Is the Netherlands Keeping the Promise?

The civil society evaluation of the UNGASS-commitments

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Executive Summary

The UN General Assembly Special Session (UNGASS) on HIV/AIDS, held in 2001, was the first such session devoted entirely to HIV and AIDS. A comprehensive and binding list of starting points and objectives for the global fight against AIDS was decided upon. Now, five years after UNGASS, the World AIDS Campaign has initiated a civil society evaluation of government involvement in HIV/AIDS prevention and care. STI AIDS Netherlands was asked to coordinate this process in the Netherlands. A steering committee was assembled of leaders in the field of HIV care and prevention. The steering committee decided to focus on the position of asylum seekers and illegal migrants with HIV as a case study. The study consisted of desktop research and telephone interviews with representatives of Dutch civil society. Additional interviews were held with five HIV positive women who were still going through or had recently been in an asylum procedure.

Generally, one could say that HIV/AIDS services in the Netherlands are quite good. Medical treatment, prevention, and care and support are well taken care of, although there is of course room for improvement as well. The same is true for research. The biggest problem is that the government does not have an overarching, comprehensive view on HIV/AIDS. Developments in the field of HIV/AIDS prevention and care are not guided by a national HIV/AIDS policy, although the government does have policies for particular sectors.

- A comprehensive HIV/AIDS policy is needed;
- More investment in prevention, care and support, and research is warranted, especially for vulnerable groups.

Another problem is the lack of coherence between national policy and what is being done locally or regionally. The local authorities act autonomously when setting their priorities for health and health promotion. Some regions don't pay enough attention to the HIV/AIDS epidemic. This needs to be addressed at national level, especially where marginalized groups are concerned.

- Local authorities should be stimulated to invest in HIV/AIDS policies.

Asylum seekers and illegal migrants are a very vulnerable group, both because of their precarious status in Dutch society and because of their high risk of being infected with HIV. The mere fact that they are HIV positive is not taken into account during the asylum procedure. Even the availability of medication is not taken into account. A temporary status on medical grounds is available only for people who are in the final phase of their disease. Although medical care is provided for, basic necessities like 'bed, bread and bath' are unavailable for the ones whose (first) appeal for a residence status has been rejected. Prevention, care and support are largely absent for this group.

- Immigration procedures should be more humane;
- Asylum seekers and illegal migrants should be involved in policies and activities that concern them.

Background

This study

The UN General Assembly Special Session (UNGASS) on HIV/AIDS, held in 2001, was the first such session devoted entirely to HIV and AIDS. A comprehensive and binding list of starting points and objectives for the global fight against AIDS was decided upon. The member states agreed, among other things, to make more money available for the fight against AIDS. The Declaration of Commitment on HIV/AIDS also sets specific goals in terms of prevention and care: a 25% reduction of HIV prevalence among young people in 2005 for the most afflicted countries and in 2010 worldwide. The member states agreed to safeguard, no later than 2003, the human rights of people with HIV and AIDS and of vulnerable groups and to consider the treatment and care for people with HIV and AIDS as being as fundamentally important as prevention is (www.unaids.org) (STI AIDS Netherlands, 2005).

In many ways, the Dutch response to HIV/AIDS has been regarded as a good example, especially because of an open attitude towards homosexual men and intravenous drug users. From the beginning, HIV/AIDS was seen as a public health problem in the Netherlands. The approach was therefore pragmatic rather than moralistic (Sandfort, 1998). Furthermore, the health care system is very good, so infection rates have remained relatively low, although some groups have been disproportionately affected. In many ways, the UNGASS declaration may have been more relevant for countries where the pandemic has taken more uncontrollable forms. However, the Dutch government has pledged a commitment by signing the UNGASS declaration, not only for its foreign policies, but also at home.

Now, five years after UNGASS, the World AIDS Campaign has initiated a civil society evaluation of government involvement in HIV/AIDS prevention and care (Worls Aids Campaign, 2005). This evaluation is being undertaken in twenty countries, including the Netherlands. The question is mainly whether governments have been keeping their promises. World Aids Campaign asked STI AIDS Netherlands to coordinate this process in the Netherlands. A steering committee was assembled of leaders in the field of HIV care and prevention (for a list, see appendix). The steering committee commissioned a researcher and decided to focus on the position of asylum seekers and illegal migrants with HIV as a case study. Due to the short time available, little attention could be paid to other issues, like children with HIV, insurance, and living with HIV in rural areas. The study focuses on problematic aspects of the Dutch HIV/AIDS policies. The successes of the Dutch approach are not taken into consideration. The evaluation was based on a format and documents of World Aids Campaign and others.

The study consisted of two parts. First, desk research was carried out - looking at written material, mainly research and policy reports (for a full list, see appendix). Second, members of civil society were approached for telephone interviews. They were selected by the steering committee for their involvement with asylum seekers and illegal migrants. Eight interviews were held (see appendix). Additional interviews were held with five HIV positive women who were still going through or had recently been in an asylum procedure. Their stories are used as illustrations of the points made in this report (using fictitious names). The information obtained in the telephone interviews is used without reference to the actual informant(s). The information they provided largely overlapped. Where informants did not agree, their opposing views are shown in the report.

Baseline statistics

By the end of 2003, an estimated 16000 to 23000 people were living with HIV/AIDS in the Netherlands. As of June 2005, a cumulative total of 10619 HIV cases had been reported (table 1). Men who have sex with men (MSM) still account for the majority of the registered cases

(52%), although the proportion decreased between 1993 and 2001. In 2004, the MSM percentage increased again. The number of heterosexually acquired infections has increased in recent years but declined for the first time in 2004. Of the 938 new HIV diagnoses in 2004, MSM accounted for 49% and heterosexuals for 40%. The proportion of intravenous drug users (IDUs) remains fairly small, 1%. There were 240 new AIDS diagnoses in 2004 and 85 people died of AIDS. The number of AIDS diagnoses and deaths has dropped sharply since 1997, mainly because of the availability of HAART (Van de Laar et al., 2005).

Table 1: Number of HIV cases, by gender and transmission risk group (Van de Laar et al., 2005)

	homosexual	**heterosexual**	**other/unknown**
men (N=8215)	5556 (68%)	1415 (17%)	1244 (15%)
women (N=2404)	0 (0%)	2050 (85%)	354 (15%)
TOTAL (n=10619)	5556 (52%)	3465 (33%)	1598 (15%)

Most HIV positive heterosexuals are not of Dutch origin (see figure I for the geographic distribution of women). The majority of the non-Dutch heterosexuals acquired the HIV infection abroad; in sub-Saharan Africa and to a lesser extent in Latin America and the Caribbean. Among heterosexuals, more women than men are known to be HIV infected. HIV prevalence in the Netherlands is highest among MSM (0-32%) and IDUs (0-26%)[1]. HIV prevalence among heterosexuals varies from 0 to 1.8%. In 2004, national screening of HIV in pregnant women was implemented in the Netherlands. The HIV prevalence was 0.06% in the first half of 2004 (Van de Laar et al., 2005).

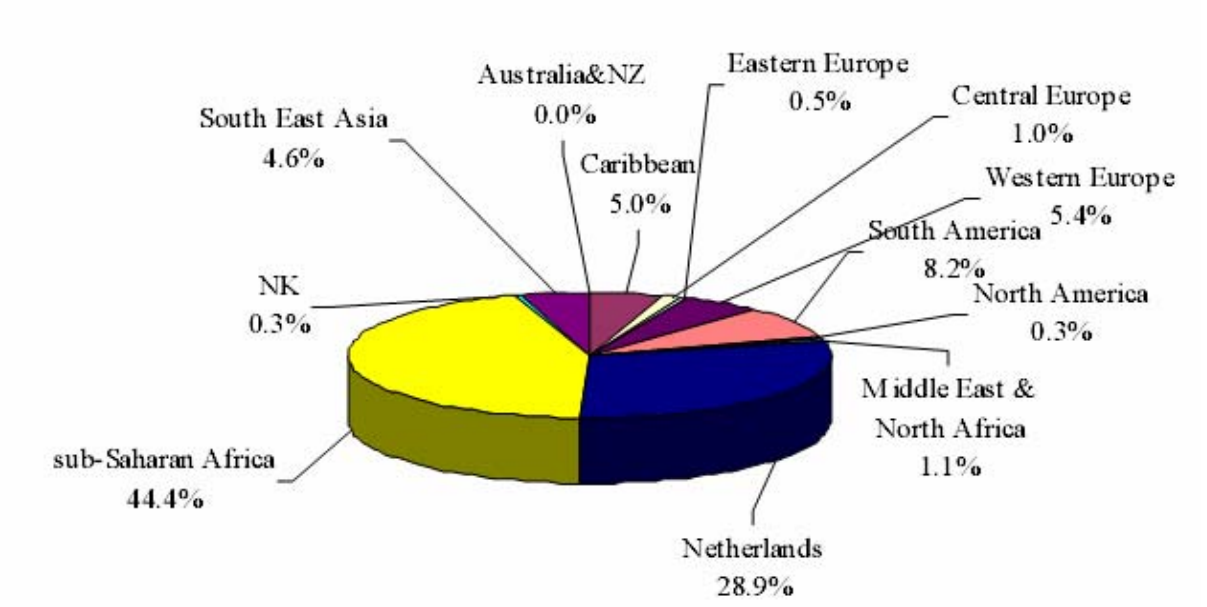

Figure I: Geographic distribution of HIV cases, for women (taken from Van de Laar et al., 2005)

In 2006, the Dutch government is expected to spend 12.5 billion euros on health care. Almost 700 million euros are meant for prevention and health protection. Of this, about 83 million

[1] In the Netherlands, HIV prevalence is usually measured in specific settings, for example among visitors of STI clinics. Prevalence therefore varies. The percentages mentioned cannot be generalized to the population as a whole. There are no general prevalence estimates available for different transmission risk groups.

euros (less than 0.7% of the national budget) is meant for reducing infectious diseases. How much of this budget is intended to be used for HIV/AIDS prevention is unknown. The exact amount of money being spent on HIV/AIDS prevention is very difficult to determine, because much of the budget is regionally allocated, without earmarking it for HIV/AIDS prevention.

In November 2003, there were 209 children under 13 who were known to be HIV positive. Of these children, 79% had at least one parent who was not of Dutch origin. Most of the children (56%) had at least one parent from sub-Saharan Africa. The majority of the children were infected by mother-to-child transmission (76%). Their viral load is relatively high, as compared to adults. The percentage of children diagnosed with HIV amongst the total annual number of people diagnosed with HIV decreased from 2.4% in 2001 to 0.7% in 2004. However, the significance of this decline has not yet been established (HIV Monitoring Foundation, 2005).

Political commitment

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. This WHO definition of health (1948) is the basis for Dutch health policies, so Dutch health care involves more than just medical treatment. It also encompasses mental health care, psychosocial support, and – importantly – prevention.

People are believed to be primarily responsible for their own health. It is assumed that people are capable of taking on this responsibility. For certain groups there are, however, barriers to be able to do so, for example a lack of (financial and other) resources, hardly any social support, and limited knowledge of the Dutch language. Preventive interventions may not reach these groups and therefore have little impact on them. It is the government who should make it possible for people to take responsibility for their own health behaviour.

Combating HIV/AIDS is one of the main themes of Dutch foreign policy, especially with regard to developing countries. Although it is a theme in national policies as well, it's not as prominent as it is in international policies. National HIV/AIDS policies are mainly governed by the health department, although other departments are involved as well. There is no comprehensive policy regarding HIV/AIDS. Prevention, medical care, and support are separately governed so different organizations are responsible for prevention and care. Because of the lack of a comprehensive HIV/AIDS policy, the government does not actively stimulate innovation in HIV treatment, prevention and care. At times, the government is slow to react to innovations initiated by civil society when it comes to supporting new developments through policy and funding.

Public mobilization

Although international agreements like the UNGASS Declaration of Commitment are important in focusing government involvement, they don't usually reach the general public. Even many professionals in the field of HIV/AIDS prevention and care are unaware of the UNGASS declaration. Of the nine professionals interviewed, only three had heard of UNGASS.

HIV/AIDS is an issue of public interest. A study conducted in 2001 showed that the Dutch population considers AIDS to be the third most serious problem in the world, after terrorism and wars. AIDS is considered to be the greatest health problem in the world. For the Netherlands, AIDS is seen as the fifth most important health problem, after cancer, cardiovascular diseases, obesity and depression. Another indicator that public awareness of HIV/AIDS is still quite good is that the results of Aids Fonds and STOP AIDS NOW! fundraising appeals continue to improve. Furthermore, there are many Dutch NGOs involved in dealing with international HIV/AIDS challenges.

On the other hand, the social position of HIV positive people is not without challenges. Stigma, in particular, is a serious issue. The most affected communities are already stigmatized groups - for their sexual orientation, their drug use, or their non-Dutch origin. Despite the fact that HIV plays a major role in the lives of many HIV positive people, quite a number of them choose not to be open about their HIV status within a social or work environment. Research shows that keeping their HIV status secret is very important to many people, that stigmatization plays a major role, and that there are still many taboos and much ignorance in terms of sexuality.

Publication of new HIV and STI incidence rates can count on much media attention. This attention usually focuses on higher rates of infection. If there is an increase, it is invariably assumed that this is because of a rise in unsafe sex. Like government policy, public opinion believes more and more in personal responsibility, not only for one's own health, but also for the health of others. Unsafe sex is therefore increasingly regarded as a moral issue rather than merely a public health issue. So a one-sided focus on unsafe sex is stigmatizing people with HIV/AIDS.

In several life domains, people living with HIV/AIDS are worse off than people without HIV. The income of the chronically ill is on average 25% lower than that of the average Dutch person. Moreover, in 2001 chronically ill people spent an average of 450 euros out of their own pockets on disease-related expenses. Insurance poses other problems. If HIV positive people need or want to change their health insurance policy, they will only be able to get a relatively expensive standard package. They are refused supplementary insurance. They are also generally excluded from life or disability insurances. Furthermore, people living with HIV/AIDS are more likely to be unemployed than people without HIV, although the difference is not great.

National HIV/AIDS Policies

Policy administration and financing

It is characteristic of the way the Netherlands approaches the fight against HIV that the government does not take the lead. Professionals in the field develop the points of departure and the government then formalizes those starting points. As was mentioned in the section on political commitment in the previous chapter, government policies regarding HIV/AIDS lack coherence. Prevention, treatment and care are not generally treated comprehensively.

Much of the responsibility for prevention, care and support has been decentralized to the municipal authorities. This worked well in the early nineties. The main advantage was that activities could be set up to suit each specific situation. Recently, problems with this policy of decentralization have become more pronounced. Local authorities seem to be less inclined to invest in HIV/AIDS policies, especially in the bigger cities. In smaller towns, HIV/AIDS has always been less of a concern because they are not as heavily affected as the cities. Another problem is quality control. Many of the local initiatives are small-scale and difficult to evaluate. A third issue is a lack of coherence between national and local/regional policies.

Funding for HIV/AIDS policies comes from: the government, specifically the health department; the Council for Medical and Health Research (ZonMw), which provides government funding for innovative projects, research and implementation; health insurance companies; municipal authorities, which finance the Municipal Health Departments; and citizens who pay taxes and who contribute to the AIDS Fonds and STOP AIDS NOW!

Prevention

The Dutch government has formulated a prevention policy, prioritizing groups of people who are most affected by HIV/AIDS. However, there is a problem with the funding of prevention. There have been no new investments in the field of HIV/AIDS prevention. Regional funding is also under pressure. And prevention for high risk groups is the first to suffer from decreases in funding.

Three modes of prevention can be distinguished. Primary prevention methods promote safer sex, preventing new infections. Secondary prevention aims at early detection of HIV infection. Tertiary prevention is closely related to treatment and care; it is meant to prevent avoidable suffering from HIV/AIDS for people who are HIV infected. Lately, the focus has shifted from primary prevention to access to HIV/STI testing and counselling. Testing in the Netherlands is available on a voluntary basis and it can be done confidentially. Pre- and posttest counselling are standard parts of the procedure. The main reason for the focus on testing was the introduction of antiretroviral therapies. However, the number of people who are aware of their serostatus remains low in the Netherlands.

In the early years of the HIV epidemic, preventive action primarily targeted gay men/MSM and intravenous drug users. During the past few years, the attention has shifted to migrant groups, because their share in the epidemic has become larger. Civil society organizations are attempting to find entry points in these communities. The government does not actively take the lead, neither in formulating policy nor in funding initiatives.

Treatment

HIV treatment is well taken care of in the Netherlands. In order to maintain the highest possible standard of care, HIV treatment takes place in 22 HIV treatment centres. This concentration of expertise ensures that optimal care can be offered with regard to the often rather complex medical problems of HIV and AIDS. Four of the HIV treatment centres are specialized in the treatment of children with HIV. Research done by the Dutch HIV Association indicates that patients are generally very satisfied about the treatment and care

they receive in HIV treatment centres. Next to medical treatment, patients receive care from nurses who are trained in the field of HIV/AIDS. If necessary, the nurses can refer patients for psychosocial counselling or support.

Care and support

Although many people with HIV cope very well with their disease, for most of them the impact of HIV is profound. Care and support are therefore very important. That starts with good post-test counselling, including referrals to medical and psychosocial care. Patients would generally like to have more psychosocial support, especially from their doctors. This, however, is difficult to achieve. As already mentioned, HIV/AIDS nurses provide support from within the HIV treatment centres. In big cities, some mental health and social support organizations have special programmes for people living with HIV/AIDS, assuring high quality care. However, this form of support is not available for everyone.

The Dutch HIV Association (HVN), an advocacy organization of and for people living with HIV/AIDS, is funded by the government for organizing a supportive environment for People living with HIV/AIDS. Apart from the funding that other patient associations also receive, HVN gets additional funding because of the UNGASS commitment. The main reason for this is the stigmatized position of people living with HIV/AIDS. HVN is also responsible for some of the preventive information aimed at people living with HIV/AIDS.

AIDS has led to an innovative form of care that is now also being used in connection with other diseases: one-on-one care provided by ‘buddies’. Buddies are volunteers who give practical and emotional support to people with HIV (or other illnesses). A national network of buddy projects has been established in the Netherlands. The largest and most well-known of these is the Schorer Buddy Programme, which is available for gay men and lesbians in Amsterdam. In the Netherlands as a whole there are more than 400 HIV positive people with buddies.

Monitoring and Evaluation

The Netherlands has an extensive infrastructure of knowledge-supporting research on HIV and AIDS. Basic medical research is funded through NWO, the Dutch organization for scientific research, and an important funder in the field of health promotion is ZonMw, the Council for Medical and Health Research.
Dutch HIV/AIDS research has a high international standing; its practical applicability is particularly admired. An important aspect of Dutch HIV-related research is that the field (civil society organizations) is directly involved. The impetus for new research frequently comes from the field itself and organizations of people living with HIV/AIDS are often involved as well. As we have seen in other areas of HIV/AIDS policies, here again the government does not take the lead. There is no specific plan for any monitoring and evaluation with regard to HIV/AIDS.

Monitoring

For a long time, HIV/AIDS monitoring was limited. During the past few years, this has improved a lot, especially because of the establishment of the HIV Monitoring Foundation to monitor epidemiological developments. The Foundation not only looks at the trends in infection rates, but also at the medical care given to patients, including its effectiveness and side effects. Apart from the scientific reports from the HIV Monitoring Foundation, a yearly report is published by RIVM, the National Institute for Public Health and the Environment. This gives an overview of epidemiological developments for both HIV and other STIs. There are also some studies monitoring risk behaviour (for example among MSM: Hospers et al., 2005).

A recent innovation is the QUI database, which monitors preventive interventions. This database is maintained by the Dutch health promotion institutes, coordinated by the Netherlands Institute for Health Promotion and Disease Prevention. It includes interventions in diverse health-related fields, including sexual health.

Evaluation

Evaluation of preventive interventions is still not common practice (Vogels et al., 2002). If interventions are evaluated at all, the effects of the intervention are generally not measured in a scientifically rigorous way (De Wit & Picavet, 2004), although there are some notable exceptions in the Netherlands. An intervention that was well evaluated and implemented was Long Live Love, a school-based sexual health curriculum. It proved to be effective, at least in improving knowledge and attitudes,. but the effect on behaviour was limited. The government increasingly demands evidence-based interventions. However, funding for large-scale implementation and evaluation studies is difficult to obtain.

Needs assessment

Now and then, studies are conducted on the quality of life of people living with HIV/AIDS, but no structured monitoring of the needs of people living with HIV/AIDS is done. The Dutch HIV Association sometimes initiates applied research, for example measuring the degree to which people living with HIV/AIDS are satisfied with their treatment. Also, qualitative studies are sometimes conducted among people living with HIV/AIDS.

Case Study: The position of HIV positive asylum seekers and illegal migrants

This chapter explores the HIV/AIDS policies affecting asylum seekers and illegal migrants. These people form one of the most vulnerable groups in Dutch society, with a high risk of being or becoming infected with HIV. The term migrants, as we use it, refers to people who were born outside the Netherlands, or of whom at least one of the parents were born outside the Netherlands. They live (or intend to live) in the Netherlands permanently. This definition includes asylum seekers and illegal migrants.

In 2001 Esther had already been rejected for citizenship, when she became pregnant with her first baby. She was found to be HIV positive. With the help of a lawyer, a new procedure was started, now for a status on medical grounds. In 2004, just two months before her permit expired again, she was told that this status only applied for the period 2002-2004. She immediately filed for an extension of her status. The immigration 'service' has not responded yet, although they have no reason to refuse her. Because her status expired over a year ago, she may lose her housing and income. She and her two children will then be out on the street again during the course of the proceedings.

Asylum procedures

With regard to asylum seekers, the first priority in government policy is to establish whether or not they can stay in the Netherlands. The Netherlands is not a country of immigration. Prosecution in the country of origin because of, for example, race, or political or religious affiliation is seen as the only sufficient reason for political asylum. The justice department is primarily responsible for asylum seekers. Most HIV positive asylum seekers do not come to the Netherlands because of their HIV status (Smeets et al., 2004). This means they usually don't start off with a procedure to get a status on medical grounds. Many migrants have their original application refused.

When the first application for asylum is rejected, people are forced to leave their accommodation, often a shelter or reception centre. If in the meantime they are found to be HIV positive, they can try to apply for a second procedure, now for a status on medical grounds. They need proper legal support in order to be able to start a second procedure. HIV as such is not sufficient reason to receive a status. People may not be repatriated to their country of origin if they are in the final (fatal) phase of a disease. However, a status on medical grounds is temporary. If the health status of the immigrant improves, for example because of medication, the temporary status may not be extended. Many of those whose application is rejected or whose status is not extended stay in the country illegally.

Medical care and provisions for asylum seekers should be the same as for Dutch citizens. However, in a study on the effect of medical aspects on immigration, it was concluded that these are not taken sufficiently into account during immigration procedures. The result is that physical problems are often diagnosed too late. This can lead to complications which could have been prevented (Smeets et al., 2004).

For illegal migrants, the situation is more serious. They have the right of access to medical care if that care is necessary (if there is a serious health risk for the person involved or for his/her environment). HIV positive illegal migrants therefore should be able to get treatment for their HIV. Other care, like housing, is unavailable to illegal migrants, apart from private initiatives.

The Dutch practice is in accordance with the European Declaration of Human Rights, although it sticks to the agreed minimum. In certain circumstances an exception can be made, for example when there isn't even a theoretical possibility of getting the necessary medical

attention in the country of origin, or when there are relatives who live (legally) in the Netherlands.

When she was pregnant, Suzanne was tested for HIV as part of the screening programme in the Netherlands and found to be positive. Her CD4 blood counts are still at such a good level that she doesn't need any medication yet. This means she doesn't qualify for a civil status on medical grounds. None of the official shelters would take her in during her pregnancy or after the birth. She has lived in an unofficial shelter with her baby for two years, but now she has to leave. She fears being arrested, because she has no papers and will face forced repatriation. The father of the baby has been waiting for a status, an asylum seeker for over seven years now. Suzanne's only hope is that the father will get a status, so she can hide in his home. Or, of course, that her blood values get worse…

The professionals interviewed all agree that the Dutch policies regarding asylum procedures for migrants with HIV could and should improve. Several of the informants speak of a death sentence when migrants are forced to repatriate. It should be easier for people living with HIV/AIDS to get a status in the Netherlands. Not only theoretical possibilities for getting medication in the country of origin should be taken into consideration. Practical barriers to get such care should be taken into account as well. Such practical barriers include a lack of financial means to get the medication or a long waiting list. Stigma plays a role too. It is almost always impossible to return to their own community if they are infected with HIV. Women and children are particularly vulnerable. The asylum policies are mainly of a legal nature, but health policies should also be incorporated in these procedures, and the health ministry should be more involved.

There are practical problems related to the asylum procedures. One of these is that they usually take a long time. Not all people waiting for a decision have enough time available. For migrants who are in a second procedure for a status on medical grounds, the long time before a decision is made can be very problematic. They often have no accommodation and no support. Another practical problem is that a migrant whose first application was rejected needs proper legal support for filing an application on medical grounds. This sometimes goes wrong, for example due to frequent moving from one accommodation to another or language problems. Finally, many of the people who are not allowed to stay in the Netherlands cannot be repatriated to their country of origin. For these people, the situation really is hopeless.

There's another side to the current practice as well. Adherence to the medication is essential in the treatment of HIV/AIDS. Medication only works if pills are taken continuously and in the right way. When people don't adhere to their treatment regimens, they risk viral mutations causing new viral strains that are resistant to medication. For the individual this constitutes a disaster, but it could also lead to a public health problem which is likely to affect Western countries as well as developing countries.

Prevention

Many asylum seekers come from countries with a high prevalence of HIV/AIDS. Infection rates among asylum seekers are therefore also relatively high. Traumatized people, like many of the ones seeking asylum, are likely to be more vulnerable to HIV infection. Primary, secondary, and now also tertiary prevention (the latter mainly aiming at increased adherence to the medical regimen) are therefore essential. Prevention is a task of the community health services for asylum seekers (MOA), who have several (primary) preventive interventions at their disposal. The informants are positive about the MOA efforts. It was not the government

who took any initiative in establishing the preventive role of MOA. Civil society has been mainly responsible for this.

For a long time, the needs of migrants with HIV/AIDS - including their prevention needs - were largely disregarded. Prevention efforts were mainly aimed at either the general public or the risk groups of MSM and intravenous drug users. The interventions that were developed for these groups were not easy to apply to the growing migrant population (both HIV negative and positive) as the government did not incorporate cultural knowledge in their HIV/AIDS policies. During the past few years, this situation has gradually begun to change.

A relatively new route of providing prevention to asylum seekers is through migrant organizations. These organizations provide culturally sensitive and appropriate prevention, but also care and support. In their experience, it is difficult to keep prevention and support separated, even though they are separated in government policy. Their work is aimed at increasing knowledge and skills for HIV-infected individuals themselves, but they also want to raise HIV/AIDS awareness in the communities. A problem for migrant organizations is that it is difficult to get funding. Regional and national migrant organizations recently started a national platform (NAMIO), supported by the Netherlands Institute for Health Promotion and Disease Prevention. The platform should provide an advocacy function and promote good practices.

Prevention is not easy among asylum seekers. HIV/AIDS is a subject people don't find easy to talk about. One reason for this is the association with sexual behaviour. It is therefore advisable to incorporate HIV/AIDS prevention in a broader perspective on sexual health. This is all the more relevant, because asylum seekers have other sexual health problems as well. For example, abortion among asylum seekers is about ten times as prevalent as among women of Dutch origin (Krikke, 2000). Prevention aimed at illegal migrants is even more difficult, because they are difficult to find. Knowledge about HIV and ways of preventing HIV infection is often limited, and false beliefs about HIV are common. This poses a serious health risk, both for the illegal migrants themselves, but also for the people around them. Until now, too little attention has been paid to prevention aimed at undocumented migrants.

Testing for HIV is often seen as an opportunity for secondary prevention. Because of the high rate of HIV infection among asylum seekers, it has been suggested that they should all be tested before they get a status. Luckily, it is not current practice to have mandatory testing. Everyone should be informed about the HIV test before it is performed and asked for permission. For many people, the information that they are HIV positive is not something they can deal with psychologically. For others, it is better not to know, for example when he or she wants to buy a house with a partner. Pregnant women, however, are routinely tested, unless they object to the test.

Treatment

Everyone in the Netherlands should be able to get medical treatment. This is true for all Dutch citizens, but also for asylum seekers. Illegal migrants don't have access to medical treatment, unless it is absolutely necessary. In the case of HIV/AIDS, treatment is always necessary of course. However, there are some hospitals, dentists and health institutions that don't accept undocumented migrants as patients, even if there are funds available to compensate medical institutions. Out of fear of being arrested, migrants tend to go to hospitals with other people's identification cards or they give false names. They also fear that they could receive a large hospital bill later. This situation is of course undesirable, both for the people involved (they might not get optimal care) and for the hospitals.

The way the disease is experienced by non-Western ethnic minorities often differs from the way Westerners experience it. HIV treatment centres are faced with the following problems in providing good care to ethnic minorities (Middelbeek, 2004):

- communication problems and cultural differences;
- a lack of well-coordinated written and visual information materials;
- the lack of basic medical knowledge;
- laxity in therapy adherence ('I don't feel sick, so I'm going to skip my pills today');
- appointments not being kept.

Many HIV positive people from a non-Western ethnic minority only make it to an HIV treatment centre in a late stage of their disease (Van Bergen, 1998). This is undesirable due to the risks for the health of the individual and for public health in general. The process of making health care more intercultural is currently an important consideration for HIV treatment centres. Nurses are being trained by their own professional associations, by STI AIDS Netherlands and by the Netherlands Institute for Health Promotion and Disease Prevention (NIGZ).

Rose came to the Netherlands illegally with her boyfriend. Last year she was taken to a hospital specialized in TBC. During this treatment she was granted a temporary status for a period of six months. But the doctor told her that she had HIV as well. She has been in a procedure to get a status on medical grounds since that time. She was put in a shelter in the north of the country, far away from the hospital. She now has a baby of three months and the father of the baby is in a detention centre after a period of abuse. He threatened to take the baby away from her. This is why she wanted to find another place to stay, where he couldn't find her. Although this was permitted, she needs to go to the shelter every week to have her permit stamped by the police. The train ticket costs her 39 euros, while she only gets 40 euros each week for food and necessities. Her social worker tried to get her into a reception centre, but this proved to be impossible. She therefore depends entirely on private help.

Care and support

For HIV positive asylum seekers (who are in their first asylum procedure), basic needs are covered. They have accommodation, often in a shelter or reception centre, receive medical care, and are given some money for necessities. Their problems are largely the same as for other asylum seekers. The most important problem (next to the asylum procedures) is that they don't have a lot to do. They are not allowed to work, not even as volunteers. Thus, they have little opportunity to do something meaningful with their time. This situation seems to be slightly better for the ones who have their own homes.

The situation is quite different for HIV positive illegal migrants. As mentioned already, illegal migrants have no rights besides necessary medical treatment. This means that basic human needs like food and shelter cannot be met. People are out on the street or rely on private initiatives for support, for example from a church. Sometimes, the Aids Fonds can help with a small amount of money. For professionals in the field who deal with people in need, the lack of facilities for undocumented migrants is very painful, especially because they cannot even provide people with the basic necessities of a 'bed, bath, and bread'.

An organization which is involved in improving the situation for people living with HIV/AIDS is the Dutch HIV Association (HVN) with almost 2000 members. Workers in HIV care refer people to HVN and their information materials. For many people living with HIV/AIDS HVN is a powerful resource. Some people who are not of Dutch origin find it harder to get the help they need from HVN. The vast differences between groups of people living with HIV/AIDS make it difficult to serve everyone's interests in one organization. Therefore other organizations have emerged, like AFAPAC for sub-Saharan Africans, ASERAG for asylum seekers and refugees, and the Positive Women of the World. These organizations provide care and, even more importantly, support for the people who need it.

Churches play an important role in the care for HIV positive migrants. They can do a lot of good for individuals in need of care. However, the other side of the coin is that churches can pose barriers to realistic thinking about one's future. The possibility of a (forced) return to the country of origin, even for people with a temporary status, is often not considered within the context of the church. Another problem is that issues like pre- and extramarital sex, homosexuality, and condom use cannot be discussed. This is problematic, because it hampers effective prevention.

Sandra came to the Netherlands, looking for a job. Not having a residence permit, all she could find was an unofficial job: cleaning a hairdressing salon. There she met the father of her son. When she became pregnant, she was tested for HIV. She wasn't nervous about it, because she had been tested before. However, this time she was positive. Her boyfriend took off and left her right away. She thought she was going to die and feared that her child would be deformed because of the medication. She's now staying in an unofficial shelter and has joined the support group 'Positive Women of the World'. She feels a bit better because of their support. However, her status remains uncertain. Her first application has been turned down so she has to file for a court decision.

Stigma

Asylum seekers and undocumented migrants usually don't tell anyone that they are HIV positive. HIV/AIDS does not seem to be a topic of discussion among asylum seekers. Most of them come from a culture of silence and denial, especially when sexuality is involved. Sex is seen as something you have with only one partner, even though the reality is completely different for many people. The denial sometimes goes so far that a person does not even go to hospital for the necessary care, because he claims not to have HIV. Even if someone does acknowledge that he or she has HIV, the step to getting treatment or participating in programmes may be too big. Much of the stigma is related to false beliefs, like everyone with HIV being either homosexual or a prostitute. Also, HIV is believed to be a curse and people don't want to be seen to be cursed.

Hospitalized for TBC, Lorna was found to be HIV positive when she was only sixteen. She was devastated and wanted to die. Being a minor she didn't have a status but also could not be sent back and she didn't want anyone to know about her HIV infection. All she really wanted was access to education. When in the end she got a permanent status, she moved to a students' residence. She also had a baby. When the Social Services told her to find a job, she refused, saying she was ill. She didn't tell anyone about her HIV status until she found someone she trusted at the job centre. This woman arranged for Lorna to go to school. However, when Lorna needed to do an internship, she was pressed to be open about her HIV status. Even though risking expulsion from school, she didn't give in to this pressure. Only her boyfriend and another good friend know she's HIV positive.

The reluctance to 'come out' about one's HIV status is not unjustified. Many people are rejected by their families if they do. Women in particular are often abandoned by their partners when their HIV status becomes known, for example because of the HIV screening of pregnant women. In the Netherlands, male partners are not tested with their female partners, which makes HIV a problem for the woman only. There is hardly any organized care for these women. The position of women is precarious anyway, because they are regarded as sex objects rather than equal partners by too many men. When people turn to support agencies, their first question is usually not: how to tell people about their HIV status, but instead: how to keep others from knowing. Even at AFAPAC meetings, the focus is often on health, not

HIV per se, because people don’t want to talk about HIV in public. They fear gossip. Many of them even avoid getting into a close relationship because they don’t want to bring up the matter of HIV or even condoms.

Conclusions and Recommendations

Generally, one could say that HIV/AIDS services in the Netherlands are quite good. Medical treatment, prevention, and care and support are well taken care of, although there is of course room for improvement as well. The same is true for research. The biggest problem is that the government does not have an overarching, comprehensive view on HIV/AIDS. Developments in the field of HIV/AIDS prevention and care are not guided by a national HIV/AIDS policy, although the government does have policies for particular sectors.

Another problem is the lack of coherence between national policy and what is being done locally or regionally. The local authorities act completely autonomously when setting their priorities for health and health promotion. Some regions don't pay enough attention to the HIV/AIDS epidemic. This needs to be studied at national level, especially where marginalized groups are concerned.

Asylum seekers and illegal migrants are a very vulnerable group, both because of their precarious status in Dutch society and because of their high risk of being infected with HIV. The mere fact that they are HIV positive is not taken into account during the asylum procedure. Even the availability of medication is not taken into account. A temporary status on medical grounds is available only for people who are in the final phase of their disease. Although medical care is provided for, basic necessities like 'bed, bread and bath' are unavailable for the ones whose (first) appeal for a residence status has been rejected. Prevention, care and support are largely absent for this group.

General recommendations

- The health ministry should take the lead in formulating an HIV/AIDS policy, involving other departments as well;
- An HIV/AIDS policy should incorporate a view on the issues of medical treatment, prevention, and care and support, but it should also encompass a view on the social position of people living with HIV/AIDS, especially the most vulnerable groups;
- Local and regional authorities should be stimulated to increase their efforts in fighting the epidemic, but also in improving the quality of life of people living with HIV/AIDS;
- With regard to vulnerable groups, a community approach is essential. Where municipal health centres do not have enough expertise to reach and work with the most affected communities, their capacity should be improved. Also, community organizations should be involved and funded for their work;
- Additional investments are warranted, especially in prevention, care and support, and research. This is necessary for keeping up the current standard, but also for innovation.

Recommendations with regard to asylum seekers and illegal migrants

- A residence permit should be given on medical grounds as long as it has not been determined without any doubt that care for the individual in the country of origin will be sufficiently guaranteed. That means that the treatment in the country of origin must be geographically within reach, affordable and accessible for the person in question;
- If it is to be expected that the knowledge of someone's HIV status in his or her country of origin will lead to them being excluded, the person should be given a permanent residency status on humanitarian grounds;
- Basic facilities such as 'bed, bath and bread' are necessary throughout the procedure;
- Women who turn out to be HIV positive during the HIV screening for pregnant women should receive a residence permit on medical grounds. The HIV screening for

pregnant women could lead to an HIV positive pregnant woman being banished (along with her still unborn child) from her family or community;

- Even though it is difficult to get asylum seekers and illegal migrants organized, it is essential to involve them more in the work that is being done for them.

Appendices

Members of the steering committee

- Bouko Bakker, Schorer, institute for gay and lesbian health.
- Ton Coenen, executive director of STI Aids Netherlands and the Aids Fonds, (chairman of steering committee).
- Maria Knapen, Netherlands Institute for Health Promotion and Disease Prevention.
- Marion Kreyenbroek, Academic Medical Center, Amsterdam.
- Robert Witlox, managing director of the Dutch HIV Association.

Professionals interviewed

- Eric Akum, ASERAG, Asylum Seekers and Refugees Aids Control Group, doing outreach work for asylum seekers.
- Ronald Brands, lawyer, Policy Officer Social and Legal Affairs and Advocacy for STI AIDS Netherlands & the Dutch HIV Association
- Froukje Lijfering, social worker for Humanitas Rotterdam, HIV care division.
- Marion Kreyenbroek, social worker at the Academic Medical Center, Amsterdam, the largest Dutch HIV treatment site, with a substantial migrant patient population.
- Marjan Mensinga, works at Pharos, Refugees and Health Knowledge Centre, and secretary of Lampion, a collaboration of several (mostly national) organizations, involved in health care for illegal migrants.
- Adanse Pipim, president of AFAPAC, an organization of and for sub-Saharan Africans, providing counselling and HIV prevention.
- Leo Schenk, chairman of the stigmatization working group of the Dutch HIV Association.
- Jakob Wedemeijer, immigration lawyer.

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Charles Picavet received his MA in Cultural Psychology. He works as a researcher and consultant at the Rutgers Nisso Groep, the Dutch expert centre for sexuality. He has published on the coming out process of lesbian and gay teenagers, sex education, and HIV/STI prevention.