## I live my rights I respect other people's rights

Access for all to HIV prevention, treatment and care is a critical part of human rights



World AIDS Day 2010





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## Message from the REGIONAL DIRECTOR



#### In the Name of God, the Compassionate, the Merciful

World AIDS Day this year comes with news of advancements in understanding and responding to the HIV epidemic. We have witnessed positive changes in commitment, attitudes and response interventions. However, the HIV pandemic continues to be characterized by persistent stigma and discrimination against

those living with the infection and those most vulnerable to it. World AIDS Day 2010 is therefore dedicated to reflecting on human rights in the context of universal access to HIV prevention, treatment and care.

Let me remind you that this pandemic is still striking humankind very hard: there are 33.4 million people living with HIV today, and for every 2 people that gain access to treatment 5 others become infected. But we must not give up. The efforts and resources dedicated to fight HIV are bringing results, and new programmes are reaching out to those most in need and most vulnerable.

Most countries in the Eastern Mediterranean Region are still experiencing low prevalence in comparison to other areas of the world. Nevertheless, we are seeing the prevalence of HIV grow among the most-at-risk populations, reaching concentrated epidemic levels in several countries of the Region. We still have a window of opportunity to control the epidemic. This must be through inclusive policies that de-stigmatize and reach out to populations at increased risk and to people living with HIV.

A key to highest standards of health in relation to HIV is knowing our HIV status. However, most people living with HIV in the Region are not aware of their HIV status. Furthermore, it is estimated that only 13.1% of those in need of antiretroviral therapy are actually receiving it. Scaling up HIV testing and counselling is therefore a critical step for increasing access to services. But people will only seek HIV testing if they feel secure in doing so, and if they think they will benefit from it.

Despite the positive steps taken in the Region to increase the availability of voluntary confidential HIV testing services, access to them is still very limited. The scarcity of services, combined with low risk awareness, and a very real fear of stigma and discrimination are hampering a higher uptake of voluntary testing. A rights-based approach to HIV testing and counselling responds to this situation by observing confidentiality, consent and provision of counselling to those tested.

Universal access to HIV prevention, treatment and care means universal access for all people, irrespective of who they are, how they live and what they do. The right to the highest attainable level of health for every human being is a fundamental value in WHO's Constitution. It is only by dismissing our prejudices that we can observe this right for all. We must re-double our efforts, challenge policies of mandatory testing, and demand and work for strict confidentiality around HIV. A human rights approach is the only way to universal access. And universal access is a human rights imperative.

Hussein A. Gezairy MD FRCS WHO Regional Director for the Eastern Mediterranean

World AIDS Day 2010 has as its theme universal access and human rights. This is an invitation for all of us – those infected and affected by the HIV virus, policy-makers, health care providers, activists and community members – to reflect on how universal access is contingent on programmatic and legal approaches that are solidly founded on respect for human rights, and how, at the same time, universal access is a human rights imperative.

The first article of the Declaration of Human Rights states that "All human beings are born free and equal in dignity and rights". Human rights are therefore inherent to all of us, including people living with HIV and those at most risk of getting infected. In the context of HIV, we are witnessing a lot of effort paid to ensure that the life, dignity and health of those groups are preserved. However, we are also witnessing a lot of injustice. Examples of human rights in the context of HIV include the following.

#### The right to life

For a person living with HIV, the right to life means the right to have access to antiretroviral therapy, and to health care in general. In our Region, despite the efforts of national AIDs programmes, ministries of health, civil society and international partners, it is estimated that only 10% of those who need antiretroviral therapy are actually getting it.

For a person at increased risk, the right to life means the right to life-saving prevention material and interventions.

#### The right to work

Several countries of the Region report preemployment mandatory HIV testing. A person's

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employment offer is often rescinded if the person is found to be HIV positive. If found HIV positive, migrant workers are deprived of their work permits and deported back to their home countries.

#### The right to form a family

Compulsory pre-marital HIV testing results in denying people living with HIV the right to marriage. It has been reported that women living with HIV are discouraged from getting pregnant, persuaded to terminate their pregnancy or even denied professional care by health care providers when presenting pregnant with HIV.

#### The right to privacy

The right to privacy encompasses one's own health status, including HIV status and physical privacy, and the right to decide whether to be tested for HIV or not. The right to privacy is often denied to individuals, first by forcing them to get tested, and then by disclosing their status to people other than themselves.

#### The right to education

All children should be able to go to school and enjoy an education and the companionship of children their age. However, children living with HIV are often rejected by schools and by other children if they learn of their HIV status.

#### The right to freedom of movement

For migrant workers, moving across a border is often critical to earn a living that will sustain their family. However, many countries have compulsory HIV testing for these individuals and restrictions on entrance to the country for those that are HIV positive. Furthermore, people living with HIV can sometimes be expelled from their host countries if they are known to be HIV positive.

# The right to the highest attainable level of health

At some point in their life most people will need health care, whether for treatment of a disease or as support for natural physiological conditions such as pregnancy. We expect that health care providers will open their doors to us and give us assistance. For people living with HIV, this is not always the case. Often they are rejected by health care providers on the ground of their HIV status.

Some individuals are at a higher risk of infection. They are outlawed and are highly stigmatized. This situation makes them difficult to reach by prevention programmes.

Stigma and discrimination against people living with HIV and against those at most risk of infection are sending the message that getting tested might not be such a good idea. People whose lifestyles diverge from social norms are severely stigmatized and judged, more so if they are women. Because HIV is commonly associated with sexuality or drug use, a person living with HIV is judged harshly by family and communities. Often, people living with HIV are accused of wrongdoing. This stigma puts a lot of pressure on people who are living with, or suspect they have been exposed to, the virus to hide their condition, and sometimes to defer seeking health care services.

In the Eastern Mediterranean Region, it is estimated that fewer than 10% of those infected are actually aware of their HIV infection. This represents a serious shortcoming in our capacity to provide treatment and care for those who need it and to ensure that new infections are minimized. Testing is therefore crucial

to ensure universal access to treatment, prevention and care. But it must be testing that observes human rights: testing that is voluntary, confidential, consensual and accompanied by counselling.

Testing, in our low and concentrated epidemic levels, should strategically target those who are most at risk of HIV transmission. Stigma and discrimination against those groups is a major deterrent.

The highest attainable level of health is therefore a right that is closely interlinked with other human rights. Without it, our attempts to control the HIV epidemic will not achieve the desired goals.

### **A HUMAN RIGHTS APROACH TO HIV TESTING**

Since the HIV test became available back in 1985, WHO and UNAIDS have advocated to perform it only under three conditions, the so-called "3Cs": it is **confidential**, accompanied by **counselling** and conducted only with the client's **consent**, such that it is both informed and voluntary. The "3 Cs" continue today to be at the core of WHO/UNAIDS guidelines to HIV testing. UNAIDS and WHO do not support mandatory screening on public health grounds. The only exception is the systematic testing of blood for transfusion or transplants.

**Confidentiality** is a cornerstone in the process of HIV testing. It means that health providers, although encouraging disclosure, will not reveal the test results to anyone other than the individual undergoing the test without the consent of the client.

Testing for HIV should always be voluntary and done with a person's informed **consent**. It should never be imposed on a person forcibly or without their knowledge. This means that the person should understand what the testing procedure entails and its risks and benefits in order to consent to perform it. A person should be able to refuse to take the test when offered.

**Counselling** is an integral component of the HIV testing process. It is a confidential interaction in which the counsellor helps the person seeking help (the client) to explore any difficulties or dilemmas they are experiencing and find ways of resolving these. In the context of HIV, it is designed to equip the client with information necessary to manage his or her health and behaviour, as well as with psychosocial support, in view of the test results.

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All human beings are born free and equal in dignity and rights

Everyone has the right to life, liberty and security of person

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence

Everyone has duties to the community in which alone the free and full development of his personality is possible

## CONFIDENTIALITY, CONSENT AND COUNSELLING: PERSONAL TESTIMONIES



The consequences of breaching the right to privacy of a person regarding HIV can be very severe, even within one's family.

#### Samer, male living with HIV

I was feeling very sick, so sick that they took me to the hospital. They found out I was HIV positive there. They told my brother before they told me. My family did not want me around the house any longer.



Respecting the right to privacy for PLHIV allows them to choose to whom they disclose their status according to their best judgment.

#### Carla, woman living with HIV

Here everything is top secret. Nobody talks about anything or knows anything. I really cannot tell many people. My parents don't know. Not so much because I think they would not accept, but because they would be so scared of my dying. Also, my brother is married and has three kids. I love them, but if their mom knew I am HIV positive, most likely she would not let me close to them.

And really, my life is good now. Why should I have to tell them?



HIV testing for pregnant women should be conducted for her and her baby's best interest.

#### Areej, woman living with HIV

I was pregnant with twins. One of them was outside the uterus and died. They had to do surgery. They didn't tell me anything; they just checked for HIV and they told my husband I was positive. He didn't say anything to me about my HIV until 3 months later.



Finding a health care provider for issues unrelated to HIV might be an ordeal for PLHIV. Sometimes, hiding their HIV status from their care provider is the only way to be cared for.

#### Julia, woman living with HIV

I don't tell doctors I am HIV positive. I never do. I go to dentists or oculists or anything that I need like that and I just don't tell them that I am HIV positive because I know what will happen. They will reject me.



C-section delivery can be a lifesaving procedure for the infants of women living with HIV, as it reduces the risk of transmission from the mother to the child.

#### Salma, woman living with HIV

When I was pregnant I knew I needed a C-section to make sure my baby would be okay. Three doctors rejected me because I told them I was HIV. So I did what I had to do and I lied. I asked this doctor if he would deliver my baby by C-section just because I was anxious. I asked to see the delivery room to make sure I was not going to get someone else infected. He delivered me and my baby is negative.



For a person who just found out that they are HIV positive, counselling is where the person can get help to cope and to make the appropriate life choices. **Adel, male volunteer for PLWHIV support group** People are very afraid of going to the VCT centre. They are really afraid of having to face the results of a test. **Barea, woman living with HIV** Information is key. You can do everything with HIV. You can live a normal life, but you need to know that!!



The stigma associated to HIV extends beyond the person infected with the virus to his/her family and acquaintances.

#### Ester, married woman living with HIV

If people found out (that I am HIV positive) it would affect all my family. My sister would not be able to marry.



#### Lack of confidentiality by health providers may have severe consequences for PLHIV. Bassem, medical counsellor for PLHIV group

A woman went to hospital for treatment and they found out she was HIV positive. The doctor respected her confidentiality, but one of the nurses lived in her neighbourhood and told on her. It became a horrible situation for the woman.



In societies that are not ready to open their arms to PLHIV confidentiality might be paramount.

#### Angelina, woman living with HIV

One of my best friends, she died of stigma, not HIV. Her husband died one day and they found out in the autopsy that he had been HIV positive. She got tested and she was also HIV positive. Life became horrible for her. His family started accusing her of having brought this thing in the house. And it was him who was sleeping around!! She died because she could not take it anymore. She had no strength left.



Fear, lack of information and stigma translates often into very discriminatory actions towards PLHIV.

#### Lamia, female prisoner

People cannot live with people with HIV around. They cannot treat them well. They (PLHIV) cannot be in the community. Better a prison for them somewhere. Manal, female community member

People would be scared of him because he is HIV positive and they would reject him. I cannot even think of being close to someone with HIV. For men, people would think he did something wrong sexually. For a woman, they would kill her. People would kill her because she is a woman.



The very right to life might be at stake if there is loss of confidentiality, especially for women and girls.

#### Randa, unmarried woman living with HIV

If my parents found out (that I am HIV positive) they would kill me. I am not married, so how did I get HIV? They would think I did bad things and they would kill me. They would never forgive me.



Lack of confidentiality hampers the ability of men who are at increased risk of sexual transmission of HIV to seek health services.

#### Freddy, male outreach worker

Men who are at increased risk cannot go to mainstream doctors and tell them about their sexual activities. There are confidentiality issues with them, they might be afraid that doctors would call the police on them.



Fear of the law hampers access to health care, including HIV testing. **Mona, female nongovernmental organization staff member** *In the most-at-risk populations there is mistrust of doctors. Because they are* 

"outlawed", they are always afraid doctors might call police on them for their illegal activities.



Women living with HIV might have even slimmer options due to their HIV status. Basma, woman living with HIV

There is this woman that wanted to leave her husband. He was beating her up and everything. She finally got a divorce and moved in with her family. They kicked her out after a month because she was HIV positive and they just did not want to live with that in the house. So she had to go back to her husband.



The fear of being seen in a place associated with HIV in any way hampers people from seeking HIV services

#### Riham, female prisoner

If they came to prison to test us I would do the test, but not out in the community.



Building trust between the service providers and the communities is paramount for increasing access to HIV prevention, treatment and care.

#### Benjamin, man living with HIV

I went to the VCT centre because a friend of mine told me about his test. He said it was safe for us to go. So I went. I was HIV positive but they treated me with respect; they did not tell anyone. I feel safe there. I tell all my friends to go, just like my friend did for me.



A health provider's attitude towards a person living with HIV can make a huge difference in his/her life.

#### Kareema, woman living with HIV

I am happy with the doctors in the HIV clinic in this city. Other doctors are hard; they will not treat me. Some do treat me but I can tell they treat me differently. For example, they put cotton around my arm to take the blood pressure. Doctors and nurses don't know about HIV. They don't know anything, they are scared. Keep the promise. Stop AIDS

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