests at all levels of health care, training of primary care staff (assuming 10% of primary health care workers were trained in epilepsy), awareness campaigns, medication purchasing, and medication distribution. The cost of implementation came out to US\$25 per PWE per year, a cost that is much less than treatment alone of many other chronic conditions (Birbeck, 2012).

## **Conclusions**

While recent action and attention has modestly improved the acceptance and treatment of epilepsy in Zambia, overall stagnation of the mental healthcare system is a microcosm of the failure of many sub-Saharan African nations to adequately address neurologic diseases and disorders. With prevalence rates relatively high and medicated treatment levels continuing to remain low, epilepsy as a medical condition shows no signs of being effectively suppressed in the near future (Birbeck, 2004).

The public stigma surrounding those with epilepsy due to its association with mental illness continues to result from the dysfunctional referral system and lack of appropriate funding to both the EAZ and the Mental Health Unit at the MOH. Increased funding to these institutions would enable the training of primary healthcare workers who can treat epilepsy at both rural and urban clinics, drastically lowering the need for referral to Chainama and the resulting associated stigma. Decentralisation of the mental healthcare

system to primary healthcare providers has been widely suggested to be the most effective strategy to increase treatment coverage and decrease epilepsy related stigma.

Although there are many actions that must be taken in order to reduce stigmatisation and discrimination against PWE, there is certainly hope for future efforts. Zambia has many institutions in place that, if well-coordinated and funded, could come together and create more comprehensive and widespread treatment options and educational programmes. The passage of the progressive Persons with Disabilities Bill indicates that there is political will and effective institutions in place that have a vested interest in improving the lives of people with disabilities. Mobilisation of these same organisations and collaboration between social, healthcare, and policy groups is crucial to reducing stigmatisation and discrimination against PWE in Zambia.

## **Acknowledgments**

We would like to thank Marja Hinfelaar, Manenga Ndulo, and the entire research staff at the Southern African Institute for Policy and Research and the Zambian Governance Foundation for their support conducting our research in Lusaka. We would like to thank Anthony Zimba and the Epilepsy Association of Zambia for their enormously helpful insight and information on the state of epilepsy care in Lusaka and the surrounding rural areas. We would like to thank Sylvester Katontoka and MHUNZA for their insight into the Zambian legislative system and how its policies are implemented in mental healthcare. Finally, we would like to thank Gretchen Birbeck for her substantial efforts in the field of neurological disorders in Zambia and the many medical, social, and economic determinants that affect them.



## References

- Atkinson, S. et al. 1999. "The Referral Process and Urban Health Care in sub-Saharan Africa: The Case of Lusaka, Zambia". *Social Science & Medicine*: 27-38.
- Baskind, Roy and Birbeck, Gretchen. 2005. "Epilepsy Care in Zambia: A Study of Traditional Healers". *Epilepsia* 46(7): 1121-26.
- Birbeck, Gretchen et al. 2006. "Zambian Teachers: What do they know about epilepsy and how can we work with them to decrease stigma?" *Epilepsy and Behavior*.
- Birbeck, Gretchen et al. 2007. "The Social and Economic Impact of Epilepsy in Zambia: A Cross-Sectional Study". *Lancet*, 6: 39-43
- Birbeck, Gretchen et al. 2008. "Women's Experiences Living with Epilepsy". *The American Society of Tropical Medicine and Hygiene*: 168-172.
- Birbeck, Gretchen. 2012. "The Cost of Implementing a Nationwide Programme to Decrease the Epilepsy Treatment Gap in a High Gap Country". *Neurology International* 4: e14.
- Birbeck, Gretchen L., and Kalichi, Ellie M. N. 2004. "Epilepsy Prevalence in Rural Zambia: A Door- to-door Survey". *Tropical Medicine and International Health* 9, no. 1: 92-95.
- "Epilepsy in the WHO Africa region: Bridging the Gap." 2004. *World Health Organisation*.
- Kapungwe et al. 2010. "Mental Illness: Stigma and Discrimination in Zambia". *African Journal of Psychiatry* 13: 192-203.
- Mbewe, Edward et al. 2007. "Epilepsy-Related Knowledge, Attitudes and Practices among Zambian Police Officers. *Epilepsy & Behavior*.
- Mental Disorders Act, Zambia § Part I (2012). *Zambia Legal Information Institute*.  
<http://www.zambialii.org/zm/legislation/consolidated-act/305>.

Mental Health Users Network of Zambia. 2012. "Position Paper on the Provisions of the Draft Constitution".

Mwape, L. et al. 2010. "Integrating Mental Health into Primary Health Care in Zambia: A Care Provider's Perspective". *International Journal of Mental Health Systems* 4, no. 1: 21.

Mwape L., and Mweemba, P. 2010. *Strengthening the Health System for Mental Health in Zambia (policy brief)*. Lusaka, Zambia: The Zambia Forum for Health Research.

Mwape, L. 2011. "Strengthening the Health System for Mental Health in Zambia". 25 August 2011. <http://www.who.int/evidence/sure/MentalhealthZambia.pdf>.

World Health Organisation. 2010. "Policy Brief 11: Developing and Adopting Mental Health Laws in Africa".

UN General Assembly. 2007. *Convention on the Rights of Persons with Disabilities: Resolution Adopted by the General Assembly, 24 January 2007, A/RES/61/106*.