

# MENTAL, NEUROLOGICAL, AND SUBSTANCE USE DISORDERS IN SUB-SAHARAN AFRICA

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Reducing the Treatment Gap, Improving Quality of Care

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## SUMMARY OF A JOINT WORKSHOP

BY THE INSTITUTE OF MEDICINE AND  
THE UGANDA NATIONAL ACADEMY OF SCIENCES

Bruce M. Altevogt, Sarah L. Hanson, Zaam Namuli Ssali, and  
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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

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Willing is not enough; we must do.”*  
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# Reviewers

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this report:

**Albert Akpalu**, University of Ghana—Medical School

**Marcelo Cruz**, Global Network for Research on Mental and  
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**Oye Gureje**, University of Ibadan, Nigeria

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Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the report before its release. The review of this report was overseen by **Richard T. Johnson**, Johns Hopkins University School of Medicine. Appointed by the Institute of Medicine, he was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.



# Preface

According to the World Health Organization, disorders of the nervous system—mental, neurological, and substance use disorders—produce substantial disease burden in the developing world. The longstanding focus on infectious disease has obscured their high prevalence and toll on societies, but these disorders, in aggregate, are significant causes of disability in adults and impede human capital formation by their effects on children. Caring for these patients poses a formidable challenge for individuals, families, governments, and societies around the world. Given the existence of cost-effective treatments for many of these disorders, improving both access to care and quality of care could go far to alleviate disease burden. However, resource constraints, disorder stigmatization, shortages of trained personnel, and a lack of understanding of the causes of the disorders limit the amount and quality of care that many individuals receive.

Despite the high prevalence and disease burden of these disorders, most countries in sub-Saharan Africa have less than one psychiatrist per million people. The situation is also grim for psychiatric nurses, psychologists, and trained social workers. The total number of neurologists in the region may be even smaller. The formularies are extremely limited, often containing only older medications with a high side-effect burden; even for these drugs, supply chains often break down, making patient adherence to often complicated medication regimens nearly impossible. These and other deficits in treatment systems result not only in needless suffering, but also in chronic disability for patients and limitations on the ability of caregivers to function outside the home.

At a national level, these consequences seriously interfere with economic development.

Despite research showing the disability and premature mortality resulting from disorders of the nervous system, systematic epidemiological data are lacking in most countries of sub-Saharan Africa. Most experts agree that the scope of unrecognized illness is far greater than the documented cases, and data on children and elderly are particularly sparse. Researchers face further challenges because often patients are hidden from the community out of fear, which makes obtaining accurate data difficult. Without more complete information about the scope of the problem, the countries' leaders are not addressing the needs of persons with these disorders. The needs include improved access to training for healthcare providers and access to better equipment, more personnel, appropriate medicines, and other needed resources. Improved quality of care for individuals suffering from mental, neurological, and substance use disorders must be a high priority for governments and societies so appropriate investments are made to provide proper care and treatment for these individuals.

Addressing the need to advance these important discussions, the U.S. Institute of Medicine's Forum on Neuroscience and Nervous System Disorders, in collaboration with the Forum on Health and Nutrition of the Uganda National Academy of Sciences, convened an international workshop on quality of care issues for nervous system disorders in sub-Saharan Africa on August 4 and 5, 2009, in Kampala, Uganda. Recognizing both the importance of providing high-quality care for disorders of the nervous system and the resource limitations of most sub-Saharan African countries in diagnosing and treating these disorders, the workshop participants explored strategies to improve care for the countless individuals suffering from nervous system disorders. Other aims of the workshop were to discuss opportunities that can be used to improve continuity of care and sustainability within a country's healthcare system, and to identify resources that are currently available or could be made available to aid in implementation of treatments and prevention projects.

Many key stakeholders attended, including more than 30 speakers, 120 audience members, and representatives from 16 countries. Stakeholders included government policy makers from African countries and the World Health Organization, clinicians, researchers, individuals representing non-governmental organizations, and patient advocates.

The workshop represented a true collaboration between the U.S. Institute of Medicine of the National Academies and the Uganda

National Academy of Sciences. Staff from each organization worked closely with an extremely dedicated planning committee that brought together an international cohort with expertise in neuroscience, ethics, pediatrics, drug abuse, international public health, mental health, and neurological disorders. Important and energetic discussions followed well into the evening reception hour, which reinforced a goal of the meeting—to facilitate networking and open discussion between various stakeholders.

Some of the major areas of emphasis and recurring themes that were discussed and presented at the workshop include

- exploring the need to consider all disorders of the nervous system, including addictive disorders;
- sharing the benefit of leveraging skills, expertise, and networks of other health fields (e.g., HIV/AIDS, malaria);
- maintaining a focus on treatment *and* prevention;
- improving the available medication formulary for nervous system disorders;
- supporting demonstration projects examining
  - mechanisms to improve availability of medications and care in rural settings and the
  - role of information technology in improving awareness, training, and treatment, especially in rural settings;
- expanding the use of high-quality, community-based care, and the training of community health workers;
- collecting further data on effectiveness; and
- supporting the need for champions who will relay these, and future, needs and concerns to resource providers.

The areas of emphasis suggest the need for more action and investment by all stakeholders, national and international. Real progress in the region will depend on forging partnerships that draw on a broad range of resources and skill sets. Most important is a commitment from stakeholders to make changes and improvements to the current system. The workshop demonstrated that there is great enthusiasm and desire to improve what is currently in place, but partners are needed. This workshop presented a timely and unique opportunity to capitalize on the rich ideas, networks, and momentum that came from participants. Clearly there is a need to improve care for individuals with mental, neurological, and substance use disorders in sub-Saharan Africa, and we hope that this

workshop and summary will help lay the foundation for continued progress.

Steven E. Hyman, *Co-chair*  
Edward K. Kirumira, *Co-chair*

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# Introduction<sup>1</sup>

Disorders of the nervous system are common to all countries and cause tremendous suffering. The stigma and violations of human rights directed toward people with these disorders often increases their social isolation and can be the cause of staggering social and economic consequences. In sub-Saharan Africa—where the majority of the world’s poorest countries with the least resources are found—the burden of mental health, neurological, and substance use (MNS) disorders is especially significant. Epilepsy, depression, and drug and alcohol abuse affect the lives of millions of Africans, disrupting the daily course of life, challenging families, and weighing on the social and economic fabric of the region (Prince et al., 2007). Current data from the more than 47 countries that constitute sub-Saharan Africa make it clear that, at a minimum, many of these problems are much more common in this region than in other parts of the world (Forsgren, 2008; *The global burden of disease: A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020*, 1996; Ngoungou et al., 2006; Okasha, 2002).

According to the World Health Organization, awareness about the importance of mental disorders for public health has greatly increased

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<sup>1</sup> The planning committee’s role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop.

and has put mental health on the policy agenda (WHO, 2008b). Many countries have developed or revised their policies, programs, and legislation related to these disorders. Despite this, as will be discussed in further detail, the treatment gap is tremendous and the resources provided to tackle the huge combined burden of MNS disorders, not just mental health, are insufficient. The “rich” countries such as the United States and England have roughly 200 times more psychiatrists than most countries in Africa. This ratio is even worse when looking at the enrollment of the medical professionals such as psychiatric nurses and clinical psychologists. To add to these challenges, within each country mental health professionals are concentrated in urban areas, where a minority of the population lives. In addition, health professionals are increasingly working in the private sector, resulting in decreased access for a significant proportion of the populations.

Many neurological disorders remain undiagnosed because of the limited diagnostic facilities at health centers, which is even worse in the rural places where the majority of the patients reside. Often much-needed drugs are in short supply or are too expensive to purchase. In the end, the patients and their families prefer to stay at home or revert to readily available and accessible remedies within their communities. For many in sub-Saharan Africa, this means relying on traditional healers for health care. These providers are more accessible than mental, neurological, or substance use disorder specialists, and they frequently provide continuity of care and social support for patients. An estimated 60–80 percent of individuals with mental disorders in developing countries first seek care through traditional healers (Abbo et al., 2008). Despite the widespread use of traditional healers in sub-Saharan Africa, there is no standard of care and there is little evidence from which to assess its effectiveness. As a result, there is an ongoing debate about whether traditional healers should be recognized as part of the healthcare delivery system, and, if so, how they could be more formally integrated into the healthcare delivery system.

Other solutions to the human resource shortfalls are also being addressed. One suggestion is to use “task shifting,” which transfers a range of medical tasks, where appropriate, from more expensive and specialized medical workers to people with shorter training and therefore a much lower cost in the health system. Many workshop participants believe this approach makes more efficient use of the human resources that are available in the health system and is one way of closing the mental health treatment gap. However, without the political will of governments and the support of international donor communities, adequate resources

for much-needed drugs, delivery systems, facilities, and professionals are unlikely to be realized any time soon. Within this context, a workshop was held in Uganda to discuss model solutions, promote collaborations, and consider what can be done to improve quality of care for patients in cost-effective ways.

## ABOUT THE WORKSHOP AND FORUMS

In August 2009 the Uganda National Academy of Sciences Forum on Health and Nutrition and the U.S. Institute of Medicine's Forum on Neuroscience and Neurological Disorders (Box I-1) jointly hosted a workshop in Kampala, Uganda, titled *Quality of Care Issues for Mental Health and Neurological Disorders in Sub-Saharan Africa*. More than 150 researchers, providers, patient advocates, and policy specialists came together to discuss the current state of care for mental, neurological, and substance use disorders in sub-Saharan Africa. The goal was to uncover strategies to improve the quality and consistency of care delivered in sub-Saharan Africa, taking into account resource constraints, infrastructure limitations, and other realities. Workshop speakers were charged to do the following:

- Discuss opportunities to ensure continuity of care and provide sustainable care within a country's existing healthcare system.
- Identify resources that are either currently available, or that could be made available in cost-effective and efficient ways, to aid in the treatment and prevention of disease.
- Examine the need for national, evidence-based policies within national healthcare systems that address quality-of-care issues for mental, neurological, and substance use disorders.
- Explore opportunities to facilitate collaborations among a variety of stakeholders, including policy makers and healthcare professionals.

**BOX I-1****UNAS Forum on Health and Nutrition**

The Uganda National Academy of Sciences (UNAS) Forum on Health and Nutrition was established in 2006 to provide a structured opportunity for stakeholder discussion and scrutiny of critical and possibly contentious scientific and policy issues of shared concern related to issues of health and nutrition in Uganda and throughout the world.<sup>a</sup> The Forum aims to do the following:

- Promote a free flow of information between public- and private-sector leaders and groups and individuals, including policy makers and others who influence public policy and opinion.
- Clarify research and policy issues, identify options for research, and encourage further exploration in the identified areas.
- Inform decision and policy makers, both in the public and private sectors, on issues related to health and nutrition both in Uganda and worldwide.
- Enable and develop initiatives that require in-depth exploration, review, or analysis, where new strategies are necessary to improve health and nutrition.

**IOM Forum on Neuroscience and Nervous System Disorders**

Established in 2006, the Institute of Medicine's (IOM's) Neuroscience Forum aims to foster dialogue among a broad range of stakeholders—practitioners, policy makers, private industry, community members, academics, and others—and to provide these stakeholders with opportunities to tackle issues of mutual interest and concern. The Forum's neutral venue provides a place for broad-ranging discussions that can help in the coordination and cooperation of all stakeholders to enhance understanding of neuroscience and nervous system disorders. The Forum concentrates on six areas: nervous system disorders, mental illness and addiction, genetics of nervous system disorders, cognition and behavior, modeling and imaging, and ethical and social issues.<sup>b</sup> Specifically, the Neuroscience Forum

- sponsors workshops for members and the public to discuss strategies to resolve key challenges identified by Forum members;
- educates the public, press, and policy makers;
- strives to enhance understanding of research and clinical issues associated with the nervous system; and
- fosters partnerships and information sharing among stakeholders.

<sup>a</sup> See [http://ugandanationalacademy.org/forum\\_hlthandnut.htm](http://ugandanationalacademy.org/forum_hlthandnut.htm).

<sup>b</sup> See <http://www.iom.edu/NeuroForum>.

# 1

## Background

### ESTABLISHING A COMMON TERMINOLOGY

Although all disorders of the nervous system are related due to their common origin, the absence of a common terminology can negatively impact the establishment of common policies. Throughout the workshop, participants used many different terms to describe the many mental health, neurological, and substance use (MNS) disorders that impact the populations of sub-Saharan Africa (SSA). However, Marcelo Cruz, president of the Global Network for Research on Mental and Neurological Health, Ecuador, suggested that in order to include a wide range of disorders that are often otherwise separated into treatment silos in developed countries, such as neurology, psychiatry, psychology, substance use etc.; the World Health Organization's (WHO's) term "MNS disorders"—covering mental health, neurological, and substance use disorders—should be adopted. Workshop participants agreed, and thus it was adopted for use during the workshop and in this summary.

MNS disorders encompass a wide range of conditions of the brain from depression to epilepsy to alcohol abuse. These and the many other MNS disorders found throughout the world are often linked in a complex way with other health conditions (WHO, 2008a). They may be comorbid or risk factors for noncommunicable and communicable diseases like HIV/AIDS, malaria, and tuberculosis. MNS also factors into sexual and reproductive health in, for example, postpartum depression or injuries from violence or traffic accidents. Furthermore, depression and substance use disorders adversely affect adherence to treatment for other diseases, often exacerbated by poverty and the presence of endemic infectious diseases.

The scientific underpinnings of MNS are now better understood. Most have their origins in abnormal brain structure or function. Therefore, given the related nature of MNS, better integration of these specialties is needed, especially neurology and psychiatry (Fenton et al., 2004;

Hyman, 2007; Insel and Quirion, 2005). In developed countries these conditions are typically treated by highly trained specialists; however, developing countries do not have enough MNS specialists, and other resources, to diagnose and treat all comorbidities. This often can result in a failure to account for diagnostic complexity where it exists (Njenga, 2004). Therefore, casting a wide net over the spectrum of disease is especially important given the resource-constrained nature of SSA and the often comorbid nature of MNS disorders in the region.

This sentiment was echoed repeatedly by workshop participants, who noted that SSA countries have an opportunity to avoid the consequences that have resulted from separating disorders into various separate “mental health” or “neurology” silos, as other countries have done, and instead recognize the related nature of MNS disorders and thus leverage limited resources across the wide (and integrated) range of MNS disorders, in order to help patients who need care. Specialists are not needed specifically for neurology or psychiatry; individuals are needed who care for disorders of higher brain function (Hyman, 2007). Advancing the use of the term “MNS disorders” will allow policy makers, healthcare providers, and advocacy groups to focus on the widest range of diseases and medical conditions, explained Sheila Ndyabangi from the Ministry of Health in Uganda.

## THE MNS DISEASE BURDEN

“Disease burden” is a term used to convey how prevalent various diseases are. Donald Silberberg, professor at the Department of Neurology at the University of Pennsylvania School of Medicine, put it plainly, “The burden of disease can be viewed as the gap between current health status and an ideal situation in which everyone lives into old age free of disease and disability. Causes of the gap are premature mortality, disability, and exposure to certain risk factors that contribute to illness.”

One common source of disease-burden guidance comes from the regular World Health Reports by the WHO, which uses the disability-adjusted life years (DALYs) method to assess the impact of certain diseases. DALYs is the sum of potential years of life lost due to premature mortality, plus the years of productive life lost due to disability. An acknowledged shortcoming of the DALYs metric is that it does not include the social or economic impacts on individuals, families, communities, or health systems—or the true burden these diseases have on the lives of those who suffer from them and those who care for them. Recognizing

these limitations, on a DALYs and years-living-with-disability basis, Africa at first glance seems to have a lower disease burden due to neuropsychiatric disorders than the rest of the world (Table 1-1).

Acquiring accurate prevalence data of MNS disorders can be difficult. But as Steven Hyman, provost of Harvard University, explained, the extraordinary burden of infectious disease and other conditions such as malaria and tuberculosis have understandably, but at the same time tragically, interfered with the recognition of burden of MNS disorders. The sheer numbers of deaths and disabilities caused by HIV/AIDS, malaria, other infectious disease, and diseases of poverty overwhelm the disease burden that can be attributed solely to MNS disorders (WHO, 2001). Because of the high need for treatment of infectious diseases, healthcare resources are focused on diagnosing and treating those diseases, and MNS disorders are often overlooked, ignored, or misdiagnosed. The result is a systemic underreporting of the true disease burden created by these disorders.

Vikram Patel from the University of London highlighted data from the WHO's 2006 Global Burden of Disease report, which shows that nearly 10 percent of the total disease burden in the world's lowest income countries is attributable to neurological and psychiatric disorders (*Global burden of disease and risk factors*, 2006) (Figure 1-1).

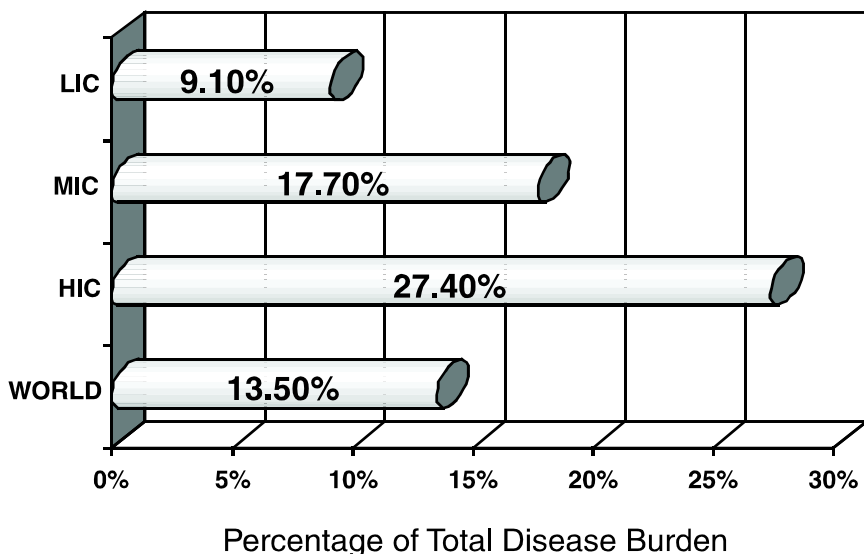
The burden of MNS is both significant and significantly underreported. It is also on the rise. The WHO estimates that depression will become the leading cause of years lost due to disability by 2030. This is not surprising knowing the comorbidity of depression with cerebrovascular disease, which is also expected to move up from sixth to fourth by

**TABLE 1-1** Disease Burden Due to Psychiatric Disorders by Region

Region	DALYs (%)	YLDs (%)
World	12	31
Africa	4	18
Americas	24	43
Europe	20	43

NOTE: DALYs = disability-adjusted life years; YLDs = years lived with disability.

SOURCE: Adapted from WHO, 2001.



**FIGURE 1-1** Disease burden of neuropsychiatric disorders.

NOTE: HIC = high-income countries; LIC = low-income countries; MIC = middle-income countries.

SOURCE: *Global burden of disease and risk factors*, 2006.

2030. Ischemic heart disease and traffic accidents (ranked second and third, respectively) also are intricately linked with MNS disorders (Figure 1-2), making the true burden of MNS disorders both overwhelming and extremely difficult to calculate.

### **MNS Disorders in Sub-Saharan Africa**

While many MNS disorders are common throughout the world, their relative impact on each region varies. Silberberg noted that with respect to MNS disorders, “The leading problems that are more common in sub-Saharan Africa are birth defects affecting the brain and spinal cord; mental retardation; cerebral palsy; bacterial, viral, and parasitic infections of the nervous system; epilepsy; and head and spinal cord trauma, mostly from road traffic accidents.” Although the number of comprehensive epidemiology studies is limited, it is widely accepted in the provider

2004 Disease or injury	As % of total DALYs	Rank	Rank	As % of total DALYs	2030 Disease or injury
Lower respiratory infections	6.2	1	1	6.2	Unipolar depressive disorders
Diarrhoeal diseases	4.8	2	2	5.5	Ischaemic heart disease
Unipolar depressive disorders	4.3	3	3	4.9	Road traffic accidents
Ischaemic heart disease	4.1	4	4	4.3	Cerebrovascular disease
HIV/AIDS	3.8	5	5	3.8	COPD
Cerebrovascular disease	3.1	6	6	3.2	Lower respiratory infections
Prematurity and low birth weight	2.9	7	7	2.9	Hearing loss, adult onset
Birth asphyxia and birth trauma	2.7	8	8	2.7	Refractive errors
Road traffic accidents	2.7	9	9	2.5	HIV/AIDS
Neonatal infections and other	2.7	10	10	2.3	Diabetes mellitus
COPD	2.0	13	11	1.9	Neonatal infections and other
Refractive errors	1.8	14	12	1.9	Prematurity and low birth weight
Hearing loss, adult onset	1.8	15	15	1.9	Birth asphyxia and birth trauma
Diabetes mellitus	1.3	19	18	1.6	Diarrhoeal diseases

**FIGURE 1-2** Predicted changes from 2004 to 2030 to the leading causes of burden of disease worldwide.

NOTE: COPD = chronic obstructive pulmonary disease; HIV/AIDS = human immunodeficiency virus/acquired immune deficiency syndrome.

SOURCE: WHO, 2008b.

community that cognitive disorders, dementia, epilepsy, and stroke are common “secondary diseases” attached to conditions that are widespread in the region, including tuberculosis, HIV/AIDS, malaria, and sickle-cell anemia (*The global burden of disease: A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020*, 1996). Widespread in sub-Saharan Africa, HIV/AIDS and malaria have significant mental health implications. Not only are there common mental health disorders that are due to, or associated, with these diseases, such as depression and substance use, but there are also many neurological disorders that can arise as direct complications from opportunistic infections (UNAIDS, 2007).

Many other MNS disorders also occur at higher rates in sub-Saharan Africa, and many disorders have predictably worse outcomes than in the developed world. For example, in Tanzania, individuals who have suffered a stroke have 10 times the mortality rate when matched for age compared with those in the Western world (Matuja et al., 2001; Walker et al., 2000). Despite the difficulties associated with diagnosing cases, the prevalence rate of cerebral palsy is at least 4 times as high in some SSA countries compared to rates in Europe (Silberberg, 2009). Epilepsy due to trauma at birth and head injury in later life is probably one of the most common MNS disorders in Africa. Childhood infections, including measles, are other common causes of epilepsy, a condition that is comor-

bid with mental illness in some cases (Njenga, 2004). Likely surpassing epilepsy in numbers of those affected are diagnosed and undiagnosed cases of depression that may or may not be linked to infectious diseases or substance use. Because these conditions (epilepsy, HIV/AIDS, malaria, and substance use) appear most prevalent in SSA, they have been singled out and addressed in more detail below.

### **The Disease Burden of Mental Health Disorders**

Mental disorders are health conditions that can affect an individual's cognition, emotion, and behavioral control and cause the person distress and difficulty in functioning. Some of the most common disorders include depression, schizophrenia, attention deficit hyperactivity disorder (ADHD), autism, and obsessive-compulsive disorder. Such disorders tend to begin early in life and often run a chronic recurrent course. Although most experts agree that mental disorders represent a substantial portion of the world's disease burden, these disorders remain highly neglected and stigmatized, making prevalence data difficult to obtain and interpret (Horton, 2007). From the limited data available, it appears that depression, schizophrenia, and bipolar disorder are the most prevalent in SSA; however, the leading mental disorders—depression and anxiety—are often grouped together and referred to as “common mental disorders (CMD)” (Silberberg, 2006). The causes of CMD in sub-Saharan Africa might be from alcohol and substance abuse, conflicts and war, HIV/AIDS, gender-based violence, or other childhood maladies resulting in stigmatization from an early age.

Regardless of the cause, mental disorders receive very little attention from most African governments. Health in general is still a poorly funded area of social services in most African countries and, compared to other areas of health, mental health services are poorly developed even though mental disorders account for approximately 350 million DALYs lost per year in SSA—significantly greater than developed countries at 150 million DALYs per annum (WHO, 2006b). Table 1-2 shows the leading cost in DALYs is due to CMD. Also noted in the table are the other major psychiatric disorders in SSA that contribute significantly to the years of productive life lost due to these disabilities as well as the economic benefits of cost-effective treatments.

**TABLE 1-2** Disease Burden and Cost-Effective Treatment of Selected Major Psychiatric Disorders in Sub-Saharan Africa

Disorder	DALYs per Year per 1 Million Population	Cost-Effective Treatment
Depression	4,905	proactive care with newer antidepressant drug (SSRI; generic)
Bipolar disorder	1,803	older mood-stabilizing drug plus psychosocial treatment
Schizophrenia	1,716	older antipsychotic drug plus psychosocial treatment
Panic disorder	777	newer antidepressant drug (SSRI; generic)

SOURCE: WHO, 2006c.

### The Disease Burden of Epilepsy

Throughout the workshop, participants stressed that although substantial prevalence data are not available, epilepsy is one of the most common MNS problems in SSA. The absence of data is the result of a variety of reasons. There is a lack of specialized personnel, particularly in neurology, needed to recognize the symptoms. Furthermore, diagnostic equipment is not available—there are 75 electroencephalographs and 25 computed tomography scanners in tropical Africa, which are frequently out of order—limiting the ability to accurately ascertain a diagnosis (Preux and Druet-Cabanac, 2005). Furthermore, screening questionnaires typically used to identify patients with epilepsy do not translate well across different populations with diverse social or cultural backgrounds, medical records are often incomplete, and terminologies for classifying seizures and epilepsy differ among studies, making comparisons difficult to impossible, which all further complicate diagnosis and epidemiology of epilepsy.

Despite these limitations, epilepsy is reported to affect 2–10 percent of the African population. The prevalence varies from country to country, and—due to the reasons cited above—it can vary from study to study within a country. But what is clear is that the number of persons in SSA suffering from epilepsy is significant. In Lesotho in 2008, “Epilepsy (was) the main mental health condition, accounting for 42 percent of outpatient department visits,” said Mathaabe Cecilia Ranthimo, acting director for Mental Health Services at the Ministry of Health and Social Wel-

fare. Osman Miyanji, chair of the Kenya Association for the Welfare of People with Epilepsy, said that although one study indicated the prevalence was about 1.8 percent in Kenya, other studies have shown different results. He believes the true number is higher (Miyanji, 2009). Although the prevalence in Tanzania ranges from 2 to 3.8 percent (Box 1-1), depending on the study, a researcher in Rwanda found approximately 4.9 percent of the population to have epilepsy in 2005 (Simms et al., 2008). In Mozambique, 13.5 percent of all households reported a case of seizure disorder, according to one report (Silberberg, 2009).

The wide range of reported numbers just on this one disorder clearly illustrates the difficulty in obtaining quality epidemiological data for policy makers. Although a number of factors can account for the reported high rates of epilepsy in SSA, common causes of epilepsy are likely to include infectious diseases, trauma, alcohol consumption, and birth asphyxia resulting from poor maternal health care—all of which are known to be high in parts of SSA. In addition, due to poor living conditions characterized by overcrowding, poor water supply, and bad sanitation, there is a high prevalence of communicable diseases such as malaria, meningitis, cysticercosis, and tuberculosis, which are also frequent causes of epilepsy. The data suggest, however, that contrary to the disease burden numbers previously presented, the prevalence of epilepsy is at or above the levels found in the United States and other parts of the developed world.

### **The Disease Burden of HIV/AIDS**

Saying that HIV/AIDS has a large impact in SSA is a gross understatement. Sixty-eight percent of people living with HIV worldwide live on the African continent, and every year, 76 percent of all AIDS-related deaths in the world occur there. In 2007, Africa accounted for 68 percent of new HIV infections in the world. In some regions, more than 20 percent of the adult population is infected, including more than 26 percent of the population of Swaziland (UNAIDS, 2007).

Thanks to better HIV/AIDS treatments using antiretroviral therapies, morbidity and mortality have decreased in HIV patients with advanced disease. However, as the number of patients on antiretrovirals increases, more and more people are living longer with HIV, raising new challenges. Furthermore, only about 30 percent of Africans who need antiretroviral therapy actually receive appropriate care (AVERT, 2008; WHO,

2008a), and current treatment guidelines often delay initiation of antiretroviral therapy during the early stages of disease. One common guideline recommends initiating therapy if a patient's CD4 white blood cell count falls below 200 (WHO, 2006a). But new studies suggest that may be too late to prevent neurological damage. Angela Kakooza-Mwesige, a neurologist from Makerere University School of Medicine, stated: "Accord-

### **BOX 1-1** **Epilepsy Care in Tanzania**

Epilepsy is the most commonly seen neurological disorder in Tanzania, with a prevalence of 2 to 3.8 percent. However, only a small percentage of these patients—perhaps as few as 5 to 10 percent—receive appropriate care and adequate therapy (Matuja et al., 2001). People with epilepsy in Tanzania have twice the mortality rate of the general population when matched for age (Jilek-Aall and Rwiza, 1992). The area of Mahenge in the Morogoro region of the country has had an epilepsy clinic since it was started by Louise Jilek-Aall in 1959. What began as a small clinic with 50 patients grew to 200 patients within 3 years. Six years ago, the Tanzanian health system took over the clinic because it was no longer staffed. Since that time, a collaborative group has worked to improve epilepsy care for people in the region. Bringing together the government, non-governmental organizations, and private partnerships, the collaboration has worked to improve the lives of people with epilepsy in the area, and remarkable advances have been made:

- All primary care clinicians and health workers have been trained to treat epilepsy.
- Health education has been provided for the families of people living with epilepsy.
- The government now supplies antiepileptic drugs to all district hospitals, which then make those drugs available to patients at reduced prices.
- Patients receive monthly follow-ups from dedicated healthcare workers.

Because of these improvements, the clinic in Mahenge now sees 4,000 patients a year, and seizure frequencies are down 60 to 70 percent since 2003. Mortality has also decreased (Winkler et al., 2010). These improvements in care are largely the result of strong collaborations. The government, which was involved since the beginning, supplies the drugs to the district hospitals for free. The Tanzania Epilepsy Association supplies personnel and educational materials. Rotary International supplied motorbikes to the district for use in monthly follow-ups and home visits. The district maintains the vehicles and supplies fuel. The Savoy Foundation of Canada, the Mahenge Dioceses of the Catholic Church, and the Kasita Seminar all work together to help rehabilitate epilepsy patients. Research is done by Muhimbili University of Health and Allied Sciences, along with colleagues from Germany and Austria. In short, disparate groups came together and made a huge impact in the lives of the local patient population.

ing to the molecular studies, we are seeing that cognitive impairment occurs much, much earlier.”

Neurological complications occur in 39 to 70 percent of patients with symptomatic HIV infection, and most are caused by opportunistic infections, which are complex and difficult to diagnose and treat with limited resources in most SSA healthcare systems (Odiase et al., 2006). Even though low-cost treatments are available for opportunistic infections associated with HIV, they are often inaccessible to most individuals living with HIV. Even for otherwise healthy patients, an antiretroviral regimen can require the patient to take many pills each day, leading them to believe they have “pill overload” and thus causing difficulty in adhering to the medication regimen, Kakooza-Mwesige said. When neurological disorders or depression are included, these challenges become larger. For example, AIDS dementia complex is a major concern because it is usually observed in the later stages of the disease. It is reportedly seen in up to 50 percent of patients prior to death (Ances and Ellis, 2007). When individuals with this complex are on a regular and effective antiretroviral regimen, a new complication arises: establishing the resources needed to care for them as they age with the associated complications.

Currently there are no robust guidelines on the interaction of HIV and therapies with the older generation medications used to treat mental health disorders commonly available in SSA. In fact, for patients with epilepsy, there are noted drug interactions between the older, commonly used antiepileptic medications, such as phenobarbitone, carbamazepine, and phenytoin, and certain newer antiretroviral regimens (Kakooza-Mwesige, 2009). Kakooza-Mwesige noted that this means patients need to be monitored—especially those on medications such as antiepileptic drugs—for both short- and long-term toxicities. The question, Kakooza-Mwesige noted, is always “do we have the available resources?” Studying, understanding, and learning to cope with the complex overlay of HIV/AIDS and MNS disorders is going to be increasingly critical to care in SSA over the next decade. Patrick Kelley, director of the Board on Global Health at the IOM, noted, “We have about 4 million people under antiretroviral therapy, yet there are approximately 30 million infected people and 2 to 3 million new infections in Africa each year.” At the same time, MNS disorders will likely grow as well. “We know scientifically, at the molecular level, that HIV affects brain cells much earlier than we anticipated in the past,” noted Elly Katabira, associate professor at Makerere University School of Medicine. This means that HIV prevention is extremely important from an MNS point of view. It also means that the success with antiretroviral therapy is raising a new policy

issue—it is not only reducing HIV transmission, but it is also affecting the prevalence or manifestations of the mental complications that can show up in persons living with HIV/AIDS.

With the growing numbers of infected people, Kelley noted, “Over the next decade to 15 years, there is going to be a tremendous increase in demand for HIV therapy. I suspect some money will follow this demand because there is a lot of compassion around the world in addressing the problem.” That, as panelists would discuss later, offers a window of hope to improve patients’ lives by attacking both problems at the same time. Leveraging the established HIV/AIDS infrastructure will provide new opportunities to raise awareness of associated MNS disorders, improve diagnosis, and establish better treatments and care.

### **The Disease Burden of Malaria**

Malaria is endemic in much of Africa, and illness due to malaria is one of the most common reasons for a visit to a health facility. For example, in Uganda 25 to 40 percent of outpatient visits are due to malaria, with 20 percent of health facility admittances due to the infectious disease. Malaria is responsible for nearly 14 percent of deaths in Uganda (Roll Back Malaria et al., 2005). Most malaria cases are uncomplicated—the disease is not normally fatal if diagnosed early and treated properly. However, all too often treatment is delayed, and the patient may deteriorate to the point where the disease becomes severe, with high risks of complications and death.

A related complication is cerebral malaria, which occurs when parasitized blood cells are found in the capillaries of an infected individual’s brain. Although most complications are transient and resolve within 6 months, about 10 to 24 percent of people who survive cerebral malaria go on to have neurological and cognitive sequelae—impaired vision, impaired hearing, impaired speech, recurrent seizures, gait disturbances, and various degrees of paralysis, noted Daniel Kyabayinze, clinical epidemiologist and research officer at Malaria Consortium Africa. However, Silberberg reported data that suggest an even greater impact on children, noting that between 50 and 75 percent of children with cerebral malaria survive, but not without consequences. He described a study that showed 32 percent of individuals had complications at a 71-week follow-up, including behavioral disturbances, epilepsy, gross motor delay, language delay, or hemiparesis (weakness on one side of the body) (Potchen et al.,

2010). Furthermore, children between the ages of 6 months and 5 years old are at a higher risk for cerebral malaria, as are travelers from non-malaria areas, pregnant women, individuals with sickle cell disease, and people with HIV/AIDS (WHO, 2006b).

Treatment for malaria complications is often delayed in part because malaria is so common in the region. For example, Kyabayinze estimates that every year there are one to two episodes of malaria for every person living in Uganda. Because so many people have had it, often more than once, many people think of malaria as a simple disease. Sub-Saharan countries with endemic malaria have an added risk for MNS disorders because the disorder may stem from delayed treatment for what appears to be just malaria. However, with improved focus on malaria prevention and awareness among healthcare providers about associated MNS complications, the portion of the burden of MNS disease arising from malaria could potentially decline.

### **Substance Use Disorders in Sub-Saharan Africa**

Unfortunately, comprehensive statistics on substance use (alcohol and drugs) disorders in SSA is limited. For example, unrecorded alcohol consumption is estimated to be about half the amount consumed in Africa and in East Africa—specifically, more than 90 percent of alcohol consumed, according to some estimates, is unrecorded (WHO, 2004). This is due in part because in many African countries alcohol is produced at the local level in villages and homes. These traditional forms of alcohol are usually poorly monitored for quality and strength, and in most countries it is possible to find examples of health consequences related to harmful impurities and adulterants.

Alcohol, tobacco, and drug-related problems are becoming an increasing concern in the African region. In addition, many African countries are used as transit points for illicit drug trade and these drugs are finding their way into local populations, adding to the indigenous problems associated with cannabis consumption. Furthermore, there is an increased demand for home-brewed beer or locally distilled liquor. Most countries have no national policies on alcohol or tobacco; consequently, their advertising, distribution, and sale are largely uncontrolled (Okasha, 2002). Increasing poverty, natural disasters, wars, and other forms of violence and social unrest are major causes of growing psychosocial problems, which include alcohol and drug abuse, prostitution, street chil-

dren, child abuse, and domestic violence. These often lead to greater substance use disorders.

Aside from the direct effects of alcohol on a person's physical and mental health, studies from Nigeria, South Africa, and Uganda have shown strong associations between domestic violence and alcohol use (Jewkes et al., 2002; Koenig et al., 2003; Obot, 2000). In South Africa levels of alcohol were particularly high for transport- and violence-related injuries with, for example, 46 percent of patients with transport-related injuries in Cape Town having levels above the legal limit for driving (0.05g/100ml), and 73 percent of patients with violence-related injuries in Port Elizabeth. In addition, alcohol abuse has been linked to risky sexual behavior and increased likelihood of contracting HIV. Alcohol use is also strongly associated with depression.

A large number of medical conditions are seen in individuals who suffer from addiction, including lung and cardiovascular disease, stroke, cancer, and mental disorders. Drug abuse has deleterious impacts throughout the body. Furthermore, a third of new AIDS cases are a result of infection through the injection of drugs such as heroin, cocaine, and methamphetamine.

## **STIGMA AND HUMAN RIGHTS**

### **The Stigma Problem: Breaking the Silence**

Throughout Europe and the United States, MNS disorders such as substance use, seizure disorders, and psychological conditions carry social stigmas. SSA is no different, and MNS sufferers face substantial stigma within their communities (Baskind and Birbeck, 2005; Satcher, 1999). To people unfamiliar with the scientific underpinnings of MNS disorders, simple behavioral changes such as confusion can be seen as madness; seizures can be seen as possession by evil or angry spirits.

The stigma of MNS disorders impacts all aspects of treatment and care of the patient—from individuals in the community, through providers in healthcare facilities, even into policies being developed by governments. It affects people in many ways, most tragically by often preventing individuals from receiving treatment. Katabira of Makerere University discussed the stigma that individuals with epilepsy receive. "Epilepsy is treatable," he said. "But it is treatable because you know there are drugs available. The ordinary man in the village may have entirely different beliefs about epilepsy. He may relate it to a curse in the fam-

ily.” However, because epilepsy is not often associated with a medical condition, it may never occur to the individual’s family that they should seek medical treatment. Instead, the families may hide the patient for fear of what the village community would think. Even when services are available in the community, they are often not used out of fear or ignorance, he said.

The healthcare community is not immune to these issues. Practitioners hold their own beliefs and, as Katabira said, their prejudices and associations are often in direct contradiction to their training. This is not the case for specialists who have received significant training. Rather, he suggested, there are few specialists in the community setting. “The majority of our healthcare workers have had very little training,” he continued. “When they see a person with an epilepsy fit, their natural instincts tend to come on first, and these may actually deter the patients from actually seeking professional health services.”

Workshop participants discussed the need to end the silence about MNS disorders, noting the importance of education—educating the communities and health workers in each local village that these MNS disorders are treatable medical conditions that should be devoid of shame and fear of, or for, the victim. Through the collection of data, instituting education, advocacy, and healthcare policies that include MNS disorders can be tools to end the silence and treat the suffering. This will be discussed in greater detail in Chapter 4 of this summary.

### **Human Rights Violations**

There is a history of human rights violations of persons with mental disorders across the world, but today the most disturbing examples are found in developing countries (Patel et al., 2006). Images displayed at the workshop by Patel were first released by *Time* magazine in 2003. These pictures depict atrocious conditions of care for people with mental disorders in hospitals in Southeast Asia. On further exploration, Patel and colleagues discovered these images were tragically representative of conditions for mentally disturbed patients that extended to intellectually challenged disabled children and women who were dispersed by war. Images of despair depicted the harsh lives of persons with MNS disorders in Africa, stripping them of their dignity. Often, these conditions are deemed necessary by family members to keep the person “safe.” For example, there was an image of a young man who was put in a cage that his parents constructed to keep him safe when they went to work every

morning because no one else was home with him. The WHO website shows a woman with a mental illness standing on a street in an African village, begging while being shackled to a log of wood, with the shackles in place more to keep her safe than any other reason.

Two models were discussed that could serve as ways the provider community could improve care and reduce stigma and mistreatment of individuals with MNS disorders. The South African Treatment Action Campaign (TAC) is one model. TAC was established to demand respect and dignity for people living with HIV/AIDS. Launched in 1998 on Human Rights day, this 10-year-old action campaign called for access to treatments and demanded dignity for people living with HIV/AIDS, first in South Africa, then in the world. Inspired by TAC, the Movement for Global Mental Health was launched on October 10, 2008. Its goals are to achieve the call for action to scale up evidence-based services and strengthen human rights protection for people with mental and neurological disorders. This movement hopes to emulate the success of TAC and bring together individuals and institutions who share a vision of human rights protection for all those with MNS disorders.



## 2

# **Systems of Care for MNS in Sub-Saharan Africa**

The delivery of care for mental health, neurological, and substance use (MNS) disorders, including mental health care, in sub-Saharan Africa (SSA) is a story of constraints, rather than opportunity. The funding, personnel, training, and equipment available are insufficient to provide the level of care that policy makers and healthcare providers would prefer, according to many speakers and participants (WHO, 2001). In that sense, the delivery of services in the region can be seen as a kind of ongoing crisis-management environment, complete with rationing and triage (Prince et al., 2007).

### **THE MNS TREATMENT GAP**

A large proportion of patients with MNS in resource-poor countries do not receive appropriate treatment for their condition. Known as the “treatment gap,” it is defined as the proportion of people with a disease or condition who require treatment, but do not receive it. The gap tends to be much higher in developing versus developed countries and for rural versus urban populations. A recent World Health Organization (WHO) study of 14 countries found that in developed counties, the treatment gap, or percentage of serious cases that did not receive treatment in the previous 12 months, ranged from 35 to 50 percent. That number rose to 76 to 85 percent for the developing, low- and middle-income countries participating in the study (Demyttenaere et al., 2004) (see also Table 2-1).

**TABLE 2-1** 12-Month Treatment of Physical and Mental Disorders in High-Income and Low- and Middle-Income Participants in the World Mental Health Survey

<b>Conditions</b>		<b>Treatment Prevalence Among Participants (%)</b>	
		High-Income Countries	Low- and Middle-Income Countries
Physical disorders	Arthritis	50.9	46.6
	Asthma	51.0	61.4
	Cancer	51.8	59.6
	Diabetes	94.4	76.6
	High blood pressure	90.2	69.8
Mental disorders	Bipolar disorder	29.1	13.4
	Depression	29.3	8.1
	GAD	31.6	7.2
	Panic disorder	33.1	9.4
	PTSD	29.5	8.1

NOTE: GAD = generalized anxiety disorder; PTSD = posttraumatic stress disorder.

SOURCE: Gureje, 2009.

Patel pointed out that in the poorest countries in the world, up to 90 percent of individuals with the most severe mental disorders—such as serious depression, psychosis, and epilepsy—do not even receive the most basic care (WHO, 2001). He said this does not mean individuals do not access care, it means that when they do access care, 90 percent do not receive the treatments known to be effective. Therefore, when patients present themselves for treatment, the symptoms may be treated, but the underlying cause is ignored. For example, if a patient presents with sleeplessness, fatigue, or soreness—all common symptoms associated with depression—the patient is often treated with hypnotics, tonics, or analgesics rather than being evaluated for the underlying cause of these symptoms.

In Tanzania, only 5 to 10 percent of individuals with epilepsy receive appropriate and adequate therapy. The treatment gap for epilepsy in developing countries has been mainly attributed to inadequately skilled personnel, cost of treatment, cultural beliefs, and unavailability of antiepileptic drugs, although lack of accessible health facilities has also been noted (Baskind and Birbeck, 2005; Mbuba et al., 2008). Other age-related MNS disorders on the rise in Tanzania, such as Alzheimer's disease and Parkinson's disease, are also poorly recognized by healthcare

workers (Winkler et al., 2010). The lack of human resources and the difficulty of retaining staff, especially in rural areas, was an important obstacle that a number of the participants said worsened the treatment gap in SSA.

Workshop participants stressed that treatment gaps do not exist because of a lack of data on treatments. Substantial scientific data are available on the efficacy of treatments for MNS disorders. The problems are in getting appropriate diagnoses for particular conditions and in putting adequate resources and systems in place so proper care can be delivered. Overall, participants agreed that the failure to diagnose and appropriately treat MNS disorders in SSA is driven by multiple factors. These include gaps in the knowledge, training, and availability of healthcare workers combined with an inability and reluctance of MNS patients to access the healthcare system for treatment.

### **Community Distrust**

As a result of the treatment gap and a strong influence of traditional medicine in certain communities, Western medical practices are sometimes viewed skeptically or at times negatively by community members. “Many people, including patients, are aware that health institutions can offer very little for chronic neurological disorders,” said Katabira. “There are shortages of specialists, physicians, doctors, and nurses. . . . [Additionally,] rehabilitation services are only available in big urban centers, yet [they] are most needed at the community level.” There have also been incidents where treatable disorders have been poorly managed, with resulting poor outcomes. “This gives negative feedback to the community,” said Katabira, driving patients back to traditional healers and remedies.

## **HEALTHCARE SYSTEM CHALLENGES**

### **Workforce Issues**

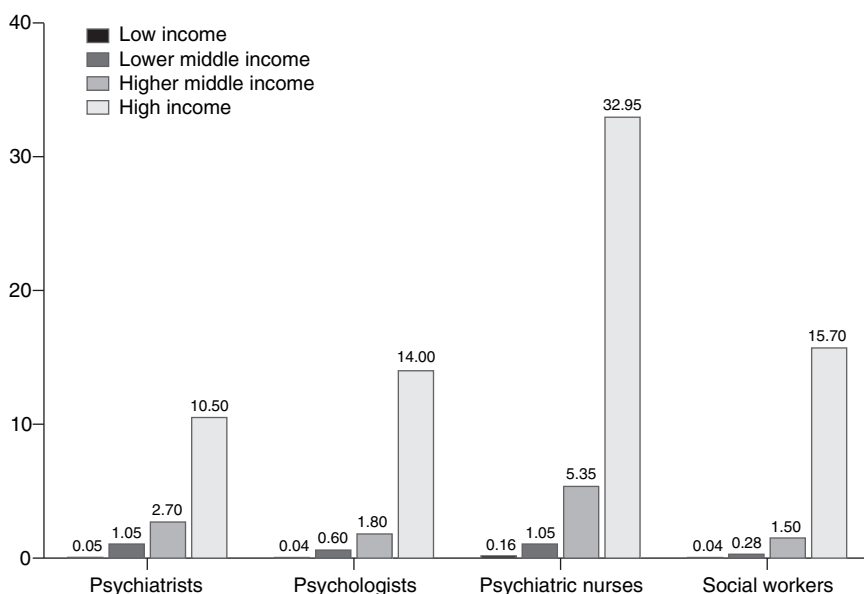
#### *Availability of Skilled Professionals*

Care for MNS disorders hinges on the availability of trained professionals, Patel said. Unfortunately, low-income African countries have few of these skilled professionals available to treat the large

numbers of persons with MNS disorders. In the clinical neurosciences (neurologists, psychiatrists, neurosurgeons), except for South Africa, the mean ratios for countries that have these medical specialists are 1 neurologist for 1 million to 2.8 million people (versus 4 per 100,000 in Europe); 1 psychiatrist for 900,000 people (versus 9 per 100,000 in Europe); and 1 neurosurgeon for 2 million to 6 million people (versus 1 per 100,000 in Europe). Most clinical neuroscience services are located in the capital cities, often the largest urban areas, where the professionals also often lecture at medical schools. As a result MNS patients often must travel long distances to consult with a doctor in the city (Silberberg and Katabira, 2006).

The absence of trained professionals is not isolated to a particular country, but rather it is widespread throughout SSA. For example, in Cameroon, there was one neurologist in 1988; by 1995 there were two and by 2005 a total of five. They all practiced in the big cities of Yaounde and Douala, where 5 million of Cameroon's 18 million people lived. Currently, there are 10 neurologists, 7 neurosurgeons, and 1 neuroradiologist (WHO, 2004). In Kenya, with a population of 38 million, 22 psychiatrists work for the government, 25 work at universities or level-6 hospitals, and another 25 are in private practice. There are approximately 500 psychiatric nurses, though the numbers are not confirmed. In Tanzania, the doctor-patient ratio is the highest in East Africa at 1:33,000, with only 60 physicians providing care. There are 3 neurologists, 6 neurosurgeons, and 15 psychiatrists for the entire country (Winkler et al., 2010).

As noted in Figure 2-1, the scarcity of human resources for mental health in low- versus high-income countries is equally low. Patel observed that the number of specialists per 100,000 people is so small as to be nonexistent when compared to the higher numbers seen in middle- and high-income countries. Furthermore, "what you can see on this chart is less important than what you cannot see. Low-income countries have so few of these professionals that these bars are not even visible. The difference with high-income countries is often 200 times. And this applies to more or less all professionals." Patel continued to explain, "The worst part of this story is that due to migration of professionals, the difference is widening rather than narrowing." In the lowest income countries, there are effectively no psychiatrists, psychologists, psychiatric nurses, or social workers available to treat patients with common mental health disorders.



**FIGURE 2-1** Scarcity of human resources for mental health.

SOURCE: Saxena et al., 2007.

### *Availability of Trainees and Retention of Trained Workers*

According to workshop participants there is a dearth of students being trained in MNS disorders, and the retention of trained specialists is a significant problem in SSA. Over the short- and long-term this will continue to have a negative impact on the availability of trained healthcare professionals. The absence of formal training programs and career paths in MNS disorders serves as a barrier. Many of the associated MNS disciplines are not represented in the medical universities that are affiliated with hospitals. Further, as Katabira of Makerere University aptly stated, “Unfortunately less than 10 percent of the people we train actually end up in public service where they are needed most.” Some individuals enter into private practice in the urban areas, but many leave the country entirely. This flight of specialists has many reasons, but largely comes down to the absence of incentives to stay and provide care through the existing healthcare systems—a problem that can be easily fixed through the establishment of new policies. Remuneration is

certainly one factor leading to the departure of many trained providers. In addition, the absence of resources and the limitations of facilities are also critical reasons, Katabira noted. When these highly trained practitioners leave the training environment and go out to the rural health institutions, they are unable to provide the care they have been trained to provide. For example, “a doctor who knows how to diagnose meningitis,” said Katabira, “is unable to do a lumbar puncture to confirm what type of meningitis it is and therefore provide appropriate antibiotics because the lumbar puncture kit last existed in the hospital some 10 years ago.” This leads to understandable frustration for caregivers, so they leave.

Another major challenge facing health systems in SSA is the international migration of health staff to developed countries or to better paying positions on the African continent. Paul Farmer, cofounder of Partners in Health, made the point that African nurses are not leaving because they want to leave their homes. They feel forced to leave because they are not given the resources they need to care for their patients nor are they provided with adequate salaries to support themselves. Farmer was quick to emphasize that it is not just the salary, but also the lack of resources, that drives skilled African workers and professionals away from their homeland. However, the establishment of student loan reimbursement/forgiveness programs that require service in underserved communities would help incentivize individuals to seek MNS training and practice in their home country.

## **Barriers to Treatment**

### *Access to Treatment Facilities*

Many barriers limit access to care for persons with MNS disorders in SSA. In addition to the stigma of brain disorders preventing a person’s desire to seek care, issues of money and transportation impact where the treatment occurs, who provides the treatment, and what treatments are made available.

SSA is made up of countries where the majority of the populations live in rural settings. Distances to health facilities are often quite far, and roads may be poor or nonexistent. It can be difficult for those who have not experienced the distances and conditions involved in Africa to understand just how tremendous this simple barrier of mobility and distance can be. Augustine Mugarura of the Epilepsy Support Association of Uganda described an example of a health center called Rubuguli in

southern Uganda. Patients travel an average of 15 to 20 kilometers (9 to 12 miles), often by foot, to the nearest healthcare unit. Unfortunately, no psychiatric services are provided at Rubuguli, so patients must travel to Kisoro hospital to receive care. The health center has no phone. Except for individuals with mobile phones, there is no way to communicate with the hospital if there is an emergency it cannot handle. A four-wheel drive vehicle—the fastest mode of transport available—takes 2 hours to travel between the Rubuguli health center and Kisoro hospital, and traveling by motorcycle taxi takes 4 hours.

Faced with these conditions, a 2-hour walk to a clinic and a 4-hour drive to a hospital capable of providing needed MNS services, it is no wonder that many stroke and physically disabled patients cannot access the care they require. As Katabira noted, “If they do, many are unable to honor follow-up appointments.” For patients who reach a hospital and are admitted, in-patient care can also negatively impact families because a member of the family needs to stay with the patient in order to provide them with basic bedside care. That removes a family member from the workforce and impacts their earnings.

### *Financing MNS*

Assuming an accurate diagnosis is made, the patient then faces the challenge of paying for treatments and medicines. In low-income countries, health insurance is rare and care for MNS disorders is paid primarily out-of-pocket by families. Even if the government provides health services, families may need to pay for medications. The decision to treat can come down to a choice between medicine for one person or food for the family, which is particularly difficult for those in need of long-term treatment.

This is just one aspect of financing MNS disorders. There is also the broader picture whereby the low financial allocations from governments to support clinician training and purchase of diagnostic equipment and treatments greatly hinders initiating and maintaining quality treatment. Building off the available burden data, additional research would provide the necessary evidence to help support the development of MNS policies. However, resources are extremely limited throughout SSA. Therefore, strategies need to be established that will minimize resource expenditures.

## **OVERCOMING HEALTHCARE SYSTEM CHALLENGES**

Although there is little doubt that SSA, from a public health perspective, is in crisis, workshop participants were not without hope, and spoke repeatedly about the future—about reducing the treatment gap and improving the quality of care in the region for those suffering from MNS disorders. Participants spoke of quality care as not just the best treatments, but using those treatments in a flexible manner to meet the unique needs of the patient population in SSA.

The good news is that much is known about treating MNS disorders. Treatments are also broadly effective, and projects such as the Disease Control Priority Project have even modeled the cost-effectiveness for a range of treatments across many mental and neurological disorders (WHO, 2006c). What is missing is how to deliver that care and, particularly, how to integrate quality MNS care into the primary care delivery systems in various regions. The key to that, participants agreed, is collaboration, innovation, and the application of available technologies.

### **Closing the Human Resource Gap**

With few physicians and specialists available to treat individuals with MNS disorders, workshop participants discussed strategies to help close the human resource gap that is present, especially in rural areas. As discussed during the workshop, one strategy is to try to increase the number of specialists who enter the field by recruiting individuals directly out of primary school and university. “We need to look for the future,” said Professor Alfred Njamnshi of the neurology department of the Central Hospital Yaoundé, Cameroon. The Pan African Association for Neurological Science has a program that sends individuals to primary and secondary schools, as well as universities, to talk about neurology, neurosurgery, and neuroscience, with the intent of leading students to careers in the field. However, as previously discussed, incentives, such as loan reimbursement/forgiveness programs, need to be established to help motivate clinicians to stay and work with underserved communities.

Workshop participants spoke of the need to do more than rely solely on a prospective and theoretical flow of new specialists. “If we rely solely on specialists we are never going to close the treatment gap, not now or indeed in the foreseeable future,” said Patel. Instead, workshop participants discussed models to better integrate MNS care into primary

care, using community health workers and possibly using technology to close the treatment gap.

### *Community-Based Care*

Central to many of the success stories described during the workshop was the concept of community-based, rather than institutional, care, particularly for mental health care. According to the WHO Mental Health Report from 2001,

Community care has a better effect than institutional treatment on the outcome and quality of life of individuals with chronic mental disorders. Shifting patients from mental hospitals to care in the community is also cost-effective and respects human rights. Mental health services should therefore be provided in the community with the use of all available resources. Community-based services can lead to early intervention and limit the stigma of taking treatment. Large, custodial mental hospitals should be replaced by community care facilities, backed by general hospital psychiatric beds and home care support, which meet all the needs of the ill that were the responsibility of those hospitals. This shift toward community care requires health workers and rehabilitation services to be available at the community level, along with the provision of crisis support, protected housing, and sheltered employment (WHO, 2001).

Community-based care moves patients away from hospitals and allows them to be treated near or at their homes, and thus it is essential for the long-term care of chronic disabilities and disorders. “The highest standard of care anywhere in the world is going to be a complement with community health workers,” said Farmer, who outlined community-based care advantages as noted in Box 2-1.

Workshop participants discussed the fact that many community health workers are currently volunteers and suggested that, in order for this system to work, these people need to be paid. The idea is that workers who are paid are more likely to continue in their position and provide continuity of care, thereby reducing the need to train new workers. Providing opportunities for further skill training may be a way of retaining workers. An example of this is provided in Box 1-1, which describes epilepsy care in Tanzania.

*Integrating MNS with Other Healthcare Measures*

According to Inge Petersen from the University of KwaZulu-Natal, South Africa has begun to integrate, with success, some common mental disorders such as anxiety and depression into primary care. However, due to the tremendous burden on primary healthcare nurses caring for individuals with HIV/AIDS and tuberculosis, it has not been possible to expand additional services to cover MNS disorders.

Kakooza-Mwesige remarked that integrating MNS with HIV care is critical to the safety and well-being of the patient. Providing HIV treatment can reduce the prevalence of comorbid MNS disorders. Katabira stressed that the HIV/AIDS resources need to be leveraged to improve all associated symptoms, including MNS disorders. Using these resources will allow improved models of care to be developed, which in turn could be applied to other MNS patients, thus improving care for all individuals with MNS disorders.

An example of this is how MNS was integrated into the “Village Health Team” in Uganda. These are members of the community who are selected by the community to take care of general health issues, including treating minor ailments, routine immunization, HIV/AIDS counseling and testing, and informing the community about services available at health units. Through the Ugandan system of training, mental health has been integrated into that Village Health Team manual so the Village Health workers recognize mental health illness. Ultimately, the hope is to change the perception of mental health illness in local Ugandan communities, which will be strengthened through collaborations

**BOX 2-1****Advantages of Community-Based Care**

- Social forces contribute to disease burden and health outcomes, and community-based care can address these forces.
- In community-based care, treatment and prevention are mutually reinforcing; both elements are essential for an effective strategy.
- Community-based support improves adherence, prolongs survival, and slows drug resistance.
- Community-based, public-private partnerships have broad implications beyond infectious diseases to any chronic disease for which there are daily deliverables (e.g., diabetes, hypertension, asthma, mental illnesses) in both resource-poor and resource-rich settings.

with traditional and complementary healers as guided by the Ugandan public–private partnership policy. Some Village Health Teams have better results than others, mainly due to a more advanced system of referring patients.

Kakooza-Mweisse believed that the need for integrated care was clear, especially given the complexity of the drug regimens to which patients with multiple issues must adhere. Because many HIV-related MNS disorders are related to seizures, often patients are put on antiretroviral drugs (ARVs) and anticonvulsants. However, due to adverse interactions with ARVs and the common anticonvulsant drugs phenobarbitone, carbamazepine, and phenytoin, these medications should not be given together. Furthermore, ritonavir and nelfinavir use may raise serum levels of these anticonvulsants into toxic ranges. This creates a dilemma whereby the drugs that are beneficial to patients like Phenobarbitone, at less than 5 cents a dose, could harm the patient on HIV drugs. Kakooza-Mweisse asked the audience, “What do we do?” Patients are not able to afford the newer generation of antiepileptic drugs on the market, which are much more expensive than Phenobarbitone. Plus, no guidelines exist on indications of protocols for treatment of new-onset seizures for HIV infection. Adherence to the complex regimens of antiepileptic drugs, antiretroviral drugs, and opportunistic infection prophylaxis is a big issue. Now, with the increased number of patients taking ARVs, HIV patients have increased rates of survival. This means care providers need to select successive new antiretroviral regimens and continuously monitor patients, especially those who are on antiepileptic drugs or anticonvulsants for short- and long-term toxicities. But the question is whether the developing world has the available resources to do so.

### *Task Shifting*

The key to success in a community-based model—or indeed any model in which general healthcare personnel are retrained to provide specialist functions—is task shifting, explained Patel (see examples in Box 2-2). Task shifting simply means that specific medical tasks can be transferred from specialists to newly trained individuals. Ultimately, setting up programs that support task shifting is one part of a coordinated strategy to increase the full spectrum of MNS providers: clinical psychologists and neurologists, clinical social workers, certified counselors, nurses and clinical officers. Often because of the limited tasks and scope of work, less training is required, significantly lowering

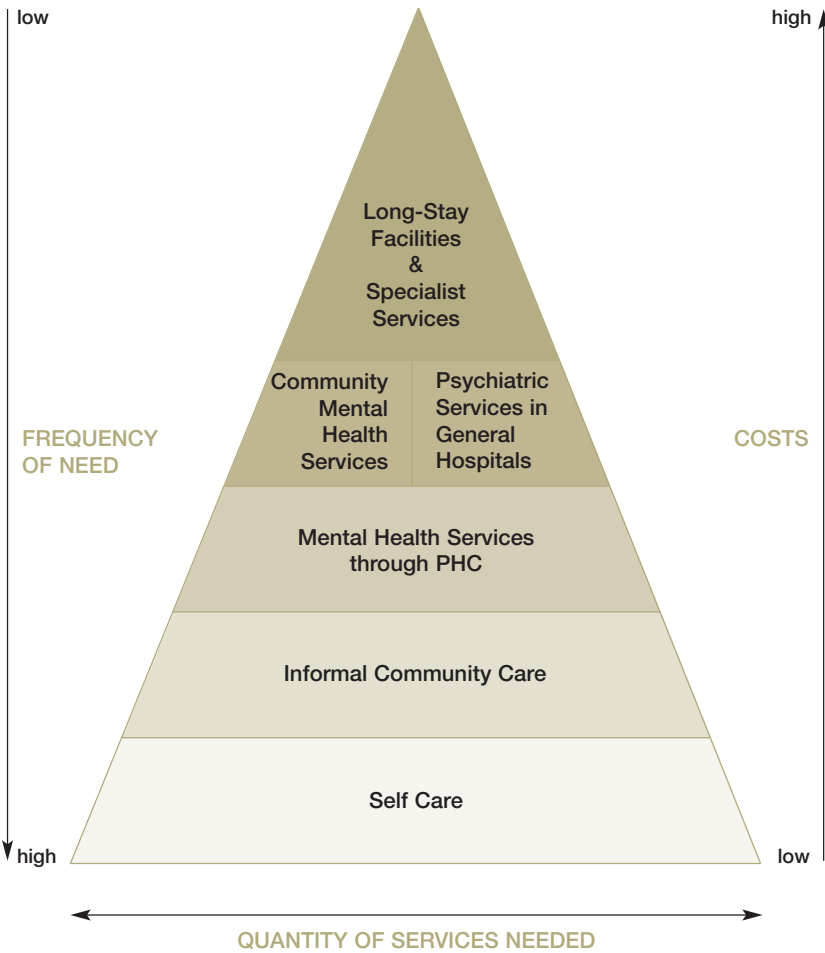
the cost to the health system and allowing a more efficient use of available human resources. For example, Patel discussed the results of a recent study published in *Lancet* on treating postpartum depression in mothers in rural Pakistan (Rahman et al., 2008). The study trained village women with little education to deliver cognitive behavioral therapy using training materials based entirely on cartoons and pictures. The training was given over a 2-day period, and the women treated were followed for 12 months. The study's authors were able to demonstrate that not only were there benefits to the mothers, but also to their babies. The babies had high rates of immunization coverage, as well as low rates of pneumonia, diarrhea, and other infections compared to those whose mothers did not receive the treatment, highlighting the importance of this program not only to the mothers but also their children.

This type of evidence does not suggest that task shifting and an emphasis on community health workers translates into a healthcare system that no longer needs specialists. In fact, all of the examples presented at the workshop involved a wide range of specialists, although their *roles* differed from one example to the next. Rather than treating a patient in one-on-one settings, they were instead the leaders of a program, developing the treatments, training, and developing materials the community health workers would use. The specialists had roles such as advocating for the patients, supervising the health workers, and receiving referrals from the community facilities (Figure 2-2). Patel sees this as a logical evolution of the specialists' role in a resource-constrained environment. "The role of specialists need[s] to be completely refashioned and redefined in a great new world," he suggests. "Rather than spending all our time seeing patients . . . really the role of a specialist needs to move from physician to public health practitioner."

David Ndeti, director of the African Mental Health Foundation, suggested that the traditional healers may be in just the right position to help with task shifting. As noted in the section on traditional healers, they are already a trusted voice in the local community, are numerous and, according to his case study, are willing to learn about more ways to help treat their patients, whether based on Western medicine or not.

But task shifting is not without its challenges. "One of the things that we have realized is that it is one thing to train somebody for a week and then send them out to provide quality mental health services," said Christine Ntulo of Basic Needs UK. "But there are still issues around proper coaching and mentoring. If we do not have those structures in place, we do more damage to the patient than good." As an example, she listed the case study of training healthcare workers in one district.

Trainees were supplied with medications and were evaluated every 3 months. One trainee thought that because three different medicines for headaches could be used interchangeably (panadol, cetamol, and rapidol), it meant that chlorpromazine could be substituted for carbamazepine because they were out of it and they both ended with the letters “ine.” As a result, the frequency of the in-person evaluations were increased to



**FIGURE 2-2** The WHO’s optimum mix of mental health services.  
SOURCE: WHO, 2010.

monthly from quarterly. Task shifting also requires additional personnel. Makerere University's Katabira noted that the problem with task shifting is that to maintain quality, a dedicated policy for supervision is needed. This requires increases in the number of specialists, doctors, and nurses to ensure sufficient capacity and supervision for the new patients achieving care. In addition, there needs to be formalized periodic continuing education programs.

With the wide use of task shifting throughout the healthcare system, Gary Belkin, associate professor of psychiatry at New York University School of Medicine, noted that further research needs to be done on the effects of task shifting, including the following:

- What is the true quality of care that is provided in task-shifted environments?
- What decision support systems are needed?
- What kind of feedback system needs to be in place to make the treatment interventions work?

#### **BOX 2-2**

##### **Task Shifting at Work: Example from Kenya and Rwanda**

###### *Kenya*

When Kenya developed its National Health Sector Strategic Plan, which ran from 2005 until 2010, a key feature of the plan was to decentralize mental health, neurological, and substance use (MNS) disorders care, moving it from specialized hospitals to primary care facilities. As the Kenyan Ministry of Health worked to implement the plan, it found it did not have enough skilled health workers to treat the diseases it was seeing. It was decided to use existing health workers and train them to increase their skills so they could deal with the MNS disorders they were seeing in the field.

To retrain the clinical officers and nurses in the facilities, a partnership was forged between the Ministry of Health, the Kenya Psychiatric Association, the World Health Organization Collaborating Centre and Section of Mental Health Policy, and the Institute of Psychiatry at Kings College in London, among others. The community health workers, along with the district mental health workers who supervise them, were trained in the knowledge, skills, and competencies involving basic mental health issues, and they were also trained on how these issues contribute to both a person's physical health and social outcomes. Part of their training included understanding the relationship between mental health and areas such as child health, reproductive health, malaria, HIV, education, and economics. Mental and neurological disorder assessment, diagnosis, and treatment were also taught. "We wanted to sensitize them," said David Kiima, director of mental health for Kenya's Ministry of Health. "They have a responsibility to

implement the community health strategy and to understand the mental health policy and legislation.”

To create a sustainable system, the training process began with facilitators, senior staff, and other trainers in 2005. From 2006 to 2009, roughly 25 people attended an intensive one-week training session, each and every week, with a total of approximately 1,500 workers trained to date. The process has not been without challenges, but significant progress has been made.

### *Rwanda*

Arguing for the mental health benefits of a broad commitment to general primary health care, Paul Farmer, cofounder of Partners in Health and professor of social medicine in the Department of Global Health and Social Medicine at Harvard University Medical School, spoke about the 1998 HIV Equity Initiative in Haiti that used community health workers to provide care in their communities. Global Fund money was used to not only strengthen HIV/AIDS prevention and treatment, but also to strengthen primary health care in general in the public sector. The result was an increase in primary care visits and HIV detection rates, and an increase in prenatal care visits and rates of vaccine administration.

This same program was brought to Rwanda, and since 2005 it has scaled up in three of four districts that have no district hospital. The program is showing results similar to what occurred in Haiti, with improved primary care, including high compliance with HIV/AIDS antiviral protocols. Consistent contact with community health workers seems to be key. “Strengthening primary health care—training people to do this in their home visits—is the highest standard of care in chronic disease management,” Farmer said. “This frees up doctors and nurses to do the things they could do best. And I would argue that the same holds true for mental health illness.”

### *Traditional Healers*

Workshop participants noted that, while there is a dearth of specialists trained in Western medicine, there are a significant number of traditional healers to whom individuals routinely turn for care. Furthermore, individuals with MNS disorders in SSA often seek care from traditional healers before seeking out Western-trained doctors.

Some of the most lively discussions during the workshop revolved around the role of traditional healers in providing care for MNS disorders. Unlike Western medicine, which is based on empirical data on the effectiveness of treatments, the effectiveness of traditional healers is not known and the approaches are not standardized, said Florence Baingana, a research fellow at Makerere University’s School of Public Health. “[Traditional medicine] may be providing a benefit,” but there

have not been any comprehensive studies, therefore we don't know the effectiveness and potential benefit to the patient.

However, some workshop participants noted that evidence can be quantitative as well as qualitative. "Certain things can only be studied by qualitative evidence, and it is not necessarily less important or less valuable than quantitative evidence," said Roy Baskind of the Division of Neurology in the Department of Medicine at the University of Toronto. "Traditional healers are very difficult to study with quantitative means, and the lack of evidence is not evidence of the lack of efficacy." Baskind and others reiterated that this did not suggest data should not be collected, but rather, that a broader understanding of the role of traditional healers must be taken.

Baskind reported the case of a child with epilepsy to demonstrate that though the traditional healers in the case did not "cure" the child, they did perform important services. First was social intervention: In this case, the child and all family possessions had been taken from its mother by the paternal grandparents after the death of the father. The first traditional healer said the seizures were caused by the angry spirit of the father and that the child and all of the family possessions should be returned to the mother to appease the spirit. Second was stigma reduction: Because many believe seizures are contagious, and refrain from touching an affected person or even visiting the house of an affected person, by performing a cleansing ceremony, the traditional healer allowed the family and village to believe they were protected from catching the seizures, reducing the stigma.

Workshop participants identified other strengths and weaknesses that traditional healers brought to caring for sufferers of MNS disorders. For example, strengths of traditional healers include the following:

- Traditional healers live in the community and know the people they are treating and their families and their histories, and they are often very good at solving family, social, and neighborhood problems.
- Traditional healers are more accessible to a community and are local. In addition, they often barter instead of requiring money, lowering the barrier to care.
- Traditional healers often spend substantial time with their patients and engage with more of the family members than is possible in a clinic.

- Traditional healers are already established as accepted and respected parts of their communities.

However, potential weaknesses do exist. For example, traditional healers may not have appropriate treatments for all diseases. This is particularly the case for neurological diseases and disorders such as psychosis or epilepsy. In addition, there is no standardization of traditional remedies and treatments among traditional healers, or even a definition of what a traditional healer is, how they are trained, or who they are.

While understanding these strengths and weaknesses, Baskind commented, “It is important to note that patients do not take sides. If you ask someone with epilepsy in rural Africa, which do they prefer? They don’t care, they want treatment that is available, they want their needs met—be it stopping the seizures or [curing] depression—but also [they want] an explanation of why they have it. They want to be able to believe in the treatment; it needs some legitimacy and traditional healers have legitimacy because they are traditional.”

Makerere University’s Seggane Musisi noted that there was recent research evidence suggesting that, in MNS care, those patients who use both Western and traditional medicine did better than those who used either method alone. Treating traditional healers with respect is critical when approaching them for collaboration. “As long as you go to a traditional healer with a spirit of partnership, then it works,” said Ntulo of Basic Needs UK. “That’s how—where we work in rural Nairobi and in Ghana—we have been able to actually break through the barriers of traditional medicine. They have been invited to the discussions as equals who have their own area of specialty. And when that happens, then they are able to open up and share.”

### *Integrating Traditional and Western Medicine*

Many workshop participants believed that collaboration between Western and traditional medicine is the most practical way forward for most sub-Saharan communities. It will be important to develop policies that formally integrate traditional healers into the health system. However, the absence of understanding between the two communities complicates collaboration and a coordinated approach for health care. “It is difficult to integrate or collaborate with people when you don’t know the essentials of what they provide, especially where you were talking about evidence-based service,” says University of Ibadan’s Oye Gureje.

Although evaluating the role of traditional healers is difficult, it is possible to divide traditional healing practices into beneficial, benign, and harmful practices.

In Uganda, the policy of the Ministry of Health is to attempt to formally work with traditional healers. Their experience has shown that by working with them, traditional healers become sensitized to the unique mental health needs of their patients and many have started referring patients to the Western health centers for treatment. Patients who want to see traditional healers may, but they are encouraged to continue to keep taking their medications and return to the health centers at any time. Critically, patients being seen in a collaborative care system are also cautioned not to take herbal remedies in addition to the Western medications. But rather than a blanket prohibition, Uganda has taken the issue of traditional herbal medicine seriously, establishing a national chemotherapeutic laboratory that works with traditional healers to analyze their medications. The compounds can be analyzed to look at the active ingredients, check for efficacy, refine them, and even package and market them while retaining the traditional healer's intellectual property.

Musisi emphasized the need to train, certify, register, license, integrate, and supervise traditional health practitioners for mental health care in primary health care and establish a formal health care category of Traditional Mental Attendants akin to the Traditional Birth Attendants of midwifery (Okello, et al. 2006). Categorizing the practice of traditional healers into categories—beneficial practices, innocent practices, and dangerous practices—would assist in encouraging beneficial practices while regulating and discouraging dangerous practices. It would further help in formalizing education practices and incorporating them into the health system.

### **Access to Care Through Technological Advances**

Technology, specifically mobile technology, offers the greatest potential for improving care in SSA. It holds tremendous value in both task shifting and bringing training and treatments to rural communities. Like the Mobile Health initiative, described below, that provides decision-tree and treatment support to practitioners in the field, there are many ways to use technology to create virtual specialists. Simply delivering the Internet and computer-based technology to the village level will do a great deal to improve the availability of quality information.

Frank Njenga, president of the African Association of Psychiatrists and Allied Professions, noted, “Everybody now has broadband connectivity. We are already using it at the district level. Imagine how beautiful it would be to teach cognitive behavioral therapy techniques to people at the [village] level using this broadband connectivity.”

The goal is to push technology—and, more importantly, connectivity—as far into the field as possible. “We are already using solar-powered computers to download information not at the district level, but at the village.” Indeed, Njenga believes technology may be one of the continent’s best hopes in advancing general health. “We in Kenya have decided that at the end of next year we will have a million computers across the country.” This is a goal for 2010.

Julia Royall, chief of international programs for the U.S. National Library of Medicine (NLM), provided background on the readily accessible information through sites provided by the NLM. For example, more than 16 million citations are available through Medline. MedlinePlus contains 700 health topics, including interactive tutorials, surgical videos, and many other sources of information. These are peer-reviewed, evidence-based resources that are free to anyone with Internet access (NLM, 2010). But health workers need to know that the resources are available.

### *Mobile Health Technologies*

One tool developed for these health workers are applications and training modules that can be used on a mobile phone, providing decision trees and checklists, called Mobile Health. “A decision tree not only guides the health workers specifically to actions that they would perform, but also to specific information that needs to be imparted during the visit,” explained Belkin. It also identifies key triggers when the patient needs to be referred up to the next level of care. Currently this type of tool is used for prenatal and postpartum care of mothers and newborns and with children.

The current plan is to expand existing tools and introduce a mental health component into the stream of work. “We are going to develop the same sort of logic tools and decision support tools for depression,” said Belkin. “These tools are part of the intervention and are also part of the quality and management processes at the same time.” Mobile tools can be developed that have the ability to create summary and tracking reports for the supervisors and the clinical staff, allowing supervision not only of the care, but also of the system that delivers that care.

But for the moment, this remains just a plan. Creating the expert system needed to treat MNS disorders, such as depression and substance use disorders, requires a substantial investment of time and money. How to implement treatments and how to coordinate processes for those treatments have yet to be determined. “These components have to be scalable as well, and I will tell [you] that those challenges are a global challenge. It is a challenge in eastern New York, and it is a challenge in East Africa,” said Belkin. “You have a working model of how that is going to be delivered, of how the quality is going to be overseen. You have crossed out that whole package together—training and process—and all those components [have to be] scalable,” said Belkin. To facilitate this, Belkin said, “The village clusters in each country are directly linked into the district and national policy-making process.”

The idea of mobile technologies could, theoretically, extend to providing patients with up-to-date information pertaining to alerts such as hospital hours or availability of new supplies and medicine. This would help address the issue of patients traveling for hours to a clinic only to find that it is closed or the medications they need are not there.

### **Financing MNS Care in Sub-Saharan Africa**

Financing delivery of care to individuals with MNS disorders presents another challenge to the delivery of quality care. This challenge is even greater in SSA due to competing priorities of other disorders such as HIV/AIDS and malaria, commented Hyman from Harvard University. However, as discussed earlier, treatment of MNS disorders should be part of a much larger integrated health network that leverages the strengths of existing infrastructure and resources.

#### *The Millennium Development Village Project*

The United Nations Millennium Development Goals consist of eight goals to end extreme poverty by 2015 (United Nations, 2009). The eight areas for development include an end to poverty and hunger, universal education, gender equality, child health, maternal health, combating HIV/AIDS, environmental sustainability, and global partnership. The Millennium Development Village Project is working to show how these development goals can be met and includes a holistic approach to health care. Belkin from New York University presented to the workshop how

the project's healthcare approach works and suggested how mental health could be integrated into primary care.

To meet the healthcare targets of the Millennium Development Goals, the project assumes that approximately \$40 to \$50 per capita must be spent on health care. Belkin explained that this assumption comes from what is needed, not necessarily what is actually happening. "This is an important thing to specify because the model that we demonstrate is in many ways locally not affordable," he conceded. "But the logic of this approach is to think about the fundamental component needs for one to be effective both in terms of the process and content, in the package as well as the delivery. This makes the point that no health system that operates on \$10 per capita can be successful . . . you have to understand what the resource needs are." The project covers 12 village clusters across 10 countries in SSA. Each cluster consists of 40,000 to 60,000 people. In each cluster, there is 1 clinic with a staff of 2 nurses and approximately 40 health workers. The health workers service 150 to 250 families each by going out into the communities and making house calls (United Nations, 2006).

The structure of the project is important—village clusters are directly linked to the district hospitals, but the community health workers walking from home to home are the ones who truly bring patients into the healthcare system. These workers participate in approximately 4 weeks of training, exams, and assessments, and they are then monitored and supported once they are in the field. Continuing support for these workers is a critical part of the project.

### *Collective Bargaining for Medications*

Many MNS disorders are relatively easy to control with the proper medications. However, ensuring that medications are consistently available in the appropriate therapeutic dose is difficult to do in many areas of Africa.

Paul Farmer, cofounder of Partners in Health and professor of social medicine at the Department of Global Health and Social Medicine at Harvard University Medical School, presented data from Partners in Health on the cost of ARVs that serve as an example of the value of collaborations. The wholesale cost for a common three-drug ARV regimen is around \$10,000 per patient per year in the United States. However, through the use of collective bargaining, Partners in Health was able to procure generic drugs for \$600 or \$700, depending on the specific drugs needed, while the International Dispensary Association—

the largest nonprofit procurer of generic medicines—was able to negotiate prices of between \$300 and \$400 for the same medications (WHO, 2006a). These data demonstrate the potential of this approach and the value it may hold for the purchase of drugs for MNS disorders.

## MNS Healthcare Policy

Weighed against the massive and growing need, there is a clear demand for well-developed, well-articulated, and aggressively implemented national healthcare policies designed to improve care and reduce the burden on those individuals suffering mental health, neurological, and substance use (MNS) disorders. It may seem odd that something as simple as a set of documents can make a difference in the health of a population, but history shows that it does. Without essential statements of purpose covering a country's vision and goals, programs to implement those goals with specific strategies, stated objectives and milestones, and finally legislation to provide for the protection of basic human and civil rights, it becomes difficult to engender action (Gureje, 2009; Ndyabangi, 2009).

According to Gureje, approximately half of the countries in sub-Saharan Africa have mental health policies in place, while few if any have comprehensive policies in place for MNS disorders (Gureje, 2009). Of those that do have policies that address mental health, more than a third of those policies were developed prior to 1990 and consequently are outdated by advances in the scientific understanding of these disorders. Similarly, only 37 percent of these policies address the special needs of children, despite the fact that 42 percent of SSA's population are minors. But even those countries that have healthcare policies may not be using them. "There are a lot of countries with policies, but they just put these documents up on the shelf, no one looks at them, and they're never implemented," said Gureje.

Gureje laid out four core elements that should be included in a healthcare policy:

1. **Vision:** The orientation of a policy sets realistic but motivating expectations.
2. **Values and Principles:** These are the overarching philosophies that will guide further action, including what standards need to be followed.
3. **Objectives:** What goals are to be reached, and what steps make up those goals?
4. **Strategies:** What resources—financial, staffing, service system, etc.—are necessary to reach the goals that have been set?

Gureje continued that a successful policy—one that actually drives action—needs to identify the following:

- **Resources:** including sources of funding, manpower and infrastructure;
- **Organization:** the system of service, including the links among primary, secondary, and tertiary services;
- **Relevant Legislation:** government actions to guide the work of practitioners and others involved in the healthcare system;
- **The Delivery System Itself:** health promotion, preventative services, treatment services, rehabilitation service, as well as the system for drug procurement and distribution;
- **Advocacy:** a driving force for government action; and
- **Measurement and Evaluation:** research and information to inform service delivery or policy changes.

Two speakers—Ndyanabangi of the Uganda Ministry of Health and Petersen of the University of KwaZulu-Natal—were invited to present their efforts to develop national healthcare (and specifically) mental healthcare policies as working examples of how different healthcare policies might look in sub-Saharan countries.

## CASE STUDY: UGANDA MENTAL HEALTH POLICY

In 2005, officials in Uganda performed a gap analysis of the Ugandan mental health system. A number of problems were identified, including the following:

- an inadequate and skewed pattern of distribution of mental health staff;

- poor health facilities with not enough capacity;
- wage bill ceilings that did not account for the high population growth rate, resulting in low pay for healthcare workers;
- the absence of a systematic continuing education program for mental health workers;
- the absence of psychological screening for patients with other primary non-MNS disorders;
- low prioritization of treatment of mental health at most levels of care;
- low awareness and appreciation for mental health services and disregard for mentally ill patients, especially by the non-medical administrators of health facilities;
- an emphasis on symptom management, with limited emphasis on prevention; and
- limited community awareness and stigma toward mental illness, possibly due to cultural explanations of mental illness (Ndyanabangi, 2009).

In addition, Ndyanabangi said the absence of a structured policy for MNS disorders, not just mental health disorders, has also been identified as a major gap. With these gaps identified, Uganda set about revising its high-level mental health policy, specifically detailing the elements as follows:

- **Vision:** to give the population access to a comprehensive and well-coordinated system of care that promotes mental well-being and full recovery from mental disorders;
- **Mission (addresses values and principles):** to provide quality, evidence-based, and equitable mental health services that are integrated into the healthcare system and delivered by well-trained, skilled, and motivated personnel, with the participation of persons with mental illness and their families;
- **Goal:** to reduce the burden of mental disorders using defined objectives; and
- **Objectives:** to reduce the burden of mental disorders, and more specifically, to do the following:
  - Promote the mental health of the population—everyone needs to understand the importance of mental health.
  - Provide quality mental health services that are accessible, affordable, and accountable to the community.

- Integrate mental health services throughout the whole healthcare system through a multisectoral approach.
- Provide equitable access to quality, evidence-based mental health care to all people in Uganda, especially the vulnerable populations such as children, women, the elderly, persons with disabilities, prisoners, and people in crisis situations.
- Provide comprehensive and interactive mental health programs for the rehabilitation and effective integration of clients through community empowerment.
- Increase the knowledge, understanding, and awareness of the population about mental health and mental illness.
- Promote and protect the human and civil rights of people with mental illness.

### **Organization of the Uganda Health System**

As a result of the mental health policy, Uganda evaluated the resources, systems, and organization needed to implement the policy. With regards to organization, at the top, the country established a mental health services coordinator at the Ministry of Health. The health system was also organized with a national referral hospital, which receives patients from mental health units at the regional hospitals. In the general hospitals, there are integrated services, each of which is to have an MNS focal person appointed by the district health officer.

Outside the hospital setting, Uganda maintains four levels of health centers, with the level-4 health centers functioning as mini-hospitals in rural settings. In an effort to improve access to MNS care further into the field, it is in the process of recruiting psychiatric nurses for these level-4 facilities, which are often quite removed from the nearest regional hospital. Level-3 and level-2 healthcare centers, which are even more removed, are staffed by general health workers who do what they can with the resources they have available, and they refer the complex cases to more highly trained specialists.

The key to success for Uganda, according to some speakers, will be the extent to which mental health care is integrated into primary care, especially in rural communities and level-4 health centers. “We depend a lot on our communities for the care of people with mental illness,” Uganda’s Ndyabangi said. “We are working to strengthen that compo-

nent [so] that when patients are treated, they are rehabilitated and reintegrated by working with already existing community systems.”

### **Village Health Team**

One component of the organization is the Village Health Team. Village Health Teams are made up of members of the community who are selected by the community to help address many associated health issues—from HIV to malaria to immunizations to mental health. The teams undergo a system of training, giving them basic skills for recognizing various medical conditions. “Mental health has been integrated into that Village Health Team manual so that they can be able to recognize [mental health problems],” explained Ndyanabangi. “If we can change their perception of mental health illness, we believe they can influence their communities.”

But training is not enough—retaining trained personnel is very important. Ndyanabangi noted that it is important to not only train and recruit relevant staff, but also to offer continuing medical education in mental health for all care providers. A critical need is in developing protocols that can be used at the local level. Given that many community healthcare workers are not professionals in mental health, definitive protocols will not only help the health workers provide care, but also provide quality assurance to ensure the care the patients are receiving is the best possible.

Backing all of these efforts is a dedicated fund for mental health medicines set up by Uganda. While the system is working, Ndyanabangi suggested it will always need refinement, especially to ensure that the right drugs are in stock at the right medical centers.

Ndyanabangi reported that Uganda is working toward finalizing the draft healthcare policy, and is in the process of aligning it with international standards and human rights.

### **CASE STUDY: SOUTH AFRICA**

South Africa does not have a new post-apartheid national mental health policy as of yet, and there is no mention of a health policy addressing substance use and neurological disorders. It uses instead a set of national policy guidelines that were drafted in 1997 alongside a Mental Health Care Act that was developed in 2002 and enacted in 2004 (South

African Department of Health, 2010). The Mental Health Care Act sets out the international human rights principles for the care, treatment, and rehabilitation of people with mental health disorders as well as for mass, community-based care and treatment, while the national policy guidelines serve to inform provincial policies and plans. The nine provinces of South Africa are responsible for planning and implementing health services within each province—a very different organizational structure than Uganda’s more centralized branches-from-a-common-tree structure.

The South African system has had both successes and failures, according to Petersen of the University of KwaZulu-Natal. The country’s two-part mental health policy has ensured that each province in South Africa now has a dedicated mental health directorate or subdirectorates in charge of mental health in the province, and review boards are responsible for regular inspections of mental health facilities to ensure that patients’ human rights are protected. Fifty-three percent of all general hospitals have been designated to provide 72-hour assessment and referral functions, and psychotropic drugs are part of the national essential drug list and are widely available.

Despite the success of the autonomous provincial system, Petersen noted that challenges exist precisely due to the differences between and within the provinces. According to Petersen, depression and maternal depression are rampant in parts of South Africa: One study found a 41 percent incidence in Northern KwaZulu Natal (Rochat et al., 2006). Furthermore, there are inequalities with regards to in-patient beds, budget allocations, and assessment and treatment protocols. Petersen explained, “The reasons for this inequity across provinces have really been attributed to a lack of a formal mental health policy which provides clear directives for provincial plans.” She went on to note that during a survey of mental health at the provincial levels, interviewees noted a lack of clarity on many issues. “Some provinces have directorates, others have subdirectorates, so they have different authority in terms of determining allocation of resources to mental health. It is at the discretion of the provinces in terms of how much of the budget should be dedicated to mental health.” This naturally leads to differing levels of quality of care. Beyond the interprovincial issues, Petersen noted additional gaps in the current policies:

- a lack of deinstitutionalized care for psychosocial rehabilitation at the community level,

- minimal integration with primary care for the management of common disorders such as anxiety and depression, and
- minimal programs for the promotion and prevention of mental health disorders.

One reason for these gaps is the healthcare system. In South Africa, basic mental health care is the responsibility of primary healthcare nurses. But due to the heavy burden of HIV/AIDS and tuberculosis in the country, nurses are often only able to provide counseling for a few common mental disorders and a few other MNS disorders. To assist these nurses, the use of a mental health counselor at the primary care level is being piloted in two regions. The counselor's duties include providing referrals as well as assisting in the training and supervision of community healthcare workers, who may themselves supply treatment for common mental disorders like depression and maternal depression. Another pilot program follows a Ugandan model, using group intervention to treat both general depression and maternal depression. Going forward, Petersen noted the following challenges:

- Provincial inequalities regarding human resources are likely to remain.
- Budget allocation will continue to be at the discretion of the provinces.
- Mental health is not a priority in South Africa, especially in the context of the heavy burden of treating HIV/AIDS in a resource-poor environment.

### **Integrating MNS Care into the HIV/AIDS Infrastructure**

To improve MNS care in South Africa, Petersen suggested it was critical to make the link between MNS disorders and other healthcare priorities, particularly HIV/AIDS, and also socioeconomic conditions. "There is a huge need . . . to actually make the links between mental health and poverty and to promote the idea that mental health can actually promote socioeconomic development." For example, given the burden of HIV dementia and its manifestations, it would seemingly be a natural bridge between neurological health and other healthcare priorities such as HIV/AIDS. If these links can be solidified in the minds of political leaders and non-governmental organizations, it may be possible to refine South Africa's mental or neurological health policy to provide

clear direction to the provinces and ensure development of an appropriate infrastructure that provides better care to all those in need.

## Needs, Opportunities, and Next Steps

The broad strategies described in previous chapters of this workshop summary for expanding the quality of care and making do with less are practical, real-world examples of local ingenuity. They offer a promising way forward and provide possibilities for linkages among different communities. But workshop participants highlighted the reality of treating mental health, neurological, and substance use (MNS) disorders in sub-Saharan Africa (SSA), where resources fall far short of the need, and in order to get those resources, leadership is needed that will make resource acquisition a priority.

How do you get the decision makers involved in the process? “There are two ways,” noted Michelle McMurry, director of the Aspen Institute’s Health, Biomedical Science and Society Initiative. “One, you can persuade people who do not have an interest in your area to become interested in it. Or, you can co-opt people: You can convince people that *their* priorities also apply to your *priorities*.” The interrelations between mental health and the endemic diseases of SSA provide that link, and were a major focus on the “way forward” part of the discussions.

### NEED FOR SUSTAINABLE, FEASIBLE STRATEGIES

Workshop participants emphasized that whatever plans or policies are put in place, they must be part of sustainable, feasible strategies. Creating a program where people are trained for a week and then sent off to do their job just does not work. To make lasting change, a system of supervision and support needs to be in place. Similarly, a one-time donation of psychotropic drugs is not enough; what happens to the patients when those drugs are all distributed and there is no system in place to

ensure a continuity of care? No one at the workshop identified any “quick fixes,” and participants repeatedly cautioned that the battle for improved MNS care in SSA was a long one that needs to be thought through from the very beginning. Luckily, there are models to learn from, such as the way care and funding have been provided and used to treat HIV/AIDS and malaria.

## **COLLABORATION**

Rather than one country or one organization addressing MNS issues independently, workshop participants spoke of the need to collaborate and cooperate with researchers and healthcare providers around the continent and across disease specialties. “I think we can begin to collaborate in Africa by looking at common problems and finding common solutions and working together,” said Njamnshi from Yaoundé Central Hospital, Cameroon. HIV was one area that was mentioned again and again as an important area to look at to see if the current interest and funding for HIV care can be used to improve care for MNS disorders. “It is very true there is a lot of money in HIV, but we should take advantage of that money to improve the infrastructure across the board,” said Makerere University’s Katabira. He noted that the current call for proposals from the Global Fund allows for infrastructure development. The improved health facilities would not only take care of HIV patients but would also address the needs of all patients. “I think we need to be innovative and take advantage of HIV at the moment to use the resources which are available,” said Katabira, “because they are not going to be there indefinitely.” However, integration of MNS care should not be limited to HIV/AIDS. Programs that support malaria and tuberculosis should also be leveraged to be better integrated with the primary care of individuals, and each of these offer lessons that can better assist in the development of more comprehensive MNS care (Box 4-1).

## **Research Needs**

Coincident with efforts to improve treatment today, workshop participants noted a significant need for research and data that would help guide the development and implementation of MNS policies. Workshop participants noted various areas that would benefit from further research efforts. Systematic epidemiological data are sparse or nonexistent in

**BOX 4-1****Lessons to Be Learned from the HIV/AIDS and Malaria Treatment Models***HIV/AIDS Treatment Model*

Through the years of diagnosing and treating patients with HIV/AIDS, a number of strategies have emerged, which Makerere University's Angela Kakooza-Mwesige noted can be lessons for those involved in the diagnosis and treatment of mental health, neurological, and substance use (MNS) disorders. First, one of the reasons HIV programs have been successful is that they encourage the use of community-based counseling and testing to drive the early identification of disease. "If we adopt this strategy," Kakooza-Mwesige said, "we will have the opportunity for early identification of those with associated mental or neurological conditions or infections that affect the [central nervous system]."

Additionally, many HIV programs are based on a comprehensive service package that uses the HIV-positive patient as an entry point for providing care and accessing dialogue with the whole family. By addressing the whole family, health workers are able to look for acute infections and manage opportunistic infections, which benefits both the HIV/AIDS patient and their family. Translating this type of model to MNS disorders means that once one person in the family is seeking treatment, the health workers would be able to help manage any other MNS disorders affecting the family. Supported by an array of centers to train for the diagnosis and treatment of disease at all levels of the healthcare system—another concept borrowed from HIV—this would drive MNS diagnosis deep into the rural communities where it is most needed and most lacking.

*Malaria Treatment Model*

The control strategies for treating malaria are early recognition and diagnosis, with prompt effective treatment. An emphasis has been put on the importance of managing fevers at the community-care level, strengthening the health system, integrating vector control, and managing cases effectively. The message is that community interventions are vital to the treatment of disease, and that early screening and identification of vulnerable populations is critical to better outcomes and the proper allocation of resources.

Malaria is truly a disease where treatment modalities have been pushed to far-reaching levels, although more work needs to be done. The use of community drug distributors in countries like Uganda to try to ensure medications are available when and where they are needed is an important step. This is a critical lesson for MNS disorders, where (as discussed) drug compliance is a critical factor to patient outcome. Ensuring access to drugs and compliance with prescription regimens will be critical to the success of any MNS program.

many countries in SSA, especially for children. Without reliable data on the true prevalence of disease, it is difficult to convince policy makers of the importance of putting money toward the training of personnel and purchasing of medications.

Unfortunately, researchers do not have data on the cost-effectiveness of such prevention and treatment programs. One workshop attendee noted, “We have not collected sufficient information on the pay-offs of effective, appropriate, [and] affordable interventions. . . . We seem to have enough information on the cost of providing services, say, to myself as an individual, but we do not have the information that we require to convince policy makers and finance ministers of the value of preventing [MNS].” Investing in the treatment of MNS disorders will help the village, the community, and the country as a whole. The ability to illustrate that benefit is what will convince policy makers to act.

### **The Role of Advocacy and Public Communication**

Participants stressed that in order to engender serious change, the issue of treating MNS disorders in SSA needs to come to the attention of a wide range of people, from community organizers to heads of state. One way to do this—as demonstrated with HIV/AIDS—is to show how the care of MNS disorders is fundamentally a human rights issue. To date, this has not been done. As Wellcome Trust’s Patel said, “I think we have completely missed the opportunity of getting this issue out there . . . not as a medical issue alone—which of course it is—but as a fundamental human rights issue.”

Workshop participants pointed out opportunities for mass communication, for example by integrating stories into television series or the solicitation of newspaper articles on the myriad of topics. “Sitting in Toronto or New York, you don’t realize how much television there is in [SSA],” said Njenga of the African Association of Psychiatrists and Allied Professionals. “And the print media is always pushing for bits and bits of pieces of information.”

Radio is also a well-used media outlet in SSA. Kenya alone has 46 regional radio stations, each targeting specific age groups, languages, faiths, and interests. They could be an important tool for communicating directly to the patient population. All of these different media channels can be used to get information about MNS disorders and treatments out to the public—breaking down the stigma associated with MNS disorders and encouraging those who need treatment to seek help (Box 4-2).

Through public education, the level of discussion about what treatments are available, how they are delivered, and how they are all paid for can also be raised.

Of course, public service announcements are not enough. Policy makers need to become engaged and involved, and this point was continually reiterated by attendees. For example, in Zambia, the vice president's wife has become the patron of Zambia's epilepsy association and the vice president opened the recent conference on stigma associated with epilepsy. This type of high-level involvement brings attention to disorders that are largely ignored or actively shunned by the general public. But it is also important to bring research to policy makers. Policy makers—be they healthcare oriented or not by mandate—need evidence on which to base their decisions. One workshop attendee noted, “It is very clear that the Ministry of Health and the Ministry of Finance do not have the evidence that paid community health workers are better than unpaid community health workers. We need to get our evidence right to the top.”

### **Opportunities for Decreasing the MNS Treatment Gap and Improving Quality of Care**

Numerous individual suggestions were made throughout the workshop about how to decrease the treatment gap and improve quality of care. They are compiled here as part of the factual summary of the workshop and should not be construed as reflecting consensus or endorsement by the workshop; the Forums; the National Academies in Washington, DC; or the Ugandan National Academy of Sciences. Investigating details about the feasibility and implementation of these ideas were beyond the scope of the workshop. They are as follows:

- **Recognize the related nature of MNS disorders** and thus leverage limited resources across the wide (and integrated) range of MNS disorders, helping patients who need care.
- **Establish comprehensive policies for MNS disorders** and not a patchwork of policies for mental health, neurology, or substance use. Policies should address not only strategies to decrease the treatment gap and improve quality of care for MNS disorders, but also to support research programs that develop data needed to help guide the development and implementation of MNS policies.

**BOX 4-2****Patient Advocacy: Kenyan Association for the Welfare of People with Epilepsy**

The Kenyan Association for the Welfare of People with Epilepsy (KAWE) was established in 1982 by the parent of a child with epilepsy. It provides an example of how careful thought about mental health, neurological, and substance use issues can combine with passionate commitment to improve the lives of patients in the sub-Saharan region (KAWE, 2010). KAWE is now a non-governmental organization with six volunteers on the Board of Directors and eight employees. The association envisions a Kenya in which people with epilepsy are free from stigma and able to access quality care from the government and other public health facilities. Its mission is to improve the quality of life of people with epilepsy and allow them to realize their full potential through a sustainable, comprehensive, and integrated program that is affordable and accessible to people suffering from epilepsy in Kenya. KAWE's three main programs encompass training, education, and awareness; medical provision and clinical support; and lobbying and advocacy.

KAWE's training program reaches all levels of healthcare providers—doctors, clinical officers, nurses, and community health volunteers—and trains them in epilepsy management. They do this because of the scarcity of physicians in rural settings. "Ninety percent of the doctors that are trained do not want to work in the rural areas. That is a fact that you are not going to change—at least not in my lifetime and not in many of your lifetimes either," said KAWE chair Osman Miyanji. "You still have to train people on the ground. The doctors are not going to walk out in the field. So, we have to rely on public health nurses, we have to rely on clinical officers and even the lower volunteers to help us." Miyanji reported that over the past 6 years, KAWE has trained more than 2,235 community health workers and 849 medical personnel (Miyanji, 2009).

KAWE also produces publications, posters, and videos to help with education about epilepsy. These materials, along with mass-media campaigns, speeches, and community outreach, are used to raise awareness among the public. In the area of medical provision and clinical support, KAWE runs three weekly clinics in Nairobi that see 4,000 active patients out of 10,000 registered. Drugs are provided on a cost-shared basis using a sliding scale. Miyanji explained, "[Most patients] are on simple drugs and 80 percent of our patients are well-controlled. This would be comparable to anywhere in the world in the best clinics. Eighty percent control of epilepsy is fantastic. And most of them on are monotherapy and only a few are on dual or triple therapy."

But beyond the clinic and the training room, KAWE is also active in lobbying activities to influence the Ministry of Health in Kenya. KAWE's training and educational materials have been recognized by the Ministry of Health and they continue to work together. "We are developing national guidelines

for epilepsy with the help of the Ministry of Health and we are working with the Division of Non-Communicable Diseases in the Ministry of Health,” said Miyanji. KAWA is an example of how an advocacy group can grow from one parent—one voice—to a group with great influence and have a real effect on the lives of people living with epilepsy.

- **Promote high-quality MNS research that will provide evidence to inform health policy.** These data would be used to demonstrate the devastating effects of MNS on the lives of Africans and on the economy of Africa. The data would inform policy decisions and help direct necessary resources toward MNS.
- **Improve the integration of basic diagnosis and treatment of MNS disorders into primary care.** Diagnosis and treatment of MNS disorders should be part of a much larger integrated health network that leverages the strengths of existing infrastructure and resources.
- **Leverage established infrastructure that is already in place** around HIV/AIDS, malaria, and tuberculosis to raise awareness of associated MNS disorders, improve diagnosis, and establish better treatments and care.
- **Educate the public and providers and reduce the stigma associated with MNS disorders.** To minimize the stigma (shame and fear) associated with MNS disorders, it is important to educate the public and healthcare providers that MNS disorders have a biological origin and are treatable medical conditions.
- **Increase the number of trained professionals with expertise in MNS disorders.** The existing treatment gap is in part a result of the dearth of healthcare professionals with any training in MNS disorders. Utilize task shifting as one such strategy to increase the number of trained specialists.
- **Develop continuing education (further education) requirements** that will ensure healthcare providers, MNS specialists and nonspecialists, are providing the most up-to-date care available.
- **Establish and use information technologies, including mobile technologies, to improve care.** Develop diagnostic, treatment, and continuing education training modules for MNS disorders that can be used by all healthcare providers, not only MNS specialists.

- **Establish student loan reimbursement/forgiveness programs.** These would provide an incentive for healthcare providers (e.g., doctors, nurses, and other community health workers) to seek MNS training and serve underserved communities.
- **Formalize community healthcare providers as an integral component of the health system.** Provide appropriate training and continuing education for these providers.
- **Develop pilot programs that can examine different strategies to integrate care between Western and traditional medicine practitioners.** Improve communication and coordination between Western and traditional medicine practitioners to provide better comprehensive care.
- **Improve the formulary of medications to treat MNS disorders** and establish demonstration projects to improve the reliable availability of medications in rural areas. Using collective bargaining agreements, such as through the International Dispensary Association, may help reduce the cost burden associated with improved formularies. Access to drugs and compliance with prescription regimens are critical to the success of any MNS program.
- **Establish an ongoing convening activity to facilitate an African continent-wide collaboration and co-operation in the care of MNS disorders.** This group should include a broad spectrum of stakeholders who would be brought together on an on-going basis to discuss issues of mutual interest and concern. It could also be utilized to help inform and advise governments and African politicians in the establishment of MNS policies.

## NEXT STEPS

The workshop concluded with reasoned hope. The discussions revealed that many of the pieces required to significantly improve the quality of care for MNS disorders in SSA already exist. There is a will to improve; there are examples of both successes and failures to draw from; new technologies are available; and, thanks to the workshop, there are new regional dialogues and crossborder synergies that can form the foundation of future progress.

Much work remains to be done. Efforts are in their infancy, and enormous challenges exist around funding, logistics, and infrastructure. But workshop participants outlined the broad work to be done and how new, systematic MNS treatment programs should work.

As a first principle, participants believed that any broad effort to address MNS disorders should consider all disorders of the nervous system, including addictive disorders. There is no need to recreate the disease “silos” seen in many developed countries, where psychiatric disorders are separate from neurological disorders and both are separate from substance use disorders.

Participants said new programs should focus both on treatment *and* prevention. Without that dual focus, any advances may be too easily undone. Critical areas for further study include epidemiology, treatment efficacy, and cost-effectiveness. The latter, many noted, will prove to be especially important as efforts are made to secure additional funding. “We don’t have access to nearly enough data to make the case for effectiveness and ineffectiveness,” said Alan Leshner, Institute of Medicine Neuroscience Forum Chair and chief executive officer of the American Association for the Advancement of Science. “Just as we need to be able to show what works and what we have been able to accomplish, we need to be able to show policy makers that we know that not everything works, not everything is a good idea. And we need to present an argument that separates what works from that which does not work, and then we can advocate for that.”

Much can be learned from the treatment of other diseases, including HIV/AIDS and malaria. The influx of funding that targets these diseases has created a living laboratory of what works and what does not, and it will be critical to leverage the skills, networks, and lessons learned from these programs as new MNS programs are shaped and promoted. Cooperation, rather than competition, is the only way to improve care for everyone.

If serious progress is to be made, there must also be cooperation across borders, particularly in areas such as education. As Baingana noted, rather than duplicating training programs in each nation, countries could send students to other nations where programs already exist. If Kenya has a training program for psychiatric social work, and Uganda does not, instead of spending money to develop a school in Uganda, those students could study in Kenya. “At the School of Public Health we have various initiatives where we come together as East Africa,” said Baingana.

Training, however, needs to start at the roots of the system. Community-based programs that integrate MNS care into the primary care system will provide the highest quality of care. To do this successfully, programs must be established to ensure quality training for health workers throughout the system, from the community health worker up to the hospital providers. The role of traditional healers cannot be ignored either.

Participants supported healthcare workers being paid and supported to ensure a higher continuity of care. As Leshner commented, “Stipending of the community health workers is an essential phenomenon. You cannot do it with volunteers alone.”

Participants also believed technology has a key role to play in supplementing this education, be it via mobile phone applications or Internet or DVD-based training or educational materials. As Leshner said, “There are a lot of ways in which we can do a better job of putting information in accessible and understandable ways and [of] find[ing] ways in which to use information technology more concretely.”

The formulary of medications to treat MNS disorders needs to be improved, and demonstration projects need to be established to improve the reliable availability of medications in rural areas. Major, broad improvements to the quality of MNS care in SSA are a major challenge, but they are not insurmountable. As mentioned, many of these pieces are in place, and the outlines of future research and programs are also in place. What is most needed now is the support to drive them forward.

Throughout the world, advocacy plays an important role in improving care in all diseases, and this situation is no different. Champions are needed to bring relevant issues in front of the people who can make the needed changes in each country. “There needs to be a voice in leadership at the policy level, and there need to be advocacy groups that will argue these causes,” pointed out Leshner. But leaders are needed at the local levels as well. Leshner went on to say, “My own experience is that advocacy by patients—by members of patients’ families—is the most effective form of advocacy.”

Educating the general public about MNS disorders is an important step to fighting the stigma that afflicts patients with MNS disorders. Change is a long process, but by continuing the hard work that has already begun, advances can and will be made—and the goal of providing quality care to those suffering from MNS disorders will be achieved.

# A

## **Putting into Context MNS Disorders in Sub-Saharan Africa**

The day before the workshop began in Kampala, members of the planning committee were invited to visit local health facilities to see first-hand the challenges and opportunities faced by those trying to provide high-quality mental health, neurological, and substance use (MNS) disorder health care in sub-Saharan Africa (SSA). Members visited three facilities: a local health clinic in a rural village, a regional hospital in Uganda's second largest city, and a community-based organization that works with parents and families of children with disabilities. These site visits reified many of the practical and technical hurdles discussed during the workshop, from insufficient infrastructure and resource constraints to social taboos and overwhelming need.

The visits also showed that these challenges can be overcome. Patient groups were organizing, and awareness was on the rise. For a visitor from the United States, the gap between standard practice in Western healthcare settings and the real-world situation in Uganda can be overwhelming. One lesson from the visit was that this gap need not be fully eliminated to nonetheless transform the lives of patients in the region. Focused effort and step-wise improvement can drive huge changes in the lives of patients on the ground. The site visits emphasized the need to start now.

### **RURAL HEALTH CENTER: THE BUDIMA HEALTH CENTER**

The Budima Health Center is located in the Budima parish of the Butagaya subcounty in the Jinja district. The health center is approximately 30 km from Jinja, the second largest city in Uganda, located on the shores of Lake Victoria approximately 80 km from Kampala. The

road to Budima is unpaved but well traveled. The health center offers a wide range of services, including a maternity ward. According to a sign posted on the wall of the center, services offered include the following:

- general medical services,
- immunizations,
- laboratory services,
- routine volunteer counseling and testing for HIV,
- antenatal care,
- maternity care,
- postnatal care,
- dental,
- health education,
- family planning, and
- preventing mother-to-child transmission of HIV.

The maternity ward consists of three rooms: a delivery room, a recovery room, and a room for prenatal visits. The clinic handles approximately 35 births per month, with each new mother and infant staying in the recovery room for about 24 hours after delivery before going home.

The clinic's role in education and outreach was evident on entering the clinic, with its walls covered with educational posters on a wide range of topics, including the importance of prenatal testing for sexually transmitted diseases (such as syphilis), childhood immunization, counseling for HIV-positive pregnant women, and information on how to avoid Schistosomiasis, locally known as bilharzia. The posters use pictograms as well as text in English and Swahili to reach the full range of patients.

During the visit to the health center site, forum participants were warmly welcomed by John Ibugo, chairperson of the Butagaya Parent Support group, a group dedicated to supporting the parents of children suffering from mental health disorders. The support group is made up of 46 members, drawn from the 67 villages in the Butagaya subcounty. Ibugo spoke of the challenges that families of disabled children face in the area. The catchment area for the clinic is large, and transportation is a major issue. Support group members have conducted more than 2,000 home visits that have helped them to locate 250 children with a wide range of disabilities, but many more may be out there. Parents often do not understand mental health disorders and simply do not know how to care for their children with disabilities. The area is poor, and there is a lack of vital resources such as medication, mosquito nets, and money to

pay for supplies. Further complicating their work, schools in the area have no resources or knowledge of how to deal with disabled children either.

At the time of the site visit, more than 50 parents and children had come to the health center to meet with the visiting mental health nurse and receive medications. The health center does not have a full-time mental health practitioner; instead a mental health nurse comes once a month to meet patients and dispense medications such as antiseizure drugs. A parent group was started as a grassroots way to help families with children with mental health issues, such as epilepsy, schizophrenia, and other disabilities. It may be a model for outreach in other areas because simply raising the level of awareness among families in the area could significantly increase the quality of care.

### **JINJA REFERRAL HOSPITAL, MENTAL HEALTH UNIT**

Part of the Jinja Referral Hospital, the mental health unit is located a few blocks away from the main hospital campus in a small complex of buildings. Organized around an open courtyard area, one building contains the Psychiatric Officer's office, a patient examination room, and a waiting area, while another contains a room for female patients and a room for male patients. The hospital has few staff—primarily a single psychiatric officer and his intern—but manages to treat a wide range of conditions. One way this is possible is intense involvement by patient families—they accompany patients and take responsibility for their daily needs, such as feeding and bathing. The hospital is an example of how limited resources can be stretched to extend the quantity of care delivered in a region by providing another resource for the rural village centers. Being at the site, however, one could feel the overwhelming demand for services and the potential for improvement with even a small injection of focused funding. At the same time, the challenge—surging demand and limited funds—was readily apparent.

### **JINJA NETWORK OF PARENT SUPPORT GROUPS**

JINJA Network of Parent Support Groups (JINEPAS) is an organization that runs both parent support groups for parents and families of children with disabilities as well as "Child Right Clubs"—clubs that serve to educate children about their rights. The district of Jinja has a population of nearly 400,000, 59 percent of which are children, according to JINEPAS. It is estimated that more than 35,000 of those children, or 16 percent, have some type of disability. The disabilities include various

mental and neurological disorders, such as epilepsy and cerebral palsy, as well as physical disabilities, such as blindness, deafness, and other physical disabilities. The Jinja district consists of 13 subcounties, of which JINEPAS is active in 9. JINEPAS is currently coordinating six parent support groups and five Child Right Clubs. The parent support group that the site visit participants met with in Budima is part of JINEPAS.

JINEPAS works to ensure that the policies in place address the needs of children with disabilities, helping them to live fulfilling lives. JINEPAS helps children with disabilities access services available from the government as well as from local and international non-governmental organizations. It also is working to reduce the stigma associated with disabilities by educating parents and helping them to become advocates for their children. JINEPAS members voiced a strong commitment to help their children but also a huge array of challenges, including

- inadequate access to pharmaceuticals,
- inadequately trained staff at health centers,
- inadequate disability units at schools,
- inadequate information sharing,
- a lack of assistive devices for physiotherapy,
- a lack of occupational therapy services, and
- a lack of vocational schools for children with disabilities.

The presence of groups like JINEPAS in the region has laid the groundwork for significant improvements in the lives of area patients. Again, with a dedicated influx of resources and attention, the sense was that much could be accomplished.

## LESSONS LEARNED

The site visits set the tone for the workshops that followed. They revealed enormous need, significant challenges, and a growing group of parents and caregivers focused on improving the quality of care for mental health disorders in the region. Progress is being made, but the need continues to grow. According to local statistics, for instance, 16 percent of children in the Jinja district are estimated to have some kind of disability, including mental health disabilities. Epilepsy is the number one mental health concern, with prevalence rates that significantly exceed rates in Western nations. Theories for why epilepsy is so prevalent include the problems of nutrition, birth trauma, malaria, and sickle cell dis-

ease. Patients suffering from disorders such as epilepsy face enormous challenges in receiving quality care, starting with basic issues like transportation. The 30 km trek between the rural health center visited by the planning committee and the local mental health hospital means that if a patient cannot be treated at the health center, he or she is unlikely to be brought into the hospital—it is just too time and cost prohibitive, especially because a family member would need to accompany the patient. The lesson learned: If treatments cannot be brought to where the patients are, patients are unlikely to come to the treatments.

Even when transportation is not an issue, other hurdles remain. Few providers are knowledgeable about mental health disorders. The mental health nurse is only able to come to rural health centers once a month to see patients, and there is only one Mental Health Officer and an intern in the region's central mental hospital. The health clinic also has a limited supply of medications that it receives from the government for treatment of mental health disorders. When the government runs out, drugs are not available to the patients. Because shortages do occur, some groups have begun to set up drug banks that purchase medications that can be used by the health center in times of shortages. But given the critical importance of consistent care in mental health disorders, ensuring the steady availability of key drugs must be a focus of any mental health reform.

The stigma associated with mental health disorders is still a huge deterrent to obtaining treatment. The parent support group spoke of people with mental health disorders being restrained in villagers' homes to avoid attention in the community. Reducing stigma is a major thrust of the parent support group mission. It is hoped that through education and a general sensitization to disabilities, stigma in the communities can be reduced, and children with disabilities will be more likely to obtain the services they need to lead better lives.



## B

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# C

## Agenda

### **Quality of Care Issues for Mental Health and Neurological Disorders in Sub-Saharan Africa: A Workshop**

Tuesday, August 4, 2009  
Workshop Agenda

Sheraton Kampala Hotel, Ballroom  
Ternan Avenue  
Kampala, Uganda

#### **Background of the Workshop:**

Neurological and mental health disorders are among the leading causes of global morbidity. More than 450 million people around the world are affected, and they account for 33 percent of years lived with disability and 13 percent of disability-adjusted life years lost. Recognizing both the importance of high-quality care for brain disorders and the economic limitation of most sub-Saharan African countries in diagnosing and treating these disorders, the workshop will explore areas where policies might improve care for mental health and neurological disorders for countries in this region. The Forum on Health and Nutrition of the Uganda National Academy of Sciences (UNAS) and the Forum on Neuroscience and Nervous System Disorders of the U.S. Institute of Medicine (IOM) will convene a joint workshop to address these issues.

**Audience:**

Policy makers from countries in sub-Saharan Africa, academia, clinicians (rural and urban practice), international stakeholders, local parishioners, and rising leaders in the area of brain disorders.

**Workshop Objectives:**

- Discuss opportunities that can be used to better ensure continuity of care and sustainability within a country's healthcare system.
- Identify resources that are currently available or could be made available, in cost-effective and efficient manners, to aid in implementation of treatments and prevention projects.
- Emphasize the need for national, evidence-based policies addressing quality of care and healthcare systems for mental and neurological disorders. Discuss how to facilitate collaborations among a variety of stakeholders, including policy makers and healthcare professionals.

8:00 a.m.          Welcome

PAUL E. MUGAMBI  
President  
Uganda National Academy of Sciences

8:05 a.m.          Introductions

ALAN I. LESHNER, *IOM Neuroscience Forum  
Chair*  
Chief Executive Officer, AAAS  
Executive Publisher, *Science*

EDWARD K. KIRUMIRA, *UNAS Health and  
Nutrition Forum Chair*  
and *Workshop Co-chair*  
Dean, Faculty of Social Sciences  
Makerere University

8:15 a.m.      Workshop Objectives

STEVEN E. HYMAN, *Workshop Co-chair*  
Provost  
Harvard University

8:25 a.m.      Keynote Address: Task Shifting to Close the Treatment Gap for Mental and Neurological Disorders

VIKRAM PATEL  
Professor of International Mental Health  
London School of Hygiene and Tropical  
Medicine

8:55 a.m.      Moderated Discussion with Workshop Participants

STEVEN E. HYMAN, *Workshop Co-chair*  
Provost  
Harvard University

<p><b>SESSION I: BURDEN OF MENTAL HEALTH, NEUROLOGICAL, AND SUBSTANCE USE DISORDERS IN SUB- SAHARAN AFRICA</b></p>
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Session Objective: Review the prevalence and burden of mental health, neurological, and substance use (MNS) disorders in sub-Saharan Africa (SSA), including an examination of the economic and social impacts on communities and health systems.

9:10 a.m.      Introduction and Session Objectives

DONALD SILBERBERG, *Session Chair*  
Professor  
Department of Neurology  
University of Pennsylvania School of Medicine

9:15 a.m.      Prevalence of Neurological Disorders in SSA, Economic and Social Impacts of Under- or Nontreatment of Neurologic Disorders

DONALD SILBERBERG, *Session Chair*  
Professor  
Department of Neurology  
University of Pennsylvania School of Medicine

9:30 a.m.      Barriers to Care for Individuals with Neurological Disorders in SSA

ELLY T. KATABIRA  
Associate Professor  
Makerere University School of Medicine

9:45 a.m.      Prevalence of Mental and Substance Use Disorders in SSA, Economic and Social Impact of Under- or Nontreatment of Mental Disorders and Substance Abuse

HARVEY WHITEFORD  
Professor  
Department of Psychiatry and Population Health  
University of Queensland

10:00 a.m.      Barriers to Care for Individuals with Mental and Substance Use Disorders in SSA

FLORENCE BAINGANA  
Research Fellow  
Makerere University School of Public Health

10:15 a.m.      Moderated Discussion with Session Panelists

DONALD SILBERBERG, *Session Chair*  
Professor  
Department of Neurology  
University of Pennsylvania School of Medicine

10:45 a.m.      TEA BREAK

**SESSION II: CURRENT NATIONAL HEALTHCARE POLICIES**

Session Objective: Discuss current healthcare policies in place for MNS disorders in various SSA countries and describe what resources and infrastructure investments were needed to implement these policies.

11:00 a.m.      Introduction and Session Objectives

OYE GUREJE, *Session Chair*  
Head, Department of Psychiatry  
University of Ibadan College of Medicine

11:05 a.m.      Panel Discussion: National Healthcare Policies for Mental and Neurological Disorders (*presentations 10 minutes each*)

World Health Organization

THÉRÈSE AGOSSOU  
Regional Adviser for Mental Health and  
Substance Abuse  
WHO Regional Office for Africa,  
Brazzaville

Uganda

SHEILA P. ZARAMBA NDYANABANGI  
Principal Medical Officer, Mental Health  
Section  
Ministry of Health, Uganda

South Africa

INGE PETERSEN  
School of Psychology  
University of KwaZulu-Natal

11:45 a.m.      Moderated Discussion with Session Panelists

OYE GUREJE, *Session Chair*  
 Head, Department of Psychiatry  
 University of Ibadan College of Medicine

12:15 p.m.      LUNCH

<p><b>SESSION III: EFFECTIVE HEALTHCARE SYSTEMS: LESSONS LEARNED</b></p>
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Session Objective: Examine models for providing effective health care that may have used health systems, training programs, and dissemination of information. Discuss what can be learned from these models, how they can be expanded, and what can be applied rapidly in other SSA countries.

1:15 p.m.      Introduction and Session Objectives

CHARLES NEWTON, *Session Co-chair*  
 Senior Clinical Fellow  
 KEMRI-Wellcome Research Programme

MICHELLE MCMURRY, *Session Co-chair*  
 Director  
 Health, Biomedical Science and Society  
 Initiative  
 Aspen Institute

1:25 p.m.      Panel Discussion 1: Service Models  
*(presentations 10 minutes each)*

- How was care for mental health, neurological, and/or substance use disorders integrated into the healthcare or information dissemination model? What challenges did you face when integrating care for mental health, neurological, and/or substance use disorders into the service model?

## Millennium Development Village Project

GARY BELKIN  
Associate Professor  
Director, Program in Global Mental Health  
New York University School of Medicine

## Neurology in Africa: Service Models

ALFRED K. NJAMNSHI  
Department of Neurology  
Yaoundé Central Hospital, Cameroon

## Patient Advocacy and Support Organizations

OSMAN MIYANJI  
Board of Directors Chair  
The Kenya Association for the Welfare of  
People with Epilepsy

## Training Healthcare Workers Programs

DAVID KIIMA  
Director, Mental Health  
Ministry of Health, Kenya

## Dissemination of Evidence-Based Resources

JULIA ROYALL  
Chief, International Programs  
U.S. National Library of Medicine

2:15 p.m.

## Moderated Discussion with Panel 1 Discussants

- What can be learned from these models and what can be applied rapidly in other SSA countries? How can these models be expanded to become part of an effective national healthcare system?

MICHELLE MCMURRY, *Session Co-chair*  
Director of the Health, Biomedical Science and  
Society Initiative  
Aspen Institute

2:45 p.m. TEA BREAK

3:00 p.m. Panel Discussion 2: Disease Models  
(presentations 10 minutes each)

- What were/are the challenges and opportunities in using disease models to improve diagnosis and treatment of mental health, neurological, and/or substance use disorders?

#### Epilepsy Model

CHARLES NEWTON  
Senior Clinical Fellow  
KEMRI-Wellcome Research Programme

#### HIV/AIDS Model

ANGELINA KAKOOZA-MWESIGE  
Department of Pediatrics and Child Health  
Makerere University School of Medicine

#### Malaria Model

DANIEL JAPHETH KYABAYINZE  
Clinical Epidemiologist  
Research Officer, Communicable Diseases  
Malaria Consortium, Africa

3:30 p.m. Moderated Discussion with Panel 2 Discussants

- What can be learned from these disease models and what can be applied rapidly in other SSA countries? How can these disease models be leveraged to improve quality of care for mental health, neurological, and/or substance use disorders?

CHARLES NEWTON, *Session Co-chair*  
Senior Clinical Fellow  
KEMRI-Wellcome Research Programme

4:00 p.m.      Summary of Day One

ALAN I. LESHNER, *IOM Neuroscience Forum  
Chair*

Chief Executive Officer, AAAS  
Executive Publisher, *Science*

4:15 p.m.      Discussion with Workshop Speakers and Attendees

- Given the state of the disease burden, healthcare policies, and models, what can be learned from today's discussions and how can these be expanded to become integrated into a national healthcare system?

ALAN I. LESHNER, *IOM Neuroscience Forum  
Chair*

Chief Executive Officer, AAAS  
Executive Publisher, *Science*

EDWARD K. KIRUMIRA, *UNAS Health and  
Nutrition Forum Chair*

and *Workshop Co-chair*  
Dean, Faculty of Social Sciences  
Makerere University

5:00 p.m.      ADJOURN TO RECEPTION

Lake Side Terrace Victoria Room  
Sheraton Kampala Hotel

## **Quality of Care Issues for Mental Health and Neurological Disorders in Sub-Saharan Africa: A Workshop**

Wednesday, August 5, 2009  
Workshop Agenda

Sheraton Kampala Hotel, Ballroom  
Ternan Avenue  
Kampala, Uganda

8:00 a.m.      Welcome and Review of Day One

STEVEN E. HYMAN, *Workshop Co-chair*  
Provost  
Harvard University

EDWARD K. KIRUMIRA, *UNAS Health and  
Nutrition Forum Chair*  
and *Workshop Co-chair*  
Dean, Faculty of Social Sciences  
Makerere University

8:15 a.m.      Keynote Address

PAUL FARMER  
Cofounder  
Partners in Health  
Professor of Social Medicine  
Department of Global Health and Social  
Medicine  
Harvard Medical School

8:45 a.m.      Moderated Discussion with Workshop Participants

STEVEN E. HYMAN, *Workshop Co-chair*  
Provost  
Harvard University

**SESSION IV: DEVELOPING FEASIBLE HEALTHCARE  
SYSTEMS**

Session Objective: Explore feasible strategies to improve care for mental health, neurological, and substance use disorders given the current financial and resource constraints. Discuss opportunities that can be used to better ensure continuity of care and sustainability within a country's healthcare system. Identify resources that are currently available or could be made available to aid in implementation of treatments and prevention projects.

9:00 a.m.            Introduction to the Session

MARCELO CRUZ, *Session Co-chair*  
President  
Global Network for Research on Mental and  
Neurological Health  
Ecuador

EDWARD K. KIRUMIRA, *Session Co-chair*  
Dean, Faculty of Social Sciences  
Makerere University

9:10 a.m.            Traditional Healers and Epilepsy Treatment

ROY BASKIND  
Division of Neurology  
Department of Medicine  
University of Toronto

9:25 a.m.            Continuity of Care, Sustainability, and Standardization

OYE GUREJE  
Head, Department of Psychiatry  
University of Ibadan College of Medicine

9:40 a.m. Partners in Health

PAUL FARMER  
Cofounder  
Partners in Health  
Professor of Social Medicine  
Department of Global Health and Social  
Medicine  
Harvard Medical School

9:55 a.m. Moderated Discussion with Session Panelists

MARCELO CRUZ, *Session Chair*  
President  
Global Network for Research on Mental and  
Neurological Health  
Ecuador

EDWARD KIRUMIRA, *Session Co-chair*  
Dean, Faculty of Social Sciences  
Makerere University

10:25 a.m. TEA BREAK

<p><b>SESSION V: IMPROVING THE PRESENT, LOOKING TO THE FUTURE: DEVELOPING EVIDENCE-BASED HEALTH POLICIES</b></p>
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Session Objective: Explore the greatest opportunities for improving evidence-based health policies, leveraging resources, and developing meaningful collaborations between various countries and healthcare networks.

10:40 a.m. Introduction to the Session

FLORENCE BAINGANA, *Session Chair*  
Research Fellow  
Makerere University School of Public Health

10:45 a.m. Panel Discussion: Opportunities for Improving

## Evidence-Based Health Policies

## Lesotho

MATHAABE CECILIA RANTIMO  
Acting Director, Mental Health Services  
Ministry of Health and Social Welfare, Lesotho

## Kenya

DAVID M. NDETEI  
Director  
African Mental Health Foundation

## Rwanda

YVONNE KAYITESHONGA  
Coordinator, Mental Health Department  
Ministry of Health, Rwanda

## Neurology Perspective

MARCELO CRUZ  
President  
Global Network for Research on Mental and  
Neurological Health  
Ecuador

WILLIAM B. P. MATUJA  
Consultant Neurologist  
Department of Neurology  
Muhimbili University College of Health  
Sciences  
Muhimbili National Hospital

## Psychiatric Perspective

FRANK NJENGA  
President  
African Association of Psychiatrists and Allied  
Professions

11:45 a.m.

Moderated Discussion with Session Panelists

FLORENCE BAINGANA, *Session Chair*  
 Research Fellow  
 Makerere University School of Public Health

12:30 p.m. LUNCH

## SESSION VI: NEXT STEPS

Session Objective: Identify practical next steps by which to facilitate collaborative activities among stakeholders that are aimed to improve the quality of care of mental health, neurological, and substance use disorders.

1:30 p.m. Closing Remarks: Where Do We Go from Here?

EDWARD K. KIRUMIRA, *UNAS Health and  
 Nutrition Forum Chair*  
 and *Workshop Co-chair*  
 Dean, Faculty of Social Sciences  
 Makerere University

ALAN I. LESHNER, *IOM Neuroscience Forum  
 Chair*  
 Chief Executive Officer, AAAS  
 Executive Publisher, *Science*

2:00 p.m. Moderated Discussion with Session Panelists and Attendees

What next steps were identified during the workshop that could (1) better ensure continuity of care and sustainability within a country's healthcare system; (2) aid in implementing treatments and prevention projects; (3) better emphasize the need for national, evidence-based policies; and (4) facilitate collaborations among a variety of stakeholders, including policy makers and healthcare professionals?

ALAN I. LESHNER, *Moderator*  
Chief Executive Officer, AAAS  
Executive Publisher, *Science*

EDWARD K. KIRUMIRA, *Moderator*  
Dean, Faculty of Social Sciences  
Makerere University

3:00 p.m.

ADJOURN

PAUL E. MUGAMBI  
President  
Uganda National Academy of Sciences



## **D**

### **Registered Attendees**

Christian Acemah  
Institute of Medicine

Thérèse Agossou  
WHO Regional Office for  
Africa, Brazzaville

Juliet Akao  
Joint Clinical Research Centre

Bruce M. Altevogt  
Institute of Medicine

John V. Amany  
National Care Centre

Eva Baguma  
Uganda Society for Disabled  
Children

Hilary Bainemigisha  
New Vision Group

Florence Baingana  
Makerere University

Micheal Bamuwamy  
Ministry of Health, Uganda

William Banage  
Uganda National Academy of  
Sciences

Paul Bangirana  
Makerere University,  
Department of Psychiatry

David Basangwa  
National Referral Mental  
Hospital

Roy Baskind  
University of Toronto

Gary Belkin  
New York University School of  
Medicine

James Boogere  
Gulu University

Francis Buwembo  
Uganda National Academy of  
Sciences

Brian Byamah Mutamba  
Butabika National Referral  
Mental Hospital

Justus Byarugaba  
Makerere University Medical  
School

Pamela Collins  
U.S. National Institutes of  
Health

Marcelo Cruz  
GNRMNH, Ecuador

Patricia Cuff  
Institute of Medicine

Justine Epelu-Opio  
UNAS

Paul Farmer  
Partners in Health

Oye Gureje  
University of Ibadan

Cephas Hamba  
World Vision Uganda

Sarah L. Hanson  
Institute of Medicine

Steven E. Hyman  
Harvard University

Rebecca Harshbargen  
New Vision Group

Richard Idro  
Mulago Hospital

Judy Illes  
University of British Columbia

Grace Isebatya  
Wakiso Kira Health Centre

Kiberu Joshua  
Kawolo Hospital

Margaret Kahwa Saimo  
Uganda National Academy of  
Sciences

John T. Kakitahi  
MUSPH

Angelina Kakooza-Mwesige  
Makerere University

Joram Kasiri  
UNAS

Elly T. Katabira  
Makerere University

Gordon Katende Sematiko  
Member of Parliament

Alice Katengeka  
Crystal Counselling

Richard Kavuma  
*The Observer* Newspaper

Yvonne Kayiteshonga  
Ministry of Health, Rwanda

Prima M. Kazoora  
HEPS-Uganda

John Kelley  
McLean Hospital

Patrick Kelley  
Institute of Medicine

Fred Kigozi  
National Referral Mental  
Hospital

David Kiima  
Ministry of Health, Kenya

Eugene Kinyanda  
Medical Research Council,  
UVRI

Edward K. Kirumira  
Makerere University

Donald Kokonya  
Woodley Consultants

Joseph Konde-Lule  
Makerere University

Walter Koroshetz  
U.S. National Institutes of  
Health

Daniel Japheth Kyabayinze  
Malaria Consortium, Africa

Muhammad Kyeyune  
Mental Health Uganda

Alan I. Leshner  
American Association for the  
Advancement of Science

Henry Lutaaya  
*Sunrise* Newspaper

Susan Marino  
U.S. National Institutes of  
Health

Magirigi Martial  
National Care Centre

William B. P. Matuja  
Muhimbili National Hospital

Michelle McMurry  
Aspen Institute

Samar Mehta  
Joint Clinical Research Centre

Kathleen Michels  
U.S. National Institutes of  
Health

Marissa Mika  
The University of Pennsylvania

Osman Miyanji  
The Kenya Association for the  
Welfare of People with  
Epilepsy

Emmanuel Mufumba  
Jinja Hospital

Joseph Mugambe  
Member of Parliament

Lynda Nakalawa  
MUK

Paul E. Mugambi  
Uganda National Academy of  
Sciences

Noeline Nakasujja  
Makerere University/Mulago  
National Referral Hospital

Augustine Mugarura  
Epilepsy Support Association of  
Uganda

Edith Nakku-Joloba  
College of Health Sciences,  
Makerere University

Margaret Mungherera  
Consultant Psychiatrist, Mulago  
Hospital

Etheldreda Nakimuli Mpungu  
Butabika Hospital

Julius Muron  
Butabika Hospital

Paul Nampala  
Uganda National Academy of  
Sciences

Seggane Musisi  
Mulago Medical School

Zaam Namuli Ssali  
Uganda National Academy of  
Sciences

Stephen Matovu Muwonge  
Mulago Hospital

Harriet Nanfuma  
Uganda National Academy of  
Sciences

Franklin Muyonjo  
Uganda National Academy of  
Sciences

Aidah Nanyonjo  
Uganda Science Journalists  
Association

Jackie Naava  
JAFRA

David M. Ndeti  
African Mental Health  
Foundation

Catherine Nabagirinya  
Infectious Disease Institute

Lori Nadig  
Science Writer

Charles Newton  
KEMRI-Wellcome Research  
Programme

Nelson Naisye  
Kampala City Council

Emmanuel Ngabirano  
TPO Uganda

Alfred K. Njamnshi  
Yaoundé Central Hospital,  
Cameroon

Sebastiana Nkomo  
WHO-Harare

Frank Njenga  
African Association of  
Psychiatrists and Allied  
Professions

Henry Nsubuga  
Makerere University School of  
Public Health/CDC  
Fellowship Program

Chris Ntulo  
Basic Needs UK

William Odinga  
Uganda Science Journalist  
Association

Elialilia Okello  
Makerere University

Joseph Olanya

David Olema  
Mbarara University of Science  
and Technology

Robert Opoka  
Makerere University,  
Department of Psychiatry

Emilio Ovuga  
Gulu University

Vikram Patel  
London School of Hygiene and  
Tropical Medicine

Inge Petersen  
University of KwaZulu-Natal

Jennifer Pfau  
Case Western/UCI

Ellen Pieters  
Mental Health Uganda/Youth  
Organization

Evelien Pieters  
Mental Health Uganda/Youth  
Organization

Mathaabe Cecilia Ranthimo  
Ministry of Health and Social  
Welfare, Lesotho

Julia Royall  
U.S. National Library of  
Medicine

Patrick R. Rubaihayo  
Uganda National Academy of  
Sciences

Alibusa Seddie Wilfred  
Independent Psychiatrist

Patricia Serugendo  
MEHASO

Donald Silberberg  
University of Pennsylvania  
School of Medicine

Daphne Ssebugwawo  
UNHCO

Hussein Ssenyonjo  
Neurological Department,  
Mulago Hospital

Walunguba Thomas  
Masaka Regional Referral  
Hospital

Peter Wamboga Mugirya  
Science Foundation for  
Livelihoods and Development

Josephine Watera  
Research Department,  
Parliament of Uganda

Harvey Whiteford  
University of Queensland

Wilson Winston Muhwezi  
College of Health Sciences, UK

Matthew Wong  
University of Virginia

Sheila P. Zaramba Ndyabangi  
Ministry of Health, Uganda

## E

### Speaker Biographies

**Thérèse Agossou, M.D.**, from the Congo, is regional adviser for Mental Health and Substance Abuse in the World Health Organization's (WHO's) Regional Office for Africa in Brazzaville. Dr. Agossou is a mental health professional (psychiatry and child psychiatry) who has been working at the WHO since 2002. Since 2003, she has been in charge of the program for promotion of mental health, prevention of psychoactive substance abuse, and management of related public health problems. This program supports the 46 countries of the African Region in their efforts to consider in their national agendas mental health as a major factor in well-being, safety, and development, and to develop and implement policies, action plans, and legislation that reflect the various contexts. Before joining the WHO, Dr. Agossou worked for 22 years as a practitioner and professor of child psychiatry in the areas of clinical practice, education, training, and research. Mobilization of the key players in the communities to work toward the health and well-being of families and children strengthened her involvement in formal and informal women's networks on the community, national, regional, and international levels. She recognizes that involvement as having been and still being a source of enriching experiences.

**Florence Baingana, M.D.**, is a psychiatrist who has been working as a Research Fellow with the Makerere University School of Public Health since 2007. From 2004 to 2006, she worked as a consultant with the World Bank, where she was one of the editors of *Disease and Mortality in Sub-Saharan Africa*. From 2000 to 2002, Dr. Baingana was a senior

health specialist responsible for mental health, seconded to the World Bank by the World Federation for Mental Health, with the support of the MacArthur Foundation. The position was then supported by the U.S. government through the Center for Mental Health Services and the National Institute of Mental Health from 2002 to 2004. From 1999 to 2000, Dr. Baingana established the Mental Health Unit in the Ministry of Health of Uganda. She is a finance committee member and an honorary member of the World Psychiatric Association; an advisory committee member of the Children and War Foundation; and a member of the University Council and vice chairperson of the Finance Committee, International Health Services University, Kampala, Uganda. Dr. Baingana is an editorial board member of *Interventions* and an international committee member of Consensus Research on Mental Health and Psychosocial Issues in Humanitarian Settings. Dr. Baingana completed her M.B.Ch.B. in 1983 and M. Med. in Psychiatry in 1990 at Makerere University. In 2009, Dr. Baingana began a 30-month Master's Fellowship with Wellcome Trust; she will pursue an M.Sc. in Health Policy, Planning, and Financing, a combined degree from the London School of Economics and the London School of Hygiene and Tropical Medicine, where she hopes to specialize in mental health economics. She will then return to Uganda and carry out a study on mental health financing as part of the Fellowship support.

**Roy Baskind, M.D., FRCPC**, is a neurologist practicing in Toronto, Canada. Originally from South Africa, he completed medical school at the University of Texas Southwestern Medical Center in Dallas and went on to complete postgraduate training in neurology at the Montreal Neurological Institute of McGill University. His interest in neurology in the resource-poor world developed during his residency, when he spent an extended period working in a small rural hospital in Zambia under the direction of Dr. Gretchen Birbeck (Director of the International Neurological and Psychiatric Epidemiology Program at Michigan State University). He was closely involved in studies of traditional healers in epilepsy care. He has also served as an adviser to the Highlands Hope project, which is aimed at improving neurological care in rural hospitals in Tanzania.

**Gary Belkin, M.D., M.P.H., Ph.D.**, is an associate professor of psychiatry, New York University School of Medicine, and deputy director of the Department of Psychiatry, Bellevue Hospital Centre, New York. As a doctoral-trained historian, Professor Belkin has been interested in the value of historical scholarship to inform medical practice, with a particu-

lar focus on using history to think about the political and ethical dimensions of medicine and public health. Professor Belkin is completing a book study under contract with Oxford University Press on the work of the Harvard Brain Death Committee and evolving care for hopelessly ill individuals as a way to gain historical understanding of the bioethics movement, the uses of medicine as a source of ethical discourse, and attitudes about medical progress, ethics, and technology. This work questions assumptions about the historical appearance and value of bioethics. Professor Belkin has also been pursuing work on an eventual book-length exploration of the uses and meanings of explanations of behavior and “social psychiatry” in political and clinical thought and ethical practice. This latter interest also stems from developing demonstration projects and related research efforts that move forward community-based model approaches to mental health (and the relevance of such approaches to social development and public health strategies globally and locally), as well as to model the intellectual content and direction of public mental health as a discipline and policy-relevant domain.

**Marcelo Cruz, M.D.**, is president of the Global Network for Research on Mental and Neurological Health. He has published on neuroepidemiology, epilepsy, parasitic diseases, and neurodevelopmental disabilities. His current research examines cerebral cysticercosis as the cause of epilepsy, hydrocephalus, and dementia, as well as the clinical description, the distribution, and means of prevention and control of this parasitic infection. Dr. Cruz is the former Minister of Public Health of Ecuador and a World Bank consultant for health reform. He is an honorary member of the American Academy of Neurology. He also belongs to the Latin American Society of Pediatric Neurology, the Pan American Society of Neuroepidemiology, and the Francophone Network on Research of the Nervous System.

**Paul Farmer, M.D., Ph.D.**, is a medical anthropologist and physician. Dr. Farmer is the Maude and Lillian Presley Professor of Social Medicine in the Department of Global Health and Social Medicine at Harvard Medical School, where he is also vice chair, and the founding director of Partners In Health, an international nonprofit organization that provides direct healthcare services and undertakes research and advocacy activities on behalf of those who are sick and living in poverty. Dr. Farmer’s work draws primarily on active clinical practice and focuses on community based treatment strategies for infectious diseases in resource-poor settings, health and human rights, and the role of social inequalities in de-

termining disease distribution and outcomes. He is the associate chief of the Division of Global Health Equity at Brigham and Women's Hospital (BWH) in Boston, Massachusetts, and he served for 10 years as medical director of a charity hospital, L'Hôpital Bon Sauveur, in rural Haiti. Along with his colleagues at BWH, in the Program in Infectious Disease and Social Change at Harvard Medical School, and in Haiti, Peru, Russia, Rwanda, Lesotho, and Malawi, Dr. Farmer has pioneered novel, community-based treatment strategies for AIDS and tuberculosis (including multidrug-resistant tuberculosis). Dr. Farmer and his colleagues have successfully challenged the policy makers and critics who claim that quality health care is impossible to deliver in resource-poor settings. Dr. Farmer is the recipient of the Carter Award for Humanitarian Contributions to the Health of Humankind from the National Foundation for Infectious Diseases, the Salk Institute Medal for Health and Humanity, the Duke University Humanitarian Award, the Margaret Mead Award from the American Anthropological Association, the American Medical Association's Outstanding International Physician (Nathan Davis) Award, the Heinz Award for the Human Condition, and the Skoll Award for Social Entrepreneurship. In 1993, he was awarded a John D. and Catherine T. MacArthur Foundation Award in recognition of his work. Dr. Farmer is the subject of Pulitzer Prize Winner Tracy Kidder's *Mountains Beyond Mountains: The Quest of Dr. Paul Farmer, a Man Who Would Cure the World* (Random House, 2003).

**Oye Gureje, M.B.B.S., Ph.D., D.Sc., FRCPsych, FRANZCP, FWACP**, is a professor and head of the Department of Psychiatry at the University of Ibadan, Nigeria, and consultant psychiatrist at the University College Hospital in Ibadan. He received his medical training in Nigeria and postgraduate training in both Nigeria and England. His research interests include epidemiology of common mental disorders and of dementia as well as studies of aging, among others. He is currently president of the Association of Psychiatrists in Nigeria and president-elect of the African Association of Psychiatrists and Allied Professionals.

**Steven E. Hyman, M.D.**, is provost of Harvard University and professor of neurobiology at Harvard Medical School. From 1996 to 2001, he served as director of the National Institute of Mental Health (NIMH), the component of the National Institutes of Health (NIH) charged with generating the knowledge needed to understand and treat mental illness. Before serving as director of NIMH, Dr. Hyman was a professor of psychiatry at Harvard Medical School, director of psychiatry research at Massa-

chusetts General Hospital, and the first faculty director of Harvard University's Mind, Brain, and Behavior Initiative. In the laboratory he studied the regulation of gene expression by neurotransmitters, especially dopamine, and by drugs that influence dopamine systems. This research was aimed at understanding addiction and the action of therapeutic psychotropic drugs. Dr. Hyman is a member of the Institute of Medicine of the National Academies, a Fellow of the American Academy of Arts and Sciences, and a Fellow of the American College of Neuropsychopharmacology. He is editor-in-chief of the *Annual Review of Neuroscience*. He has received awards for public service from the U.S. government and from patient advocacy groups such as the National Alliance for the Mentally Ill and the National Mental Health Association. Dr. Hyman received his B.A. from Yale College in 1974, *summa cum laude*, and an M.A. from the University of Cambridge, which he attended as a Mellon Fellow studying the history and philosophy of science. He earned his M.D. from Harvard Medical School in 1980, *cum laude*.

**Angelina Kakooza-Mwesige, M.D.**, is a pediatrician and lecturer in the Department of Pediatrics and Child Health, School of Medicine, Makerere University College of Health Sciences, Kampala, Uganda. Her major research interests are neurology and infectious diseases, and she has vast experience in the field of HIV/AIDS among children. The bulk of her educational training has been in Uganda. However, she has also attended several short courses in pediatrics, neurology, and public health in various countries in Africa, Asia, and Europe. She took a course on clinical management of HIV at the Johannesburg Medical School, University of Witwatersrand in South Africa. She has worked as a sessional pediatrician in specialized HIV units in Uganda, including the Mild May International Center, Kajjansi, Uganda (a center for specialist training on HIV/AIDS and management of HIV/AIDS patients). She also worked at the Baylor College of Medicine Children's Foundation, a pediatric and adolescent HIV center of excellence. She is a member of the South African HIV Clinicians Society and an alumnus of the African International Brain Research Organization-funded schools. She was a recipient of the International Scholarship Award from the American Epilepsy Society in 2005, which she undertook at Children's Hospital Boston and Harvard Medical School under the supervision of Professor Frances Jensen. She has conducted a study observing features associated with epilepsy in children with HIV/AIDS and currently is pursuing her doctoral studies at Makerere College of Health Sciences and Karolinska Institute, Sweden.

**Elly T. Katabira, M.D.**, is a professor of medicine, Department of Medicine, School of Medicine, Makerere College of Health Sciences. He is a neurophysician who has also been working in the field of HIV/AIDS care and research since 1985. He is president-elect of the International AIDS Society and a founding member of the Academic Alliance of AIDS Care and Prevention in Africa. He is also a founding member of the AIDS Support Organization and still serves as the organization's medical adviser. Dr. Katabira received his medical education in Uganda, England, Scotland, and the United States. He is a former deputy dean for research in the Faculty of Medicine at Makerere University. Dr. Katabira is also the author of more than 150 published scientific articles and abstracts.

**Yvonne Kayiteshonga** is a coordinator at the Mental Health Department at the Ministry of Health in Rwanda. Her duties include defining strategies and plans of action in mental health policies and ensuring their application; advising the minister of health in the coordination and support of international exchanges in the mental health domain; and serving as a focal point for non-governmental organizations (NGOs), associations, and others intervening in that field. The most common illnesses and situations her center encounters are epilepsy (most common), trauma, psychosomatic disorders, and schizophrenia. She is a psychologist and holds a Master's Degree in Clinical Psychology.

**David Kiima, M.B.Ch.B.**, is the director of mental health in the Ministry of Medical Services in Kenya. He obtained his M.B.Ch.B. and Master of Medicine at the University of Nairobi. He has a Diploma in Child and Adolescent Psychiatry from the Institute of Psychiatry London. He has worked for the Kenyan government as a medical officer since 1981; a consultant psychiatrist (1987–1992); the deputy director of mental health (1992–1997); and the director of mental health (since 1998). He participated in the development of the *WHO Resource Book on Mental Health, Human Rights and Legislation 2005* as well as the *WHO Mental Health Policy and Service Guidance Package 2003*.

**Edward K. Kirumira, Ph.D.**, is dean of the faculty of social sciences at Makerere University, Kampala, Uganda. He is a Fellow, council member, and chair of the Forum on Health and Nutrition of the Uganda National Academy of Sciences. He has worked extensively with various aspects of population, fertility, and health in the Ugandan context, and also with reference to the current HIV/AIDS crisis throughout sub-Saharan Africa. Professor Kirumira has more than 20 years of experience

in program formulation, monitoring, review, and evaluation, mainly in relation to the health sectors, but also in relation to rural development, good governance, institutional development, and public-sector management. He has served as an external examiner and visiting professor in a number of international universities in Europe, the Far East, and United States. He is a member of various professional bodies, including the Population Association of Uganda, the Organisation of Social Sciences Research in Eastern and Southern Africa, and the International Union of the Scientific Study of Population. Professor Kirumira has published widely on population and development, reproductive health, sexuality, and HIV/AIDS. He received his Ph.D. from the Department of Sociology at the University of Copenhagen in conjunction with Harvard University's Department of Population and International Health. He holds an M.A. in Population Research from the Institute of Population Studies, Exeter University, United Kingdom, and a B.A. in Sociology from Makerere University.

**Daniel Japheth Kyabayinze, M.B.Ch.B., M.Sc.,** is a clinical epidemiologist and research officer at Malaria Consortium–Africa. Dr. Kyabayinze was trained at the two best medical schools in Uganda, Makerere University, College of Health Sciences for an M.Sc. in Epidemiology, and Mbarara University of Science and Technology for an M.B.Ch.B. Dr. Kyabayinze has received training at international universities, including postgraduate training in molecular epidemiology at the University of California–San Francisco, the University of Cape Town South Africa in regression modeling, and the University of Washington in point-of-care diagnostics. He also had medical training at Tameside Hospital in Manchester, United Kingdom, as an elective student. Dr. Kyabayinze has a wealth of experience in research on tropical diseases, particularly malaria, HIV, and neglected diseases; he has more than 20 publications in peer-reviewed journals, and he volunteers as a reviewer of various journals in his field of expertise. Dr. Kyabayinze has presented his work at various local and international meetings in Africa, the United States, and Europe. He is a recipient of various research and training grants, including a European and Developing Countries Clinical Trials partnership fellowship grant in 2005, an NIH Fogarty International training grant, and a Swedish International Development Agency and American Society of Tropical Medicine and Hygiene networking and training grants. As an epidemiologist at the Regional Centre for Quality of Health Care and quality control manager at Uganda Malaria Surveillance Project, Makerere University, he coordinated projects funded by the U.S. Agency for

International Development. Dr. Kyabayinze was previously a teaching assistant at Makerere University. He has worked in various parts of urban and rural Uganda as a clinician, researcher, and implementer of disease prevention interventions. With this broad experience, Dr. Kyabayinze now has the burden of bridging the gap between research and policy and translating ongoing research into health policies that will improve the health of Ugandans.

**Alan I. Leshner, Ph.D.**, is chief executive officer of the American Association for the Advancement of Science (AAAS) and executive publisher of its journal, *Science*. Previously Dr. Leshner had been director of the National Institute on Drug Abuse and deputy director and acting director of the NIMH. Before that, he held a variety of senior positions at the National Science Foundation. Dr. Leshner began his career at Bucknell University, where he was a professor of psychology. Dr. Leshner is an elected member (and on the governing council) of the Institute of Medicine and a fellow of AAAS, the National Academy of Public Administration, and the American Academy of Arts and Sciences. He was appointed by the U.S. President to the National Science Board, and he is a member of the Advisory Committee to the Director of the NIH. He received an A.B. in Psychology from Franklin and Marshall College and M.S. and Ph.D. in Physiological Psychology from Rutgers University. Dr. Leshner has been awarded six honorary Doctor of Science degrees.

**William B. P. Matuja, M.B.Ch.B., M.R.C.Psy., M.R.C.P.**, is a professor of neurology and coordinator of the Neurology Unit at Muhimbili University of Health and Allied Sciences (MUHAS) in Tanzania. Professor Matuja serves as coordinator of the Postgraduate NOMA Programme at MUHAS and is also an honorary professor of medicine (neurology) at the Aga Khan University of East Africa. He also serves as president, Tanzania Epilepsy Association; chair, National Polio Expert Committee at the Ministry of Health and Social Welfare; member, Technical Committee of Cysticercosis Working Group in East and Southern Africa; and member, National Institute for Medical Research Taskforce on Cysticercosis, Tanzania. Professor Matuja has researched and published widely on neurology, epilepsy, the elderly, and other mental health issues. He is also a recipient of several research grants. Professor Matuja completed his undergraduate studies in medicine and surgery at Makerere University in Uganda before specializing in neurology and psychiatry at the University of Newcastle upon Tyne in the United Kingdom. He received further postgraduate training in internal medicine at the same university.

**Michelle McMurry, M.D., Ph.D.,** is director of the Health, Biomedical Science, and Society Policy Program and the Aspen Health Forum at the Aspen Institute. She trained in pediatrics and molecular immunology. Since transitioning into health and science policy, her work has focused on the intersection of biomedical research funding policies, healthcare disparities, and global health inequities. She has been a Global Health Fellow at the Council for Foreign Relations and is an adjunct assistant professor of health policy at George Washington University. She was a Robert Wood Johnson Health and Society Scholar at the University of California at Berkeley and San Francisco. She formerly oversaw health and social policy issues for Senator Joseph Lieberman and was the senior health policy adviser for the Lieberman for President Campaign. She also worked to improve diversity in graduate science education in the Office of the Director of the National Science Foundation as an AAAS Science Policy Fellow. She received her M.D. and Ph.D. in molecular immunology from Duke University and her undergraduate degree in biochemistry at Harvard University.

**Osman Miyanji, M.D.,** graduated from Makerere University, Kampala, in 1971, and completed his postgraduate studies in Pediatrics (Master of Medicine) at the University of Nairobi in 1976. He obtained a Diploma in Neuropsychiatry and a certificate in Electroencephalography in 1981 from the University of Vienna, Austria. He served in the Kenya public service in various positions from 1971 to 1979, including provincial pediatrician and consultant. Since 1980 he has been based at the Aga Khan University Hospital, Nairobi (AKUH-N), starting as hospital pediatrician, and later as chair of the Department of Pediatrics (1994–2004). Dr. Miyanji has been a consultant in pediatrics and pediatric neurology at the AKUH-N and Gertrude Gardens Children's Hospital, Nairobi. He is an honorary lecturer at the AKUH-N. He also played a leading role in developing pediatric neurology and epilepsy services in Kenya. He was one of the founding directors of the Kenya Association for the Welfare of People with Epilepsy in 1982 and has been its chair since 1997. For many years he has been a council member of the Kenya Society of Epilepsy.

**Paul E. Mugambi, M.Sc., Ph.D.,** is a founding member and president of the Uganda National Academy of Sciences. He is also the vice chancellor of Nkumba University, one of the nascent chartered universities in Uganda. Professor Mugambi has vast experience in university administration; he served as head of the Department of Mathematics, dean faculty of science, and director, Institute of Computer Science, among others at

Makerere University from 1976 to 1996. He has made significant contribution to the formulation of national policy frameworks; the most recent was the National ICT Policy Framework, for which he served as chairperson of the drafting committee. He holds a B.Sc., M.Sc., and Ph.D., and he is the first professor of mathematics in East Africa. In 1991 he was awarded a Medal by the African Mathematical Union in recognition of his contribution to the development of mathematics in Africa. In 1999 he was awarded a Certificate of Merit for 25 years of meritorious service to Makerere University. He is involved in active teaching, sits on a number of academic bodies, and belongs to a number of professional organizations, including the American Mathematical Society, Biometric Society, and Uganda Mathematical Society, of which he was the founding president in 1970. For 10 years starting in 1992, he served as the main coordinator of all projects of Makerere University under the Norwegian Universities' Committee for Development Research and Education program.

**David M. Ndetei, M.D.**, did his undergraduate medical training in Kenya and postgraduate training in psychiatry at the Institute of Psychiatry, London. He earned his Doctorate in Psychiatry at the University of Nairobi. He is professor of psychiatry at the University of Nairobi, a position he has held since 1995. He is the founding director of Africa Mental Health Foundation, a non-governmental organization (NGO) dedicated to research for evidence-based policy, as well as practice in and promotion of mental and neurological health and healthy behavior. He is also a member of the Kenya Medical Research Institute National Ethical Research Committee. Since 1998, he has held various administrative positions at the University of Nairobi, including chair of the Department of Psychiatry and member of the University Senate. He has published more than 200 papers and chapters in different peer-reviewed journals. He is editor of *The Africa Text Book of Psychiatry and Mental Health*, bringing together 69 contributors from all of Africa, including South Africa. He has finished editing three other books and is in the process of editing another for top-range mental health practice and research in Africa. Professor Ndetei is currently involved in several research activities on various aspects of mental and neurological health, such as HIV, malaria, and neurobehavioral development in early childhood; the prevalence of depression, anxiety, and drug use among community-dwelling adults seeking HIV testing in Nairobi, Kenya; and training on the UNODC Gloj71 Master Trainer on the Treatnet Training Package and Community-Based

Detoxification and Rehabilitation of Alcohol Abusers, Kangemi, Nairobi, Kenya.

**Sheila P. Zaramba Ndyanabangi, M.D.**, is a principal medical officer and head of the Mental Health Unit at the Ministry of Health, Uganda. She also serves as the chairperson of the Tobacco and Health Forum; as focal person, Alcohol and Drug Abuse Control; and as a member of the Legislation Taskforce at the Ministry. Dr. Ndyanabangi is also vice chairperson of the University Council at Uganda Christian University, Mukono. She has researched and published on varied issues in mental health. She holds a bachelor's of Medicine, bachelor's of Surgery, and master's of Medicine in Public Health from Makerere University. She has also attended short courses in mental health and child illnesses in various countries in Africa and Europe.

**Charles Newton, M.D.**, was born in Kenya and qualified in Cape Town, South Africa, with postgraduate training in Pediatrics in Manchester and London, United Kingdom. As a lecturer at the University of Oxford, he went to Kilifi in Kenya to help set up a unit to study severe malaria in African children. Then he spent two years as a Postdoctoral Fellow at Johns Hopkins University in Maryland, studying mechanisms of brain damage in central nervous system (CNS) infections. He went to Great Ormond Street Hospital, UK, to complete his training in pediatric neurology. In 1998 he was awarded a Wellcome Trust Senior Clinical Fellowship to return to Kilifi to study CNS infections in children. He became head of clinical research in Kilifi, and he has published on a wide variety of subjects concerning sick children in tropical countries. He continues to live in Kenya, where he conducts research on CNS infections in children; epidemiological studies of epilepsy and neurological impairment; tetanus, jaundice, and sepsis in neonates; and sick children admitted to district hospitals in Africa. He is currently conducting epidemiological studies of epilepsy in five countries in Africa.

**Alfred K. Njamnshi, M.D., M.A., DMS, FMH**, is Swiss board-certified as a consultant neurologist and clinical neurophysiologist, and he heads the Neurology Department of the Central Hospital Yaoundé (Teaching Hospital). He is also vice dean in the Faculty of Medicine and Biomedical Sciences of the University of Yaoundé 1 in Cameroon. He is the founding president of the Society of Cameroonian Neurologists and First Vice President of the Cameroonian League Against Epilepsy, in charge of international affairs. Professor Njamnshi has shown leadership in the

development of neurology in Cameroon and now contributes to the development of neurology and neuroscience in other African countries. Formerly, he was subdirector in charge of disease control, and later, of scientific networks in the Ministry of Public Health of Cameroon, contributing to evidence-informed policy in neurological disorders. On the international scene, Professor Njamnshi is president of the Pan African Association of Neurological Sciences, regional director for Africa of the World Federation of Neurology (WFN), and chair of the Africa Committee of the WFN. He is also a board and faculty member of the Africa Committee of the International Brain Research Organisation (IBRO). In these capacities, he has played a key role in the EFNS-IBRO-WFN-sponsored neurology teaching courses and in many neuroscience schools in Africa, mentoring a good number of young African neurologists and neuroscientists. Professor Njamnshi has published significantly in the areas of epilepsy, stroke, and neurological manifestations of AIDS.

**Frank Njenga, M.D.**, is the current president of the African Association of Psychiatrists and Allied Professions and treasurer of the Royal College of Psychiatrists, Africa Division. He is a visiting research associate with the Institute of Psychiatry, UK–Health Service Research Department. He has authored and edited several books, including the landmark *Essentials of Psychiatry for Sub-Saharan Africa*. He is also author of many book chapters, and he has published extensively in peer-reviewed journals on a variety of subjects, including culture, posttraumatic stress disorder, childhood disorders, and policy development. He is a regular participant in regional and international meetings. He runs a private psychiatric hospital in Nairobi. He has hosted a weekly TV program titled *Frankly Speaking*, which helped to break stigma barriers in mental health in East Africa. He graduated from Maudsley Hospital in 1980. He is a Fellow of the Royal College of Psychiatrists and a member of the American Psychiatric Association.

**Vikram Patel, Ph.D.**, is a psychiatrist with a special interest in global mental health. His passion is to contribute to the goal of closing the treatment gap and to protect the human rights of people with mental disorders worldwide. The Wellcome Trust has supported Dr. Patel's work since 1996, and he is currently a Senior Clinical Research Fellow in Tropical Medicine. Dr. Patel works for most of the year in Goa, India, working with Goan NGOs and the government of Goa's Directorate of Health Services. Dr. Patel is the cofounder of Sangath, a Goan NGO that won the MacArthur Foundation's International Prize in 2008, an editor

of the influential *Lancet* series on global mental health (2007), a leader in setting up the new Movement for Global Mental Health, and the author of the mental health care manual for non-specialist health workers, *Where There Is No Psychiatrist*. Dr. Patel is currently working on the development of a *Lancet* series on universal health care for all of India.

**Inge Petersen, Ph.D.**, is a professor and previous head of the School of Psychology at the University of KwaZulu-Natal, South Africa. Dr. Petersen received her Ph.D. on the integration of mental health into primary health care from the University of Cape Town. She previously served as convenor of the national mental health policy commission of the African National Congress in the build-up to the first democratic elections in South Africa in 1994. Dr. Petersen is currently a research collaborator on the Mental Health and Poverty Project.

**Mathaabe Cecilia Ranthimo** is the acting director of mental health for the Ministry of Health and Social Welfare in Lesotho. Ms. Ranthimo is a psychiatric nurse. She held the position of senior nursing officer at the National Mental Hospital in Lesotho. Before then she held a senior position as a middle manager in the female ward at the National Mental Hospital. During this time she was also appointed as a clinical instructor. She obtained a degree in Nursing Administration from the University of Natal, South Africa.

**Julia Royall** is chief of international programs at the National Library of Medicine. For all of her career, Ms. Royall has been committed to bringing together technology and information—first as executive producer of a theatre company she founded on this premise while a doctoral student at Carnegie Mellon University in 1976 and later as a project coordinator at the Massachusetts Institute of Technology Media Lab. As deputy director of SatelLife, she initiated and directed the HealthNet Information Service, which served and continues to serve African countries. As director of the Multilateral Initiative on Malaria (MIM) Communications Network, she led an initiative to launch fast and reliable Internet connectivity all across Africa, to provide access to current medical literature. Royall has been working in telecommunications in health in Africa since 1990 and has 30 years of experience in the communications field. She was recruited to the National Library of Medicine at the National Institutes of Health in 1997 to create a malaria research network to support scientists in Africa as part of the MIM. For this work she has received the NIH Director's Award and was recently honored by *Federal Com-*

*puter Week* magazine. Her research interests include African American history, the history of the slave trade, PanAfricanism, and the relationship between African traditional communication systems and the Internet.

**Donald Silberberg, M.D.**, is a professor of neurology at the University of Pennsylvania School of Medicine. He received his M.D. from the University of Michigan School of Medicine, trained in neurology at the NIH, and then was a Fulbright Scholar at the National Hospital, Queen Square, London, and a Fellow in Neuro-ophthalmology at Barnes Hospital. Dr. Silberberg joined the faculty of the University of Pennsylvania's School of Medicine in 1963; he served as chair of the Department of Neurology from 1982 to 1994 and as vice dean for International Programs from 1994 to 2004. He serves as an adviser to the NIH, WHO, the World Bank, the National Security Council, the Department of State, the International Clinical Epidemiology Network, and the National Multiple Sclerosis Societies of the United States and the United Kingdom. Dr. Silberberg served as editor-in-chief of the journal *Multiple Sclerosis*, he serves on numerous editorial boards, and he has published 310 scientific reports, chapters, and reviews.

**Harvey Whiteford, M.B.B.S., M.P.H., D.Univ., FRANZCP, FAFPHM**, has trained in medicine, psychiatry, and public health in Queensland and at Stanford University. On his return to Australia in 1986 he established what is now the Queensland Centre for Mental Health Research, one of Australia's leading mental health research centers. Dr. Whiteford has held senior clinical and administrative positions in Australia, including those of director of mental health in Queensland (1989 to 1996) and the federal government (1997 to 1999). In 1999 he was appointed to the first mental health position at the World Bank in Washington, DC, where he worked to develop the Bank's capacity to respond to the rising global burden of mental disorders. He continues to work with the Australian government and international agencies on the design, implementation, and evaluation of mental health programs.