



Double stigma, double challenge:

Mental health and HIV/AIDS in Central and Eastern Europe and the Newly Independent States

an advocacy and information document

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Global Initiative on Psychiatry

Global Initiative on Psychiatry aims to promote humane, ethical, and effective mental health care throughout the world, and is particularly active in the countries of Central and Eastern Europe and the Newly Independent States, where mental health care is still usually substandard and service users' human rights are frequently violated. It also campaigns against the political abuse of psychiatry wherever it occurs.

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Foreword from the World Health Organization

Mental health is central to building a healthy, inclusive and productive society, according to the World Health Organization (WHO 2005a). But WHO also regards HIV/AIDS as the most demanding public health and social challenge of the last 25 years (WHO 2005b). Perhaps surprisingly, the connection between these two issues is rarely made in the minds of the public, policy-makers or health professionals, and mental health concerns are often overlooked in programs for HIV prevention and care. Yet mental illness is inextricably linked with HIV/AIDS, as a causal factor and as a consequence, while mental health treatment and support for people living with HIV/AIDS is key to both improving their quality of life and preventing the further spread of the infection.

The mental health problems associated with HIV infection are well documented. Mental illness and addictions increase vulnerability to HIV infection, while being diagnosed with HIV/AIDS can have profound effects on mental wellbeing - through the associated stigma and discrimination, as well as through the progression of the disease itself. Around three-quarters of people with HIV/AIDS will have at least one psychiatric disorder in their lifetime (Baingana et al 2005). The poor economic and social conditions that underpin burgeoning HIV infection rates also underpin proliferating mental health problems.

Combating HIV/AIDS is a Millennium Development Goal endorsed by the United Nations and WHO. Access to HIV counseling, testing, treatment and care is central to WHO initiatives, which are resulting in increasing numbers of people coming forward for testing and will inevitably make more people aware of their HIV status. This increase in numbers will create a corresponding increase in the need for mental health care and treatment, and it will require different sectors of health and social care to work much more closely together. There is a growing amount of relevant guidance and experience available (see Box 1 for some examples), including the recent fruits of collaborative work within WHO itself, whose headquarters departments of mental health and substance abuse and AIDS have jointly produced a set of educational booklets (WHO 2005c). The joint WHO/European Union declaration and action plan on mental health in the European region, endorsed by all 52 member states in Helsinki in 2005, also provides inspiration and direction (WHO 2005d).

The issue is of great concern in Central and Eastern Europe and the Newly Independent States, where the AIDS epidemic is growing fast while rates of mental illness are also rising, and the resources and facilities available to treat both conditions pose difficult challenges. This advocacy document provides valuable information and ideas to help the region tackle them. WHO is pleased to work with Global Initiative on Psychiatry and the government of the Netherlands in their efforts to speed up improvements through a major new project, and commends the approach outlined below. We ignore at our peril the mental health needs of people at risk of infection or already infected with HIV in this region. If these needs continue to be unmet, the epidemic will continue its rapidly expanding impact, at deadly cost to individuals, communities and countries.

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Box 1: Some international standards and agreements relevant to mental health and HIV/AIDS

* UN Millennium Development Goals, especially number 6, 'Combat HIV/AIDS, malaria and other diseases'

* UN Declaration of Commitment on HIV/AIDS, 2001

* WHO Framework on Mental Health, Human Rights and Legislation, 2005

* WHO Mental Health Policy and Service Guidance Package, 2005

* *Mental Health: facing the challenges, building solutions*. WHO/European Union Declaration and Action Plan on Mental Health, European Ministerial Conference, Helsinki 2005.

Introduction

The countries of Central and Eastern Europe and the Newly Independent States (CCEE/NIS) are experiencing one of the fastest-growing epidemics of HIV/AIDS in the world. An estimated 1.6 million people in the region are living with HIV, a catastrophic figure representing an almost 20-fold increase in less than a decade (UNAIDS 2005). Those known to be infected are a relatively low proportion of the region's 410 million people, at 0.4%; the true number may well be much higher. HIV/AIDS affects communities and the whole fabric of society, as well as individuals and their 'significant others' such as partners and families. Socioeconomic conditions in the region such as mass unemployment, labour migration, economic uncertainty, and deteriorating health systems are highly conducive to its spread. A number of mental health concerns have been identified, including high rates of suicide, substance misuse, alcoholism and depression. Unfortunately, however, mental health care is institutionalised, inadequate and poorly resourced to meet the needs of people with mental health problems. There is an urgent need to address both HIV and mental health issues in this region, and to address them together as well since they interact in powerful ways.

This brief overview of mental health and HIV/AIDS in CCEE/NIS has been produced by the Global Initiative on Psychiatry as part of a project it is implementing with the support of the Ministry of Foreign Affairs of The Netherlands (2005-2008). The project aims to improve the quality of life and reduce the suffering of people with HIV/AIDS who have mental health problems, and of their partners, carers and families, in South Eastern Europe, the Caucasus and Central Asia. It is establishing nine new expert centers on mental health and HIV/AIDS in the region that will collect and disseminate information; run education and training programs for people living with HIV/AIDS (PLHA), carers, families and the general population; develop effective ways of dealing with HIV/AIDS-related mental health problems; and act as resource and activity centers.

This foundation document sets out the basic facts on the interaction between mental illness and HIV/AIDS and its impact on individuals and communities in the region. Above all it is intended as a spur to action, aiming to raise awareness of the importance of addressing mental health issues in HIV/AIDS, and thereby advocating increased emphasis on mental health issues in all areas of HIV prevention,

treatment and care. It explores the implications for health policy and practice, and suggests how to provide better support and assist the empowerment of people infected and affected by HIV, including self-management and social/community support. It draws on existing evidence, but is not itself a new study; rather, it summarises existing information in an accessible way. It is being adapted, summarised and translated into local languages for local use.

The primary target readership for this document is all those involved in health and social policy-making and activism in the countries of central and eastern Europe and the former USSR, particularly the countries involved in our project. They include politicians, policy-makers and other opinion-formers in countries; those responsible for planning and managing health and social care services; education leaders; organizations of professionals working in health and social care; donors; and organizations representing PLHA and mental health service users.

The links between mental health and HIV/AIDS

Developing AIDS or simply being HIV-positive has a major impact on individual mental health. All chronic, life-threatening conditions bring particular stressors such as long-term discomfort, physical deterioration, physical and financial dependence and the prospect of untimely death. Additional issues such as discrimination, social denial, stigma, isolation, lack of disclosure, fear of infection, multiple death and loss, and the sheer cumulative impact of such stressors, mean that HIV/AIDS has profound psychological and social impact. Mental health problems can emerge at any stage of HIV infection, including the time around HIV testing, disease progression, illness and death, and are associated with the many mental, physical and spiritual adjustments and losses that individuals confront. Those who develop the infection often come from groups who have already experienced social rejection, disadvantage and poor health. In both developed and developing countries, there is firm evidence of the link between HIV disease and poverty, leading to a downward spiral of poorer health and decreased access to health care.

Furthermore, mental health problems, drug and alcohol misuse, and learning difficulties can influence behavior in ways that lead to greater risk of HIV infection. Populations who are particularly at risk already have higher rates of mental illness, including injecting drug users, sex workers, refugees and migrants, and prisoners. Failure to treat mental health problems can lead to decreased survival time, reduced quality of life, and difficulties in adherence to HIV care and treatment. Lack of treatment and support can also diminish the person's ability to behave in ways that protect health, and increase behaviors that spread HIV. Those attempting to provide health care and social support to the individual with HIV infection often suffer from demoralisation, stress and burnout.

On the other hand, treating mental health problems brings numerous benefits for the individual, their community and society as a whole. These benefits include improved quality of life for PLHA and their families, partners and the community; improved health and effectiveness of treatment; reduced morbidity associated with HIV, other diseases and substance misuse; increased productivity which benefits society; and more efficient use of health care services. Moreover, the significant role that mental health care could play in the prevention of HIV should not be ignored.

Case study 1: Giorgi

Giorgi, 26, is an active injecting drug user. He was 18 when he first started to inject drugs in a group of close friends. A month ago one of his friends needed blood transfusion for urgent surgery and Giorgi went to the hospital to give blood. Testing revealed that he was HIV and hepatitis C positive. Giorgi was shocked - he had not expected anything like this. His life lost its meaning in one single moment.

He did not know where to go or to whom to talk. The hospital staff gave him information on the National AIDS Center for confirmation of the result and counseling services, but he was afraid to go there. He believed that AIDS was incurable and nobody could help him. He was very depressed and isolated from his friends, and thinking of suicide.

Listening to the radio one day, he heard a message from a self-help center for people living with HIV/AIDS, inviting people to get in touch. After a few days thinking about it, he phoned and made an appointment. People at the center were extremely helpful - they provided counseling and accompanied him to the National AIDS Center for follow-up testing. He was also referred to the Narcology Institute for a substitution treatment program. Now Giorgi is on antiretroviral therapy (ART) and takes methadone daily. He is thinking about quitting drug use, and feels much more optimistic about his future.

This case study is based on a true story from Georgia, but names and some details have been changed

The regional context

Rapid economic and social changes in CCEE/NIS have been accompanied by a decline in mental health, with increasing rates of drug and alcohol-related disorders, violence, depression and suicide (Box 2). Suicide rates in the region are extremely high, especially among men, with the incidence three times greater than in western Europe (WHO 2001). Such conditions have created fertile ground for HIV transmission (Box 3), as noted by Hamers and Downs (2003): "The profound social and economic upheaval in the former Soviet Union in the 1990s has resulted in a sharp increase in the incidence of substance abuse, prostitution, HIV, and other sexually transmitted infections... Rapidly declining socio-economic conditions and increasing inequity bring a sense of despair and hopelessness that is fertile ground for HIV transmission through increased risk behavior including prostitution and drug use. A struggling economy means fewer resources for prevention and care."

Despite this gloomy picture, urgent action could nip the epidemic in the bud. HIV/AIDS prevalence rates in the region are still low, with official figures ranging from less than 0.1% in, for example, Bulgaria and Lithuania, to 1% in the Russian Federation, 1.1% in Estonia and 1.4% in Ukraine. Yet some of these countries have the fastest-growing HIV/AIDS infection rates in the world. The number of PLHA reached an estimated 1.6 million in 2005 - an almost 20-fold increase in less than 10 years (UNAIDS 2005). In 2005 alone, an estimated 270,000 people were infected with HIV and 62,000 adults and children probably died of HIV-related causes. Young people are hardest hit: over 80% of those living with HIV in the region are under 30. In western Europe, in contrast, only 30% of reported cases are in this age group (UNAIDS 2004a).

Box 2: Mental health issues in CCEE/NIS

- * High rates of mental illness
- * Highest male suicide rates in the world
- * Stigma & social exclusion
- * Knowledge base outdated
- * Huge treatment gap, services inadequate:
- * Primary health care deficiencies
- * Warehouse asylums
- * Few community-based services
- * Human resources & drugs in short supply
- * No focus on intellectual disabilities
- * Daily abuse of human rights
- * Some countries spend <2% of health budget on mental health care

The rapid spread of HIV in the region is closely linked with the alarming rise in injecting drug use that followed the collapse of the USSR, in the context of economic crisis, rapid social change, increased poverty and unemployment, and increased levels of sex work. Injecting drug use is the main route of transmission in all countries in the region. In Kyrgyzstan, for example, it is estimated that at least 2% of the adult population injects drugs (UNAIDS 2004a) carrying a serious risk of rapid and extensive spread of HIV. In Georgia 70% of those registered with HIV have injected drugs, and it is thought that the actual number of drug users is much greater than official statistics suggest.

Box 3: HIV/AIDS in CCEE/NIS

- * Fastest-growing epidemic in the world, especially in the Baltic States, Russia & Ukraine
- * Around 410 million people in the region, of whom at least 0.4% are known to be infected
- * 1.6m PLHA in 2005: 62,000 deaths, 270,000 new infections
- * Figures probably grossly under-reported
- * 75% of new infections reported in 2000-2004 were in people under 30, mostly men; young people especially vulnerable now
- * Mainly fuelled by injecting drug use
- * Also driven by prostitution
- * Heterosexual and vertical transmission rising
- * Hidden epidemic among men who have sex with men
- * Prevention, treatment, care, support often minimal

The definition of what constitutes CCEE/NIS varies, but in this document it is held to comprise 27 countries: Albania, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, the Czech Republic, Estonia, Georgia, Hungary, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Poland, the Republic of Moldova, Romania, the Russian Federation, Serbia and Montenegro, Slovakia, Slovenia, Tajikistan, the former Yugoslav Republic of Macedonia, Turkmenistan, Ukraine and Uzbekistan.

The patterns of the epidemics are changing in several countries, however, with sexually transmitted HIV cases comprising a growing share of new diagnoses. In the Republic of Moldova, for example, 45% of all new reported HIV infections were attributable to unprotected sex in 2004 (EuroHIV 2005). While most of those in the region currently infected with HIV are men, increasing numbers of women are being infected - many by male partners who become infected while injecting drugs. More children are being born to HIV-positive mothers, making prevention of mother-to-child transmission a priority (UNAIDS 2005). Increasing numbers of children will lose their parents through death or abandonment; many will be cared for in institutions, and will be affected by the psychological and social stressors associated with HIV/AIDS. There are also concerns about hidden outbreaks among men who have sex with men, since the strong stigma attached to homosexuality may inhibit many from seeking or securing testing or treatment. There is evidence of high levels of unprotected sex among such men in the region, with a significant proportion also having sex with women (WHO 2004).

The Russian Federation accounts for 70% of all HIV infections in the region, but the potential for epidemics in other countries is also a cause for concern. The number of registered infections continues to rise and the major drivers of HIV infection are present. In Moldova, for example, HIV prevalence of almost 5% has been found in street-based sex workers; one in 10 also reported a history of injecting drug use (UNAIDS 2004a). Almost 2% of men who have sex with men tested HIV-positive in sentinel studies in the capital Chisinau (WHO 2005b).

The difficulty in obtaining accurate data is a major problem. The prevalence rates given above only reflect the situation among people who come into contact with testing programs, and are almost certainly underestimates. Little is known about those who do not come into contact with HIV testing services or are treated in other health services. The lack of effective referral systems or collaboration between the many different services used by people with known or undiagnosed HIV/AIDS is also an obstacle to effective and speedy treatment. These services include mental health, primary health care, reproductive and maternity care, infectious diseases, sexual health clinics and addiction centers. While HIV treatment and prevention programs have expanded, the number of people receiving antiretroviral drugs lags far behind the number in need of treatment (UNAIDS 2005).

Access to treatment of any kind is rare to non-existent for HIV-positive injecting drug users. This is a cause for great concern, because the potential for extremely rapid spread of the virus, among users and to the general population, is an important feature of HIV epidemics among injecting drug users. Evidence from cities including Odessa, Bangkok and New York indicates that once HIV prevalence reaches 10%, it can surpass 40-50% in one to four years (Centre for Harm Reduction 2003). In addition, there is even greater potential for rapid spread through needle-sharing and unprotected sex where many injecting drug users are sex workers or in prison. HIV spreads most quickly when injecting equipment is shared among many people, but may also be spread by injecting tainted drug preparations and by injecting from a common container. These are ideal conditions for transmission of HIV and other blood-borne viruses such as hepatitis B and C. An estimated 60-90% of all injecting drug users infected with HIV also have hepatitis C, and the associated liver damage is a leading cause of death among people with HIV (Patrick et al 2001). HIV-positive injecting drug users are also particularly susceptible to tuberculosis and bacterial pneumonia.

Case study 2: Elena

Elena, 51, is a single mother with a son aged 13. Four years ago she discovered she was HIV-positive while having hospital treatment and taking the blood test. Her first reactions were suicidal thoughts – she felt there was no point in going on living – followed by fears for her son’s future. She has no relatives who could support her and her son. She became addicted to alcohol before she learned of her HIV status, attributing this to her constant feelings of depression: no desire to live, no energy, and no willpower. She then lost her job. She does not want to be treated at an AIDS center because the first time she attended, the professional she saw was unsupportive and seemed uncaring. She has not tried to find other AIDS professionals to support her, because she feared meeting this type of reaction again, and she did not believe that anyone could help her anyway. Finally, with the support and encouragement of a doctor at the center where she is treated for her addiction, she accepted a referral to the hospital responsible for ART. She is now waiting for her treatment, which she hopes will start soon.

This case study is based on a true story from Kyrgyzstan, but names and some details have been changed

Substance misuse frequently occurs alongside mental health problems, including mood disorders such as anxiety and depression, and schizophrenia and bipolar disorder that induce psychosis (Regier et al 1990). HIV-positive injecting drug users have higher levels of cognitive impairment, mood disorders, suicide attempts and completed suicides compared to HIV-positive people who are not injecting drug users (Kalischman 1995). People who have these co-existing problems face multiple types of stigma relating to their HIV status, mental illness and substance misuse, and may have difficulties accessing and adhering to HIV treatment and care.

Case study 3: Dany

Dany displayed the first signs of paranoid schizophrenia when he was 19. The crisis was manifested through vagrancy, refusing to eat, fearing he would be poisoned, and thinking he had no place in his family home. At the age of 22 he was admitted to the psychiatric hospital for the fourth time, from the place where he had lived with other drug users. Dany was tested for HIV without being asked for his consent, because testing was compulsory for people from at-risk groups. He was found to be HIV-positive. His mother worked at the hospital as a nurse and, learning about his HIV status, rejected him. Neighbours and colleagues did the same. He is alone and lives on the street. The only help he gets is from a community mental health center set up by a nongovernmental organization. The center aims to help Dany achieve some stability in his life and cope with his diagnoses of schizophrenia and HIV.

This case study is based on a true story from the Republic of Moldova, but names and some details have been changed

Mental health problems and HIV/AIDS: identification, treatment and prevention

A higher prevalence of mental health problems has been found in HIV-positive people in a number of countries (UNAIDS 2004b). Mental health difficulties may predate the diagnosis of HIV infection and can be exacerbated by associated stressors, including some HIV medications. Many people with HIV experience multiple problems, which may emerge at different times during the course of the disease. They may experience a wide range of psychological and psychosocial issues throughout the experience of living with and adjusting to the disease. Difficulties may arise at every stage of infection including around the time of testing for HIV; when symptoms develop; receiving an AIDS diagnosis; beginning anti-HIV medication; and in terminal care. It is therefore vital for PLHA to have help with their mental health problems, both for their own sake and to control the spread of HIV (Box 4).

Box 4: Why people with HIV/AIDS need mental health support

- * Untreated mental illness & addiction > risky behavior > spread of HIV
- * Untreated mental illness & addiction > lower adherence to ART > spread of HIV & poorer prognosis
- * ART > side effects damaging to mental health
- * AIDS > brain impairment & other impacts on mental functioning
- * Untreated mental illness & addiction > poorer quality of life for PLHA
- * Untreated mental illness & addiction > greater stress on carers and families
- * Lack of social and community support > social exclusion > more illness, poverty, despair

Not everyone with HIV/AIDS will develop chronic mental health problems, but some factors increase vulnerability. These include poverty, humanitarian crises, gender inequalities, child and adult sexual victimisation, existing mental health problems, substance misuse, intellectual disabilities, and stigma and discrimination. A number of stressful events have also been identified which affect psychological response, including HIV disclosure, medication and treatment decisions, bereavement, reproductive issues and family and relationship problems. The extent and nature of psychological problems in HIV infection will be influenced by all these factors. There may be adjustment reactions, anxiety and depression, suicidal thoughts and behavior, relationship and sexual difficulties, substance misuse, and various decision-making dilemmas. In addition, HIV-related brain impairment can result in mild to severe psychological effects which can cause problems for the individual and their significant others. Each of these issues is considered in more detail below (more extensive reviews are available elsewhere, eg Catalan et al 1995).

Adjustment reactions

People living with HIV/AIDS face a number of life stressors, decision-making dilemmas, losses, and transitions that can result in transitory or more chronic emotional adjustment reactions. Notification of a positive HIV test result will usually result in transient adjustment reactions that may include expressions of despair, shock, denial, helplessness, hopelessness, grief, guilt, loss of self-esteem, anxiety and depression. These reactions generally subside in the months after diagnosis, but can be prolonged when HIV remains highly stigmatized - people may conceal their diagnosis from partners, family and friends, or face rejection and threat if their status

becomes known. Stigmatization by health care workers is very high in the region; most people with known HIV/AIDS are not treated in general health services because health workers are afraid of being infected, attitudes that contribute to more severe adjustment reactions.

Anxiety

Anxiety is commonly experienced, manifest as transient reactions to any of the following: illness progression, threat of disfigurement, pain, fear of becoming dependent on others, decision-making about medical treatments, telling others, fear of rejection, fear of infecting others, isolation, and death of friends with AIDS. Anxiety levels vary from mild to extreme but may become chronic for some people. Fear associated with the prospect of dying may also exacerbate anxiety, and increases with symptomatic HIV disease. Anxiety may also be a complication of some of the prescribed medications, or drug withdrawal.

Depression

The many psychological and social stressors associated with HIV can lead to depression, the most common mental health problem affecting people living with HIV/AIDS. It is characterised by a persistent sad mood, feelings of emptiness, hopelessness, suicidal thoughts, feelings of guilt and self-loathing, loss of interest or pleasure, decreased energy, fatigue, concentration difficulties, sleep disturbance, appetite and/or weight changes, restlessness and irritability. It may be more prevalent in the early phases of HIV disease, and with the onset of HIV-related illness. People are more prone if they have a previous psychiatric history, poor social support, guilt or lack of acceptance about sexuality or lifestyle, and lack of an adequate social infrastructure.

Suicidal thoughts and behavior

Depression increases the likelihood of suicidal thoughts and behavior. The social and psychological vulnerability associated with HIV disease may increase the risk of suicide, which may be particularly high when people develop HIV-related illness. Suicide risk is increased with previous mental health problems and suicide attempts, drug and alcohol misuse, low social support, loneliness and economic deprivation.

Sexual and relationship difficulties

Sexual difficulties in HIV disease are common and are often due to a complex combination of psychosocial and organic factors. They may include erectile dysfunction, ejaculatory difficulties, loss of interest, loss of libido, sexual aversion, sexual phobias and, commonly, communication and relationship discord. Other difficulties include fear of infecting sexual partners, difficulties in negotiating and maintaining safer sex, and low self-esteem related to changes in body image due to illness.

Substance misuse

The majority of those infected in the region are injecting drug users. Reactions to a positive HIV test, illness progression, or other stressful events can include increased alcohol and drug misuse. Factors such as declining health, pain, fear, anxiety and grief also increase individual risk of resuming or escalating drug use. Assessing substance misuse and establishing links with drug and alcohol dependency agencies is important in the medical and psychological management of HIV infection.

HIV-related brain impairment

Neurological impairment can occur as a direct effect of HIV/AIDS on the central nervous system, or can result from HIV-related infections. Neurological disorders, including dementia and cognitive-motor impairments, are most likely to occur with late-stage illness, and remain among the most challenging and anxiety-provoking manifestations of HIV disease. Fear of dementia itself can become a significant problem for HIV-infected people.

Relationship and social problems

Psychological distress associated with HIV naturally has an impact on those close to the person infected. Relationship difficulties such as fear of infection, lack of HIV disclosure and sexual problems, are associated with increased mental health problems, whereas social support has been linked with improved psychological well-being and decreased depression and anxiety. Accessing social support may be complicated, however, by the potential negative outcomes of disclosing diagnosis, such as social discrimination and rejection by partners, families and the community. Psychosocial support is an ongoing process that includes meeting the physical, emotional, social, mental and spiritual needs of those affected by HIV/AIDS and mental health problems (REPSSI 2004).

Carer burnout

Everyone living with HIV confronts uncertainties about their health and prognosis, but the psychological impact extends much wider to loved ones, families, parents, children and young people, care staff and communities. Caring for people with HIV/AIDS who have mental health problems can be very stressful for both health care staff and volunteers. The stressors include the fear of infection; grief and bereavement overload; the intensity of HIV/AIDS work; inadequate skills or knowledge; discomfort in addressing issues of sexuality and drug use; stigma, secrecy, discrimination and ethical dilemmas; the pressures of financial hardship; and lack of support. Carers or partners may themselves be HIV-positive, creating an additional burden of problems associated with caring for others while coping with their own condition.

Implications for policy and practice

This brief review of the mental health problems associated with HIV/AIDS highlights the importance of tackling them, for individuals, communities and societies (Box 5). It also indicates their great complexity. They are by nature very difficult to solve, while the people who experience them may be hard to reach and help. Health and social care systems in the region cannot at present cope with this enormous set of challenges. Except for a few private services accessible only to the wealthy, they are mostly underfunded and poorly equipped and supplied, and lack professionals with adequate training, knowledge and expertise. Modern medicines are often hard to obtain.

Mental health care in the region is inadequate and outdated. Most psychiatric in-patient care is still given in large asylums, where the quality of care and facilities is usually very poor, based on containment through custody and heavy medication rather than individual empowerment through therapy, appropriate drugs and rehabilitation. Patients' human rights are routinely violated. Community mental health services are rare, and there are few initiatives to help people and significant others develop support and empowerment skills to manage their own problems more

effectively. The number of adequately trained mental health workers (whether psychiatrists, psychologists, nurses or social workers) is insufficient to meet the needs; their training, where it exists, is usually out of date and there is little continuing professional education. Professionals in other parts of the health system, including national AIDS centers where most people diagnosed with HIV are treated, have little expertise in mental health. The new and specific challenges of meeting the needs of people with HIV/AIDS will create extra work for existing mental health and primary care services, and will demand increased awareness, knowledge and skill.

Box 5: Consequences of failure to provide mental health care to people living with HIV/AIDS

- * Faster spread of HIV
- * Spread of HIV to non-excluded groups
- * More illness
- * Earlier deaths
- * Poverty and misery
- * Social exclusion
- * Family and relationship breakdown
- * Community breakdown
- * Negative impact on economy
- * Possible uncontrolled & catastrophic regional pandemic

Those currently most at risk of HIV infection - injecting drug users and sex workers - are often hard to reach due to factors such as high levels of stigma and discrimination in health systems and among the public. These people's frequent experiences of imprisonment, reluctance to access services, chaotic lifestyles, and mistrust of officials present a number of challenges to providing services, which should be tailored to the specific needs of those affected by HIV and mental health problems. This will require significant shifts in attitude and culture, greater knowledge, full collaboration between services, multidisciplinary teamwork and user involvement - all ingredients necessary to create a modern, ethical, client-oriented care system.

Just as importantly, the breakdown of social networks, communities and families throughout the region is a powerful negative influence. People living with HIV/AIDS and their immediate carers and communities may have even less support, and their decline into poverty is not offset by the existence of close-knit communities with mental or economic resources to help. Much of this community spirit has been damaged or destroyed by poverty, civil war, migration, corruption and the breakdown of traditional attitudes, practices and cultures that helped people to cope with hardship.

Initiatives to create civil society, promote social inclusion and build capacity will all be crucial in tackling HIV/AIDS and mental ill health. The implications for policy and practice extend far beyond the traditional boundaries of health services. Action is urgently needed in the following key areas, and others: human rights, addressing stigma and discrimination, involving service users and their significant others, and providing effective mental health care.

Human rights

HIV strikes hardest where human rights are least protected (UNAIDS 2004b), particularly among those on the margins of society such as sex workers, injecting

drug users and men who have sex with men. Safeguarding human rights is therefore an essential part of responding effectively to HIV/AIDS at individual, national, regional and global levels. According to the UN, a human rights-based approach to HIV/AIDS involves:

- Protecting a person's right to achieve the highest attainable standard of physical *and mental* health.
- Ensuring a participatory process linking service users and care providers, which improves the relevance and acceptability of public health strategies.
- Fostering non-discriminatory programs that include marginalized groups vulnerable to HIV infections.
- Scaling up the HIV/AIDS response by empowering people to claim their rights to gain access to HIV prevention and care services.
- Enhancing the accountability of states through people seeking redress for the negative consequences of health policies. Legal action based on human rights has been a vehicle to enforce people's right to gain access to health care, including antiretroviral treatment.

Addressing stigma and discrimination

The double stigma associated with HIV/AIDS and mental health problems and has a negative impact on prevention and care efforts. It creates a context in which people are reluctant to come forward for testing, and has strong psychological consequences for those who are HIV-positive, increasing social isolation and depression (UNAIDS 2002). Addressing stigma and discrimination in health care systems and the wider community is an essential part of HIV prevention and care.

Involving service users and their significant others

People living with HIV/AIDS should be centrally involved in policy formation and service delivery. Their involvement is crucial to the success of programs that challenge HIV-related stigma, discrimination and human rights violations, and that increase access to prevention, care and treatment. Their involvement in the planning and delivery of mental health support will similarly contribute to the development of relevant services, including peer-led initiatives, and can empower them by building self-esteem, decreasing isolation, and enabling openness about their HIV status. They can become involved in a number of ways, including policy-making and strategic planning, formation of support groups, counseling programs, positive living courses, and inclusion in the training of mental health professionals.

Involving partners, friends, families and 'significant others' in policy, service planning and care delivery is also important. Provided care is taken to ensure that their views and demands genuinely reflect the views and demands of the people they support, their contribution should be encouraged and valued. In addition, these carers have their own needs for support and respite care, to maintain their own mental health.

Providing effective mental health care

Traditional treatment approaches to mental health problems include medication and a range of psychological therapies, many of which have demonstrated efficacy with depression, anxiety, and a range of other problems - although their use in the region is still limited. The effective and ethical provision of mental health care in the context of HIV requires a range of social and political initiatives. These should include the involvement and empowerment of people living with HIV/AIDS who have mental health and addiction problems; programs to reduce stigma and discrimination; and

practical support to improve the quality of life of infected people and significant others.

Counseling, social support groups, family education programs, drop-in centers and advocacy programs can help address these complex psychosocial needs. These interventions are also effective in alleviating the complexity and stress associated with care-giving for both health care staff and volunteers. Psychosocial interventions are compatible with psychiatric treatment. The complexity of the needs of HIV-infected populations suggests that more than one treatment approach is often required.

Some steps forward

Some organizations and projects are beginning to tackle the issue of mental health and HIV/AIDS in CCEE/NIS. To date the focus has been primarily on harm reduction, and providing counseling for people living with HIV/AIDS. These initiatives, while welcome, are having no impact on mainstream mental health services, or on the wellbeing of the majority of those suffering from the dual diagnosis and double or triple stigma.

Global Initiative on Psychiatry, the leading international NGO promoting mental health service reform in the region, is now focusing on the development of expertise necessary to address HIV/mental health-related issues. It is running a major project aiming to improve the quality of life and reduce the suffering of people with HIV/AIDS who also have mental health problems, and of their partners, carers and families, in South Eastern Europe, the Caucasus and Central Asia (Box 6). The MAIDS project involves the creation of a network of expert centers on mental health and HIV/AIDS. Centers have already been established in Georgia, Kyrgyzstan and Moldova and are being followed by centers in Armenia, Azerbaijan, Bulgaria, Serbia and Montenegro, Kazakhstan and Tajikistan. They act as resource centers to motivate and educate change agents and to develop destigmatization, education and training programs for people with HIV/AIDS, carers, families and the general population. Working closely with policy-makers and opinion-formers from all sectors, they are developing effective ways of dealing with HIV/AIDS-related mental health problems.

Recommended actions

GIP's project work and the literature referred to in this document point to a range of actions recommended to PLHA, policy-makers, planners, managers, service providers, advocates and activists at all levels, local, regional, national and international, to tackle the double stigma and double challenge of HIV/AIDS and mental health.

- Assess the HIV awareness, expertise and training needs of health and social care services (state and nongovernmental) that provide mental health care and/or HIV/AIDS treatment, as a foundation for developing programs and strengthening referral networks.
- Provide training for primary and secondary health and social care staff in the recognition, prevention and treatment of mental health problems in HIV. People living with HIV/AIDS and mental health service users should be involved in the planning and provision of training.
- Identify existing materials for training, education and self-help and adapt and translate into local languages for local use and development of new materials

based on needs assessment. The resources should be widely available in books, journals, web sites, CD-roms and videos.

- Enhance provision of HIV-related mental health care, including counseling, psychosocial support groups, treatment of substance use, psychological and psychiatric assessment and treatment, self-help resources and social interventions such as occupational training.
- Improve the ability of service providers to make appropriate referrals to both mental health and HIV services and to substance misuse treatment when necessary.
- Strengthen community awareness by establishing partnerships and networking with a range of stakeholders such as primary care, hospitals, prisons, community groups, schools, existing mental health user support groups, the media and policy-makers.
- Address stigma and discrimination associated with mental health problems and HIV at policy and practice levels, including public education and awareness campaigns.

Box 6: The MAIDS Project

Global Initiative on Psychiatry, a leading mental health NGO based in the Netherlands, was commissioned by the Ministry of Foreign Affairs of The Netherlands to run a major project in 2005-2008. Its overall aim is to improve the quality of life and reduce the suffering of people in South Eastern Europe, the Caucasus and Central Asia with HIV/AIDS and mental health problems, and of their partners, carers and families.

The focus of the project is to establish a network of expert centers on mental health and AIDS in the region that will:

- * conduct research on epidemiology and needs assessment;
- * develop and implement destigmatization and education programs for people with HIV/AIDS, carers, families and the general population;
- * train professionals and expert clients in mental health aspects of HIV/AIDS;
- * develop effective ways of dealing with HIV/AIDS-related mental health problems;
- * act as resource centers with easy access to relevant publications and learning materials.

The main project funding comes from a thematic grant from the Dutch Ministry of Foreign Affairs of 3.6 million euros, with additional funding of 105,000 euros from the Open Society Institute.

For more information see www.gip-global.org or mail the project manager, Jane Salvage, at jsalvage@gip-global.org

Conclusion

We ignore at our peril the mental health needs and human rights of people at risk of infection or already infected with HIV in Central and Eastern Europe and the former USSR. If their needs continue to be unmet, and their rights ignored, the epidemic will continue its rapidly expanding impact, at deadly cost to individuals, communities and countries, and the region as a whole. The currently low prevalence rates should not be an excuse for complacency or inaction. The regional epidemic can be nipped in the bud now, if urgent action is taken.

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