

**THE WORLD FEDERATION FOR
MENTAL HEALTH
AFRICA INITIATIVE**



**EXECUTIVE SUMMARY REPORT FROM
THE INTERNATIONAL EXPERTS
FORUM: ADDRESSING THE MENTAL
HEALTH CONSEQUENCES OF HIV/AIDS**

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Introduction

The World Federation for Mental Health (WFMH) International Experts Forum was held in Cape Town, South Africa on the 29-31 of January 2008. Over 20 mental health and AIDS sector leaders from Cameroon, India, Kenya, South Africa, Swaziland, Tanzania, Uganda, United States, Zambia, and Zimbabwe gathered together for an exploratory meeting on addressing the mental health consequences of HIV/AIDS. Particular attention was given to the needs of care givers, people living with HIV and vulnerable children - groups identified as often experiencing the most significant mental health challenges as a result of AIDS.

In opening the forum, Secretary General of the WFMH Preston Garrison said: "It is clear from our grassroots partners and members that there is demonstrated need for strengthened mental health services addressing stress management, social support and self-esteem among people living with and affected by HIV. Caregivers in particular experience high levels of stress and their role can take a substantial mental health and physical toll as they care for the physical, emotional and economic needs of their family members." Professor Brian Robertson, WFMH Board Member and Lead Volunteer on the Africa Initiative, went on to describe the AIDS epidemic as a humanitarian catastrophe, and challenged participants to consider whether current AIDS interventions were being undermined by a lack of accessible and effective mental health interventions. This was echoed by Dr. Frank Njenga, President of the African Association of Psychiatrists and Allied Professions, who offered an overview of the status of mental health in Africa and concluded that a scale-up of comprehensive mental health services working in collaboration with national and local AIDS programs was urgently needed.

Goals to focus the discussions

After the opening addresses, forum participants were invited to contribute their expertise on a variety of issues through roundtable discussions, individual and panel presentations. Discussions were geared towards the following meeting goals:

- Developing information, perspective, and context to guide the Initiative's strategic planning
- Identifying gaps and unmet needs that might be addressed through the Initiative
- Identifying ideas on how to promote greater communication and collaboration among mental health (MH) and HIV/AIDS NGOs
- Receiving suggestions as to how WFMH might contribute to the on-going work of grassroots mental health and HIV/AIDS organizations in Africa
- Receiving suggestions for possible collaborative efforts with organizations and agencies working the fields of mental health and HIV/AIDS

- Identifying organizations that might want to be part of WFMH and the Initiative's network (as key informants, collaborators, endorsers, etc.)
- Receiving ideas regarding the usefulness of organizing and convening an All-Africa Conference/Forum addressing the mental health consequences of HIV/AIDS
- Identifying concerns, cautions and challenges for the initiative in going forward

The interaction between mental health and HIV/AIDS is multi-faceted

In terms of giving context to the forum and the eventual WFMH Africa Initiative, considerable discussion took place on the interaction between mental health and HIV/AIDS. Professor Melvyn Freeman, a consultant in mental health and HIV/AIDS policy, suggested that a range of people are "mentally affected" by HIV/AIDS, and that society as a whole is also affected. Not only might those who are infected with the virus and their carers encounter mental health problems, but so too might those who are unsure about their status and then ruminate about whether or not they are positive. He further presented research from various African-based studies which had concluded that: there is evidence of a link between mental health and AIDS in Africa; mental disorders are higher in People Living with HIV/AIDS (PLHA) compared to the general population; and, that the relationship between mental disorders and HIV is bi-directional. Mental disorders were shown to be both a risk factor and a consequence of HIV.

Dr. John Anderson, Senior Director of the Office on AIDS at the American Psychological Association, also referred to increasing American-based data on the complex interactions driving the epidemic, particularly with regard to issues of substance use and trauma. It was further suggested that it be recognized that in order to treat a physical disorder, such as HIV, attention must be paid to the individual's mental health given that mental health issues often develop during times of major physical illnesses, regardless of the presence or absence of effective treatment.

With this multi-faceted interaction between mental health and HIV/AIDS recognized, how this interaction has been addressed was considered. While there was evidence of some exceptions, it was generally felt that while the interaction isn't new and has been well recognized, mental health has yet to be highlighted as a major issue in the context of the HIV/AIDS epidemic. It was suggested that there is a significant gap between what is known about mental health and HIV/AIDS and what is done in practice, and that this "treatment gap" is a critical issue to be addressed through advocacy, policy, education and awareness. Challenges to achieving this were recognized, particularly around the issues of stigma, discrimination, and lack of knowledge throughout the population including the medical fraternity, policy makers, and the general public. The need to produce and disseminate high quality, relevant and evidence-based

information adapted to the African setting was seen as an integral part to any initiative.

Exploring gaps in mental health and HIV/AIDS response

A series of roundtable discussions explored gaps in mental health that could be addressed via the WFMH Africa Initiative in order to optimize the well-being of people infected or affected by HIV in Africa. The discussions were dynamic and the input varied, but a number of themes emerged. The need to train health care workers in order to reduce mental health and HIV related stigma was suggested, and was seen as an example for increased collaboration.

Mr. Sylvester Katontoka, President of the Mental Health Service Users Network of Zambia, noted the lack of integration of the needs and voices of people experiencing mental health problems, and stated that increased empowerment of these people is needed. The National Director of the Zimbabwe AIDS Network, Mrs. Lindiwe Chaza-Jangira, expressed the thought that increased community-level support is needed for those who receive a positive diagnosis, and that better understanding is needed around how mental health problems increase the vulnerability of individuals to HIV infection.

Need to expand community capacity to address mental health and HIV/AIDS

The need to expand community-level capacity was a strong theme throughout all of the discussions. Mrs. June Koinange, President of the Kenya Psychological Association, expressed strongly the need to train key community leaders who can enhance community mobilization related to AIDS and mental health, and stated that these community mobilizers are key to securing the action required to respond to needs when they arise at a community level. Cascade-style training and the development of materials and methodologies to support the mainstreaming of mental health and HIV issues into broader programs was raised as an important roll out strategy by psychologist Vivi Stavrou, Deputy Executive Director of the Regional Psychosocial Support Initiative (REPSSI). Many participants also raised the importance of ensuring appropriate quality counseling is offered to support different aspects of the AIDS response including HIV testing, treatment and care. It was also felt that the mental health sector must take in to account the impact on communities when effective treatments are unavailable and recognise that some communities may be living in a climate of poor mental health and wellbeing.

Defining possible strategies to promote increased communication and collaboration among mental health and HIV/AIDS NGOs and governmental agencies

The Forum participants gave attention to the need to promote and encourage an increased level of communication, cooperation and collaboration among NGOs working in the mental health and HIV/AIDS sectors, and between mental health and HIV/AIDS governmental agencies and commissions. Among the potential strategies that should be considered for inclusion in the WFMH Africa Initiative to address this need are:

- Find models of best practice & materials that have been used in communities and have demonstrated effectiveness
- Recognise the various layers of psychosocial support services
- Many countries have good plans but implementation is often difficult and unsteady
- Mental health must be more directly addressed in national HIV/AIDS plans
- The '*psycho*' in '*psychosocial support*' has been largely ignored & needs to be packaged differently in order to be a meaningful component of mental health service delivery for PLWA
- Mental health issues must be addressed both as an integral component of HIV/AIDS services, and as a component of primary health care

Identifying possible WFMH Africa Initiative program elements

Having identified a number of gaps, discussion turned to possible activities that had the potential to be able to address these issues through the WFMH Africa Initiative. Possible initial elements of the Initiative were identified as follows:

- Presenting a Follow-up Forum at the Association of African Psychiatrists and Allied Professions (AAPAP) Conference in Accra, Ghana in mid-2008 to gain input from national mental health NGOs
- Introducing the initiative in existing HIV and mental health forums:
 - Hosting a symposium at the AAPAP Conference to introduce the concept and framework of the Initiative
- Collaborating and networking with local and international agencies
- Developing funding proposals to support the Initiative
- Raising awareness, potentially through events such as World Mental Health Day
- Continuing to expand and refine WFMH's network of organizations and individuals in Africa interested in the WFMH Africa Initiative (including the development of an e-newsletter etc)
- Developing an Online Directory of Resources addressing mental health and HIV/AIDS
- Preparing WFMH policy statements and/or position papers on relevant issues identified by the Experts Forum (e.g. orphanages, understanding the link between HIV/AIDS and mental health, integrating HIV/AIDS care into mental health service delivery, promoting mental wellness of people living with HIV/AIDS).
- Cultivating funding for a pilot project to promote the development of Peer

- Support & Recovery Programs in two countries through collaboration with selected WFMH member organisations
- Developing and disseminating basic information and awareness packets for general health workers and community-based mental health and HIV/AIDS NGOs
 - Continuing effective and informed advocacy at both the local and international levels
 - Seeking opportunities to develop and implement collaborative or joint projects with other organizations around specific identified needs and issues

Exploring the possibility of an All Africa Partners' Forum on the Mental Health Consequences of HIV/AIDS

The concept of an All Africa Partners' Forum on Mental Health and HIV/AIDS in 2009 was also considered as an element of the Initiative. It was felt that such an event would be valuable and could be held in partnership with other stakeholders. The need for participation from a wide representation of attendees was encouraged, including representatives of national co-coordinating mechanisms, custodians of national plans, people from Francophone Africa, and people living with HIV/AIDS/mental health issues and their families. Having special interest tracks was suggested, as was publishing a journal issue of several key conference papers. Numerous conference themes were discussed, and it was decided to invite additional ideas for themes/special interest tracks from future partners if the event were to develop further. Some of the identified possible themes are:

- Children: mental health and care for vulnerable children. Integration of children into programmes
- Development of alternative strategies to institutional care for children orphaned because of AIDS
- A systematic approach based on life progression; based on stages of care (how mental health is being addressed in each stage)
- Trauma: violence/sexual-related impacts of HIV/AIDS
- Loss-complicated grief and its mental health consequences for family members of people dying from AIDS
- Challenges of managing people with alcohol & substance abuse problems in HIV programmes
- Treatment specific issues related to integrating mental health services into HIV/AIDS services

Establishing guiding principles for the WFMH Africa Initiative

Guidance on establishing principles for the WFMH to select which activities to address through their Africa Initiative was then sought. Following group

discussion, a number of principles were articulated by Dr Rita Thom (University of Witwatersrand Division of Psychiatry), as follows:

- Choose interventions with maximum potential impact
- Don't try to 'reinvent the wheel,' but access and utilize effective existing strategies and resources
- Strengthen WFMH's existing network and use it in collecting and disseminating information to those who need it most
- Stress the inescapable link between mental health and HIV/AIDS, and market it as something that can help people living with HIV/AIDS and its mental health consequences
- Work to educate and improve the attitudes of mental health and general health workers about people living with HIV/AIDS and its mental health consequences
- Promote increased supports for health workers serving people living with HIV/AIDS
- Advocate for greater integration of HIV/AIDS care into the mental health service systems of countries in Africa

The need to access and utilize effective existing strategies and resources was particularly strong throughout the discussions, and was seen as both a way to improve quality and enhance capacity, as well as a method to increase collaboration. A panel discussion was held through which selected forum participants gave examples of best practices from their own countries, and a number of strategies were identified for promoting increased communication and collaboration among mental health and HIV/AIDS NGOs and governmental agencies

Some major trends emerging from the Forum discussions

The two full days of thoughtful, open and energetic discussions that characterized the WFMH International Experts Forum resulted in the emergence of a number of trends that will serve to guide formulation of the ultimate programs and activities that will become elements of the WFMH Africa Initiative. These trends include:

- The need for a commitment to a Public Health model, effectively addressing MH and HIV/AIDS support services.
- The increasing recognition that in order to treat a physical disorder attention has to be paid to the individual's mental health. Mental health issues often develop during times of major physical illnesses, irregardless the presence or absence of effective treatment.
- The need to address stigma and discrimination. Mental health disorders and HIV/AIDS both are affected by stigma and discrimination. For people with

mental illnesses, stigma has been one of the most difficult barriers to improving services, treatment. The same has been true for HIV/AIDS in many parts of the world.

- The importance of using the media to get more accurate and useable information available and to begin to normalize the understanding, recognition and acceptance of MH issues as well as HIV/AIDS and the relationship between the two.
- The needs of caregivers, not just family members or close friends but also mental health workers and general health workers, requires more serious attention and greater allocation of resources.
- There remains a significant gap between what we know about the treatment/prevention of mental disorders/HIV/AIDS and what we actually do. This is a critical barrier to be addressed through advocacy, policy, education, awareness.
- Definitions are a problem in communicating to the public and to other sectors. “Mental health” - “Mental illness” – “Psychosocial Support”, “Well-being”. We need to recognize the confusion and clarify messages
- Societal aspects and impact on community of the unavailability of effective treatment and support. Also, the impact of poor public mental health. Communities and nations may live in a climate of poor mental health and wellbeing. To address these factors, the mental health sector has to address broader societal aspects/impacts.
- A significant amount of good work is already occurring. Need to bring knowledge of that work together in a way that others can access it and learn from it. Avoid duplicity. Enhance capacity/collaboration.
- Advocacy for improved public policy, increased allocation of resources, and greater integration of mental and physical health services in a must to improving conditions in many countries.
- Education & awareness-building are important strategies to help the general public become more accepting of both mental health/illnesses and HIV/AIDS

Conclusion: Moving Forward with the WFMH Africa Initiative

In conclusion, it was agreed to move forward in mobilizing an Africa-wide initiative to address the complex and multiple interactions between mental health and AIDS through a focus on community-level mobilization.

The initiative will seek to mobilize further interest at the AAPAP Conference in Ghana, compile an online directory of joint HIV and mental health resources, develop a series of policy papers and information packs for key workers, and convene a partners' forum in early 2009 exploring the mental health consequences of AIDS for people living with HIV, their families, caregivers and communities.

In the aftermath of the Forum, the WFMH Secretariat has begun to set a number of the recommendations in motion, including the preparation of a baseline on-line directory of resources and programs, a bibliography of journal articles relating to the mental health consequences of HIV/AIDS, and a directory of organizations providing psychosocial support services in countries in Africa to people living with HIV/AIDS. These documents can be accessed on the WFMH website www.wfmh.org on the dedicated website section on the WFMH Africa Initiative.

Preliminary program element exploration and discussions have been commenced for the design and development of several initial program elements through which the WFMH Africa Initiative will be launched.

Roster of Participants – WFMH International Experts Forum Addressing the Mental Health Consequences of HIV/AIDS

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