

# enah

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DISCRIMINATION  
EXPERIENCED BY PEOPLE  
LIVING WITH HIV AND AIDS



GOOD PRACTICE AND  
PHONE LISTENING



POSITIVE LIVING

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## FOREWORD

When all of the country members of the U.N. unanimously declared their commitment to fight against HIV/AIDS at the extraordinary meeting on AIDS in New York, June 2001, the following was agreed in paragraph 58 - chapter 5, about HIV/AIDS and human rights:

*“Between now and 2003, create laws, regulations and other measures intended to stop discrimination against people living with HIV/AIDS and vulnerable groups, and ensure that they are able to benefit from all of their rights – particularly, access to education, to their heritage, to employment, to healthcare, to social and medical services, to prevention, to support, to treatment, to information, to legal protection, to protection of privacy and confidentiality – and elaborate strategies aiming to fight stigmatisation and social exclusion.”*

We are now approaching the end of 2003 and it is sad to acknowledge that stigmatisation and discrimination are definitely still present.

In their everyday work, the counsellors of the AIDS helplines that have joined forces under ENAH – the European Network of AIDS Helplines - register the

many discriminating episodes reported by callers. It is obvious that HIV/AIDS relentlessly acts as a social diagnosis. Discrimination experienced in such context takes many faces and is perpetrated at different levels. The ENAH members wish therefore to promote awareness and attention around such dramatic situations.

Pursuant to the UNAIDS approach, this report is intended to offer a contribution to the worldwide initiative within the European Community. It aims at being a mouthpiece for the many, many callers and clients of the ENAH member organisations. Furthermore, it details recommendations for the definition of strategies designed to more effectively fight against discrimination.

## INTRODUCTION

History reminds us that every era has witnessed diseases charged with a moral judgement. People hit by infections were considered as bearers of illnesses endangering the survival of the whole community, and communities have always tried to isolate and discriminate against infected individuals. A critical reading of such events suggests that these interpretations were not only erroneous, but brought additional pain to sufferers, adding psychic and moral grief and consequent humiliation.

HIV related discrimination is an obvious universal phenomenon. Stigma, discrimination and social exclusion have gone hand in hand with HIV/AIDS since the very beginning of this global epidemic. Although many efforts have been made, and despite the development of medical treatments which have brought decisive improvements in terms of life expectancy and quality of life for those infected the general discriminatory attitude remains unchanged.

The origin of discriminating attitudes and behaviours may be traced back to the social depiction given in the early days of AIDS. The fact that AIDS was first diagnosed mostly among homosexual men and intravenous drug users intensified non-caring, humiliating and sometimes irrational reactions on the part of society. Being (also) a sexually transmitted disease, AIDS stirred moral and ideological issues and touched taboos. Prejudice, lack of information, irresponsible media reporting on the epidemic and fears related to illness and death were and still are additional reasons for stigmatising people living with HIV. While reading through the pages, we will realise that there has been little improvement in the twenty years that have gone by; what is still happening today cannot be tolerated any longer. It is time to devote great effort and resources to the fight against discrimination.

## BACKGROUND

The history of AIDS now spans some twenty years. Looking back over the past two decades, we can highlight the different developments and changes in the HIV/AIDS perspective. For example, as far as the subject of AIDS as an epidemic is concerned, the exponential rise in infection rates that was originally predicted to occur in the so-called industrialised Western countries, where a collective awareness of AIDS developed first, did not become a reality. In contrast to this, the continuing rapid increase in the number of infected individuals and AIDS victims accompanied by high mortality rates in sub-Saharan Africa and in some Asian countries is an alarming reality and represents an enormous problem to which there is no easy solution.

While medical progress, namely the development of antiretroviral therapy, brought about an existential improvement in the situation of infected people on the one hand, it also induced a paradigmatic change with regard to AIDS: the changeover from a fatal immunity disorder to a chronic illness. However, the only individuals to benefit from an improved and prolonged life are those with access to proper medical treatment. The current

situation, which strikes us as being extremely cynical and contemptuous of human life, shows that there is a chronic lack of or indeed no medication available at all in the areas where HIV is most widespread. Thus, we are already in the middle of the problematic area that revolves around discrimination and social exclusion.

However, even those infected persons who are lucky enough to receive combination therapy, which enables them to maintain a more stable state of health and therefore fulfils an important requirement in terms of their ability to live a fully-fledged life and experience social integration, are nevertheless exposed to persistent stigmatisation and discrimination. On the one hand, there is a tendency to subsume AIDS as just one among many chronic illnesses. This increasingly leads to HIV/AIDS being relegated or neglected on the public health agenda. The budgets for prevention and care, which to some extent have been cut dramatically in many countries, and not merely those in Europe, are proof of this. On the other hand, the social climate in which AIDS is discussed, assessed and given appropriate importance hardly appears to have changed. The diffused threat associated with AIDS

that came into being during the first era two decades ago along with the discovery of the virus is clearly still rooted deep in people's minds. Fears, which to some extent are extremely irrational as well as the taboos that are continuously associated with HIV/AIDS still foster immense rejection. This subtext of a defensive attitude fuelled by several sources makes it more difficult for individuals and society as a whole to be open about and deal with the HIV/AIDS phenomenon in a "normal manner". For this reason, it is neither coincidence nor a randomly chosen focus that the theme of the current World AIDS Campaign 2002/2003 is stigma and discrimination.

## DISCRIMINATION

The conditions and the basic mechanism of discrimination have been present in society or culture at all times. For the constitution of a collective sense of belonging together and keeping it upright there is always a casual need for distinction – and that is exactly what is meant by discrimination in the literal sense. Identity and the feeling of being part of the community are guaranteed by delimitation to the “others” or the supposed, pretended “others”. The long history of discrimination, however, shows one circumstance very clearly: the process of distinction and the differences that are created thereby are hardly ever happening in an atmosphere of equality or on a level of the same rank. Discrimination can be defined as an unfair differentiation of judgement, a disparity of treatment in contempt of the fundamental principles of social and political equality. Discrimination happens based on race, sex, colour, religion, political or other opinion, language, national or social origin, property, birth or other status. The discriminatory mechanism of distinction produces different, sub-cultural, stigmatised groups in a society. It is important to underline that it is always the individual, the single human-being who suffers from discrimination. When someone does not comply

with prevailing social or moral models, they are excluded from their community and subjected to social outcasting.

This report treats discrimination in context with HIV/AIDS. In order to meet the complexity of the phenomenon our publication deals with discrimination on three main-levels: social discrimination, interpersonal discrimination, intrapersonal / self-discrimination. Of course these three levels – in terms of their impact on the individual – are interconnected. When dealing with discriminatory factors, we also need to distinguish between overt and subtle discrimination. As a matter of fact the latter occurs more indirectly and therefore it is more difficult to recognise; nevertheless the more subtle appearances of discrimination are as harmful to the individual as the obvious ones.

Unlike other illnesses, HIV/AIDS is perceived to be a social construction that is linked to marginality and sexual promiscuity, sometimes with a notion of perversity. The whole life of people living with the illness is affected: their family, professional and medical environments, to name just a few. Any stigmatisation and discrimination is, of course, unjust and its consequences

are to the greater detriment of those infected or affected as they increase both their solitude and their marginalisation. They also increase vulnerability to HIV infection, just as they do to the general health status of marginal groups like homosexuals, IV drug users and migrants. Stigmatisation and discrimination are also present in situations of personal interaction (between families, friends...) which are not affected by laws regulating the rights of individuals. Even though stigmatisation and discrimination do exist, people living with HIV/AIDS have to decide if starting legal action is the right thing to do considering their health status, their income and other priorities, not to mention the lengthy process of such an action and its uncertain result. What is more, the forms taken by discrimination and stigmatisation change according to the variety of realities that affected people live in.

## SOCIAL DISCRIMINATION AND HIV/AIDS

We refer to social discrimination in association with HIV and AIDS whenever afflicted individuals, HIV positive people or AIDS patients as a collective group encounter social exclusion, discrimination or injustice on a structural level. Social discrimination is founded on guidelines and provisions effected at governmental level, in particular in the area of legislation; authorities, bodies, associations and similar communities also pave the way for social discrimination.

At the time of its emergence, AIDS was in fact an incalculable, deadly risk: the medical profession, at that point still unaware that HIV is the virus that leads to AIDS, proved to be largely powerless against this new, mysterious disease, and the majority of those infected were faced with an early death. Owing to the lack of treatment options, the potential for risk was still high, even after the virus and the modes of transmission had been identified. In light of this background, it becomes understandable why protection from HIV/AIDS was the pivotal answer and appropriate reaction to the new phenomenon.

The information, messages, recommendations, for that matter, instructions

that have emerged during the course of worldwide prevention campaigns are to date still fundamentally sensible, necessary and useful. The concern for protection, however, automatically led to extremely problematic and damaging notions, in particular that protection against HIV implied (and unfortunately still does) the need to avoid afflicted individuals, which is paramount to excluding people living with HIV. One fatal analogy has unfortunately become a reality: “I don’t want to come into contact with the virus, so I’ll keep away from those infected, or even better, I’ll systematically exclude them”. It is not infrequent, therefore, that motives for protecting oneself from the HIV infection simultaneously contain the seed of discrimination. On a structural level, this meant nothing other than the desire to gain control over the spread of the virus by applying measures to register and monitor persons infected with HIV. For example, politicians instigated motions, which aimed to permanently monitor and quarantine HIV positive people. There were even serious efforts to have infected persons marked with a form of tattoo in their intimate parts, in other words, to literally and physically assign a stigma. Despite the fact that plans such as these, which are so blatantly contemptuous of human life,

were not ultimately put into effect in democratically ruled countries, social discrimination nevertheless intervenes in the lives of HIV positive people and AIDS patients.



PERSONAL RELATIONSHIPS

One of the most difficult things for people who have just learned of their HIV positive status, besides the shock of the announcement, is disclosing it to the people they are closely related to, and particularly to their family. The negative representations associated with HIV/AIDS often make it difficult for people to reveal their HIV status. They anticipate being subjected to various forms of rejection following the disclosure.

*"I have to be really careful all the time that it does not get out; it is not easy, especially as all the medication is so easily recognisable. Talk about it? No way, it's like admitting you're queer or an addict... The only people I can turn to are others like me."*

*"When my friends talk about AIDS, they say that people infected deserve it! Imagine what they would say if I were to tell them I am sick... That would be the end. And, to be honest, I would rather not say anything than have them turn their backs on me, I couldn't bear that. I know you must be disappointed in me, but that's the way it is. Things are difficult enough already without making the situation worse."*

The fact of keeping one's HIV status a secret is exhausting both physically and psychologically. In the long term the situation often causes a feeling of guilt and stress that can sometimes lead to severe psychic disorders.

*"I'm exhausted from lying; it's going to have to come out even if it means my life will get even worse."*

*"I don't dare go to the dentist. Not only would I have to tell him I'm infected... Even if he did take me as a patient, I'd be so scared of contaminating him if anything went wrong."*

Taking the risk of revealing one's HIV positive status can lead to violent reactions and brutal rejection.

*"I gathered my courage and told my best friend that I'm HIV positive. She went pale when she heard. She didn't say anything, just that she had to leave... Then, of course, she never answered my calls, or when she did she was very evasive. I lost my best friend, or the person I took to be my best friend anyway. I can talk about it calmly now, but at the time it was a very painful experience."*

Revealing one's HIV positive status, however, can also result in the opposite happening: greater support and reassurance.

*"I was very touched when my mother found out. One weekend when I was staying with my parents, I forgot to close my diary. I wrote in it a lot at the time, I still do, there was no one else I could confide in then... My mother must have come across it when she was doing the housework... She took me in her arms, she was crying. She did not say anything, but I knew that she knew. Since then she has been there for me, a little too present sometimes, but at least it means that my life is now better."*

The witness accounts that we receive on our helplines show that stigmatisation and discrimination especially affect people living in small communities. It is harder in such circumstances to keep one's anonymity compared to large cities. In small communities news travel quickly and everybody know one another. People living with HIV/AIDS have to constantly take care not to disclose their illness.

*"It's hell living in a place this small. Everyone knows I'm HIV positive... I can't bear being considered to be trash anymore. It is unbearable."*

*"I've been feeling a lot better since I came to live in Bordeaux. People don't even look at you. It's nothing like the little village I lived in before. People would talk about me. It was almost like they were cleaning up after me every time I went past."*

Isolation and the relatively poor knowledge of the issues linked to HIV seem more present in smaller communities. Sometimes stigmatisation can even be expressed towards people who are not directly concerned by the illness. Their only fault is to have shown an interest in the illness, by receiving information leaflets about HIV, for example. In such a context, it is understandable that people living with HIV decide to travel far from their homes for treatment. Fear of being discriminated against predominates in areas where there is no available support network.

*"I'm tired of having to travel 70 miles every time I need to see my doctor. That's the way it is... AIDS is a shame-*

*ful illness where I live. I don't want my daughters to have any problems... People can be merciless."*

In some cases, people do prove themselves to be more compassionate and show more solidarity. When people have been infected following a blood transfusion, they are often considered to be victims, the general idea being that they did not "deserve" it.

Also within ethnic and cultural groups, people living with HIV/AIDS are stigmatised and discriminated against by their peers. In the gay community, for example, visible signs as lipodystrophy are sufficient for the person to be identified as HIV positive under treatment. Such physical change causes stigmatisation and rejection by HIV negative people terrified of becoming infected.

*"The illness is part of my life. It is difficult to forget about it because it is visible not only on my face but I can also feel it when thinking about my almost inexistent relationships... I don't have any other choice than going to darkrooms to find the pleasure that would be very hard to find otherwise."*

**(PERSONAL RELATIONSHIPS) ■**

In some cultures, in which sexuality is a taboo and AIDS is considered to be divine punishment inflicted on those who have chosen to have sex outside the bounds of marriage or normal behaviour, the rejection of people infected by HIV is considerable.

*"My own parents are putting me through hell. I don't know if it is to punish me, but it's really hard to be treated like this... even the dog gets better treatment than I do. I have to eat separately, with my own crockery... and I have to wash that separately too."*

What is more, the category of the population that is influenced by such beliefs discriminates in a manner that can be judged to be somewhat arbitrary. For example, if someone suffers from symptoms deemed to refer to HIV such as loss of weight or persistent cough, that person might be suspected of being infected with the virus.

Migrant populations see themselves even more forced to keep their HIV positive status a secret. This can be easily understood because they have to fear double discrimination: they are discriminated against

in their host country because they are foreigners, and also in their own community - most have a culture of living in groups - in which HIV positive people and those living with AIDS are banished. Specific religious and cultural beliefs might worsen their individual situation and thus deepen the feeling of isolation and insecurity. Geographical distance from one's origin and belonging to a specific community group are thus factors which multiply vulnerability: communities such as the deaf, the blind, those with physical and mental difficulties can of course also be affected by HIV. In such case stigmatisation and discrimination are reinforced by the very fact that these different communities are themselves minorities within society.

**EMPLOYMENT / WORK ■**

The availability of new pharmacological treatments and the recognition of the infection as affecting the whole community and not only homosexuals and drug-users have brought about a normalisation process in the history of the AIDS epidemic. A job and working routine have become important components both for the reconstruction of life projects and for the social reintegration of people affected by HIV/AIDS.

Today, issues appear to be more assorted and articulated compared to a few years ago. Surveys disclose that the fear of being infected and of sharing space with an HIV positive colleague is unchanged because of prejudice and of a still superficial information.

*"There's no way I'm saying anything about my status to my colleagues. A friend of mine did who thought his colleagues were open-minded enough. He's been living in hell ever since! I'm not going to fall into that trap... not even our work doctor knows about me... I'm not mad."*

*"Some of my colleagues won't get into the lift with me... what's worse, is that some of the people on my floor go upstairs to use the toilet... What do I think about it? Nothing,*

*except that their stupidity really hurts me... I have to fight so many enemies in order to survive... both the illness and the ignorance of some!"*

*"I was afraid of returning to work. A friend told me that my colleagues knew about my illness. I also knew that some of them were not pleased about me returning to work... What is more, I had not received any messages of support or wishing me a speedy recovery since I left hospital. I don't know who told them, and I don't want to know. That is not what hurts the most..."*

Employers worry about higher costs and lower efficiency. They do not know how to manage the relationship between the HIV positive worker and the other employees, are afraid of negative repercussions in the various departments and in any event tend to prefer employees who do not cause excessive burdens with continued requests for health check-ups or for the frequent, often prolonged, absences from work due to disease.

European countries still maintain different legislation concerning the employment of people with HIV/AIDS. Private employers as well as public ones try and take measures to

keep out staff members with an HIV/AIDS diagnosis. A few examples of the different cases: some airlines ask for a negative HIV test result before signing the working contract with candidates; some public services like the police or the forces of law and order refuse admission to HIV positive candidates; in other instances medical staff working in surgery rooms and intensive care units must give evidence to be HIV negative.

In some countries in which employers negotiate medical healthcare policies of employees, it may happen that an employee refuses treatment due to being afraid of "being discovered" to be HIV positive. The risk is twofold: either that the employer has to pay more for treatment, or that the HIV positive status of the employee is made public knowledge. It is the fear of being identified, stigmatised, discriminated against, harassed or even sacked that motivates such behaviour. It seems to be a frequent phenomenon in small companies. The matter of privacy protection is particularly significant, not only considering the personal and private life of an individual, but also in relation to discrimination arising out of its violation, during the hiring phase as well as during the work relationship. Getting into further detail,

several forms of discrimination have been identified. Most are perpetrated by employers who break confidentiality and disclose the HIV positive status or illness of their employees. Some of them are unaware of the constraints inherent to taking medication and of their side effects, and do not allow infected people any flexibility in working hours or change in their duties.

*"It's not easy to take medication at work, especially when you have to do it in secret in the toilets. What makes it harder is when you have to take medication at specific times. I have to keep coming up with new reasons for leaving the office. It's such a bore."*

*"I work in a hairdressing salon. I'm on my feet all day. Sometimes it just gets too much... My boss knows about my illness. She says I should count myself lucky that she keeps me on... I can stay as long as I don't take any time off..."*

*"I was a chef in a restaurant. My boss sacked me when I told him I was HIV positive. I had no choice but to leave as I had often been absent from work... He must have been scared that people would find out and stop coming to the restaurant."*

**(EMPLOYMENT / WORK) ■**

Sometimes a new job might appear to be the solution, except that it is never that easy. It would mean finding a job suiting the professional experience of the HIV positive person. It would also mean explaining why one is leaving the previous employment, and the long absences due to being hospitalised. And, also, losing the advantages related to the duration of one's employment history within the company.

The transformation of work environments, characterised today by flexibility, mobility, atypical contracts, entails less protection and difficult collocation for weaker working forces. The "handicap" is more burdensome and less compatible with the recruiting and efficiency standards required by the system.

**MEDICAL / HEALTH SERVICES ■**

A high number of the reported discriminatory episodes concerns the access to public or private health facilities by HIV positive people. A critical matter needing in-depth debate is the hospitalisation of HIV positive people in departments segregated from the rest of the hospital buildings, therefore especially devoted to infected patients. The justification produced in this circumstance is the protection of HIV positive patients from the pathogens brought by other patients, that could worsen their clinical status. This is a false issue, since in such special infective diseases departments HIV positive people - or people with an otherwise damaged immune system - share rooms with other patients in the same condition, thus exposing themselves to other diseases. The only reasons for this behaviour are discrimination and the denial of the AIDS issue, which lead to separating HIV positive people from the rest of the community.

Respecting the confidentiality of medical records is also a problem. Medical staff are required to respect medical secrecy. Indiscretions sometimes occur, however. Some patients have been consulted directly in the waiting room, in flagrant disrespect of rules of confidentiality. Other doctors leave files lying around where

anyone can see them, files that bear the names of patients. Flagrant discrimination still exists towards people living with HIV/AIDS in regard to treatment delivery. This is manifested in several ways: from refusing to provide treatment to showing contempt for patients by ignoring or even insulting them. Such cases are obviously not widespread; medical personnel specialised in HIV/AIDS are less likely to practice discrimination.

People living with HIV/AIDS report that doctors are often unprofessional when prescribing antiretroviral or complementary treatments. Some, for example, continue to prescribe medications that do not suit the patients, without listening to them, without entering into any form of dialogue, giving little or no attention to reported side effects. Other doctors do not agree to the emotional state of patients asking for a sick leave. Medical staff therefore need to listen much more to their patients and to fully inform them about available treatments, taking individual needs into account.

There are also subtle forms of discrimination that seem to be motivated by the social representations of the pathology. Some doctors are prey to them too. For example, in the case of HIV/AIDS, they

are less likely to recommend the HIV test to people they do not judge to be at risk, such as women, heterosexual men and the elderly. They may also give an erroneous diagnosis in the presence of symptoms that are typical of HIV infection. In this way, people are late in finding out they have been infected - often not until they have become ill.

*"I consulted my doctor several times for a persistent cough that then started to affect my chest... I collapsed and was taken to the emergency ward. It was there that I was asked, at the age of 67, to take an HIV test so as to explore all the possibilities. You know the rest..."*

The stigma associated with HIV/AIDS is one reason why not only doctors but also patients do not openly discuss the possibility of taking an HIV test. They fear that medical staff might think they are homosexuals, IV drug users or promiscuous. Many callers complain about being refused treatment by dentists and sometimes discrimination occurs upon simple suspicion.

*"My dentist refused to treat me when I told him I was HIV positive. He pretended that not only was he not allowed to, but also that he did not*

*have the necessary equipment to treat me. He simply gave me the phone number of an organisation that works in the AIDS field."*

*"I went to see a dentist in the area I work because I had a toothache. My partner came with me. When the dentist found out I worked for an AIDS organisation she asked me if I was HIV positive. I said that I wasn't. She told me I should go and see my usual dentist, even though she knew that he was on holiday."*

Also other medical fields like surgery are not exempt from discrimination.

*"I had a problem with my veins and wanted to undergo an operation. When the medical staff realised that I was HIV positive, the surgeon who was going to operate me told me that he would go ahead with the surgery only if I agreed to have myself sterilised."*

The medical sector shows that comprehensive information about HIV and AIDS does not guarantee protection from discrimination. It seems to be common sense that the main reason for keeping one's distance

from HIV positive individuals is simply due to fear of getting infected. Members of medical professions in particular should be able to exactly distinguish between potential risk and completely riskless situations in connection with an HIV infection. Still, people living with HIV and AIDS suffer from offending, excluding and humiliating situations and experiences in the medical context. The cause for that therefore cannot be found in actual fear of infection, but rather in irrational anxiety or unreflected attitudes. Obviously, much of the discrimination faced by people with HIV is only partly based on their being HIV positive.



## ACCOMMODATION

People living with HIV/AIDS suffer discrimination when trying to find accommodation, particularly in the private rental market. Examples of expulsion are profuse. Some owners intrude too much into their tenants' private life. In some cases, they ask for papers which show that social services will be paying part of the rent due to the tenant being ill. This often results in the person being refused the tenancy, or the renewal of the tenancy. Saying that one is HIV positive generally incites fear rather than support.

*"When people found out I was HIV positive, I was constantly harassed... my landlord wanted me to vacate the premises as soon as possible... they tried all sorts of tricks... I managed to hold out for a while... but then I couldn't take it any more!"*

*"I've been looking for decent accommodation for months now... my health is getting worse... on a psychological level, it is hard feeling rejected."*

It is hard to bear such distress, especially since people concerned are often already marginalised and have low incomes. Not having a

permanent abode makes the person more vulnerable to the effects of the HIV infection, on both a mental and physiological level. Some people are living in extreme poverty, on the street or in hotel rooms paid for by AIDS organisations. This last case is unfortunately very rare given the small amount of available accommodation and the high cost of looking after people individually. There is a severe shortage of accommodation for people with very low incomes, and waiting lists are very long. Some have to live in insalubrious accommodations which are damp, badly heated and very often located far from essential services such as pharmacies, supermarkets, etc. Sometimes their income barely reaches subsistence levels once the rent is paid, and therefore they cannot pay for adequate food and complementary medications.

*"How am I supposed to look after my health? I live in one tiny room. I don't have a fridge in which to keep some of my medication... Moving might be a solution, but I'll never find somewhere else to live... I can't prove I'll be able to pay. I've tried many times but each time I get the door slammed in my face."*

It is not simply a question of doing away with the discrimination faced by people with HIV/AIDS who are trying to find an accommodation. The emphasis needs to be placed not just on their difficulties in finding a decent abode, but also on the sanitary conditions in which marginalised people live. As for people who try to buy somewhere to live, they face difficulties being accorded loans and insurance.

*"I declared I was HIV positive on a medical questionnaire for an insurance related to a mortgage application. My bank called me back to say that since the insurance company had refused to cover me, they could not give me the mortgage..."*

## INSURANCES / MORTGAGE

Gaining access to insurance for HIV positive people has been a crucial issue since the very beginning of the epidemic. Access to adequate medical treatment and care for people living with HIV/AIDS has become an almost insurmountable obstacle, especially in countries with insufficient public health insurance coverage. Private insurance companies are allowed to ask any questions related to health conditions, and to reject application requests on the basis of eventual declared risks; instead of mutualising risks and benefits, they individualise them thus discriminating and excluding people with HIV as well as other people with different chronic diseases.

Antiretroviral treatments brought about increased mid and long term life expectancy, enabling people to invest in both personal projects like buying a house, a flat or a car, as well as in professional ones like starting one's own activity. Therefore, the fact that insurance policies linked to loans are by far those most commonly refused is untenable.

*"My partner and I want to get a mortgage to buy a flat. I have been HIV positive for 7 years and I am well. We went*

## IMMIGRATION

*through all of the procedures with our bank's financial advisor. Now we have problems with insurance."*

*"What do I risk if I don't declare my HIV positive status on the medical questionnaire?"*

*"I am getting a mortgage. The insurance company wants to know if I've ever had an HIV test. Is this legal?"*

The few people who managed to gain access to policies were in most cases proposed prohibitively expensive premiums – so expensive that they were equivalent to being refused insurance. And being excluded from insurance means being excluded from society.

HIV positive people are discriminated by entry and residence regulations. The majority of countries worldwide have passed restrictive legislation. For people with HIV and AIDS – like for anyone else – travelling is an important aspect which improves quality of life. Entry restrictions considerably impair the personal freedom. Even if a tourist permit from one to three months does not usually represent a problem for people with HIV, long term stays – often motivated by the need or desire to work or study, or by the wish to settle in the foreign country – represent an insurmountable obstacle. Some countries request evidence of HIV negative status for any person staying longer than two weeks or one month. Others ask to all individuals "susceptible" of being HIV positive to take the HIV test, which opens the door to all sorts of abuses based on country of origin, race, sex and sexual orientation. Others openly refuse access to people living with HIV or AIDS. Some countries ask for a certificate indicating the HIV test result before granting a visa. Even if most European Union countries do not have restrictive entry regulations for people with HIV/AIDS entering their territory, this does not protect from being harassed or insulted during immigration procedures. Often discrimination occurs on the basis of subjective or tenuous

criteria, such as being in possession of documentation about HIV/AIDS. Being in possession of antiretroviral medication can be the basis for being refused entry to a given territory. One person was refused entry following a medical incident during which he mentioned being HIV positive in order to receive appropriate care. He was violently taken back to the border by order of the courts.

The justification given to support enforcement of such restrictive measures is the safeguard of public health. For the people concerned, such discriminatory measures represent a hardly acceptable and unbearable situation, which is even harder for HIV positive or sick people married to spouses living in countries where such restrictive measures are applied. They have no other alternative than to leave the country before expiration of their authorised stay and then re-apply to return.

*"I work in a country that demands an HIV test for any stay longer than three months. I thus have to leave the territory every three months. It is both tiring and stressful. And that's without mentioning the hassle of having to hide my medication in other packaging."*

#### MEDIA

*"I was born in the USA and now live in the EU. Recently I wanted to visit my former home-country in order to spend some time with my family and friends; regardless of the fact that I am still an American citizen entry was denied to me because of my serological status."*

Unfortunately, media tend to picture AIDS as a spectacular event, reporting the huge figures of the pandemic, pre-condemning HIV positive individuals, making a show of the misery of African countries, etc. They rarely present in-depth analysis of the issues related to the medical and psycho-social aspects of the epidemic, or episodes of discrimination against HIV positive people. On the contrary, most show a discriminatory attitude thus reinforcing defensive reactions and mechanisms in public opinion.

In fact, crimes committed by HIV positive people are normally emphasised, suggesting that the health status of the individual increases the level of cruelty of the crime. The reporting of personal data and of the health status of individuals is a violation of the law protecting the privacy of all citizens, and therefore is an illicit act. The lack of serious scientific prevention information is to be underlined in almost all instances.

We have just seen an overview of the some of the areas that are affected by discrimination. It is self-evident that this section cannot cover all areas of discrimination. We

see that all aspects of life can be affected. It is nevertheless important to further mention that discriminatory episodes occur in the military environment, in prisons, in the context of leisure and spare time activities, etc.

The population affected with HIV shows, unfortunately, the presence of a hierarchy created by the social representation – fed and wanted by some cultural and political components and by the mass-media – that generates deeper discrimination between people who share the same condition.

This hierarchy discriminates between those who “looked for” AIDS and those who are the victims of injustice or bad luck. Drug-addicts and migrants (especially when African) are at the bottom of the list, followed by homosexuals and by “easy” women. Elderly people and heterosexuals score in the middle of the list, while those who were infected during the exercise of their profession share the top position with children and recipients of infected blood transfusions. Social actors who identify themselves in this hierarchy find it difficult to acknowledge themselves as a unique subject able to fight against discrimination. They are fragmented in categories, which is useful only to those who have an interest in abating or annulling the joint power of all people with HIV.

#### DISCRIMINATION AGAINST MIGRANTS

*“My doctor was rude to me. He even dared say that we Africans were to blame for all disease.”*

Many migrants do not understand HIV/AIDS well. Most of them consider it to be an illness linked to marginality and Western culture. These false beliefs make it very hard for them to deal with the issue when they learn they are HIV positive, especially when they are already racially discriminated against because of their country of origin. Some of them cumulate factors of discrimination: they are migrant, HIV positive, but they may also be drug users, homosexuals, prostitutes, delinquents or even simply women. Most migrants live on the poverty line and this makes them more vulnerable to the HIV infection, particularly if they are drug users or sex workers. This increases the stigmatisation and discrimination they face, which is perpetrated even by medical staff.

It is difficult for AIDS organisations to develop programmes specifically targeted to these population groups, because sexuality – and homosexuality in particular – often represent taboo issues for them.

#### DISCRIMINATION AGAINST HIV DRUG USERS

*“I’ve just found out that I’m HIV positive. It took me a while to understand the consequences of AIDS, but my wife does not want to think about it. She wants children. It’s the only thing that counts... I don’t know what to do, and all the while our families are pressing us to go ahead.”*

Discussing AIDS with migrants automatically means taking into account their culture and lifestyle.

*“I can’t find a job, and even less somewhere to live... I’ve got financial problems but no bank is going to lend me any money... So you can see why AIDS is the last of my worries... I’m fortunate that my health is still good.”*

This population was for a long time rejected, insulted and largely misunderstood by people, including the forces of law and order. Most are homeless or live in catastrophic sanitary conditions. They are destitute and in many cases of foreign origin. The illegality of drugs reinforces the negative perceptions of society towards them, especially if they are infected with HIV. They are largely ignored by social, legal and health bodies.

What makes this population vulnerable to becoming infected with HIV is sharing needles. Since IV drugs are illegal, some people have problems in buying needles in pharmacies, because such act implies drug use.

Specifically targeted needle exchange projects have been developed for this population group; some are more effective than others, because they succeed in establishing a relationship with drug users and in transferring them the

kind of information they are specifically interested in. Drug users who are also HIV positive do not necessarily stop taking drugs. Because of this and of the consequent prejudices and erroneous perceptions, some doctors refuse to prescribe them antiretroviral therapies. Some medical staff find it difficult to approach several problems at the same time (HIV, drug use, etc.) Furthermore, in some countries treating people who have illegal practices can cause them problems as they could find themselves being charged with complicity. This indirectly causes drug users to be excluded.

DISCRIMINATION AGAINST  
GAYS, LESBIANS, BISEXUALS, MEN  
WHO HAVE SEX WITH OTHER MEN,  
TRANSEXUALS

In the context of HIV/AIDS, the representations of homosexuality are essentially negative from the legal, social and cultural perspectives.

During adolescence, gays and lesbians do not find much support from their family, friends or teachers. Very often, they are subjected to contempt and physical or mental violence. The appearance of HIV/AIDS in the homosexual community gave rise to a strong association between the stigma of AIDS and that of homosexuality. This reinforces the negative image of homosexuals and people who are HIV positive, and is manifested in several ways: people living with HIV/AIDS can be stigmatised or encounter discrimination because they are presumed to be homosexual, and gay men can be victim of discrimination because it is presumed they are HIV positive, or even the cause of the epidemic.

The calls received show that a large proportion of gay men who have unsafe sex do so because they feel isolated and rejected. This is particularly true in the case of young men.

*"I felt so bad within myself... isolated, lost... I thought there was no point in protecting myself, why would*

*I want to, what would be the point?"*

The availability of anonymous HIV testing is a good way to encourage tests, especially for vulnerable populations. Unfortunately it is not always available in all countries.

*"I don't trust the testing centre. A friend of mine went there. He talked about his "abnormal" sexual practices, as they called them. The news (of his homosexuality) spread everywhere. He was lucky he didn't test positive."*

Our calls show that gay men prefer to tell their close friends and lovers rather than tell their families. They get a more sympathetic reaction from them. For parents, finding out about their son's illness can open old wounds about homosexuality and all it represents.

*"I knew when he told me he was gay that it would all end in tears. Just as I knew that AIDS was out to get him. Just imagine what people would think if they knew. It's awful!"*

We have received several testimonies regarding how difficult it is to work in a homophobic environment due to the stress induced. It is difficult for victims of abuse of power to start legal action, because of the lengthy procedures and the absence of laws to punish homophobia.

*"Since my colleagues have known I'm ill, it's never stopped: queer, poofter, etc. What should I do? My employer joins in too."*

In terms of health and prevention, it is essential that medical personnel are comfortable and knowledgeable about sexual practices between men, so that they can better evaluate what underpins the taking of risks in terms of sexual behaviour.

*"I had to change doctor because the one I had was uncomfortable every time I mentioned my sexuality. He sometimes made unpleasant remarks about my HIV positive status."*

One of the great discriminations experienced by homosexuals is being unable to inherit from one's partner. When

a death occurs, the partner of the deceased is often left with nothing. The situation is very difficult to cope with.

*"My partner died from AIDS. We had been together for 7 years. I quit work to nurse him through his last few months. His family, who had always rejected him, inherited everything. What can I do? Nothing, except remember the good time we had together."*

*"My partner has just left me (died), but the most difficult thing for me was being held at arms length by his family. They didn't let me say good bye to him."*

Lesbians living with HIV/AIDS are also faced with stigma and discrimination. If they are infected then it means they have sex with men or are IV drug users. Not all the sexual practices of lesbians are safe.

Transsexuals are most certainly the population that suffers discrimination most. They are often stigmatised, humiliated and even ignored as they have great difficulty in being accepted, even by the gay and lesbian communities. They have little hope of finding work. They are badly treated in bureaucratic matters,

since their sexual identity is not taken into account. In hospitals and prisons, they are allocated rooms according to their sex at birth. It is in prison that they are the most exposed to danger since they become victim to physical, mental and sexual attacks.

*"We have a hard life. We are insulted and despised everywhere we go... The police show no respect for us, they treat us like we are worthless... We are forced to prostitute ourselves to make some money. That's how I caught AIDS."*

They are also discriminated against in treatment centres due to their need for hormones, especially if they are infected with HIV/AIDS. There are rejected everywhere and there are no laws to punish such discrimination. Transsexuals to a high degree end up on the street as sex workers or drug users; both activities make them extremely vulnerable to the HIV infection. This population group still needs comprehensive information since very few prevention programmes have been targeted at them.

DISCRIMINATION AGAINST  
SEX WORKERS

Sex workers are seen as being transmission vectors of sexually transmitted infections, especially of HIV. Even in case of need, they cannot rely on a large number of services (police protection, medical treatment etc.) as they are rejected by them, often rudely. Some prostitutes, when harassed or raped by clients, do not have the means to start legal action because of the illegal nature of their work. The repression they face from the forces of law and order makes their problems worse:

*"At the hospital pharmacy, in front of everyone, the nurses constantly made comments about how I caught AIDS, telling stories to make everyone laugh."*



### DISCRIMINATION AGAINST PRISONERS

*"My friend died in his cell without any consideration being taken. His family were only advised at the last minute."*

It is thought that the prevalence of HIV is a lot greater in prisons than it is in the population at large. The risk of being infected with AIDS in prison is far greater. This category of people is victim of stigmatisation and discrimination by prison staff, other prisoners and the general public. Besides being infected with HIV/AIDS, they are suspected of having homosexual sex and using IV drugs. There are very few programmes for these people as it would shock public opinion if a needle exchange programme or free condoms were made available to prisoners. In the first instance, it would mean condoning illegal drug use. According to the directives of the World Health Organisation on AIDS infection in prisons, all prisoners have the right to receive treatment, including prevention materials, without being discriminated against; this is so as to avoid HIV transmission via unprotected sex (common in prison) and the exchange of dirty needles.

The fear of being judged and stigmatised, or the conditions of detention themselves,

prevent prisoners from taking the safety measures required. Confidentiality concerning the serological status of prisoners living with HIV/AIDS is constantly flouted. There have been cases of prisoners being released so that there would be no risk to prison staff and prisoners. As for treatments, prisoners living with HIV/AIDS often are not given the most appropriate and recent antiretroviral therapies, nor adequate complementary medication.

*"I was refused a pain killer when I was in agony with an abscess. I was told that I only had myself to blame – that it was my own fault..."*

### DISCRIMINATION AGAINST WOMEN

Women are more vulnerable to the HIV infection. Besides biological, cultural and social reasons for this, a power struggle also exists between men and women, for example, when negotiating the use of condoms. Several factors need to be taken into account: economic dependence, fear of being alone, fear of being victim of violence, shame, etc. Such reasons do not incite them to access support or information networks.

Doctors still do not prescribe an HIV test to women for the reasons we evoked earlier. When they request one, they are asked a series of questions they judge to be stigmatising and discriminative about their sexual behaviour or drug use. On the other hand, some doctors do not hesitate to impose the test or simply carry it out on women judged to be "at risk" such as African women.

When receiving a positive result to the HIV test, women need to be adequately supported, and medical staff should pay particular attention to their specific concerns, which mostly refer to the difficulty in disclosing the HIV condition to the partner and the possibility to have children. Women have reported being discouraged by medical staff from having

### DISCRIMINATION AGAINST HETEROSEXUAL MEN

children, or even encouraged to terminate a pregnancy in progress.

As women are more often in contact with the family environment and those close to them, if they test HIV positive they are more exposed to rejection than men are. When they test positive, they are suspected of having engaged in "perverse" and frequent sexual practices.

As for heterosexual men, they are often not even mentioned when the epidemiological aspect of AIDS is discussed. The HIV infection is generally associated with specific population groups. The heterosexual population feels that this pathology does not concern them. Just as with women, some doctors do not propose men the HIV test and so it is not possible to diagnose symptoms associated with AIDS soon enough; this leads to a considerable delay in terms of access to treatment.

The main complaints of heterosexual men living with HIV/AIDS concern the safeguard of their rights in the relationship with their children.

*"My wife does not want my own children to visit me. She is scared that I will infect them. It's ridiculous! She's told everyone that I'm infected, so that they turn against me. I'm taking her to court."*

### DISCRIMINATION AGAINST YOUNG PEOPLE

Epidemiological data in European countries show that HIV affects more and more young people. They in fact badly negotiate prevention strategies and sexual behaviours. Most school curricula about sexuality and HIV are full of moral judgement and taboos. Head teachers and teachers influence the way in which the lessons are given; some choose to ignore questions about sexuality and sexual orientation. This is why many young people do not find answers to the many questions they ask themselves about sexuality.



DISCRIMINATION AGAINST  
CHILDREN

Several measures and behaviours discriminate against children: from the family being isolated by their environment to children being rejected from groups/schools.

*"My sister doesn't come to visit us anymore since she found out my son is HIV positive. The fact that he doesn't see his cousins anymore hurts him a lot. I don't know what to say to him."*

Some families find it hard to keep their child's HIV condition confidential. They think that close family, friends and teachers need to be informed.

*"I had to talk about it, because sometimes my daughter needs to be given treatment when I cannot be around."*

Others believe it is vital not to say anything at all, for fear of their children suffering from the consequences.

*"If the others knew my daughter is infected she would be harassed from morning till night. People are so cruel towards the ill."*

Nurseries still turn away children who are HIV positive. The lack of knowledge and information about the infection makes the nursery staff and the other parents react this way. Stigmatisation and discrimination are also present in other institutions: primary schools, junior high schools, etc. Programmes about sexuality and STIs would help in changing attitudes of both students and teachers.

The assimilation of discriminating behaviours produces self-outcasting and self-exclusion. For a great part a person's self-esteem depends upon the opinion others have of them and how much of their energy is spent in trying to obtain the approval of those they care about.

SELF - DISCRIMINATION  
AND HIV/AIDS

People begin to exclude themselves from their social context because they fear social deprivation; they cut off relationships with acquaintances, friends and relatives and even give up their sex life. Their individual self mostly depends on the importance the rest of the world gives them, or on what they imagine others think about them. Such judgement heavily determines their psychological balance. It is difficult for individuals to assert themselves when they do not match the standard of normality - when they do not follow the average lifestyle. In such cases, people see themselves as "different" and may develop a tendency to self-discriminate.

Even now, in year 2003, people refuse getting tested for HIV. They imagine that if they find out they are HIV positive their life will dramatically change and nothing will ever be the same from that moment onwards. They easily overcome the embarrassment of communicating to acquaintances about other health problems, but they are not prepared to tell, not even to themselves, about their HIV status. They foresee the worst scenarios in the case they test positive and therefore decide it is best not to know. Individuals adopt a self-discriminating attitude long before testing; it might be even best to say self-

discrimination is one of the main reasons for not testing.

*"I am not going to test for HIV because I cannot accept the idea of sharing with someone else the result of the test. The other person involved could see me in other places, recognise me and tell people about my condition. Until there is no chance to be the only one to read the result, I prefer not to test"*

*"I don't want to know about my HIV status because I know that I would not accept a positive result. I would think that my life is finished and that the other people would run away from me. It's better not to know, so I don't have to face that kind of horrifying truth and I can maintain the social relations I have now. For me, this is the only acceptable solution."*

Another very illuminating example:

*"I have to undertake a delicate surgery. I want to make sure the hospital staff don't test me for HIV before the surgery. How can I be sure? What will happen if they ask for my consent to test and I refuse? Would they think that I have HIV? Would they test me anyway? If there is no chance to make sure*

*they are not going to test, I will not undertake the surgery. I don't want to know, and I don't want them to know. This means I won't take care of my kidneys and this could cause me severe problems in the future, but in my mind now this is nothing compared to what could happen to me in case I turn out to be HIV positive."*

Other people develop self-discriminating attitudes immediately after having been informed they are HIV positive. The moment the personal condition sinks in is a moment marked by a profound crisis. HIV positive people perceive themselves as "different" in terms of being infected, contagious, dangerous for others, etc., and picture and endless stream of future sexual and parental opportunities vanish before their very eyes. In these circumstances, they are the first to refuse friendships or sentimental opportunities. There have been various opportunities to observe how self-discriminatory behaviours are manifested within differing contexts. In the first instance, within relationships:

*"I don't go places any longer because there's always someone who knows me and tells everyone else I'm HIV*

positive. I am sick of living in my small town, where people seem to know everything about you, but if I think about moving elsewhere I start to panic: I should have to find a new doctor, a new dentist, and so on. This could be even worse than what I am facing now. Now I live in isolation, but I found a way to survive and to maintain those relationships I need for surviving. I don't feel I could afford any additional stress."

"I used to play football but I don't do it any longer. I am scared to get hurt and bleed. The others would surely come around and help me, but they would touch my blood. To avoid it, I should tell them that I am HIV positive, and they would be terrified and kick me out of the team. By the way: if I tell them beforehand, I am certain they would not let me join the team."

Self-discrimination often prevents people with HIV from taking good care of their health or of their physical aspect:

"It's been ages since I have been to see my gynaecologist. I don't want to tell him about my HIV status. I fear he will reject me. Now I have problems and I don't know what to do."

"I would so much like to have a pedicure, a manicure, a deep facial cleansing made by a good professional! Things that are normal for all women are a real dream for me now. I don't feel ready to tell the beautician about my condition, but then I don't want to expose her to any risk: she would very likely get in contact with my blood, and I would never forgive myself if she got infected. I know it's her duty to protect herself and to sterilise all the tools she utilises, but you never know... Plus, I am sure no beautician would want me as her client if she knew about me."

In all the above cases, living in a small town heightens this sense of distress and fear and also, as a result, the tendency to self-discriminate. Big cities, on the other hand, help to hide among the crowd.

Within sentimental relationships, all prospects for new relationships are quashed, interrupting as a result any kind of further contact with potential partners. In this way, the individual avoids any anguish deriving from partner rejection, because he/she is convinced the partner will inevitably be incapable of accepting the situation.

"I will never look for a steady partner any longer. I know from the start that nobody will ever accept the fact that I am HIV positive. Who would want to make a project for life with someone who is going to die soon, or could transmit the HIV virus? On the other hand, I know I will never have occasional partners either. I am not good at negotiating safer sex and I don't want to find myself in that sort of situation. I don't think I deserve a sexual life any more anyway; I should have paid attention back then, when I acted as a fool. Now I am paying for my mistakes and this is it."

"My partner knows I am HIV positive. We have very aseptic sexual activities, i.e. we limit ourselves to protected vaginal intercourse – very little kissing, no oral sex. I know exactly what the risks are and what risks he would run with the different behaviours, but I feel uneasy in talking frankly about the matter and I can see that he barely touches me; if I tell him I would like a different type of sexual contact, may be he would think I am a nymphomaniac. Sex has become a duty for me and I don't feel any pleasure any more, while through vaginal penetration he has his regular orgasms anyway. I feel I still have the

right to enjoy sex, but I cannot speak up."

Self-discrimination also strikes at work. Job seeking is interrupted even when people with HIV are in good health as they see themselves as "sick" and, more than anything else, are terrified that the hiring procedure might include medical tests.

"I am not looking for a job because sooner or later the truth will come out: may be I will get sick too often, or somebody else will see me while taking medications, or my lipodystrophy will become an evident sign of my health status, or else I will be hospitalised in a department for infectious diseases... People will find out some way and they will reject me. I am sure it would be awful and therefore I choose to avoid going through all that pain."

"I won't accept that promotion because they might ask me to travel to countries where I cannot enter because of HIV, like the USA. What should I do then: tell my boss I cannot go because of HIV? I would surely be fired immediately! And what about if I take the risk and go anyway, and at the customs I am refused entry because

some officer finds my medications? This would make me feel even worse, plus I would probably be asked to reimburse the price of the plane ticket to my company."

Furthermore, self-discrimination appears to worsen when a person experiences different difficulties (i.e. HIV positive, drug addict, and/or former prisoner, and/or jobless, homeless). Each of these situations alone makes relationships difficult and their overlapping increases the sense of "inferiority" with regard to everyone else who is "normal".

The work of the ENAH counselling professionals is that of helping the other accepting the rejected identity. The aim is to get the individuals to overcome their crisis by supporting them in perceiving themselves no longer as different, and by guiding them in exploring their own HIV condition, until they consider it simply a difficulty, but no longer the "end of their existence" or something too big to be beaten. It is always valuable to inform people of the progress made by scientific research and the availability of new medications. It's also important to inspire their outlook towards the future "despite" their HIV status – not to give up on treasured projects, as long as

these are still genuinely realistic (buying a house, going on a trip, changing jobs). Each person is also encouraged through discussing the experiences of other people in the same situation who have reached important objectives: professional success, marriage, maternity, a good relationship, etc.

In some cases, the tendency to self-discriminate fades away as time passes. People realise that, despite their worst fears, life goes on and they find stability. Sometimes they discover that sharing with others the fact that they are HIV positive by no means jeopardises friendships or sentimental relationships, or even their sex life. Sometimes they fall in love and are themselves loved "despite" being HIV positive. Overcoming one difficulty in one area (relationships, sentimental, professional) usually paves the way towards resolving more problematic issues and, consequently, a more profound acceptance of their actual condition and original identity, which leads to the rebuilding of an individual "normality".

## RECOMMENDATIONS

1

Research should be undertaken to map the current prevalence of HIV prejudice and types of HIV discrimination experienced in Europe, and the organisations part of ENAH should establish a database of case studies. AIDS organisations are in fact the most appropriate places for the gathering of data on discrimination affecting people living with HIV/AIDS. Their proximity to HIV positive people is a factor of richness and gives legitimacy to their instances.

2

European governments should establish a cross-departmental coordinating mechanism to oversee the legislative and other changes needed to combat social exclusion caused by HIV. They should revoke laws encouraging stigmatisation and discrimination of people living with HIV and introduce new legislation punishing discrimination acts which are currently not penalised.

3

European AIDS organisations have to be provided with the means to create legal counselling, legal information, advice and referrals. The many discrimination cases referred to ENAH helplines are not followed up by legal means because most organisations do not have the human or financial resources required to start legal actions. A Europe-wide legal service would enable the victims of stigmatisation to find help, information and support.

4

European governments should fund and endorse national public information campaigns to reduce stigma and prejudice about HIV, involving people with HIV and those who support them.

5

The European Departments for Work and Pensions should work with HIV organisations to ensure that people with HIV receive appropriate support in returning to or obtaining work, alongside legislative sanctions against discriminatory employers.

6

The Departments of Social Security of the European Community should review benefit regulations to make them more flexible for people with long term chronic medical conditions and the Departments of Work should consider ways of supporting those people with HIV who are able to work to do so.

7

The Justice Departments and prison services of the European countries should recognise the prevalence of risk activities within prisons and take steps to prevent HIV transmission, including access to condoms and cleaning materials for injecting equipment.

8

Education, information and professional training programmes on HIV/AIDS issues should be encouraged. Awareness programmes about HIV/AIDS would contribute to fight effectively stigmatisation and discrimination experienced by those living with HIV. Adequate training of professionals (medical staff, care workers, social workers, teachers, etc.) is necessary to promote acceptance and support for those affected by HIV/AIDS.

9

Complete and comprehensive information on AIDS and education on sexual orientation must be integrated in school programmes, taking into account age and maturity level of the students. Introducing sexual education, sexual orientation and STIs prevention will help children and adolescents to adopt individual prevention strategies later in life.

10

In the workplace, laws should be enforced to put an end to discrimination perpetrated towards people living with HIV, designed to punish all infringements of confidentiality and false redundancies, and to allow employees living with HIV to adapt their working hours according to their state of health.

11

Health promotion agencies producing information on sexual health and HIV should include, as appropriate, messages countering prejudice and discrimination both in the general population and within targeted communities.

12

HIV prevention information targeting migrants should be produced taking into account their specific cultural background by directly involving each different ethnic community.

## CONCLUSION

In order to respond positively and effectively to HIV/AIDS related stigma and discrimination, work has to occur simultaneously on several fronts. The greater empowerment of people living with, and affected by, HIV and AIDS is essential for the HIV response. Community mobilisation, advocacy and social change must take place alongside interventions to change the broader context in which individuals and communities live. Vitally important is communication and education to encourage better understanding of AIDS and HIV. An equitable policy and legal context is central to success. One of the greatest challenges relates to increased access to treatment drugs. Globally, stark inequalities exist between countries where antiretroviral treatment is available and those where it is not.

Two priority levels of intervention can be identified and they affect directly the role played by non-governmental organisations: a juridical-political level and a more operative one. The first level calls for an interlocutory relationship to be built such to create a real encounter between institutional and social actors with the purpose

to issue new norms or modify existing ones. New norms should protect people with HIV (and also all those individuals affected with critical and invalidating pathologies) from the social and work points of view, guaranteeing income and a dignified life. We should no longer think only in terms of length of life but in terms of quality of life. The second level calls for the application of a work methodology characterised by the synergy with the various social actors dwelling in a given territory, able to valorise social-cultural differences such as field associations, services, companies, cultural organisations, schools, mass-media, etc. The rights of people with HIV cannot be but mediated rights, and as such, they call for the creation of spaces apt to mediate and manage the conflicts.

Enumerating the recommendations to end a report that aims to significantly reduce the number of inequalities, stigmatisations and discriminations to which people living with HIV and AIDS are subjected to is not sufficient. In order to make sure that goals granting comprehensive and adequate support and care for people with HIV/AIDS are met, there needs to be reliable means to

check that the recommendations have been applied and an evaluation of the aspired changes is carried out. For this, a partnership between various AIDS organisations and both public and private institutions and companies is needed. In Europe, the ENAH members work to take care of the issues and needs raised by those living with HIV/AIDS and constantly elaborate tools and strategies to answer them. Political lobbying should make governments aware that they need to take into account such necessities and expectations, and above all to better promote and protect the rights of people living with HIV/AIDS.

This charter has been elaborated from the experiences of the AIDS Helplines composing the network. The European Network of AIDS Helplines welcomes other European AIDS telephone services that share its principles and objectives.

**I**  
Ethical principles

- The AIDS helplines offer non-judgemental, non directive and personally centred listening.
- They guarantee the anonymity of the caller and insure that any information taken remains confidential.
- They promote the caller's self-esteem and also respect his/her personal beliefs.

**II**  
Their functions are as follows

- To broaden the knowledge level of the public at large and thereby to assist in the implementation of personal strategies of risk assessments.
- To provide accurate information, support and orientation on all aspects related to HIV and AIDS.
- To support those who are directly affected by HIV and AIDS.
- To break the taboos surrounding HIV and AIDS.
- To facilitate the access to comprehensive care and the common respect of social rights.

**III**  
Objectives of the European Network of AIDS Helplines

- To improve the quality of services provided to the callers by the participating helplines.
- To create means and structures of information and expertise exchanges within the network.
- To promote actions of prevention for all populations as well as comprehensive care (medical, psycho-social) for people with HIV in the specific arena of AIDS helplines.
- To disperse accurate and current information to all members.
- To be an observer of the HIV epidemic for the European Union.
- To apply the know-how of AIDS helplines to other health issues: i.e. hepatitis, STIs.
- To be able to refer EU citizens to national or regional services of each member country.
- To strive to provide access for all EU citizens to accurate information.
- To improve collaboration between ENAH and other networks and organisations dealing with public health issues connected to HIV.

**IV**  
Means of the European Network of AIDS Helplines

- Sharing experiences, information and training materials (Internet, library, journal...).
- Creating working groups and collaboration on specific issues.
- Organising regular meetings between the participating helplines.
- Encouraging the AIDS helplines to give the most accurate information.
- Reflecting on the elaboration of common ethical rules.
- Initiating common training sessions on particular topics.



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DISCRIMINATION



GOOD PRACTICE AND  
PHONE LISTENING



POSITIVE LIVING

EUROPEAN NETWORK OF AIDS HELPLINES  
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