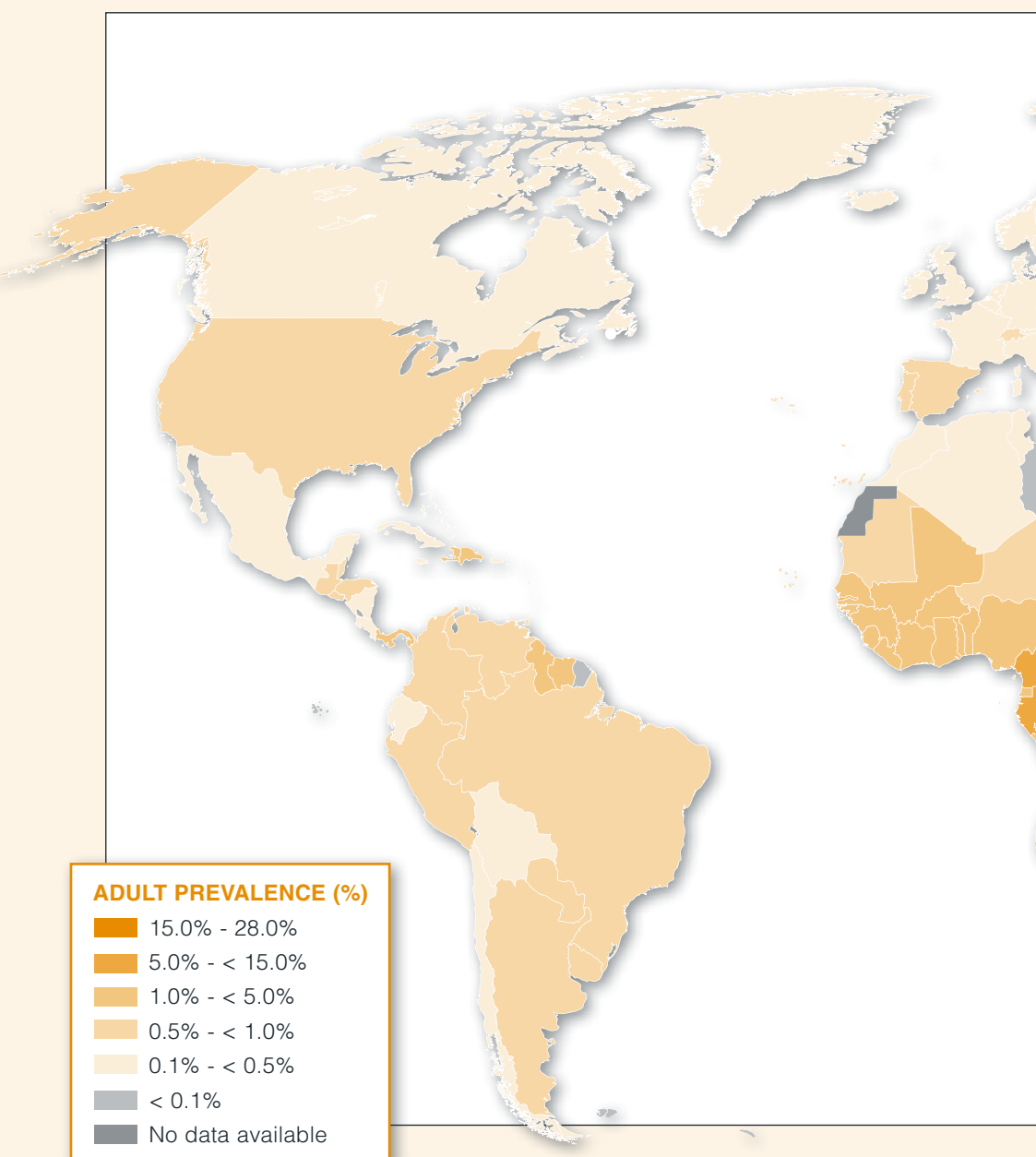


Mental Health and HIV/AIDS



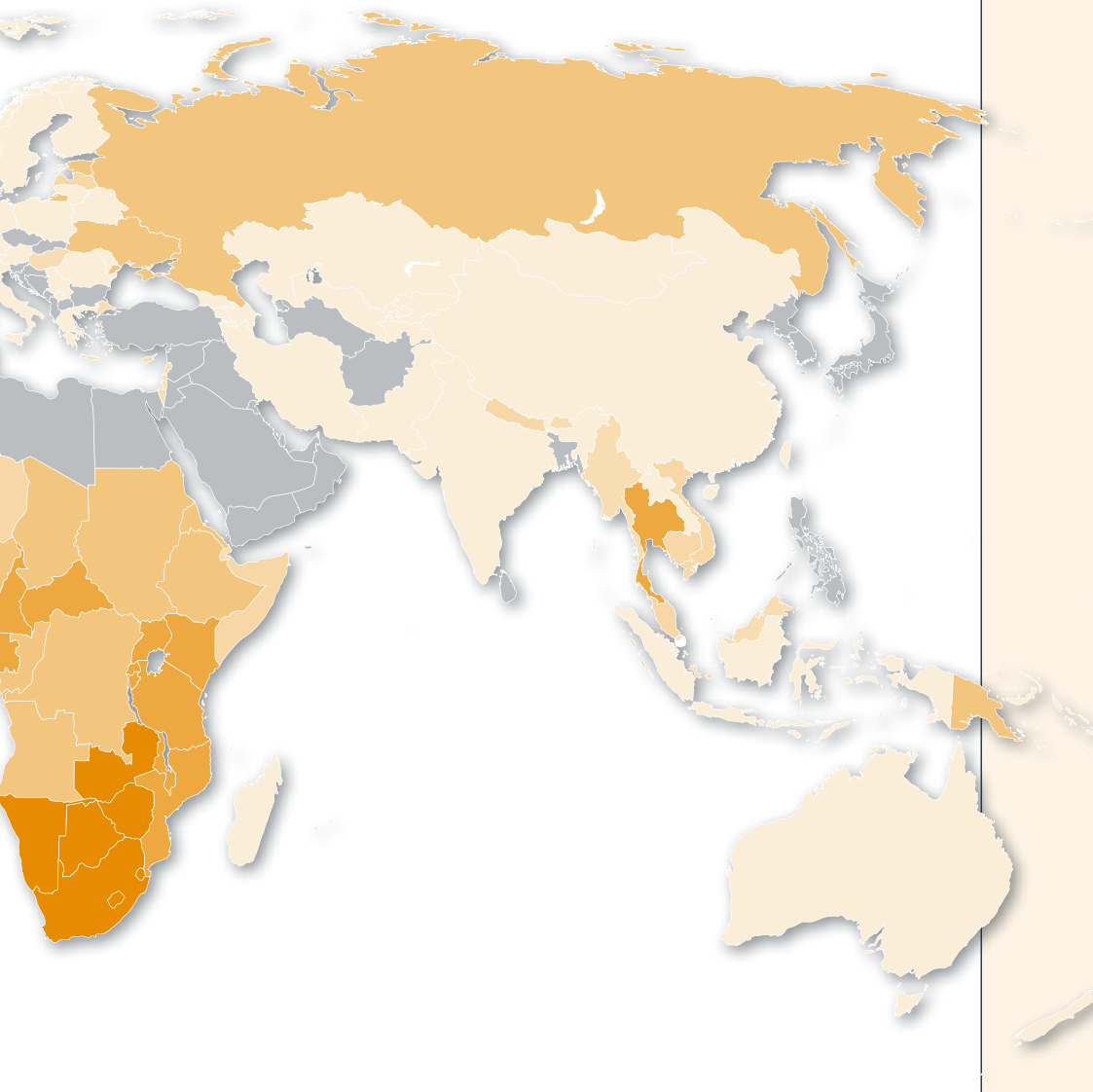
Mental Health and HIV/AIDS

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- Globally there are around 33 million people living with HIV/AIDS, approximately three quarters of these are in sub-Saharan Africa.
- More than 2 million people die annually of AIDS.
- An estimated 370 000 children become infected per year.
- Approximately 15 million people living with HIV also have a mental disorder.
- There are currently around 12 million children who have been orphaned by AIDS. Many of these children are negatively psychologically affected.

The figures above are well publicized and relatively well known around the world, however at times numbers as large as these blur the individuals concerned and the colossal human pain and loss that continues to be experienced as a result of the epidemic. For most people seeing these figures is a little like hearing that there were 40 million casualties in World War 1 (19 million deaths), that 6 million Jews were killed in the Holocaust or that 450 million people world-wide suffer from mental disorder. Such numbers are simply too large to integrate and digest and the statistics often inadvertently hide the human suffering behind them. The numbers also hide the many millions of others who have endured personal losses as a result of these mass human tragedies. So while the statistics are important, it is critical for all of us to contemplate the human misery and the mental impacts that accompany these figures and to also consider what can be done to either prevent these tragedies from occurring or to mitigate the outcomes – including the mental health consequences. Fortunately with regard to the HIV/AIDS pandemic a lot can still be done to prevent further infections and deaths and to assist the alleviation of the consequent suffering.



Why AIDS is important to GIP

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Why is an organization whose primary concern is with the human rights and health care of people with mental disabilities concerned with HIV/AIDS? The simple answer is that in the same way that HIV is currently devastating and changing global physical health, so too is the AIDS epidemic destroying and changing mental health - and with this social and economic development and security. Moreover, despite the fact that mental health/ mental disorder and HIV/AIDS are inextricably linked, hardly any attention has thus far been paid to the mental health consequences with regard to both people infected and affected by the virus. This violates the internationally recognized right to the highest attainable standard of care. In addition people with HIV/AIDS and mental health problems face “double stigma” and hence double discrimination – another important human rights abuse. Given both the numbers involved and the extent of the personal suffering endured, HIV/AIDS is arguably the most important current global public mental health issue, and is central to the GIP concern with mental health and human rights.

Given the scale of HIV/AIDS not nearly enough is being done to prevent the spread of the epidemic and to treat those infected. This is an interminable debate and not the issue here. However it appears that the contributions of organizations (such as UNAIDS, PEPFAR and the Global Fund to fight AIDS, Tuberculosis and Malaria) and the inclusion of AIDS as one of the Millennium Development Goals is starting to make some concrete difference with regard to both the spread of the epidemic and the death rate resulting from it. Moreover organizations such as UNICEF have been examining the impacts of the epidemic on children. Initiatives from various organizations of how to deal with the social, educational and economic crises resulting from HIV are gaining momentum. However peoples' mental health has failed thus far to be adequately identified as an important HIV/AIDS issue within most initiatives dealing with the HIV epidemic.

This is a critical omission that needs urgent attention from NGOs and governments. The widespread exclusion of mental health when addressing HIV/AIDS is serious for a number of reasons:

- Mental health is one of the important “drivers” of the epidemic;
- There is increased morbidity of mental disorder as a direct result of HIV/AIDS;
- Treatment and the course of the disease is often directly affected by mental health;
- The mental health of many additional people, notably children, caregivers and even health workers, are profoundly negatively impacted on.

There is what has been termed a “vicious circularity” between mental health and HIV/AIDS. This means that initiatives to curb the spread of the disease and to keep people alive and healthy are indeed important to improve mental health, but conversely initiatives to deal with mental health will positively impact on the spread and the impacts of HIV/AIDS.



1. Mental health as a “driver” of HIV/AIDS

People with serious mental disorder have been shown to be less likely to wear condoms, to have multiple sexual partners, to trade sex for money or goods and to inject drugs. They have also been shown to have less knowledge of HIV/AIDS, to lack the appreciation of risk, to have lower levels of assertiveness, to be more likely to be coerced into sex or to be homeless – all of which increase the risk of contracting HIV. Common mental disorders also increase risk-taking behaviours. For example a study in South Africa found that youth who were depressed engaged in more risky sexual behaviours than those that were not depressed. People who abuse alcohol have also been found to engage in risky sexual behaviour. Identifying and treating people with mental disorders is therefore an important strategy for the prevention of HIV/AIDS. In most countries though, especially countries with high HIV prevalence rates, the availability of mental health services are seriously limited.

2. HIV/AIDS increases the prevalence of mental disorders

Studies in both more and less developed countries show that just under half of all people living with HIV/AIDS (PLHIV) also have a diagnosable mental disorder. Approximately 10 million people in Sub-Saharan Africa alone have both HIV and a mental disorder. To some extent the high proportion of PLHIV who have mental health problems can be accounted for by the reasons mentioned in the previous paragraph, however there are also biological and psychological reasons for this high prevalence that occur after HIV infection. It is known for example that the virus penetrates the brain resulting in dementia for some people. It is also possible that the weakening immune system may result in depressive symptoms – though more research is needed on this. In addition, for a number of people an HIV diagnosis is a major shock and this can have serious psychological consequences – even resulting in mental disorder. The stigma associated with being HIV positive can also greatly exacerbate this situation.

Hearing what some PLHIV say is illustrative:

- “I was ready to slit my wrists. But now I think I should use more heroin as long as I can, because there’s no difference between dying of an overdose or of AIDS” (Male, Kazakhstan)
- “I’m struggling to cope; there is no peace in me. I can say the right things to people, go through the motions...but when I am alone it’s a different story. My fear is that it changes you so much; it eats away at you until you’re unrecognisable even to those who know you well” (Woman, South Africa)
- “Depression was dominant. It brought unbelievable despair and questioning of what I am going to do” (Male, Georgia)

Even with the greater availability of anti-retroviral therapy PLHIV still often experience high levels of psychological distress and mental disorder. Difficulties often include problems and decisions around relationships, having children, side-effects of medication and dealing with stigma.

3. Mental disorder affects the course of the disease

Mental disorder affects the course of HIV/AIDS in two fundamental ways. Firstly there is increasing evidence to show that where mental illness and HIV co-occur, physical health suffers. Secondly mental disorder affects adherence to medication.

Depression has been linked to disease progression and death due to HIV in developed and developing countries. On the other hand access to mental health services has been shown to decrease AIDS progression and mortality.

The exact number of times that a person may safely neglect taking their anti-retroviral therapy (ART) is currently under review. However successful therapy requires constant and ongoing adherence.

People with depression and anxiety have been shown to be less likely to start ART. Helping people with mental disorder is thus an important aspect of starting and continued adherence to ART.

4. Many people are affected by HIV (even if they are not infected)

A range of people who are not HIV positive themselves are profoundly psychologically affected by HIV. These include family and caregivers; people bereaved (often by multiple bereavements); children whose parents are ill, die and leave them orphaned and even health workers who work with PLHIV.

Since HIV/AIDS occurs mainly among young adults, older people and children often have to care for the sick and dying. This puts a particularly high physical, economic and psychological strain on the caregivers. Losing an adult child or a parent is extremely difficult for those left behind. Because of the nature of the clustering of HIV, there are often multiple losses within the same family. Very few people are provided with mental health services to assist them to cope in these circumstances.

A number of studies have illustrated negative psychological consequences for children orphaned by HIV/AIDS. Support to these children, ideally from remaining family and community, is critical for emotional health as well as the intellectual and moral development of the child. Some families taking in children may need psychological assistance with the integration process. Some orphaned children may also need psychological help in addition to having needs such as accommodation, education and food security.

Our work thus far – The MAIDS project

GIP has been involved in Mental Health and HIV/AIDS (MAIDS) since 2005 in the Caucasus, Central Asia and South-eastern Europe. Expert Centers focusing on the relations between mental health difficulties and HIV/AIDS have been established in 9 countries (Armenia, Azerbaijan, Bulgaria, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Serbia and Tajikistan). Work in these areas is important because though the general prevalence of HIV is low there is substantial drug use, prostitution and considerable human trafficking and migration which all play an important role in spreading the virus. Services for PLHIV are poor and stigma and discrimination high. The GIP program helps to improve the quality of life of PLHIV as well as their partners, carers and families.

The centers engage in advocacy and awareness-building to increase understanding among health professionals and others and to decrease social stigma. They conduct research and trainings and promote the development of comprehensive mental health assistance to PLHIV. Importantly the centers also work with policy makers to understand the important links between mental health and HIV and to plan programs accordingly.

Some of the countries have already included mental health in their plans for HIV/AIDS care and treatment.

Each center has a team of professional trainers with experience and knowledge of mental health and HIV. In addition to trainings organized by the centers, the experts are also invited by other organizations and health services to conduct trainings.

The mental health and AIDS Expert Center in **GEORGIA**

HIV/AIDS is spreading rapidly in Georgia and there are fears that it will pose serious problems if it is not tackled comprehensively, including the neglected aspect of HIV/AIDS and mental health.

The Expert Center has helped to raise the issue of mental health and HIV/AIDS and through this mental health was included in the 2006-2010 National Strategic Plan for Universal Access to HIV/AIDS Prevention, Treatment, Care and Support. This means that Mental Health and HIV is considered a priority issue for the country. Moreover the Head of the Parliamentary Committee of Health and Social Affairs has established a working group on HIV and mental health related issues.

Research on “Mental Health issues and support structures concerning PLHIV in Georgia” was conducted and a forward was written by Sandra Elisabeth Roelofs – the First Lady of Georgia. Further research on “HIV/AIDS related stigma and mental health” was also accepted at a high political level by inter alia The Minister of Labor, Health and Social Affairs, the Vice-speaker of the Georgian Parliament and the Head of the Parliamentary Committee of Health and Social Affairs.

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The Expert Center has conducted 20 trainings with a total of 331 participants. MAIDS (Mental Health and HIV/AIDS) training modules have been accredited by the Continued Medical Education Center of the Ministry of Labor, Health and Social Affairs. Liaisons between professionals working with PLHIV (people living with HIV/AIDS), mentally ill persons and Intravenous Drug Users have been formed. Informal referral systems have also been formed between relevant sectors and individuals following trainings at the Expert Center.

Some of our plans for the next few years

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- Our MAIDS projects in the Caucasus, Central Asia and South-eastern Europe will continue. HIV/AIDS is a growing problem in these areas and we fully intend to make sure that the mental health aspects are not neglected. Moreover by highlighting mental health while HIV rates are at a relatively low level we can ensure that mental health becomes an integral part of prevention, care and treatment programs in this region.
- In line with the GIP objectives of growing into Africa, and given the extent of the HIV/AIDS epidemic on this continent it is logical and indeed imperative that we will expand our work in HIV/AIDS and mental health into Africa.
- As the main epicenter of the HIV/AIDS epidemic is in Southern Africa we will be setting up a formal collaboration with the University of the Witwatersrand in Johannesburg (South Africa) to co-operate in service development and research in the area of mental health and HIV/AIDS.
- We will also be working with local non-governmental organizations in Southern Africa to increase the mental health services available for people infected and affected with HIV/AIDS. (Contacts with NGOs in a number of countries have already been made).
- Experiences of working in the area of HIV/AIDS and mental health will be shared across continents.
- The services planned will ensure that the millions of children infected and affected by HIV will be included in GIP interventions.
- A small project in The Netherlands will be realised with support of the Dutch AIDS Foundation. GIP will develop a booklet for patients in the Netherlands about the relationship between HIV/AIDS and mental health.
- Together with our Polish partner SKA (Social AIDS Committee) GIP will soon start an EU-project "Developing of HIV/AIDS and mental health programs in new EU countries".

The mental health and AIDS Expert Center in **KYRGYZSTAN**

The GIP Expert Center in Kyrgyzstan has paid particular attention to raising awareness about HIV/AIDS among specialists involved in delivering mental health care. It focused on the importance of affordable and high quality mental health services for people living with HIV/AIDS (PLHIV). Forty specialists have been trained using educational modules prepared by GIP. These specialists have now become change agents by applying their knowledge to their practices.

The Expert Center initiated a study aimed to assess the role of physicians in stigmatization of PLHIV and their willingness to provide mental health service. 560 physicians were interviewed and preliminary results show that there is a big gap in both knowledge of HIV and stigmatization of patients among physicians who have been trained in HIV and those that have not.

In 2007, the Expert Center initiated a quarterly magazine aimed at providing information on Mental Health and HIV from articles published in high-quoted and advanced international medical journals. Five issues of the magazine were printed focusing on:

- 1 Stigma and Discrimination and their impact to Mental Health;
- 2 Youth's Mental Health and HIV;
- 3 Mental Health Service and its respond to HIV epidemic;
- 4 Mental Health in prisons;
- 5 Women, children and HIV (in press).



The Expert Center has also supported the establishment of a Social Center for PLHIV living in Bishkek and Chui oblast. More than 120 PLHIV are provided with a wide range of services delivered by Bishkek city AIDS center and the establishment of this Social Center extends this service to include mental health care.

How you can get involved

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Financial support: GIP does not currently have an endowment and is dependent on charitable donations and project funds. We therefore welcome your financial support, large or small.

Providing expertise: GIP and its projects often benefit from significant pro-bono or reduced rate services, for things like training, assessments, and other project tasks, from mental health professionals.

Letting us know how we might assist people on all continents who are working to improve mental health care: We appreciate being informed of people, organizations and projects that may benefit from the expertise and collaboration that GIP can offer.

In-kind support: We welcome some forms of in-kind support. Particularly useful are subscriptions to high-quality psychiatric journals or other publications or assistance in translating key texts into various languages for broader reach.

Receiving our materials: If you would like to receive our materials (annual reports and strategy papers) or our Mental Health Reforms journal please send an email to hilversum@gip-global.org.

The mental health and AIDS Expert Center in **SERBIA**

Probably the most important achievement of the Serbian mental health and HIV/AIDS project is that the relationship between mental health and HIV has been accepted as an important matter within both the professional and PLHIV communities. With this relationship acknowledged and accepted the space was created for the expert center to equip a critical mass of change agents through consultations and sharing of relevant literature. The Expert Center succeeded in becoming an important resource center for professionals and PLHIV alike.

Destigmatization of PLHIV has been achieved by:

- introducing PLHIV as lecturers and trainers on courses;
- having significant number of persons with HIV on training courses;
- having mixed groups of professionals and PLHIV as participants.

This not only allowed the professionals to understand that discrimination against PLHIV was painful and unnecessary, but it also empowered PLHIV to be proactive. PLHIV were enabled to become change agents in establishing needed services for persons affected by HIV. Several new organizations were established during the course of the project. PLHIV used resources of the Expert Center and its parent organization International Aid Network to develop their organizational capacities, and develop psychosocial support programs.

The Expert Center has managed to get three modules of training “Mental health and HIV/AIDS” accredited by the Ministry of Labor and Social Policy. In 2008 the Expert Center on mental health and HIV/AIDS delivered several additional training sessions for diverse groups of participants supported by the Ministry of Health (i.e. social workers, HIV volunteers, NGO activists and PLHIV).



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