Access to Care: Privilege or Right?

Migration and HIV Vulnerability in Europe

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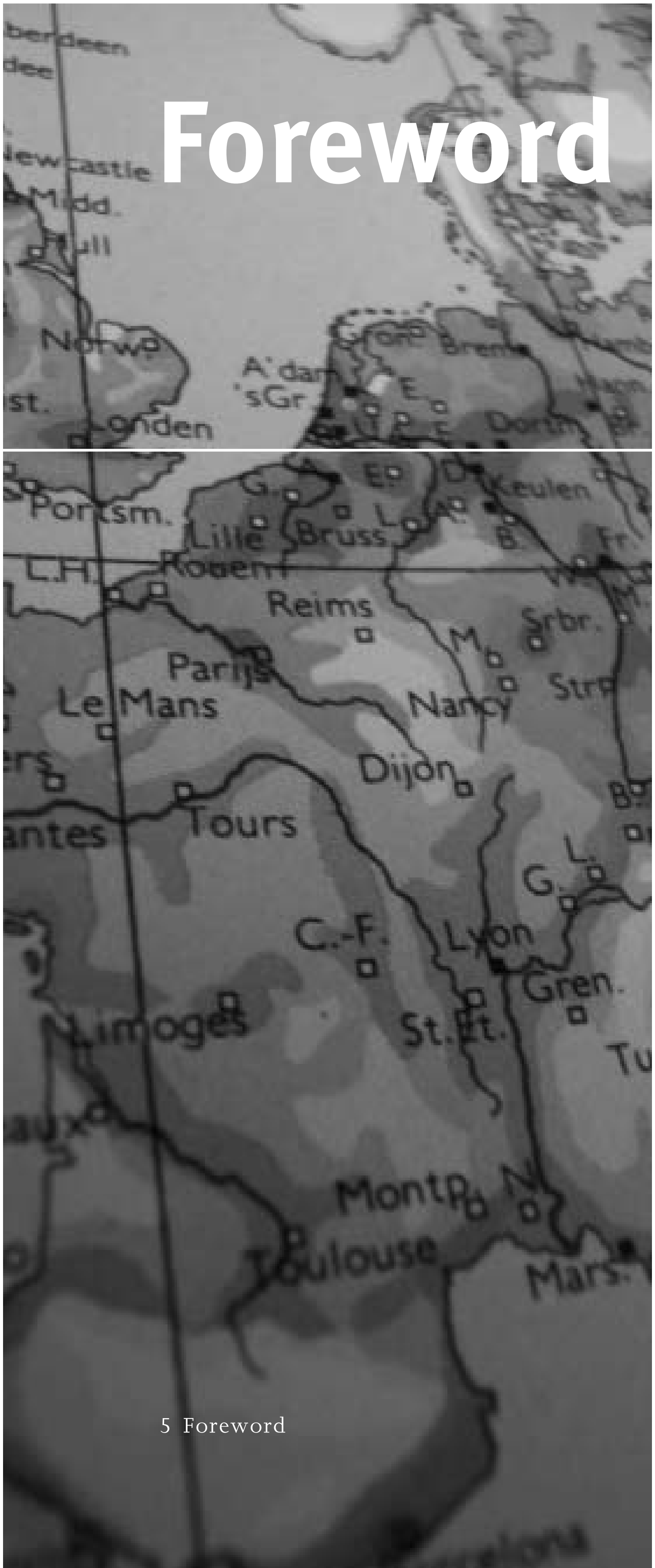
Contents

> **“The Assembly considers that the right to health associated with access to health care is one of the basic universal human rights and should be equally applied to all people, including migrants, refugees and displaced persons.”**

Council of Europe, Parliamentary Assembly Recommendation 1503 (2001) on ‘Health conditions of migrants and refugees in Europe’

Foreword



The European Project AIDS & Mobility (A&M) is a networking project on the issue of migration and HIV/AIDS in Europe. The project strives to stimulate the exchange of knowledge and expertise among health professionals at all levels – from community-based workers to policy makers – and to disseminate information nationally and throughout Europe. A&M fulfils its tasks in close collaboration with National Focal Points (NFPs) in the European Member States. The project is based at the Netherlands Institute for Health Promotion and Disease Prevention (NIGZ).

In previous years, A&M has published two reports about the situation of migrants and ethnic minorities in Europe in relation to HIV/AIDS. The first publication (De Putter, 1998)[1] provided an overview of migration patterns, epidemiology and responses by health authorities, NGOs and society at large. The second report (Clarke and Bröring, 2000)[2] focused more on policies and interventions dealing with care and support aspects of migration and HIV/AIDS. Issues like testing, medication and the situation of migrants living with HIV/AIDS played a major role in this report.

At a meeting of the AIDS & Mobility NFPs in Portugal in November 2001, a need was felt for an update on the situation in the different European member states. After all, the state of affairs concerning migration in general and migration related to health/HIV in particular is changing rapidly. The populations involved as well as policies and interventions in the different countries are constantly shifting. At the same meeting, the NFPs made agreements about the country reports. NFPs were requested to follow an outline to facilitate comparing the information provided. In addition, they were asked to find partners in writing, so that the issue was highlighted from different angles (such as the governmental and the non-governmental perspective). The outline and the different angles are reflected in most of the reports. Some NFPs compiled the report themselves; others commissioned one or more experts. The reports reflect solely the views of the author(s), and the NIGZ/AIDS & Mobility cannot be held responsible for their contents. I thank all those who were involved in the production of the country reports. Their efforts are very much appreciated.

Not all European member states are represented in this publication. In Germany, the post of NFP was vacant in the last project period, and no report was submitted. The NFP for France was not able to submit a report due to internal reorganisations. The same goes for Norway, which is not an EU member state, but which participates in the AIDS & Mobility Project.

The reports were reviewed by an editorial board. Dr Nicola Schinaia, epidemiologist at the Istituto Superiore di Sanità in Rome and member of the A&M advisory board, Dr Bryan Teixeira, director of the Naz Project London and NFP for the United Kingdom, and Mr Chris Canter, editor at the NIGZ, were members of the editorial board, and I express my gratitude to them. Their experience and insights were very helpful to identify the common thread in all the different reports, and to draw conclusions that are valuable both at the national and the European level. The editors' analysis of the data can be found in the Conclusions.

I thank the main funding agencies of the AIDS & Mobility Project: the European Commission (DG SANCO) and the Netherlands Aids Fonds. Without their financial support, the project in general and this publication in particular could not have been realised.

The country reports in this publication make clear that the AIDS epidemic in Europe is far from over, and that the consequences of the disease are particularly striking in migrant and ethnic minority communities. The country reports from 1998 and 2000 were used by many people as tools for advocacy. The issues that are identified, and the solutions that have been developed in some countries, may help to bring into effect policies and interventions that will improve access to care and support for migrant populations. I sincerely hope that this publication will contribute to tackling many of the problems and challenges that are described, thereby leading to safer living conditions for those who are among the most vulnerable in the societies of Europe.

Georg Bröring
Coordinator European Project AIDS & Mobility
Netherlands Institute for Health Promotion and Disease Prevention (NIGZ)

Woerden, The Netherlands, October 2003

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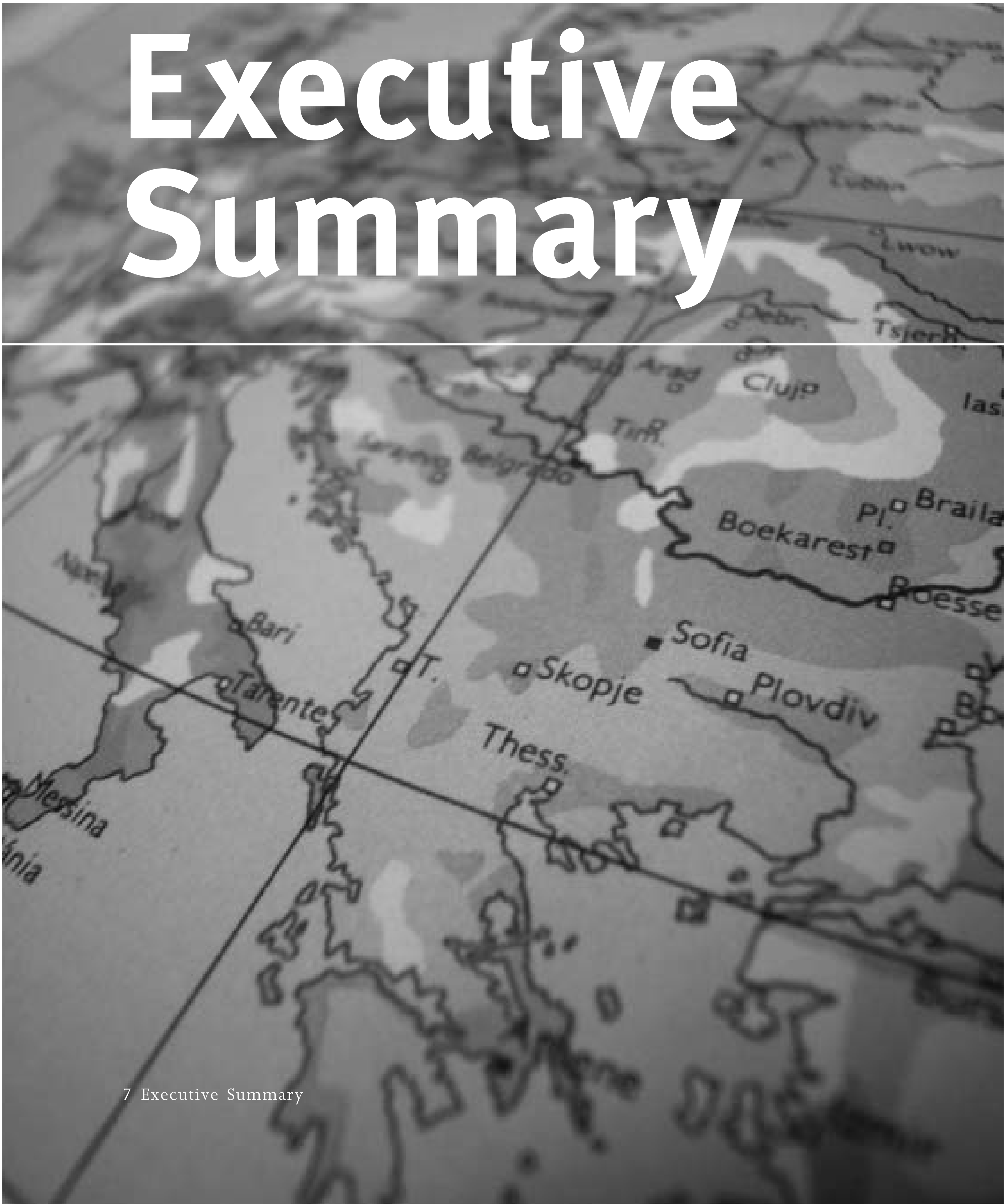
1 De Putter, J. (Ed.) (1998). AIDS & STDs and Migrants, Ethnic Minorities and other Mobile Groups; The State of Affairs in Europe. Woerden: NIGZ.

2 Clarke, K. & Bröring, G. (Eds.) (2000). HIV/AIDS Care and Support for Migrant and Ethnic Minority Communities in Europe. Woerden: NIGZ.

Executive Summary



The country reports contain comprehensive information about the situation of migrant and ethnic minority communities in relation to HIV/AIDS. The authors – National Focal Points of the European Project AIDS & Mobility, or experts who have been commissioned by them – have access to in-depth knowledge, either through their position in their own migrant or AIDS service organisation or through their national network partners. Many areas are covered, including

- migration patterns in the respective countries,
- attitudes and responses by society at large,
- policies and politics,
- information about the communities involved,
- epidemiological developments,
- access to treatment, care and support,
- the relation between statutory and community-based organisations,
- questions concerning (the need for) research.

Migration patterns

The country reports highlight the global dimension of mobility and migration. Political and economic crises have an impact on migration patterns. Laws and regulations in one European country will influence push and pull factors within Europe. The health situation in countries of origin – such as access to HIV treatment – is playing an increasing role. Health seeking migration may be a critical issue in the future.

From a public health perspective, the political focus should not be on how to influence migration and mobility, but on how to reduce the health risks for the individual and for society at large. At the European level, countries with more experience can assist those that are in the phase of developing policies and interventions. Countries in Central and Eastern Europe need specific attention in the future, and the health situation in the countries and regions of origin must be taken into account.

Attitudes and responses by society

Most reports confirm that migration is a hot issue in the country in question. Attitudes in society towards migrants and ethnic minorities are part of a wider political climate, to which various factors contribute: the economic situation, unemployment rates and global events or developments. The majority of the authors report that stigma and discrimination are a problem in their country. Discrimination can be observed in society at large but also in the practice of health service provision. Insufficient representation and participation of migrants and ethnic minorities in society and social life is reported by various countries and needs to be improved in virtually all countries.

Policies and politics

The authors describe a wide range of insufficiencies and inconsistencies in (health) policies for migrants and ethnic minorities. In general, immigration policies are becoming stricter. Dispersal policies complicate access to care and support services for asylum seekers. Several authors complain that the rights of people and standards for access to care are unclear. The way in which HIV testing is carried out among asylum seekers and the standards of communication about testing are far from satisfying.

The expulsion of undocumented migrants with HIV remains a sensitive point. The wider availability of anti-retroviral therapy in more countries leads authorities to expel people under treatment more easily, even though continuation of treatment is often only available in theory and cannot be effectuated after expulsion. The privatisation of health care and the increasing importance of private insurance and patient contributions, which can be observed in many European countries, is particularly affecting those who live in the margin of society and who were not able to save up money.

It is recommended that national health policies address and include the specific needs of migrant and ethnic minority communities. There is a pressing need for clarity about the rights of (migrant) persons with HIV. Legislation must provide satisfactory access to prevention, care and support, and expulsion must not take place unless treatment in the country of origin is available in practice.

The communities involved

The populations described in the reports have a diversity of social, economic and legal backgrounds and a diversity of needs. The main distinction made by the authors is that between the more traditional migrants (as migrants from former colonies and labour migrants), who are fairly integrated, and the new arrivals (asylum seekers, undocumented migrants) who often live in precarious circumstances.

Scepticism about and mistrust of (health) authorities is found in many migrant communities due to several factors, for instance: inappropriate treatment by immigration offices or health care providers in the host country or traumatic experiences before and during migration. Several reports mention stigmatisation of migrants and ethnic minorities by the host society but also from within communities – for instance, due to the AIDS taboo. Migrant organisations and health care providers are increasingly paying attention to the problems of young people and families.

Epidemiology

The prevalence of HIV among migrants and ethnic minorities depends to a great extent on whether the main populations originate from endemic areas. Some reports call for better epidemiological monitoring of the different HIV subtypes, improved and internationally compatible ethnic monitoring, and a better insight into heterosexual versus homosexual transmission. Possible changes in the epidemic should be taken into account, such as a stronger influence of infection through injecting drug use due to increased East-West mobility.

A worrying phenomenon that is repeatedly reported is the epidemic split between migrant and indigenous populations. While in the general population, many people with HIV do not develop AIDS due to good monitoring and treatment, this is often not the case for HIV positive migrants and individuals from ethnic minorities. This is particularly ascribed to the fact that the latter cannot access testing and treatment facilities as early and effectively as the general population. There is a need for collecting accurate and consistent epidemic data both nationally and on a European level in order to understand trends in migrant and ethnic communities.

Access to treatment, care and support

A major theme of the reports is the disadvantages faced by migrants and ethnic minorities in accessing care and support services. The more traditional migrants and ethnic minorities, who are fairly well integrated into European societies, generally do not encounter legal obstacles to accessing services. For them, the barriers are mainly due to culturally inappropriate services or complicated bureaucratic procedures. Undocumented migrants are often excluded from health services and receive medical treatment only in emergency situations.

Another obstacle to access mentioned in various reports is the low priority of health issues for many members of migrant and ethnic minority communities. Coping with economic, social and cultural problems is often seen by them as a more immediate need.

The reports offer solutions to improve access to services. One possibility is a holistic approach, where health care providers combine health issues with socio-economic and cultural aspects. Policy makers should develop legal regulations to achieve rights-based access to services for those whose lives are at risk. Efforts must be made in the field of communication in order to create a better understanding of health services and health care structures.

Statutory and community-based organisations

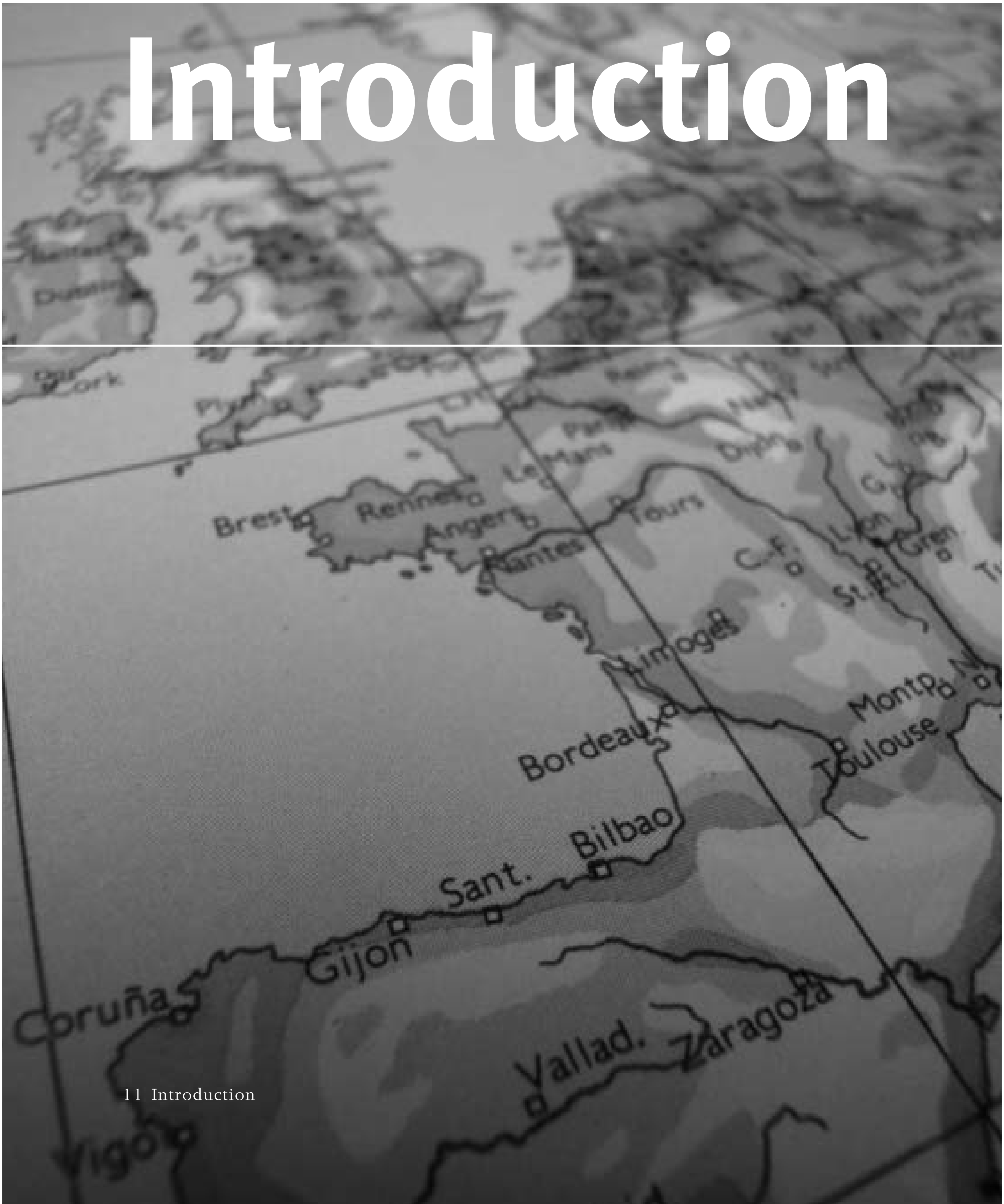
The reports stress the need for good collaboration and communication between governmental and non-governmental organisations. Community-based organisations may have a valuable input in the training of health professionals. Communication between governmental or municipal health services and migrant communities can be facilitated by organisations that are close to these communities. Especially where multiple issues need to be addressed, combined forces can lead to greater effects.

Health care providers – both community-based and statutory – need to ensure that theoretically available services are accessible in practice. Statutory and community-based services should increase efforts to reach out to undocumented migrants. Their access to and contact with services is not only important for the health of the individual, but also for public health in the respective country.

Research

Several reports mention the importance of gaining better insight into certain populations (such as asylum seekers) or certain issues (such as gender). It is suggested that HIV policy for migrants and ethnic minorities should be based on their actual needs as determined by research. Epidemiological research needs to pay more attention to migrant issues (like different HIV subtypes in Europe). Research into migrants and ethnic minorities needs to incorporate epidemiology, clinical research and social sciences, in order to establish comprehensive services. The involvement of migrants in research projects – at all stages – may provide vital information.

Introduction



Migration to Europe and within Europe has been and still is an actuality and a sensitive issue at various levels. At the European level, policy makers discuss common immigration and asylum guidelines and procedures. At the national level, political debate varies from asking for more restrictive immigration policies to a more liberal and integrative approach. Societies at large in many countries have a critical attitude towards (new) migrant populations, and towards undocumented migrants in particular. The limited economic growth and considerable levels of unemployment in Europe contribute to the sensitivity of the issue.

Data of the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV[3]) show that the percentage of persons with AIDS from endemic areas (all outside of Europe) is increasing in the European statistics. There is a lively debate about appropriate policies and interventions for tackling HIV/AIDS and other health issues among migrants. Health care providers and (migrant) community-based organisations are concerned about insufficient access to prevention, care and support services. Late reporting of HIV positive status in migrants, for instance, limits therapeutic treatment.

The availability of research data on the health situation of specific populations, such as refugees and asylum seekers, is limited. Different professions – epidemiological, social and clinical sciences – are currently operating separately, while joint efforts would be able to provide more comprehensive knowledge on these populations.

National governments are reluctant to stimulate and finance interventions for better access to HIV services, in particular for undocumented migrants. Here again, the economic situation and the pressure on health care budgets worsen the already precarious situation. Nonetheless, the European Commission has included the taking on of inequalities in health in its 'Community action in the field of public health'[4].

The country reports that are included in this publication provide comprehensive information about the situation of migrant and ethnic minority communities in Europe in relation to HIV/AIDS. The authors – National Focal Points of the European Project AIDS & Mobility, or experts who have been commissioned by them – have access to in-depth knowledge, either through their position in their own migrant or AIDS service organisation or through their national network partners. Many areas are covered, including
- migration patterns in the respective countries,
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- epidemiological developments,
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- the relation between statutory and community-based organisations,
- questions concerning (the need for) research.

These main areas are also reviewed in the Summary, conclusions and recommendations.

Different angles, different styles

All authors were requested to follow a structural outline, which asked for specific attention to questions of access to HIV services. Most countries had produced a country report before, and the authors were asked to describe major changes since the previous reports. They were asked to formulate priorities for the future and define necessary action. The reports have different accents: the report of the United Kingdom, for instance, looks in particular at the situation of asylum seekers, while the Belgian report concentrates on the situation of (undocumented) migrants living with HIV/AIDS. Despite this diversity, the main areas that are mentioned above are addressed in most country reports.

The content, style and language of the country reports may vary considerably according to the organisational, political and linguistic background of the authors. They are affiliated to a variety of organisations, from community-based migrant organisations to governmental institutions. These different angles are reflected in the way policies and interventions are described or judged. Governmental organisations may tend to be more favourable to national policies, while community-based organisations may be more critical of the measure of (financial) support by national authorities. Several reports were co-written by diverse organisations. The Portuguese report, for instance, was written by a governmental and a non-governmental organisation; in Austria, one author comes from a large AIDS service organisation, while the second is affiliated to a community-based organisation.

Terminology

Terminology varies throughout the country reports. Some authors speak about immigrants, others about foreigners, yet others about black and minority ethnic groups. This divergence can be only partly ascribed to the fact that many authors are not native English speakers. More important is the fact that the discussion about migrant populations varies in the different countries according to migration patterns. Countries in which the phenomenon of immigration is more recent, tend to speak about migrants or immigrants, while countries with a longer migratory tradition tend to use different terms, such as ethnic groups. In the Summary, conclusions and recommendations we use the term ‘migrants and ethnic minorities’, as we believe this to be the most comprehensive one.

Topicality

The situation around services, populations involved, legal regulations, etc is changing constantly. Many countries are currently developing or changing their laws and policies. It is therefore difficult to provide up-to date information. Although the authors strove to keep the information provided as recent as possible, the situation may already have changed.

“It still requires an enormous effort on the part of policy makers and service providers before equal access to HIV care and support services for migrants/ethnic minorities and the general population is achieved” (Clarke and Bröring 2000, p. 174)[5]. This was the conclusion drawn in the previous collection of country reports. The reports in this publication will highlight what has been achieved over the last years, and what needs to be done in the various countries and on a European scale.

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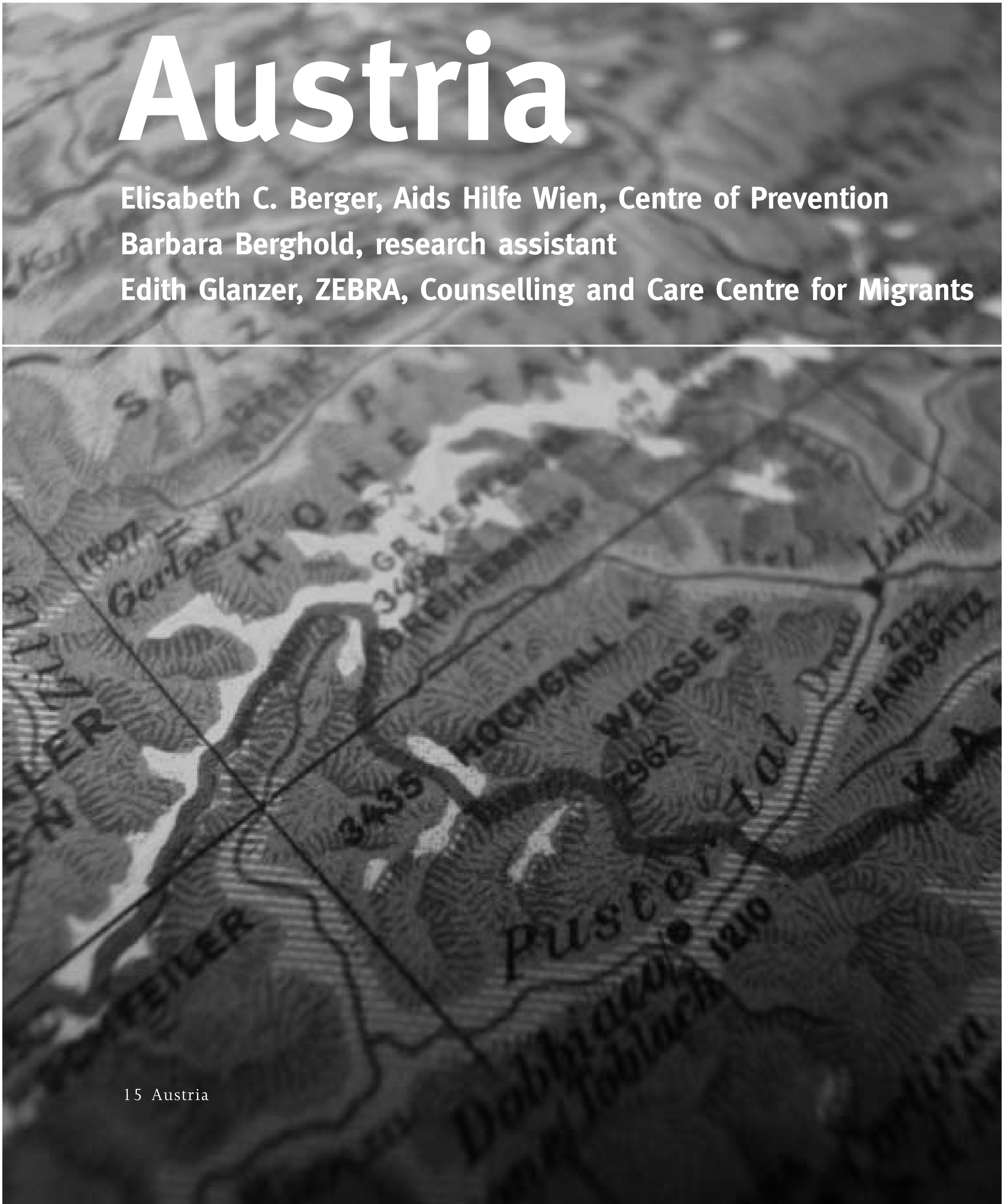
[3] www.eurohiv.org

[4] Decision 1786/2002/CE (OJ L 271/1 of 9.10.2002); www.europa.eu.int

[5] Clarke, K. & Bröring, G. (Eds.) (2000). HIV/AIDS Care and Support for Migrant and Ethnic Minority Communities in Europe. Woerden: NIGZ.



Austria

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1. Introduction

Since World War II, Austria has been the destination of numerous refugees from areas of conflict. There was migration to Austria from Eastern and Central Europe, Hungary (1956), the Czech Republic (1968), Poland (1980/81) and East Germany (1989). Austria received Chilean and Iranian refugees in the seventies and was a transit country for Jewish emigrants from the former Soviet Union. In 1988, more than half of the refugees came from Poland, Hungary and Rumania. Three years later, the majority of migrants and asylum seekers came from the former Yugoslavia. During the last decade the asylum applications declined because of more restrictive asylum laws and a discouraging administrative practice.

The discussion about whether or not Austria is a typical country of immigration has been continuously picked out as a central theme in politics, science and the media. Because Austria was never a European colonial power, there has been no migration from colonies to the motherland as was the case for Great Britain, France, the Netherlands and other countries. After the immigration during the first years of the post-war period, Austria had an increasing demand for labour force, so foreign labourers (called guest workers), became an essential part of the Austrian employment market. Their recruitment started in the early sixties and was concentrated on Yugoslavia and Turkey (today, guest workers are also attracted from other parts of Eastern and Central Europe). Although the original plan was to recruit guest workers for a short time and then send them back home, they ended up staying and bringing their families over. Their children, and eventually their grandchildren, grew up in Austria.

The immigration of guest workers was not systematically legislated until 1993, when their numbers were checked by quota and restrictive legislation. The immigration of family members of people working in Austria for a longer period of time was also regulated. Since 1993 the application for immigration has to be submitted from the home country. Since 2003 only candidates for key positions, seasonal workers and family members of guest workers are allowed to immigrate to Austria.

Most immigrants in Austria are from countries with a low HIV/AIDS prevalence where there's a lack of knowledge about HIV/AIDS/STDs. Organisations such as LEFÖ, MAIZ and LENA work with migrant sex workers and pay special attention to HIV prevention. Most sex workers are from Eastern Europe, Latin America and the Dominican Republic.

New trends and facts in epidemiology were presented in the context of World AIDS Day on December 1, 2002. At the 13th Austrian AIDS congress in November 2002, Dr Jean-Paul Klein of the Ministry for Health reported about five hundred new infections in 2002. Compared to the constant numbers of the last years, this is an increase of 20%. Dr Klein also reported another new development in Austria: the laboratories in cities like Vienna still report constant numbers for 2002, while laboratories in the rural areas report increases of new infections. According to Dr Klein, this signifies a shift of HIV/AIDS from the congested urban districts to the rural areas.

2. Defining the target group

Asylum seekers are persons who apply for political asylum or asylum from persecution. They have the right to an asylum procedure, but are not by law entitled to Bundesbetreuung (accommodation and food from the public authorities). An economic emergency in the home country does not entitle one to asylum. Refugees are people who have proven that they are persecuted in their home country. Social workers dealing with refugees and asylum procedures have pointed out that in practice, war in the home country is the only reason to receive permission to stay in Austria. According to personal communication, refugees from Nigeria and other politically instable and very poor countries have no chance to get a permit. Between January 1 and August 31, 2002 there were 23,231 asylum applications, 664 of which have been approved.

A new guideline came into force on October 1, 2002. It determines exactly who receives accommodation and food in the Bundesbetreuung. The original citizenship is decisive. Citizens from the EEA (European Economic Area) as well as citizens from countries whose participation in the EU is pending are not included. If there is a negative decision in the first instance, migrants from Russia, Armenia, Turkey, Macedonia, Azerbaijan, the former Yugoslavia and Nigeria are excluded too. Before the enforcement of the new guideline, 34% of all asylum seekers were in the Bundesbetreuung. Half a year later, this was the case for 19% of all asylum seekers.

According to the federal institution of statistics (STATISTIK AUSTRIA), the official percentage of foreign persons in Austria went down from 9.40 to 9.36% from December 2001 to June 2002, which is the first decrease in years. During 1985 and 1995 Austria registered the highest numbers of foreign persons. The following table shows the original citizenship of immigrants with a regular residence in Vienna.

Table 1. Original citizenship of immigrants with a regular residence in Vienna

	2000	2001
Total, former Yugoslavia	125,207	116,563
Federal Republic of Yugoslavia	81,116	73,123
Croatia	16,863	16,704
Bosnia-Herzegovina	20,815	20,304
Macedonia	5,604	5,688
Slovenia	809	744
Turkey	43,950	40,316
Poland	17,433	14,133
Czech Republic	1,943	1,876
Slovakia	3,347	3,331
Hungary	5,464	4,202
Romania	4,789	3,949
Germany	13,715	13,181
Other EU countries	14,418	12,798
Egypt	4,696	3,026
Iran	6,976	4,241
Others	48,753	39,355
Total	291,717	256,971

The second table shows the numbers of people without Austrian citizenship living in Austria.

Table 2. Numbers of people without Austrian citizenship living in Austria

	Former Yugoslavia		Turkey		Others		Total part of the resident population	
2000	341,179	44.5%	134,243	17.6%	290,633	37.9%	766,055	9.4%
2001	328,369	45.0%	130,081	17.8%	271,789	37.2%	730,239	9.1%

‘Foreigners’ are seldom accepted as individuals by the public, but instead are often seen as an anonymous mass with unacceptable habits. If people do not look ‘normal’ to the public at large, they are automatically identified as foreigners – the non-Austrians, even though these groups are very heterogeneous. Even people with Austrian citizenship are categorised as foreigners and called ‘foreigners’ when their names sound foreign or the colour of their skin is different. In public discourse, no distinction is made between refugees and guest workers, even if there are considerable legal, social and economic differences between these groups. Further, the term ‘illegal’ is often used as a political, rhetorical method to create a negative, simplified image of foreigners. It may therefore be preferable to speak about illegalised people instead of illegal people.

On the other hand, the law concerning the employment of foreigners (‘Ausländerbeschäftigungsgesetz’) does indeed categorise foreigners. The chance to get a residence permit depends on a person’s position in the legally defined hierarchy. Native-born people stand the best chance, followed in hierarchical order by:

- admitted refugees
- people who are allowed to work in Austria and people who are not subject to the law concerning the employment of foreigners: EU citizens, the immigrated wives and husbands of Austrians, Turkish people who are subject to the ‘Assoziationsabkommen’ (an agreement allowing for the immigration of Turkish family members)
- foreigners who have a claim to unemployment benefit (they must have worked for at least one year)
- the so-called ‘de facto refugees’ and asylum seekers. According to personal communication with social worker Sylvia Bayer from Aids Hilfe Wien (the AIDS Help Centre in Vienna), the latter have practically no chance of obtaining a residence permit.

3. Resources

Detailed reports of different projects and interventions, information leaflets, literature and handbooks of migrant organisations and health care institutions offered a wide range of qualitative material for the facts and data in this report. Databases and homepages on the Internet, mainly those of migrant organisations, presented the facts and information about legal aspects, official data, press coverage about certain issues and a good introduction to the different organisations and institutions working with migrants. Through personal communication and interviews with social workers and people working for migrant organisations or consulting centres, we obtained practical information about how laws for immigrants are actually put into practice by authorities in Vienna and other federal states. Telephone interviews with Aids Hilfe or immigrant organisations in each federal state gave a convenient overview of the situation of immigration and health in Austria, including social, political and economic aspects. A number of sections of this report were written by our partner ZEBRA, an NGO offering counselling and care to foreigners in Styria. This broadens the view on governmental as well as political processes and how they are experienced by an NGO working within different community-based organisations. To ask a Styrian organisation for a partnership in writing was obvious for us, because Vienna, Styria and Upper Austria followed by Tirol show the highest activity of immigrant organisations and communities dealing with health issues in Austria at the moment. The colleagues from ZEBRA also work in close cooperation with the Styrian Aids Hilfe (one of the seven Aids Hilfen Österreichs).

4. Partners in writing

4.1 Aids Hilfe Wien – Aids Hilfe House

Due to rising demands in the fields of prevention work and education and care of people with HIV/AIDS, a drop-in centre for everyone who is affected and interested had to be created. The ideal centre to realise these targets opened its doors on December 1, 1997, on the 10th International World Aids Day. The Aids Hilfe House was made possible by private donations as well as a unanimous resolution of the Viennese city council in June 1996 to provide € 3,488,296 for the renovation a and further € 581,383 for furniture, office infrastructure and technical equipment at the house Mariahilfer Gürtel 4. This generosity made it possible to create 1,700 square metres of floor space for information, education, workshops, counselling, care and leisure activities. These services are offered by five centres: the Counselling Centre, the Day-care Centre, the Active Centre, the Self-help Centre, the Prevention & Education Centre and Public Relations.

Since the spring of 1999, Aids Hilfe Wien has increased its efforts in providing information about HIV/AIDS/STDs and carrying out special projects of primary prevention for immigrants. Since the infection rates for women are increasing all over the world, female immigrants are a main target group within the field of HIV prevention. The Parkproject – an HIV/AIDS/STD outdoor prevention campaign aimed especially at women in the parks of Vienna – has been carried out each summer since 1999 (more about the Parkproject can be found under ‘Projects, interventions and health services’). Efforts to prevent HIV among immigrants are mainly focused on compensating their lack of information due to the language barrier. Aids Hilfe Wien has specially educated health consultants who are Turkish and Serbo-Croatian native speakers (so-called ‘peer leaders’). They do most of the work in the Parkproject and give lectures to migrants throughout the year.

4.2 ZEBRA

ZEBRA has existed as an NGO in Graz since 1986. Its goals include promoting tolerance for minorities, rehabilitating victims of torture and other forms of violence, promoting equal treatment of resident aliens and Austrian citizens, and encouraging aliens to permanently integrate into the job market and society. Target groups of ZEBRA’s legal and social counselling and care are asylum seekers, refugees under the Geneva Convention, torture victims and severely traumatised persons, and immigrant workers and their families. ZEBRA aims to increase their ability to help themselves and stand up for their own affairs. According to the problem and the situation, clients are cared for either by a social worker, a psychotherapist or a physiotherapist, or the social worker tries to find adequate help for the client among one of ZEBRA’s network partners.

Since 1999, ZEBRA offers an educational project for immigrants and asylum seekers.

Several persons from different countries were trained in a six-month course in matters of physical and psychological health. Among other things, the training covers HIV. So far, 45 asylum seekers and refugees have participated in the courses. The trainees were asked to spread their knowledge in their ethnic community.

In the last three years, ZEBRA has counselled twenty clients with HIV or AIDS. Most of them arrived in Austria as asylum seekers. ZEBRA is trying to obtain a 'refoulement' (temporary protection status) for one client whose asylum application was turned down, because medical care for him in his home country is not guaranteed.

5. Immigration and integration policy in Austria

For many years, Austria was considered to be primarily a transit country for refugees. This changed after the fall of the Berlin wall. Bordering on several non-EU countries, Austria has become a first landing place for refugees on their way to the safety of the European Union.

Austrian immigration policy was for years based on the idea of rotation. If in times of economic decline fewer workers were needed, it was chiefly the immigrants who were affected: they were sent back to their home countries. Since immigrants only served the function of a pool of manpower, the government pursued no integration methods for them or their families. During the nineties, when it became obvious that the immigrants who had been invited into the country would stay in Austria, immigration policy had to change. A new political guiding principle was established: 'integration before new immigration'. Annual immigrant quotas were introduced. At present, about 8,000 immigrants from non-EU countries are allowed into Austria annually. Because of the very low quota, the demand is far greater than the supply. Family reunion also falls under the quota. Family members of immigrants face long waiting periods that differ per federal state. Since a number of years, only family members and so-called key workers (immigrants with very high or special qualifications) have been allowed to immigrate to Austria.

The guiding principle of integration before new immigration does not only quantitatively limit immigration. It also restricts the chances for immigrants to improve their status in Austria. August Gächter from the Institute of Higher Studies, an expert in the field of the labour market and immigration, says: "There is no integration deserving this name if there is not also new immigration." The typical occupations of recently immigrated guest workers have always been poorly payed jobs for unskilled workers. If these workers are no longer replaced by new immigrants they will have difficulty pursuing their professional promotion. There are studies supporting this analysis. Integration is closely connected with raising the professional and social level. A higher than average percentage of immigrants with good job qualifications work as unskilled workers in Austria. The school diplomas and qualifications of children of immigrants are also below average and these children very frequently grow up to become unskilled labourers.

A further obstacle to integration is difficult access to the job market. People with a residence permit do not automatically get a labour permit. Up to now, family members of immigrants living legally in Austria have had to wait five to eight years for a labour permit. From January 1, 2003, this period has been reduced to one year, but it remains an obstacle.

Asylum seekers are still de facto excluded from the job market. However, the possibility for foreigners to get temporary jobs has been extended. In certain fields, foreigners including asylum seekers are now allowed to work for six months. However, they can derive practically no rights (such as a residence permit or a submission for unemployment benefit) from this regulation. It will lead to short working periods and insecure working conditions for foreigners.

In 2002, the federal government discussed for the first time measures towards the integration of immigrants. Immigrants who arrived in Austria in or after 1998 now have to take a German and integration course of one hundred hours under penalty of administrative charges or even the loss of their residence permit. They have to cover half of the expense of the course themselves (about € 100). Integration measures have so far been primarily financed on the community level or by the labour exchange. A concept for an integration policy is completely lacking.

6. The situation of asylum seekers in Austria

In Austria as in other EU countries, there are rising numbers of asylum applications and there is a debate about the issues of asylum misuse (illegal jobs, crime), the duration of the asylum procedure, care for asylum seekers during the procedure and illegal immigration. Increasing prevention of legal immigration has caused a considerable increase in illegal immigration.

Asylum applications have risen sharply in Austria in the last years. In 2000, 18,300 applications were filed, compared to 30,100 in 2001 and 37,000 in 2002. As the authorities in charge have not employed additional staff, a dramatic delay in the processing of asylum applications has been the result. Asylum seekers wait at least one and a half years, and up to five years, for a decision. The long procedures are also caused by the high number of appeals. The quality of the initial decisions made by the federal asylum office is unsatisfactory.

In Austria, severe shortcomings affect the care for asylum seekers during the asylum procedure. At the end of September 2002, less than a third of all asylum seekers were cared for by the government. As asylum seekers are not allowed to work, those who are not taken into federal care have to be cared for by the Church and other charity organisations or get public assistance from a community.

This situation was aggravated by a regulation from the Federal Ministry of the Interior in October 2002, excluding citizens of certain countries from federal care. Among them are asylum seekers from Georgia, Nigeria, Turkey and Albania. After the regulation was issued, hundreds of asylum seekers were dismissed from federal care week after week and sent into homelessness. They have no address where a decision might be sent to, nor is medical care guaranteed for them.

7. Epidemiology

In the period 1983 to October 1, 2002, 2,188 people in Austria were affected by AIDS, 1,307 of whom have died. There are 1-2 new cases of HIV every day. Currently there are 12,000-15,000 HIV positive persons living in Austria. Despite intense prevention work, there has been an increase in new cases since 1998, mainly among heterosexual women. About one million HIV antibody tests are registered in Austria every year, most of them among blood donations. Still, 60% of people with HIV are not aware of it until their disease breaks out. The tests are mostly carried out among the wrong target groups, such as retired persons.

The Otto Wagner Hospital at the Vienna Hospital of Pulmonology published the first figures about immigrants with HIV and AIDS in Austria. These figures only cover patients of the Hospital of Pulmonology. The following table shows the country of origin of most of the patients treated at the Otto Wagner Hospital from 1999 until 2001.

Table 3. Countries of origin of most of the patients treated at the Otto Wagner Hospital from 1999-2001

	1999		2000		2001		Total	
	male	female	male	female	male	female	male	female
Not known	42 53.2%	12 44.4%	28 35.4%	9 29.0%	16 16.0%	5 14.3%	86 33.3%	26 28.0%
Austria	22 27.8%	9 33.3%	37 46.8%	8 25.8%	54 54.0%	27 77.1%	113 43.8%	44 47.3%
Western Europe	22 27.8%	9 33.3%	37 46,8%	8 5.8%	54 54.0%	27 77.1%	113 42.8%	44 4.3%
Former Soviet Union	1 1.3%						1 0.4%	1 1.1%
Central Europe and former Eastern Bloc	2 2.5%	1 3.7%	4 5.1%	2 6.5%	4 4.0%	1 2.9%	10 3.9%	6 6.5%
Middle East and North Africa	1 1.3%			1 3.2%	7 7%		8 3.1%	10 10%
South and Southeast Asia		2 7.4%		4 12.9%	2 2.0%		2 0.8%	1 1.1%
Sub-Saharan Africa	3 3.8%	2 7.4%	5 6.3%	6 19.4%	9 9.0%	2 5.7%	17 6.6%	1 1.1%
North America and Greenland	1 1.3%				1 1.0%		2 0.8%	93 %
Latin America and Caribbean	2 2.5%			1 3.2%			2 0.8%	
East Asia		1 3.6%			1 1.0%		1 0.4%	
Australia and Pacific					1 1.0%		1 0.4%	
Total	79	27	79	31	100	35	258	

8. HIV/AIDS and expulsion

In 2002 the conservative government passed the 'Integration pact', to come into force in 2003. Among other things, it obliges immigrants to obtain a health certificate 'to prevent the endangerment of public health'. People applying for a permanent residence permit in Austria have to undergo a health check. They are tested for communicable diseases such as tuberculosis, leprosy, cholera, hepatitis, etc. The applicants are not tested for HIV, because according to the law HIV testing is voluntary in Austria.

A person can be expelled regardless of their health condition as long as they are able to travel by train or plane. If they are in immediate danger of death, the expulsion can be delayed. Since HIV and AIDS are not mentioned in the legislation, a positive HIV status does not matter. However, in most cases persons with HIV are not expelled. The Aids Hilfe workers try to use the diagnosis as an argument for permanent asylum or humanitarian residence or for a one-year prolongation. The EU Court of Justice says that the expulsion of an HIV positive person is 'special cruelty against life' and is 'not admissible'. The prolongation of asylum or humanitarian residence is of course non-permanent. One case has been reported of an HIV positive sixteen-year-old girl in Carinthia who received the order for her expulsion in spite of her diagnosis. At that time she was in jail and her expulsion could be delayed for the duration of her imprisonment. She has in fact a legal right to stay in Austria because she completed school in Austria (personal communication from Aids Hilfe Kärnten, November 2002).

9. Health insurance and emergency medical care

Asylum seekers are regularly insured as long as they are in the Bundesbetreuung. If their asylum procedure ends with a negative adjudication, they automatically lose their insurance. Persons who are legally in the country but are unemployed have no insurance. They can claim insurance on their own, but this costs about € 290 per month and there is a waiting period of six months. The health fund requires a valid residence permit. Officially, people living in Austria without a legal residence permit have no claim to medical care or treatment. Illegalised people only have a legal claim to emergency medical care in the case of immediate danger of death. An HIV positive person without a legal status of residence has no access to any medical care until AIDS breaks out.

10. The Austrian health care system

Austria's health care system is widely branched out, arising from long experience and tradition. The system has grown to such a size, however, that it has become a difficult structure to understand. Although it has a high quality and good standards, a number of special fields receive little or no attention. Refugees and other foreigners have special problems, including diseases caused by war, torture and trauma, the lack of experience with central European systems, specific health risks, and so on. The health care system is not prepared for their needs, and health measures therefore cannot be taken efficiently.

When a person's health is in acute danger, hospitals have to treat that person. However, the foreign police may step in when treatment is extended to asylum seekers who have not been taken into federal care or who live in Austria without legal status. There is a structural problem in the provision of medical care to asylum seekers, as they frequently live in remote inns. Getting access to a doctor may be very difficult for them, for instance due to a lack of public transport. Migrants and their relatives have the same status as Austrians as far as their medical treatment is concerned. But getting the treatment required and especially benefiting from preventive measures is difficult because there are few language experts and specialised staff in the various medical institutions.

11. Cultural and employment barriers for migrants

Most of the research projects or studies dealing with migration and health distinguish in a generalising way between the Austrians and the migrants.

'Vienna Health City' was a WHO project carried out in 1996 by the Wiener Integrationsfonds (Vienna Integration Fund). The inquiries made by this project showed that 90% of the nursing staff in Viennese hospitals mentioned they have to deal with patients who have little or no knowledge of German. Language is seen as a cultural barrier. Ninety-one percent of the nursing staff declared that "one can never be sure how much a patient really understands." According to the inquiries, 52% of nursing staff and doctors communicate with patients mostly in a very simplified German, while 17% always communicate in that way. In the last years these circumstances have received more and more attention.

Migrant organisations call for the sensitisation of hospital staff to the heterogeneity of migrants. The appreciation of internal dissimilarity and different social backgrounds must counteract the ongoing creation of stereotypes. It is essential that people realise migrants are not a health risk group just by being migrants. The exceptional social status of migrants in a foreign country and their different lifestyle are reasons why there should be specially adjusted strategies for HIV/STD prevention and health promotion for them.

Feelings of loneliness and isolation as well as problems with finding one's way in a new society often result in psychological illness. According to a study carried out by the Ludwig Boltzmann Institute for Women's Health Research in 1998, 34% of the interviewed migrant women from the former Yugoslavia reported various economic and financial problems. Then as well as today, migrant women in Austria are forced to accept employment far below their qualification.

Mental stress is often aggravated by discrimination, racism, stigmatisation and an uncertain legal situation. The study concludes that the lacking socio-cultural sensibility in the health services and the problematic access to these services (whether actual or perceived) often aggravate the situation. As a result of these findings the City of Vienna has implemented new services, such as the F.E.M. Süd.

12. Projects, interventions and health services

Every summer since 1999, Aids Hilfe Wien has carried out the Parkproject, an HIV/AIDS/STD outdoor prevention campaign aimed particularly at migrant women in Vienna's parks. Professionally trained cultural mediators talk to the park visitors about AIDS, sexuality and health. In the summer of 2002, the Parkproject team visited 60 parks within 33 days and were able to talk to a total of 2,934 people.

During the women's health activities of the Ludwig Boltzmann Institute for Cardiological Gender Studies in Innsbruck in 1999, a project took place in which migrant women from Turkey living in Tirol were informed about cardiac arrest, the main cause of death for women in Turkey as well as for women in Tirol.

Since the summer of 1999, ZEBRA has held education courses for opinion leaders in the African community as part of the project 'Preventive health work with migrants'. Opinion leaders from fourteen countries are trained and qualified in health issues, the complex Austrian health care system and specific health problems of migrants from each country. They aim to integrate migrants into the health care system.

In 2000, the Viennese bureau of the women's health commissioner ('Büro der Wiener Frauengesundheitsbeauftragten') started a project called 'Reproductive health of migrants from Africa and Asia'. This study tried to evaluate sexual education of African and Asian women living in Vienna, their relationships and their acceptance of their own body. The results of this evaluation are to be integrated into the information, counselling and care they are offered.

Austria, like ten other European countries, participated in the project ‘Women’s Network PHASE’. Focusing on women in particular, this project sought to develop new effective HIV/AIDS/STD prevention strategies by working out ‘best practices’ of gender-sensitive projects and interventions and exchanging knowledge and experience. The main recommendations for Austria’s future interventions were to emphasise equality in gender relations, to use effective channels for reaching women in appropriate settings, to encourage the participation of men, to do research on women in the general population and to effectuate a stronger participation of women in HIV/AIDS/STD prevention policy. Peregrina is a migrant organisation offering legal and social counsel and support mainly to Latin American women. The organisation publishes information leaflets and offers counselling in German, English, Serbo-Croatian, Spanish and Turkish. Peregrina offers preparation courses and examinations for acquiring the Austrian language certificate. The organisation also carries out preventive health counselling and support for sex workers and publishes information leaflets in English, Bulgarian, Polish, Rumanian, Russian, Czech, Slovakian, Hungarian, Spanish, Portuguese and Thai.

Learning Together (Miteinander Lernen – Birlikte Ögrenelim) is an organisation focusing on migrants from Turkey. It offers consulting, education and psychotherapy for women, children and families in Turkish, English, German, Spanish, Portuguese, Hungarian and Czech. The principle of their holistic work concept is to take into account the specific social and cultural backgrounds of their clients. Linguistic and psycho-social specialists try to work out a comprehensive solution to clients’ problems.

LEFÖ (Latin American emigrated women) is an organisation established in 1985 by women from Latin America who came together in Vienna to build up a communication centre and self-help project. LEFÖ reaches out to women who migrate to the rich countries of Western Europe to work in increasingly exploitative circumstances. The organisation offers a communication centre where the women can exchange their thoughts and problems; a library; workshops; German courses on different levels; family counselling with doctors, jurists and social workers; social and political counselling concerning the employment market; and psychological counselling.

LEFÖ cooperates with TAMPEP, an international intervention and research project for preventive health care for migrated sex workers. TAMPEP organises workshops with cultural mediators in Vienna and other federal states; offers free anonymous counselling; publishes information leaflets in several languages; and carries out street work by visiting brothels and other locations. TAMPEP also participates in public forums and acts as an advocate for the rights of foreign sex workers.

MAIZ is a migrant organisation in Linz, Upper Austria. The main focus of MAIZ is to strengthen the social, cultural and political participation of migrants, since their active presence in these sectors is becoming more and more essential.

The ‘Safer sex campaign’ began in 2001 within the continuing project ‘Preventive health for sex workers’. It aims to reach current and potential sex workers as well as active and potential sex consumers. Besides spreading information about safer sex, prevention and health issues, the project also aimed at developing an antiracist and antisexist consciousness among both groups to counter discrimination against migrants in sex work. The campaign reached a broad public due to invitations to organisations, politicians and local media, and announcements in newspapers, on the radio and on the Internet.

As in other federal states, 85% of the sex workers in Upper Austria are migrant women. MAIZ cooperates directly with sex workers through street work, workshops, individual counselling and conversations, education and a quarterly journal for migrant sex workers. MAIZ tries to create a network of prostitute organisations, women's organisations and health organisations. The health centre F.E.M. Süd offers support, counselling and information to migrants. Women mainly from Turkey or the former Yugoslavia receive counselling and information in their mother tongue through lectures, courses and workshops. F.E.M. Süd also offers psychological and psychotherapeutic assistance in several languages. The psychotherapist treats depressions, fear and panic attacks, functional disorders, traumas, family crises, experiences of violence, and abuse of medication. Migrant women especially are confronted with problems and discrimination, being stigmatised not only as foreigners but also as women.

F.E.M. Süd has noted that most of the Turkish migrant women living in Austria come from rural areas with no adequate medical care system. According to Hilde Wolf and Serpil Özsoy from F.E.M. Süd, ill migrant women don't seek professional help in most cases until the pain or disease becomes unbearable. Due to the lack of adequate access to information about the health care system in Austria, only four out of sixty migrants know about their rights to use the health care system. There is an urgent need for information in migrant languages and interpreters in the health service sector. For example, all medicine instruction leaflets are written in German only. According to personal communication with Serpil Özsoy, there are no migrant language-speaking gynaecological doctors for migrant women in Vienna.

13. Conclusions

13.1 Conclusions by ZEBRA

So far, there has been no concept underlying Austria's integration policy. The lack of dealing with the subject of 'integration' affects all areas of society, including the health care system. On the whole, the Austrian health care system is very badly prepared for migrants and refugees. It does not take into account the fact that migrants and refugees need a special approach and treatment (for instance, an interpreting service). Informal access barriers are created for these groups. Many asylum seekers in particular are deprived of medical treatment. They are often not supported by official authorities (federal care). They therefore have no health insurance and receive medical treatment only in the case of an emergency. But even asylum seekers who have been taken into federal care receive unsatisfactory medical treatment due to structural problems. In their preventive work, NGOs primarily see refugees and migrants as their target group.

13.2 Conclusions by Aids Hilfe Wien

Austria, which has never been a colonial power, mostly hosts migrants from countries with a low HIV prevalence such as Turkey, Serbia, Croatia, Bosnia, Poland and other Slavic countries. Aids Hilfe Wien recently established contact with organisations from Eastern European countries (for instance Moldavia and the Slavic Republic), because it is expected that these countries will play a major role after the enlargement of the European Union regarding migration tendencies (East—West, East—East, East—accession countries—West) and mobility (immigration, daily tourism, cheap destinations, sex tourism). Contrary to Central and Western Europe, where HIV/AIDS prevention has been more or less established for a long time, Eastern Europe has yet to develop specific strategies. The research into migration trends and new target groups resulting from these trends will constitute the biggest challenge for Aids Hilfe Wien in the future.

The Aids Hilfen Österreichs (Austrian AIDS Help Centres) also work with migrant communities that are low in numbers. These communities need adapted methods in HIV prevention. The Steirische Aids Hilfe and Aids Hilfe Tirol for example have projects with migrants from Africa. New information material has been produced in German, English, French, Serbian-Croatian-Bosnian, Turkish, Portuguese and Spanish. Leaflets are distributed in various languages including Russian, Thai and Arabic. In Vienna workshops are held with women from Afghanistan.

In general, the projects and workshops for HIV prevention among migrants in Austria have increased in number since the late nineties. They are more and more designed to reach various groups of people and are adapted to gender-specific needs. The subjects have broadened to a wider range of topics around HIV/AIDS/STD prevention, increasingly including gender, cultural, religious and human rights issues. This strategy will be continued in the future, combined with the wish and the need to collaborate with community-based organisations and migrant organisations. The cooperation with migrants and with institutions and organisations in their countries of origin is and will remain essential for all Austrian projects, interventions, institutions and organisations. As people become increasingly mobile, activities surrounding HIV prevention have to become increasingly flexible to different cultures, religions and social and sexual realities.

14. Health services for migrants

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www.aidshilfen.at

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Aids Hilfe Wien
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Mariahilfer Gürtel 4
1060 Wien
Tel. 01/59937
Fax 01/59937-16
www.aids.at

Aids Hilfe Salzburg
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Tel. 0662/881488
Fax 0662/881488-3
www.virushotline.at

Steirische Aids Hilfe
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Fax 0316/815050-6
www.aids-hilfe.at

Aids Hilfe Vorarlberg
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Aids Hilfe Oberösterreich
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Styria

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15. References

LEFÖ (Lateinamerikanische Emigrierte Frauen in Österreich) (2001). Tätigkeitsbericht.

MAIZ (Autonomes Integrationszentrum von & für Migrantinnen). www.servus.at/maiz (accessed October 19, 2002).

OMEGA Health Care Center Graz (2002). Wegweiser Gesundheit & Migration.

Pammer, C. (1999). Möglichkeiten für MigrantInnen zur gesunheitlichen Versorgung. Akademie für Sozialarbeit des Landes Steiermark. www.zebra.or.at/doc/gesundheit/index.htm (accessed October 23, 2002).

PHASE (Prevention of HIV, AIDS and STDs in Europe) (2001). National Report (Austria). Ludwig Boltzmann Institute for Women's Health Research.

PINK FILES – HIV/AIDS and health news for the gay and lesbian scene in Austria. www.rainbow.or.at (accessed December 4, 2002).

STATISTIK AUSTRIA. www.statistik.at/index.shtml (accessed October 11, 2002).

TAMPEP 5. National Report 2000-2002. LEFÖ/TAMPEP Austria.

Wiener Integrationsfonds. www.wif.wien.at (accessed October 15, 2002).

ZEBRA. www.zebra.or.at (accessed October 21, 2002).

Tables and statistics

ÖSTAT. Austrian Population Statistics for 2001.

Dr Piotr, Vienna Hospital of Pulmonology.

Wiener Integrationsfonds. MigrantInnen in Wien, Daten & Fakten & Recht (Report 2001, Teil II). www.wif.wien.at

Belgium

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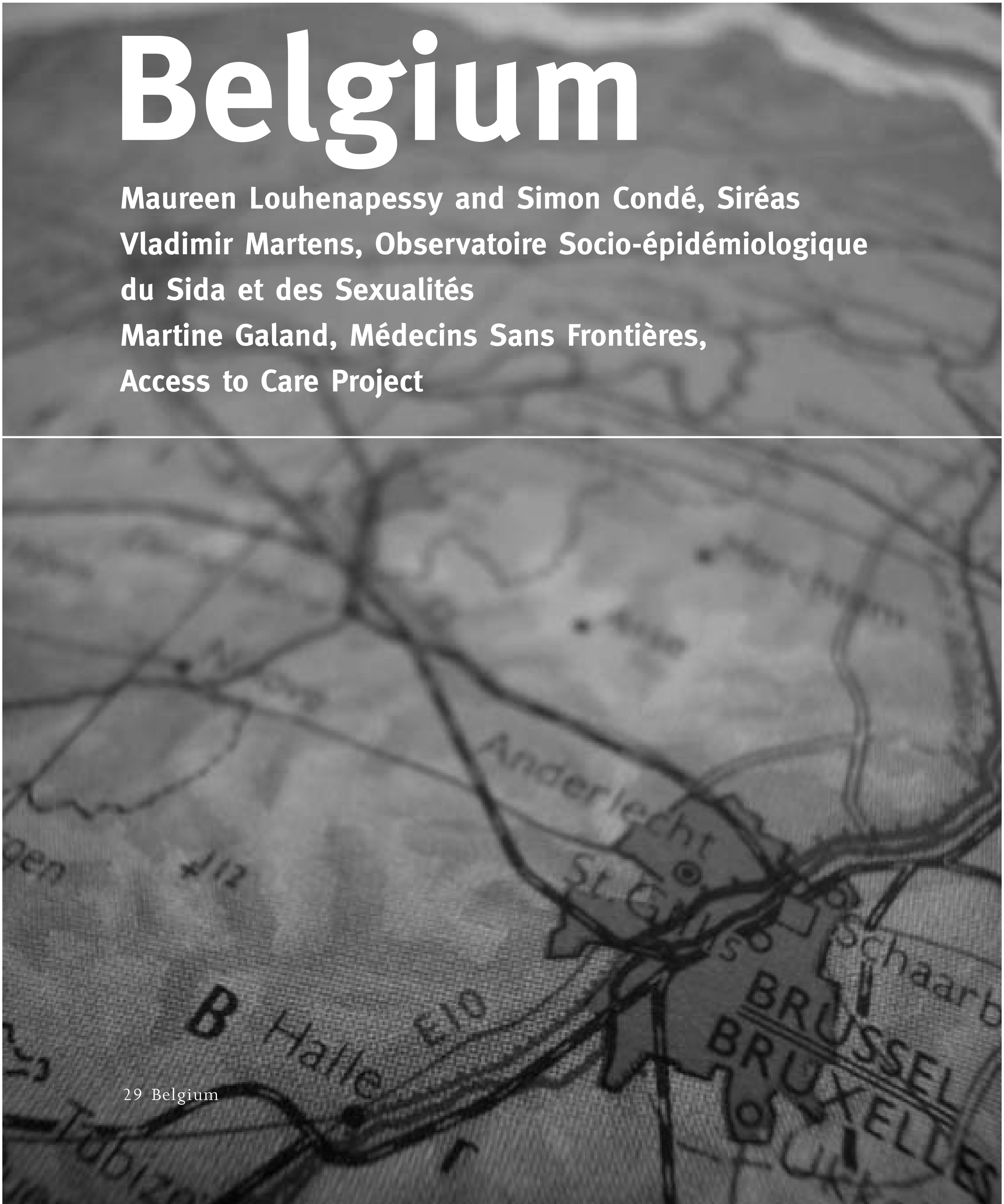

1. Introduction

This report will analyse the need for access to care and treatment for migrants in Belgium living with HIV/AIDS. Access to care means access to all health care services. For migrants, access to care is not only related to social and health services, but also to legal and administrative services. In order to provide as complete a report as possible, we decided to have it written by several expert bodies working on HIV/AIDS as well as on access to care.

1.1 Siréas

Siréas asbl (association sans but lucratif; non-profit association), previously called 'Service Social des Etrangers d'Accueil et de Formation asbl', was created in 1962. The association's objective is to provide free assistance of all kinds, focusing in particular on immigrants and refugees. Forms of assistance Siréas provides are:

- Social and legal assistance
- Research and action at the European and international level (member of the International Social Service)
- Health education to prevent AIDS and STDs
- Continuing education (éducation permanente)
- Vocational training in mechanics, carpentry, electricity, building renovation, secretarial services and hotel and catering
- Job placement and social assistance for trainees

Siréas' branch of health education and AIDS/STD prevention was created in 1986 with the objective of developing a programme for the prevention of AIDS, other STDs and tuberculosis, taking into account the specific characteristics of migrant populations. The branch tries to identify risk factors and needs of different groups, and to help individual migrants and migrant groups cope with the HIV/AIDS epidemic.

The Observatoire Socio-épidémiologique du Sida et des Sexualités (Socio-epidemiological Observatory for AIDS and Sexuality) was created in 2001 at the Facultés Universitaires Saint-Louis. The Observatory concerns itself with HIV screening, consumption of psychoactive substances and sexual risk-taking, new prevention strategies for the general population, HIV and migration, sex education, relationships and sexual orientation. The Observatory's mission is to put data, reflection tools and discussion forums at the disposal of the public authorities and the different parties concerned. The Observatory, supported by the French-speaking Community of Belgium, takes a multidisciplinary, humanities-oriented approach to AIDS and sexuality. Tasks of the Observatory are:

- To collect and collate existing data to be made available to interested professionals
- To identify emerging issues related to AIDS and certain aspects of sexuality
- To gather and analyse new data, working with partner organisations in the field
- To offer methodological advice to the parties concerned
- To make recommendations to the public authorities and interested organisations
- To make available a documentary database
- To carry out research projects individually or in partnerships

1.2 Médecins Sans Frontières

Médecins Sans Frontières (Doctors Without Borders) has several projects underway in Belgium. Here is a brief historical overview:

- 1987: MSF provided information about AIDS/STDs, vaccination and infant care at the Petit Château refugee reception centre. From the outset MSF spoke out about the problems related to refugee reception. Between 1987 and 1992 MSF arranged emergency accommodations four times.
- 1988: The ELISA Centre opened and started providing anonymous AIDS screening free of charge (see 6.2).
- 1989: MSF established two dispensaries for the homeless in Brussels.
- 1991: The two dispensaries were replaced by a mobile unit (bus) which offered social services and medical consultations to anyone excluded from the health care system. Medicines were provided through a partnership with Pharmaciens sans Frontières.
- 1992: A medical and social consultancy opened in Antwerp.
- 1994: Two new surgeries opened, one in Verviers in partnership with the Société Médicale de l'Arrondissement de Verviers and the other in Liège in collaboration with the non-profit organisation Thermos, which provides social services.
- 1996: A referral surgery was set up at MSF offices in Brussels in light of the constant increase in the number of consultations at the mobile unit and the growing complexity of both social and medical situations.
- 1999: Given the changing population coming for consultations, as well as legislative changes in recent years, the mobile unit became less and less suitable for the project and was closed down. Since then all consultations in Brussels have taken place at the rue d'Artois offices.
- 2001: In January MSF set up a new emergency reception centre for asylum seekers. The partnership with Help Centre in Antwerp ended, but MSF opened a new project called 'Access to Care' with a new team.

2. Migrants' vulnerability to HIV/AIDS

In recent years there has been an increase in the number of new cases of HIV in Belgium. The majority of cases are transmitted heterosexually. Migrants are among the groups most affected by and most vulnerable to HIV/AIDS for various reasons, including the culture of both the host and home countries, precarious living conditions and difficulty in gaining access to health care and prevention programmes. In Belgium, like in other European countries, migrants continue to encounter serious problems of inequality of prevention, diagnosis and care.

In order to reduce migrants' vulnerability to HIV, coordinated action is needed towards primary prevention and access to screening and care. This action must take place in the general context of a policy of non-discrimination.

This coordinated action encounters difficulties that are inherent in the Belgian political situation (legal provisions on immigration and access to care, but also distribution of responsibility for primary, secondary and tertiary prevention), the characteristics of certain communities (mobility, affordability) and the attitude of the medical and paramedical professionals (prejudice, questions of willingness, communication problems).

3. Epidemiology of HIV and AIDS among migrants in Belgium

Most of the data presented below appear in the annual report of the Scientific Institute of Public Health, which falls under the Ministry of Social Affairs, Public Health and the Environment. Some were supplied by Dr André Sasse of the Institute through personal communication.

3.1 Number of recorded HIV cases and AIDS diagnoses

From the beginning of the epidemic to December 13, 2001, between 13,796 and 14,872 cases of HIV have been recorded in Belgium (possible double counting of 1,076 cases). In the same period, 2,940 people were diagnosed with AIDS; hence, there is a cumulative incidence rate of 286.5 cases per 1 million inhabitants.[6] Of the 10,027 HIV positive persons whose nationality is known, 4,193 (about 41.8%) are Belgian. The remaining 5,834 (about 58.2%) have a foreign nationality. Of the 2,940 people diagnosed with AIDS, 1,507 (about 51.3%) are Belgian, while 1,433 (about 48.7%) are non-Belgian.

3.2 Recent trends in the number of new cases

Between 1996 and 2000 the number of new cases of HIV diagnosed among foreign nationals almost doubled, rising from 267 per year in 1996 to 423 in 2000. Except for a slight difference observed in 1997, there was a regular annual increase of thirty cases on average, with a peak between 1999-2000, when almost eighty new cases were recorded.

3.3 Screening results in centres for asylum seekers

The Red Cross refugee reception centres systematically offer an HIV screening test to new arrivals. According to a personal communication from one Red Cross centre official, 48 HIV positive cases were recorded in 2000 for all of the centres taken together. Given the transitory nature of stays in these centres, we cannot ascertain the total number of tests carried out. To provide some indication, the total capacity of the Red Cross centres is 1,647 places.

3.4 Distribution of HIV among migrants by age and sex

Generally speaking, the most affected age group is 20-39 years, with a noticeable peak in the 30-39 year age group for both sexes (351 men, 334 women). Men are more affected than women in all age groups, with the exception of 10-19 years and 20-29 years.

3.5 Distribution of HIV among non-Belgians by region

Of the 5,372 cases of HIV reported since the beginning of the epidemic among non-Belgians whose nationality is known, 75.1% are from sub-Saharan Africa. Europeans account for only 16.6%, while North Africans account for only 3.3%. This situation reflects global figures, which indicate that about 70% of cases of people living with HIV are from sub-Saharan Africa. This explains why special efforts must be made for migrants from sub-Saharan Africa.

3.6 Distribution of HIV among migrants by mode of transmission

In terms of the number of people living with AIDS in proportion to the population, Belgium remains among the least affected countries in Western Europe. However, the proportion of people who acquired HIV through heterosexual transmission seems relatively higher than the European Community average. Heterosexual transmission is the predominant mode of transmission among HIV cases within the foreign population (82.2%). Homosexual transmission accounts for only 8.6%. Among people living with AIDS in the foreign population, one in every three persons was acquired HIV through heterosexual transmission. Mother-infant transmission accounts for 6.3% of the cases. The extent of heterosexual transmission among people living with AIDS from sub-Saharan Africa should also be pointed out (84.2%), as should the high proportion of transmission by injecting drug use among people living with AIDS from North Africa.

3.7 Sexually transmitted diseases

Recent data on STDs does not indicate the nationality of affected people. However, the report of the sentinel network of clinicians[7] points out that 33% of physicians mention trips abroad as a risk factor. Foreign partners are also mentioned as a potential risk factor.

It is necessary to consider STDs among migrant populations to the extent that HIV transmission is enhanced by the presence of STDs.[8] Of migrants with an STD who consulted the network's physicians, 7.3% are HIV positive.

4. Tightening of Belgian immigration legislation

Although the wealthy countries, including Belgium, are to a great extent responsible for many of the problems migrants face, their only response to these problems has been a policy of closed borders and expulsion. Since 1974 there has been a law blocking immigration to Belgium. The only means of entry available to non-European foreigners are:

1) Family reunification
2) Application for residence for exceptional reasons (medical or humanitarian – Article 9.3 of the 1980 law on the residence and establishment of foreigners)
3) Application for political asylum under the 1951 Geneva Convention

The reform of the asylum application procedure undertaken last year makes the policy even more restrictive.

Locking up immigrants, including minors, in centres, forced expulsions, reinforcement of police controls and criminalisation of immigration have all increased risks for asylum seekers and strengthened criminal organisations trafficking in people. The human price paid for this policy is inadmissible in countries which claim to be democratic and to abide by human rights.

This policy is unacceptable not only in human terms, but also should be denounced and combated because it does not provide a solution to the problem. The tough rhetoric of certain ministers aims, above all, at the short-term goal of winning elections, focusing solely on the consequences of the problem and not on the causes. Replacing material assistance to asylum seekers with financial aid, strengthening the policy of expulsion and increasing border controls has not led to a decrease in the number of asylum seekers who are fleeing war, terror or poverty in their countries.

As the gap between rich and poor has redesigned the world map, within rich countries like Belgium the population is split by a new social divide as well. The number of people descending into poverty and exclusion is on the rise. The threat of a dual society that loomed twenty or so years ago has come true and the gap is becoming wider every day.

5. Access to care

5.1 Legal framework

In 1998 a reform of public health insurance legislation extended its scope, making everyone on the population register eligible for health insurance coverage. Persons with no income who meet this minimum requirement are exempt from payment. They are not required to complete a probation period either.

At about the same time, new legal provisions made homeless people eligible for aid from the Centre Public d'Aide Sociale (Public Social Aid Centre, CPAS) in the neighbourhood where they plan to reside. They could then use the CPAS address as a reference.
The CPAS provides a safety net, or second line of defence, after the social security system.

Article 57 of the 1976 law on the CPAS stipulates that 'the Public Social Aid Centre's mission is to guarantee public social aid to individuals and families (...). This aid can be material, social, medical, medical-social or psychological.'

Article 57 also states that, for illegal residents, this aid is limited to emergency medical assistance. According to the Arrêt Royal of December 12, 1996, the term emergency medical assistance covers preventive and curative care provided at hospitals and on an outpatient basis, while the care providers must be accredited by the INAMI.

Article 54 of the law on residence and establishment of foreigners requires compulsory registration with a view to ensuring harmonious distribution of asylum seekers across the national territory. Thus, the local CPAS designated by the Belgian state is responsible for both social aid and medical aid. Asylum seekers whose applications are being processed are required to register at a refugee reception centre. This centre thus substitutes the CPAS in practice and is responsible for social and medical aid.

Therefore, theoretically speaking, everyone in Belgium can receive health care coverage, whatever their residence status may be.

5.2 Realities

Although the legislators have established the legal possibility of coverage for medical expenses, this certainly does not mean that access to health care is guaranteed for everyone. In practice many people have no such access, or meet with great difficulty in trying to obtain access.

For those ineligible for coverage under the social security system (asylum seekers whose applications are being processed and undocumented residents), the legal provisions to be applied are not very precise, open to interpretation and not very familiar to either users or professionals who are supposed to implement them. Above all, these provisions require Kafkaesque procedures. Often worsened by financial, cultural and/or psychological problems, these obstacles make access to care for these categories of people somewhat hit-or-miss.

For those eligible for health care coverage under the social security system, the financial problems more and more of them experience form an obstacle that is increasingly difficult to overcome. Access to medication is particularly problematic, although paradoxically, the current government, by challenging the activities of an organisation such as Pharmaciens sans Frontières, is saying the opposite. In addition to financial obstacles, there are also very frequently psychological difficulties related to social exclusion as well as socio-cultural problems.

Difficulties or even the impossibility of gaining access to health care experienced by certain social categories have not only been observed by MSF. Practically all the frontline actors on the ground – IRIS hospital emergency rooms, medical clinics and general practitioners in poor neighbourhoods, ONE consultations, Cetim, FARES asbl, family planning centres, mental health services, CPAS, social services – have observed the same phenomenon.

5.3 Actions by Médecins Sans Frontières

MSF's action for access to health care aims to address the mismatch between practice, where certain categories of people encounter difficulties getting care, and the theoretical possibility of coverage established by the legislator.

MSF organises medical-social consultations during which each individual can see a general practitioner or a social worker. The person is informed of his or her rights and told what procedures to follow. The necessary steps are taken to enable the person to exercise the right to access to health care. A medical or social follow-up is provided if necessary.

The public authorities are challenged by MSF on questions related to access to health care, inequality in the system, contradictions between existing rights and their application in practice, and failure of the authorities to comply with national and international legislation that guarantees access to health care for all.

5.4 Cultural elements

Access to health care and health facilities is first and foremost a legal problem. But for new arrivals and migrants it is also a cultural problem in the broadest sense of the term. There is a lack of information on how the health care system works in Belgium, on what exists and is accessible (medical outreach, general practitioners, medical facilities, etc).

Health is not a priority to migrants when arriving in a host country. Social problems, housing and residence permits are more pressing issues to be resolved. Consequently, it is necessary to provide information on all of these issues as well as individual assistance.

We have observed that AIDS and STDs come far behind general health problems. The problems most emphasised in migrant communities are not AIDS and STDs, but childhood diseases (vaccination), diet and nutrition, problems related to pregnancy, tuberculosis and hepatitis, cancer, smoking, drug addiction (especially among teenagers), diabetes and teenage sexuality. Therefore broader health information should be provided which includes information on AIDS.

Another priority that has emerged is literacy, which is vital for access to health care and prevention.

Many family planning centres are confronted with repeated requests for abortion by young migrant women and with the difficulty they have in considering contraception.

STDs and AIDS are still taboo within couples, families and the community. Therefore, it is necessary to place people in a stronger position to discuss these subjects with their partners, children and friends.

5.5 Continuity of health care

The effectiveness of antiviral treatment depends on early diagnosis on the one hand, and on continuity of care on the other. We know that in the migrant community screening tends to take place at a late stage. Moreover, everything leads us to believe that in light of the difficulties described above, neither the issue of timely diagnosis nor that of continuity of care has been addressed adequately yet. Although most programmes emphasise prevention, continuity is also important. It is true that once a diagnosis has been made, the approach changes, necessitating among other things psychological support, hygiene, a new lifestyle, availability of drugs and rigorous therapy; and each stage seems yet another struggle. In this context dropping out, apathy and even fatalism prevail over reason. Often a large number of ‘dropouts’ means that the services provided are stigmatised as inadequate, setting aside the fact that the main reason for dropping out is the status and precarious daily situation of people living with HIV.

That is why it would be of interest to consider the subject of ‘dropouts’.

6. Access of migrant populations to HIV screening

6.1 Factors of vulnerability

The decision to be tested for HIV is not a trivial one and is in no way comparable to a simple blood test. This step, often triggered by an event (taking a risk, entering into a new relationship, experiencing a break-up) can lead to an irreversible upheaval if the result is positive. For some, it takes several months before deciding; others just have to know a few days after taking a risk. In both cases a structure that provides support must be available. Counselling must be available along with testing.

There are three stages of vulnerability, before, during and after HIV screening:

- Greater exposure of certain groups or individuals to the HIV virus
- Screening per se (less access, screening which is compulsory or performed without consent or where confidentiality is not respected, etc)
- Greater vulnerability due to a positive diagnosis (psychological, economic, social): access to care, impact on family and social relationships, psychological fragility, etc

The loss of anonymity together with the fear that medical secrecy will not be respected (health insurance, laboratories, public administration), embarrassment about discussing one's private life with the family doctor (fear of judgment, financial difficulties, complexity of the hospital system) are reasons often given for not consulting existing institutions that provide HIV screening. That is why, in 1988, Médecins Sans Frontières set up a free, anonymous screening centre running mainly on volunteers, the ELISA Centre, in the hope of providing access to all.

6.2 Work of the ELISA Centre

The ELISA centre is a walk-in service, so no appointment is required. There is a volunteer receptionist who gives the applicant a questionnaire to fill in which will be the basis for a discussion with the doctor. The questionnaire is strictly anonymous and confidential. It records the person's general profile, the risk profile and the reason for requesting a test.

In the surgery, a volunteer doctor sees the applicant and provides preliminary counselling (in-depth discussion prior to a blood test). During the test, the applicant receives an identification number. Using this number, the applicant receives the result at the centre from the same doctor a week later. Post-test counselling also takes place when the results are given, mainly in order to ensure that the person understands the implications of the result. Results are not provided in any other way (mail, telephone).

6.3 Barriers to HIV testing

Over the course of many years, the ELISA Centre has carried out approximately two thousand tests. Ten percent of them are for people from countries in sub-Saharan Africa, whereas this population accounts for between 65% and 75% of the tests that are positive. That is why it was important to determine how the centre could be made more accessible to this group. In collaboration with Siréas, an 'exploratory mission' was created to identify the specific characteristics of the population group from sub-Saharan Africa (if there are any) with regard to HIV screening.

The methodology consisted of setting up five discussion groups with people involved in Siréas activities. A moderator (usually a member of the Siréas team) and one or two minutes secretaries led the discussions. The subjects discussed included AIDS in general, people's perceptions in the community and the implications and benefits of testing.

Important points raised in the discussion groups were:

- The fact that 10% of the people who come to the ELISA Centre are from sub-Saharan Africa is a good thing. (The participants in the discussion, who were themselves of sub-Saharan origin, were heartened by this attendance.)
- Support is essential. A test alone, without follow-up or support, is not very accessible. This is related to the need to have confidence in a person or association in order to cope with a test and its outcome.
- Isolated HIV tests have a low attraction. A test in the framework of a general check-up is more accessible.
- There is a lack of information about screening, but also, more broadly, about everything related to AIDS (treatment, legal status, social assistance).
- A cultural approach must be taken, taking into account the beliefs and practices in people's country of origin (for instance, a young woman from Burundi explained that when someone has a test in her country, everyone knows the result before the person tested does).
- People find the subject of AIDS frightening and difficult to talk about. Some people think they may get it just by talking about it. Psychologically and socially, AIDS is frequently associated with death.
- People know about screening, but for them it is not a priority at all. first people have to succeed in talking about it. This would be easier and more easily accepted if the person talking about it is well-known in the community and is recognised as a 'specialist' on the subject.
- A special place for HIV testing alone is not ideal. There is a preference for a more ordinary place that is less specialised, where people can have a general check-up and perhaps an HIV test, too. The biggest advantages of the ELISA Centre are that it is affordable and recommended by a well-known group (Siréas).

7. Projects in Belgium

A large number of prevention projects have been launched since the beginning of the 1980s. Based on lessons learned in the past, these projects are structured in such a way as to best respond to the needs of the population. The strategies they follow have been fine-tuned, taking into account the specific characteristics of each population group. There is now a whole set of projects in Belgium. Listing all of them would require a separate study. What should be emphasised is that nowadays institutions, organisations, schools, family planning centres, health centres and social services have become involved in the prevention process by incorporating AIDS prevention into their work. Nevertheless, we must recognise the associations specifically dedicated to fighting AIDS.

Associations fighting AIDS include:

- Adzon (outreach on the street among young prostitutes)
- Sensoa
- The Foundation (buddies)
- Ex Aequo (homosexuality)
- Army Info Team
- Stag/AIDS Telefoon
- Télé Accueil (telephone helpline)
- Jeugd en Seksualiteit (AIDS prevention in youth movements)
- HIV Vereniging Vlaanderen/Witte Raven (support for people living with HIV/AIDS)
- Aide Info Sida (support for people living with HIV/AIDS)

- GIG-project of the Free Clinic (injecting drug users/addicts)
- Modus Vivendi (injecting drug users)
- Espace P (prostitution, focus on African women)
- Paioke (prostitution, focus on the African community)
- Branch of Projet Lama (drug addiction/migrants)
- Siréas project for HIV positive migrants in prison
- Siréas prevention in the African migrant community
- Médecins Sans Frontières (for people without access to care)
- ELISA Centre (MSF anonymous screening free of charge)
- In Petto (peer education and training)
- Pasop (prevention, prostitution Ghent)
- ITG project allochtonen
- GAMS (abolition of sexual mutilation)
- African Women's Associations
- Project for migrants at the AIDS Coordination Office in Liège, Namur and Charleroi
- Zorgwonen (housing for people living with HIV/AIDS)
- Fond de Solidarité SIDA (French-speaking Community of Belgium)
- AIDS Fonds (flemish-speaking Community of Belgium)

8. Conclusions and recommendations

8.1 Conclusions

Although access to health care is clearly a social and legal problem, there is much more to it than just these two aspects.

In migrant communities there are people living with HIV/AIDS who have access to health care, who do not have social problems, who are legal residents and who know how to demand their rights and bridge the cultural gap between themselves and the health services; nevertheless, they struggle with isolation from the community and rejection from those within it. They must still cope with the difficulties and burdens of treatment, anxiety and stress. The purpose of their migration is called into question as well.

For the majority of people living with HIV/AIDS in migrant communities, it is still difficult to gain access to health care. Although there may be medical assistance, social assistance is not always available, which means no housing and no food.

The problem of women and children living with HIV/AIDS in migrant communities is increasing every day. Teenagers require special attention: we are now seeing adolescents who were born with the virus, but for whom no specific assistance has been envisaged.

A life with HIV/AIDS is for many people a life of uncertainty and anxiety. There is anxiety about migration, but above all about new treatments. Will they be effective? What about toxicity? It is difficult to talk to doctors due to language or comprehension problems. There is little suitable social assistance. The treatment can be difficult to take, may have side effects and may cause physical changes. Above all, for migrants there are problems of residence, uncertain legal status, extremely unfavourable socio-economic conditions, ignorance about the health system, undeclared work, the fear of expulsion, financial problems, isolation within the community, little confidentiality, cultural perceptions, the multiplicity of services to be consulted... the list is long and illustrates just how big the problem is.

8.2 Recommendations

We recommend that the government, the health care system and aid agencies:

- Provide access to treatment for everyone, with the assurance of a secure residence status and social assistance
- Ensure that people living with HIV/AIDS will not be expelled
- Ensure that people involved with HIV/AIDS participate in the prevention process and health policy development
- Develop specific support projects for teenagers living with HIV/AIDS
- Encourage community assistance to people living with HIV/AIDS by mobilising the community and supporting local neighbourhood actions
- Educate health care and social workers about the cultural and religious approach of migrant communities
- Educate social mediators and interpreters about problems related to AIDS
- Organise and support projects proposed by HIV positive people in migrant communities in order to fight isolation and provide information on nutrition and treatment
- Teach people living with HIV/AIDS, in a culturally and linguistically suitable way, how to cope better with the systems in the host country
- Develop counselling appropriate for migrants
- Develop and strengthen prevention work in the community in order to fight rejection of people living with HIV/AIDS and denial of AIDS
- Develop projects together with migrants' countries of origin
- Develop information tools that are culturally and linguistically appropriate for people living with HIV/AIDS in different communities
- Develop day centres for African women affected by HIV/AIDS
- Strengthen communities at the grassroots level through training
- Include AIDS prevention in general health information
- Address the problems of tuberculosis and hepatitis
- Study the impact of new treatments on prevention
- Develop screening campaigns and promote screening with respect
- Devote special attention to women in migrant communities
- Combat racism, discrimination and exclusion

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6 Ministry of the French-speaking Community, ULB-PROMES, Scientific Institute of Public Health (1999). HIV and AIDS Infection in the Walloon Region and the Brussels Capital Region.

7 Van Kersschaver, G. & Sasse, A. (2002). Monitoring of STDs via a 'sentinel' network of clinicians in Belgium. Results for first reporting period, October 2000-January 2001. Scientific Institute of Public Health, Epidemiology Department.

8 Fleming, D.T. & Wasserheit, J.N., cited in Van Kersschaver & Sasse, op. cit., p. 3.

9. References

Arrêté royal of December 12, 1996 on emergency medical aid to illegal residents, entry into force January 10, 1997.

Baruani, Y.K. & Louhenapessy, M. (1997). Comprendre les obstacles à la prévention du sida en Communauté migrante africaine (Understanding the obstacles to AIDS prevention in the African migrant community). Service Social des Etrangers d'Accueil et de Formation asbl.

Besluit van de Vlaamse regering tot wijziging van het besluit van de Vlaamse regering van 31 juli 1991 inzake gezondheidspromotie (Decision by the Flemish government amending the 1991 Decision by the Flemish government on health promotion).

Institut de Statistiques et de Démographie (Statistical and Demographic Institute).

Médecins sans Frontières. Report Exclus des Soins (Excluded from Care). Brussels, Antwerp, Liège, Verviers.

Ministère de la Communauté française, Direction générale de la santé (Ministry of the French Community. General health management) (1998). Five-year programme and health promotion legislation of the French-speaking Community. Brussels.

Overlegcentrum voor Integratie van Vluchtelingen (Consultation Centre for the Integration of Refugees) (1993). Gast-Vrij België... Vluchtelingenonthaal in de praktijk (Hospitable Belgium... Refugee reception in practice). Brussel: De Koning Boudewijnstichting.

'Petit Château' refugee centre (1998). Annual Report.

Prévost, M. et al (1996). La prévention du sida en Communauté française, Plan guide triennal 1996-1998 (AIDS prevention in the French-speaking Community, Three-year plan 1996-1998). Brussels: Agence de Prévention du Sida.

Scientific Institute of Public Health. Annual Report.

Service Social des Etrangers d'Accueil et de Formation asbl. AIDS Prevention Plan 1994-1997.

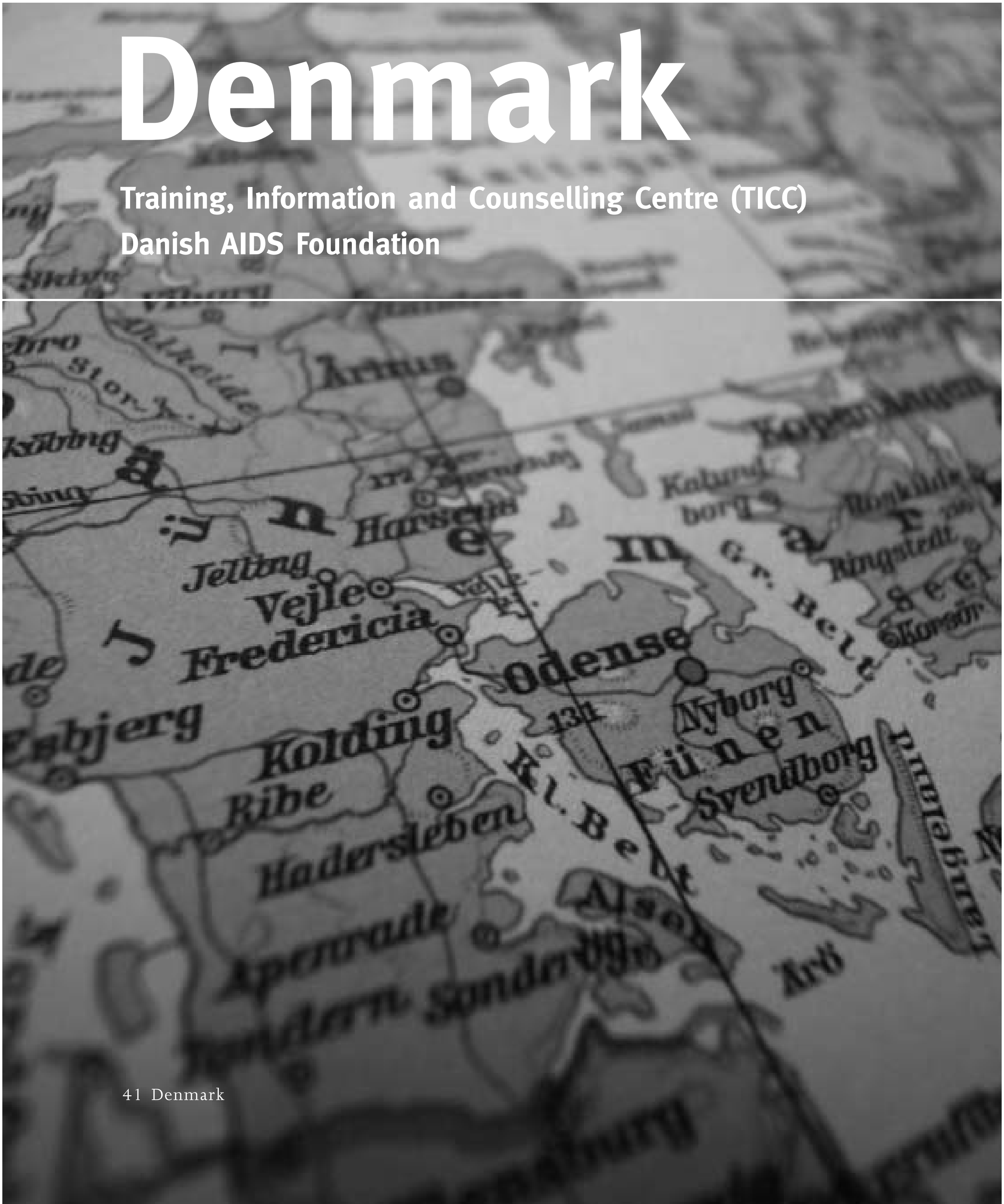
Stedelijk overleg Aids Antwerpen (Urban Consultation Aids Antwerp) (1992). Aids-werking 1987-1992. ESOC Publication no. 31.

Vlaamse Vereniging voor Respiratoire Gezondheidszorg en Tuberculosebestrijding VZW (Flemish Association for Respiratory Health Care and Tuberculosis VZW) (1996). Berichten, 6, no. 2.

Voorstel tot strategisch plan voor preventie en zorg (een Vlaams antwoord op de problematiek van aids en soa tot het jaar 2000) (Proposal for strategic plan for prevention and care (Flemish response to problems of AIDS and STDs until 2000)).

Denmark

Training, Information and Counselling Centre (TICC)
Danish AIDS Foundation



1. Introduction

The aim of this report is to provide an overview of the current situation in Denmark regarding ethnic minorities and HIV/AIDS, and specifically to outline the issues of access to treatment and health care.

During the last years important organisational changes have taken place in relation to the AIDS & Mobility National Focal Point (NFP) in Denmark. The former NFP – IND-sam, an umbrella organisation for ethnic minorities in Denmark – closed down in January 2002, and for several months it was not clear who should take over the role as NFP. However, in September 2002 it was decided that the Danish AIDS Foundation would continue as the Danish representative in this European network. The AIDS Foundation incorporates the project The Training, Information and Counselling Centre (TICC), which previously focused on HIV/AIDS under IND-sam and therefore is familiar with the work of AIDS & Mobility.

TICC is located in the same offices as the former NFP, but is presently administered by the Danish AIDS Foundation. TICC is financed by the Danish National Board of Health.

The report will first provide basic epidemiological data and focus on access to treatment for both migrants and ethnic minorities. Secondly, the actors in the field of HIV/AIDS and ethnic minorities in Denmark will be presented.

The report has been written by TICC and the Danish AIDS Foundation. It is based on official statistics and information collected by various organisations taking part in the fight against HIV/AIDS in Denmark.

2. HIV and AIDS in Denmark

The Danish response to HIV/AIDS is based on the agenda formulated by the Danish Parliament in 1987, according to which ‘the effort against AIDS is based on voluntarism; anonymity; open, direct and honest information; the individual’s safety in contacting the health care system; and, finally, the wish to avoid any form of discrimination’. Ten years later in 1997 the agenda was reaffirmed by the Parliament, encouraged by a decline in the annual number of people diagnosed with HIV.

In Denmark the spread of HIV/AIDS has not evolved into an epidemic, and the risk of becoming infected in the country is low. Currently, the risk of infection is largest for persons belonging to specific groups such as men who have sex with men, prostitutes, some ethnic communities, injecting drug abusers, and persons travelling and working temporarily in high prevalence countries.

2.1 Epidemiological data

Currently, 3,678 persons are registered as living with HIV in Denmark. An additional non-registered 1,500 persons are estimated to be HIV positive.

In 2002, a total of 281 newly detected cases of HIV were reported: 183 males (65%) and 98 females (35%). On average, during the last ten years, HIV has been detected in 282 people per year (range 211-331).

Among the reported HIV positive males in the period 1990-2002, 23% were immigrants. In 2002, 44 (24%) of the males were immigrants, a proportion that has gradually risen from 20 % in 1990. Of the HIV positive females reported during the period 1990-2002, 59% were immigrants. In 2002, 61 (62%) of the females were immigrants, compared with 40% in 1990.[9]

In total, the percentage of newly infected persons with a different ethnic background than Danish is 35%.

2.2 Access to treatment

In Denmark all persons with a residence permit have free access to the services provided by the Danish health care system, including medical treatment. This implies that all persons with a residence permit can have a free HIV test. In case the test is positive, medical treatment can be offered.

Any person who arrives in Denmark asking for asylum is offered a free HIV test. According to legislation the test is voluntary. If a person accepts to be tested and the test proves positive, the person is covered by the Danish Immigration Act § 42 a, which states: 'A foreign person who is in the country and applies for a residence permit… will have expenses for living costs and necessary health services covered by the Danish Immigration Service until the foreign person is granted permission to stay or the foreign person leaves or is sent out of the country.'[10]

Thus, treatment of and medication for asylum seekers will be provided in accordance with the current legislation. When a foreign person applies to the Danish Immigration Service for asylum, the person's HIV status is not considered and does not influence the Board's decision as to whether to grant permission to stay. An HIV positive person who is denied asylum can in principle be sent back to a country where treatment and medication are not available.

If an HIV positive person is denied asylum his last possibility is to apply to the Ministry of Integration for a humanitarian permission to stay. When an applicant has a serious disease and treatment is doubtful in the applicant's home country, this can be taken into consideration in the overall assessment of the application. However, no figures appear to exist as to how many – if any – persons have been granted humanitarian permission to stay due to their HIV status.

If a person has been granted permission to stay in Denmark for a limited period of time only – for instance, for the purpose of studying – no permanent permission to stay can be granted based on the person's HIV status. In various cases doctors at Danish hospitals have treated patients for AIDS-related diseases during their time-limited stay in Denmark, only to face an ethical dilemma when they were forced to discontinue the treatment when the patient's permission to stay expired, knowing that the patient would be sent back home to a certain death.[11]

On the other hand, provided that a permanent permission to stay has been granted to a person, no juridical barriers exist for the person to receive all needed services and treatment. The remaining problems are related to socio-cultural factors and reflect the lack of resources available to the Danish health care system to overcome cultural and linguistic differences as well as poor knowledge of taboos and stigmas existing in many ethnic groups concerning HIV/AIDS. In addition, in many ethnic communities there exists a general mistrust of Danish public systems, which often leads persons with a different ethnic background than Danish to refrain from using the available services in the areas of prevention and counselling.

3. The actors in the field of HIV/AIDS

In Denmark the response to HIV/AIDS is carried out by a variety of different actors including the health care system, the counties and a large number of privately organised interest groups. The central actor involved in activities in the field of HIV/AIDS and ethnic minorities is the National Board of Health.

3.1 The National Board of Health

The National Board of Health is a governmental institution working within the field of health promotion, disease prevention and health care for the public. The Board is nationally responsible for preventing the spread of HIV/AIDS. In order to fulfil this task, the Board works in close cooperation with both other governmental and non-governmental organisations working in the area of HIV/AIDS.

The vision of the National Board of Health is to bring down the number of HIV positive persons and to target the effort towards different high-risk groups including ethnic minorities. The Board is responsible for devising and carrying out its own activities as well as prioritising the distribution of the financial resources among other actors in the area of HIV/AIDS.

3.2 TICC

The Training, Information & Counselling Centre approaches primarily Africans living in the greater Copenhagen area. The main activity of TICC is training African HIV/AIDS advisers. To date, TICC has trained a group of forty advisers, and another fifty persons are presently attending the TICC training course. The course deals with ways of HIV infection, safe sex, counselling, the Danish social and health care system, communication, psychology and networking. Once trained, the advisers shall work partly in their own local networks, for instance at family gatherings and at HIV/AIDS information arrangements in the African communities, and partly in the asylum centres, language schools and hospitals.

Apart from training of African advisers, TICC provides information, counselling and moral support to Africans living with HIV/AIDS and their families. finally, as part of the preventive work, TICC hands out condoms to African shops and massage clinics.

The project manager of TICC participated in AIDS & Mobility meetings in Brussels in 2002 and Vienna in 2003. In addition to this, TICC has established good contacts with other National Focal Points through the AIDS & Mobility network – a collaboration which has proven fruitful as concerns sharing of experiences. At the national level, through gatherings and activities TICC has attempted to include information on the AIDS & Mobility network in order to disseminate knowledge in Denmark about the European collaboration.

3.3 HIV-Denmark and the Reach Out Project

HIV-Denmark is an organisation for all people with HIV in Denmark irrespective of mode of infection, gender, sexuality, nationality and cultural group. HIV-Denmark is engaged in safeguarding the interests of HIV positive persons, their relatives and bereaved persons. The organisation provides counselling, runs self-help groups, arranges seminars, gives courses, runs drop-in centres and publishes newsletters and magazines. HIV-Denmark is governed by a board elected by the members. The daily management is carried out by a secretariat in Copenhagen.

In December 2002 the Reach Out Project was initiated. This project aims at facilitating contact between HIV positive persons from ethnic minority groups and the Danish health care system. The primary work is to improve the cooperation between HIV positive persons belonging to ethnic minority communities and the two outpatient clinics that are working with HIV positive persons, located at Copenhagen University Hospital and Hvidovre Hospital. To work efficiently as a facilitator, at this point it is important to talk with both the staff at the outpatient clinics and HIV positive persons, and to learn more about the specific problems facing the two parties in their cooperation. Part of the work consists of facilitating workshops, lessons and so forth directed at the hospital staff on subjects they wish to learn more about.

In addition, the project undertakes counselling to some extent and aims at initiating groups of HIV positive persons from ethnic minority groups on the request of the HIV positive persons themselves.

3.4 The Danish AIDS Foundation

The purpose of the Danish AIDS Foundation (AIDS-Fondet) is to collect money for research, information and patient support. At the same time the AIDS Foundation makes an effort to provide information on HIV and AIDS and to mobilise public and political support for the fight against the disease in Denmark and in the rest of the world.

The primary effort of the AIDS Foundation rests with HIV positive people in Denmark. The foundation provides financial support to people living with HIV who experience the most hardship both physically and socially because of the disease. An important task for the AIDS Foundation is also to counter discrimination against HIV positive persons and the stigma attached to them.

The AIDS Foundation supports research, in particular into the failure of AIDS drugs and AIDS prevention, including new prevention technologies.

The AIDS Foundation financially supports the availability of information on HIV and AIDS in general, including goal-oriented information for young people and ethnic minorities.

On the international agenda, the primary goal of the AIDS Foundation is to promote the development of an AIDS vaccine and microbicides. In addition, it works to involve Danish-based international companies with activities in the developing world in the fight against HIV/AIDS (for instance, companies carrying out contracts for Danida, the Danish International Development Aid Programme under The Ministry of Foreign Affairs).

The AIDS Foundation employs ten people. Seven work at the secretariat and three are employed in projects working with ethnic minorities in Denmark. The AIDS Foundation's work and visibility are strengthened through the many volunteers who make a tremendous effort.

3.5 Cross-Over

In January 2003, the AIDS Foundation initiated another project concerning HIV/AIDS and ethnic minorities living in Denmark; Cross-Over. The starting point for Cross-Over is ethnic equality. Cross-Over aims for all people in Denmark, across cultures and languages, to have equal possibilities to obtain information on HIV and AIDS.

Cross-Over intends to form an organisation – in the course of three years – which takes its starting point in the ethnic groups' own culture and understanding of diseases and which will help ensure a sustained and continuous prevention effort which is equal in quality to what other groups in Denmark will be offered.

The core of Cross-Over is to encourage and facilitate cooperation and sharing of experience among ethnic minority groups. Knowledge must be exchanged and developed to strengthen prevention work. Cross-Over aims at reaching a large section of the ethnic communities in order to promote education and information about HIV and AIDS. Through close consultation and dialogue with ethnic groups, Cross-Over assists in analysing the specific needs and current wants of the groups concerning HIV and AIDS programmes. Through organisational, technical or financial support, Cross-Over will back up on present as well as future activities.

TICC, the Reach Out Project and Cross-Over are working closely together to increase and improve the HIV/AIDS prevention and information effort for people with a different ethnic heritage than Danish. The approach varies from project to project. However, to increase the overall effort, cooperation and coordination across the programmes have a high priority.

In addition to this, a common supportive committee consisting of doctors, social workers, and anthropologists who all have special competence within HIV/AIDS and ethnic minorities has been established to coordinate the three projects and ensure their quality.

3.6 African Foundation for Health, Information and Culture – AFHIC

AFHIC is a non-political organisation for ethnic minorities in Danish society. The organisation works to facilitate the integration between Danish society and ethnic minorities.

AFHIC offers a variety of different services to ethnic minorities. Besides offering anonymous counselling, the organisation provides information about the Danish health care system, prevention of STDs and unwanted pregnancy, cancer, cardiac diseases and diabetes.

4. The future effort

About 35% of the reported HIV cases are persons with a non-Danish ethnic background. This is far too much. Cross-cutting collaboration between the organisations which have planned and initiated activities is essential for improving the statistics. This, however, demands both human and economic resources, which must be provided by both private and public donors.

The ongoing projects deal with prevention as well as support for HIV positive persons with a non-Danish ethnic background. An increased collaboration between the projects will contribute to creating a response to HIV/AIDS which will make a difference in Denmark in the long run.

Concerning the Danish representation in AIDS & Mobility, it is hoped that the future will be more stable as the collaboration between TICC, the AIDS Foundation, and the National Board of Health will be strengthened and intensified.

[9] Epi-nyt, week 34, 20. August 2003

[10] Danish Immigration Act § 42 a

[11] Dagens medicin, 28, February 2002

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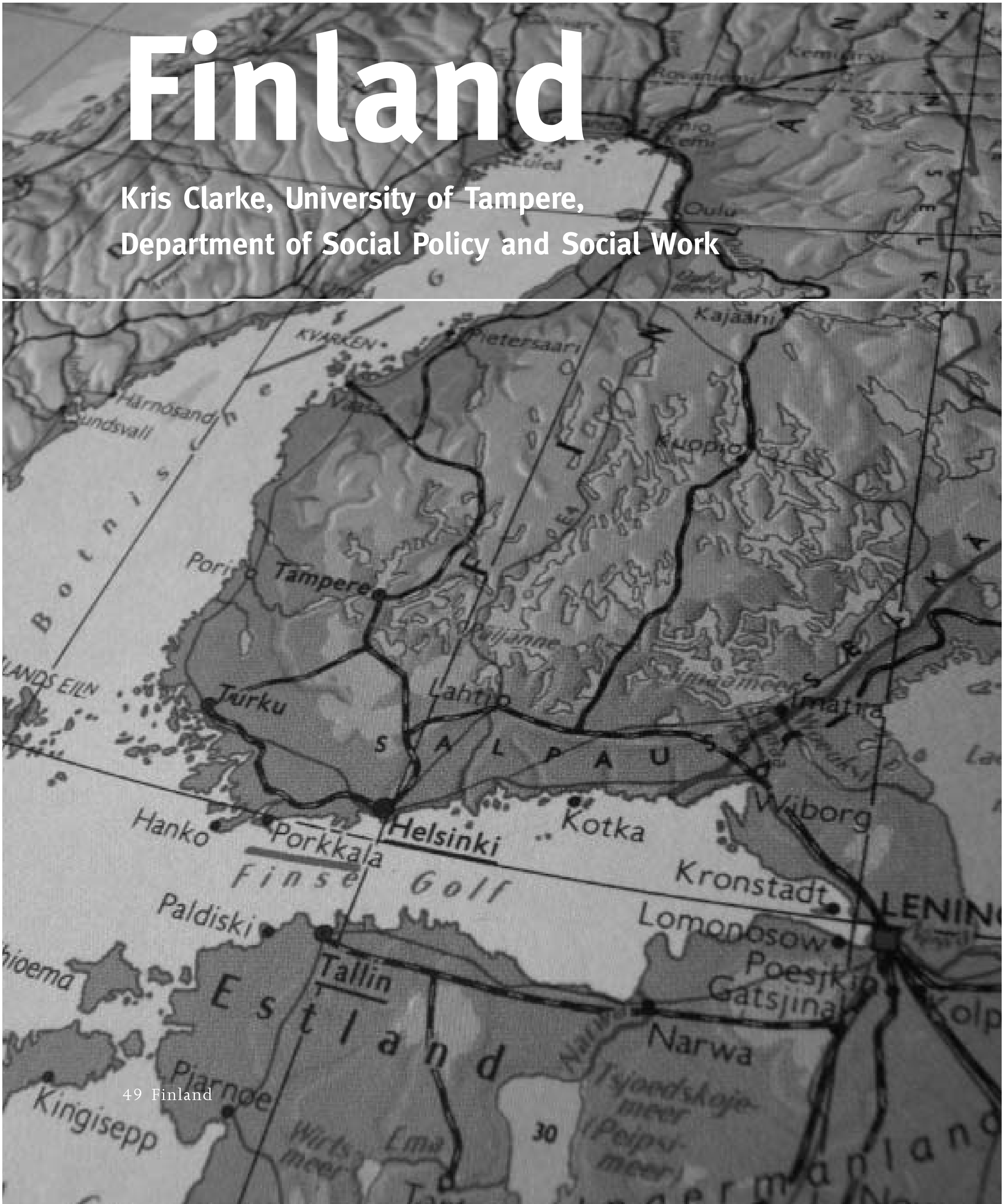

Finland

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1. How was this report written?

This report examines the local Finnish context of AIDS and mobility with a specific focus on issues related to care and treatment. One of the difficulties of comparing European nations is the enduring strength of cultural, economic and socio-historical circumstances, which – though always metamorphosing – continue to have a strong impact on social and health care policy and practice in each country. In the absence of significant epidemiological changes in the last two years, this report focuses on the current situation with regard to HIV and migrants in Finland.

Due to the time constraints of the other partners in the network, as National Focal Point I took responsibility for collecting the data and writing this report. When I received the instructions for writing, I was in the final stages of collecting interview data for my doctoral dissertation, which is also on the topic of migrants living with HIV in Finland. I therefore took to the road and sought to track down a variety of people involved with the issue of HIV from different perspectives. I interviewed four people living with HIV in different areas of Finland, two of whom were migrants. I also interviewed a policy maker at the Ministry of Social Affairs and Health as well as two workers at the Finnish AIDS Council. All interviewees consented to their interview data being used for both this report and my dissertation. This report is primarily based on qualitative findings obtained through interviews that lasted between one to four hours, though policies and empirical data from governmental and non-governmental institutions are also included.

My aim in writing this report was to include as many diverse voices as possible in order to look behind the curtain of official HIV statistics and policy statements, and to explore how migrants living with HIV experience treatment and care in Finland. I circulated a first draft among network partners as well as the interviewees for comments and have modified the text accordingly; however, I remain solely responsible for any errors.

In this report, the concept of treatment is narrowly defined in terms of health care interventions while the notion of care is considered more broadly in social terms. Care receives more attention in the report, because from my qualitative data it appeared to be the more contested area. It is also far more difficult to quantify and is often neglected or discussed inadequately in reports that focus on HIV as a disease (a medically identifiable disorder of the biological system) rather than a disease and an illness (the social and subjective experience of being sick) (Kleinman, 1988, pp. 1-5). finally, access to HIV treatment is conceived as the concrete capacity to obtain medical treatment for HIV disease as well as social and cultural support which enhance the appropriateness and effectiveness of services targeted at helping people to live with HIV as an illness.

2. HIV/AIDS in Finland (2000-2002): general epidemiological trends, access to treatment and the development of prevention strategies

2.1 Epidemiological overview

Finland began reporting HIV cases in 1986 and has a comprehensive, streamlined epidemiological sentinel system that provides accurate data on communicable diseases. Compared with many Western European countries, Finland has a very low prevalence of HIV. Despite a spike in the incidence of HIV among injecting drug users in 1998, the HIV acquisition rate has remained generally stable in Finland in recent years. The total number of people who have been notified with HIV has even declined from 145 in 2000 to 115 in 2002. The majority of cases (71 in 2000 and 55 in 2002) have been reported in the Helsinki metropolitan area. According to the most current statistics, the means of transmission is fairly equally divided between heterosexual contact (28%), homosexual contact (25%), and injecting drug use (20%), with the remaining cases of unknown origin (National Public Health Institute, 2002).

According to the 2002 epidemiological statistics of the National Public Health Institute, 29% of HIV cases and 38% of AIDS cases are among migrants. It is important, however, to be cautious when analysing HIV/AIDS statistics in Finland due to the very small number of people. For example, the increase of the proportion of migrants in AIDS epidemiological statistics from 2000 (31%) to 2002 (38%) represents an increase from five people to seven people.

2.2 Access to treatment and the law

All treatment and medications for HIV are available free of charge to Finnish citizens and migrants with social insurance cards. To receive a social insurance card, a migrant must have resided in Finland for a certain period of time and must fulfil the requirements of the Act on Residence-based Social Security. This means that residence in Finland must be considered permanent or there must be compelling reasons to issue the card. Migrants entering Finland for a limited amount of time, such as students, are not entitled to social insurance cards. Finland has a national health care service which provides all HIV/AIDS treatment, though people living with HIV/AIDS also have the option of seeking consultation in the private sector. The Law on Client Payments (3.8.1992/734) states that medication for communicable diseases classified as 'reportable' are to be provided to people living with HIV/AIDS without cost. The cost of medication and treatment is borne by the municipality in which a person is registered.

2.3 Entitlement to treatment and residence status

There are primarily two categories of migrants in Finland that have residence permits: permanent and temporary residents. Migrants with permanent residence permits are those who have been recognised as having significant ties to Finland through family, work, or refugee status. Permanent residents are entitled to a social insurance card which ensures access to free social and health care as well as subsidised medication. Migrants with temporary residence permits have fixed-term visas which usually must be renewed each year. Migrants in this category typically include students and temporary workers. Students receive health care treatment at their school or university health care service, while employers are required to provide occupational health care for their workers. Temporary residents are not necessarily entitled to a social insurance card.

Finland is one of ten countries that receive quota refugees via the UN High Commission for Refugees (Directorate of Immigration, 2002). Approximately five hundred quota refugees are brought to Finland each year, primarily from Iran, Iraq and the former Yugoslavia. Quota refugees receive permanent residence status and therefore are entitled to a social insurance card. Asylum seekers, however, must await a legal decision on their application for asylum, a process which can take many years. They are not eligible for a social insurance card. Most asylum seekers reside in a state-run reception centre, a municipality or the Finnish Red Cross. Upon arrival at a reception centre, asylum seekers are given a health screening which includes an HIV test. They have the right to refuse to take the HIV test, but few are informed or counselled about their rights or what would happen in the event that a test is positive (Sabanadesan, 2001, p. 79). During this period, asylum seekers are entitled to all acute care treatment that is documented as necessary by a physician. Medical treatment for asylum seekers is funded by the state.

People with HIV/AIDS receive treatment at their local central hospital. There are 21 central hospital districts in Finland. fifteen of them have a specialist in communicable diseases. In the remaining central hospitals, people living with HIV/AIDS are treated by internists. There are five university hospitals in Finland. University hospitals are referral centres and take care of the obstetrical needs of mothers living with HIV.

Physicians must consider a variety of individual factors including prior treatment history, possible drug resistance or interactions, CD4 count, and life situation, before recommending that antiretroviral medication be started for anyone. Asylum seekers and migrants with temporary residence permits present special challenges to formulating a drug regimen because their future in Finland is not guaranteed. Asylum seekers in Finland often receive a minimal level of social benefits while they await a decision unless they are employed. Necessary medical expenses are also taken into account when determining the level of monthly social benefits. Therefore, if a physician documents that an asylum seeker urgently requires antiretroviral medication, this is generally accepted as part of the emergency medical treatment guaranteed by the Finnish state. However, there is little information about the situation regarding access to treatment by migrants with temporary residence permits who do not hold social insurance cards.

2.4 Finnish national AIDS strategy

In 2002, the Ministry of Social Affairs and Health coordinated an expert group which formulated a national AIDS strategy for 2002-2006. The expert group was made up of various representatives of health, social, patient and advocacy groups. The purpose was to draw up an AIDS policy which could facilitate the prioritisation and allocation of resources directed at HIV treatment and prevention targets. The national strategy has eight basic proposals:

- The prevention of HIV is the cornerstone of preventive measures.
- The effectiveness of treatment and support measures is an integral part of prevention.
- It is essential to support the full empowerment of HIV positive people and to reduce their vulnerability.
- HIV tests and epidemiological follow-up systems generate information to be used in the planning of future measures.
- International cooperation is a prerequisite for conquering the HIV epidemic.
- The education of professional staff must be expanded and the level of competence must be maintained.
- Legislative reform might become necessary as the HIV situation changes.
- Management of the situation calls for improved coordination and a multidisciplinary approach (Finnish national AIDS strategy, 2002).

It is significant that the special needs of migrants, particularly regarding culturally and linguistically appropriate information and care, are not listed as one of the important aims of the new national AIDS strategy. This absence reflects the invisibility of migrants in national health policies in general and HIV/AIDS policies in particular.

2.5 Regional trends

Finland’s geopolitical location at the crossroads of the European Union and Eastern Europe raises special challenges for HIV prevention strategies. HIV arrived late in many countries of Eastern Europe due to the political isolation of the Soviet Union. However, HIV incidence has been rising faster in Eastern Europe and Central Asia than anywhere else in the world (UNAIDS, 2002, p. 13). HIV prevalence in Eastern Europe is exacerbated by socio-economic instability in the region and the consequent rise of injecting drug use and commercial sex work. It has been reported that 1% of the population of Eastern European and Central Asian countries are injecting drug users (UNAIDS, 2002, p. 17). In the Russian Federation, HIV is largely transmitted through injecting drug use by young people. Estonia has the highest rate of HIV cases in the region relative to its size (UNAIDS, 2002, p. 16).

Injecting drug use and commercial sex work have also drastically increased in Finland in recent years. There was an outbreak of HIV among injecting drug users in Finland in the late 1990s, but harm reduction interventions appear to have reduced the amount of new cases. Organised crime groups from Russia and Estonia largely control commercial sex work in Finland, bringing women from Eastern Europe to work (Helsingin Sanomat, 2002). Finland has yet to be affected by the high incidence of HIV among its eastern neighbours. Regional trends require close monitoring by Finnish public health authorities and non-governmental agencies if effective HIV prevention programs are to be implemented.

3. Projects and interventions related to access to treatment and care

HIV work and AIDS awareness programs are implemented by five agencies in Finland:

- Finnish AIDS Council (NGO)
- Body Positive (organisation for people living with HIV)
- Finnish Red Cross (NGO)
- Finnish Family Federation (NGO)
- Folkhälsan (NGO)

The Finnish AIDS Council is the main NGO in Finland that offers information and support to people affected by HIV. It has five regional drop-in centres where counselling and testing are available on an anonymous basis. It also offers adaptation training, legal advice and professional psychosocial counselling. Body Positive, an organisation for those affected by HIV, has an office in Helsinki which offers information and support. One interviewee living with HIV described Body Positive as "…a living room… for some people, this is the only place where they are openly HIV+." Both the Finnish AIDS Council and Body Positive offer free meals on certain days and provide an important place for people living with HIV to meet and share experiences as well as information. The Finnish Red Cross runs a phone helpline and organises AIDS awareness campaigns. The Finnish Family Federation offers sexual health information. Folkhälsan provides information and counselling to the Swedish-speaking community in Finland.

There are no services in Finland specifically targeted at migrants living with HIV. Very little is actually known about the needs of migrants living with HIV, because relatively few seek services from HIV agencies. In response to my enquiries, the director of the Finnish AIDS Council stated that they were not aware of any special projects directed specifically at migrants largely due to the lack of interest.[12] Migrant community organisations themselves have not taken up the issue of HIV.

One migrant living with HIV, however, is currently initiating an anonymous email list through which other migrants living with HIV could discuss common issues. As of this writing, no financial support of any kind has been given to this project, though it would be a very important forum to develop.

A qualitative research project on migrant health was initiated in 2002 as a direct outcome of the AIDS & Mobility research project on African communities in Northern Europe. The

Ministry of Social Affairs and Health funded a migrant community health research project through the University of Tampere, Department of Social Policy and Social Work, where three migrant researchers explored the policy and practice implications of the growing migrant presence in Finland through the needs and experiences of migrants in the health care system. The three communities that were researched were African mothers, Estonian and Russian sex workers and Iranian asylum seekers. This project represents one of the first attempts to empower migrants to define health issues through the eyes of their own communities.[13]

4. HIV and migrants in an increasingly multicultural Finnish society

Migrants have become the focus of attention in the Finnish media and among academics as an increasing number of immigrants and refugees have come to Finland. Although the total number of migrants in Finland remains miniscule in a European context (slightly over 100,000 or approximately 2% of the population), by Finnish standards the rise in migrants has been substantial. Finnish researchers have estimated that the number of migrants in Finland has quintupled since the late 1980s (Pitkänen and Kouki, 2002). Most of the migrant population is concentrated in the Helsinki metropolitan area and represents a wide variety of cultures, languages and nationalities. The majority of migrants nonetheless come from neighbouring countries that were in the former Soviet Union. The vast majority of the foreign-born population come from Europe (70%), followed by Asia (14%), Africa (7%) and the Americas (4%) (Institute of Migration, 2002).

In 1999, the Finnish government passed the Act on the Integration of Immigrants and Reception of Asylum Seekers (493/1999). This law stipulates that each immigrant or refugee must participate in an individualised integration program that includes Finnish culture and language classes as well as vocational training in order to receive social welfare benefits. The individualised plan is negotiated with a counsellor at the migrant's local labour office. Failure to follow the plan can result in a reduced level of social benefits. However, as Pitkänen and Kouki point out, the notion of what integration actually means in Finnish society remains 'elusive', though it implies a conception of Finnish society as a coherent and singular cultural order (Pitkänen and Kouki 2002, p. 107).

The view of integration as the absorption of diverse cultures into a mainstream 'objective' medical culture tends to dominate Finnish health and social care service provision. The significance of culture and vulnerability factors specific to the migration experience in the social and health care encounter is often unappreciated by caregivers. Cultural competence is not a core requirement in the skills curricula of most social work, nursing or medical schools. There are few migrant social workers or health care providers working in the field. One migrant living with HIV told of being referred to a psychologist for depression only to realise that the professional's proficiency in English was insufficient to communicate properly. Such experiences tend to instil a sense of futility in migrants when considering seeking help from Finnish social and health care agencies.

Immigration has been an explosive political issue in some of the Nordic countries, though not in Finland. Further, the issue of migrants and HIV has not been prominent in Finnish discourse on immigration and integration. This is partly because public health officials and policy makers do not want to stigmatise migrants by emphasising an association between immigration and HIV. Nor have migrant communities been active in promoting AIDS awareness, perhaps because other practical matters (housing, residence permits, discrimination, education) are far more pressing issues in their everyday lives. Migrants living with

HIV remain largely invisible because they do not figure in projects, information campaigns or policies. Interestingly, the new national AIDS strategy perpetuates the invisibility of migrants by not addressing migrant issues. While the strategy delineates preventive targets for injecting drug users, prisoners, homosexuals and heterosexuals, it does not explicitly mention the needs of migrants. This is a curious absence when considering the high percentage of migrants living with HIV relative to the migrant population in Finland.

There is very little qualitative or quantitative research on the needs of migrants and much of the information remains speculative or anecdotal. As an example, several of the Finnish interviewees for this report felt that migrants did not use HIV services because they feared that other people from their community would learn of their positive HIV-status. However, neither migrant informant mentioned any fear of stigma from their own communities as having an influence on using HIV services. Rather, they mentioned the lack of information as the most significant barrier to seeking help.

In interviews, migrant informants underlined the impact of social isolation in Finnish society on their sense of well-being. Both informants stated that it was difficult to make friends in Finnish society. Additionally, being unable to read Finnish and lacking information on migration and HIV issues in their own languages, the migrant interviewees both said that they had struggled with depression. They said they were stressed by fears of losing their jobs if their HIV status would be discovered. Indeed, few Finnish people are public with their HIV status precisely due to such fears. Migrants seem to lack a social network and tacit knowledge about social and health care services in Finland that might enable them to seek help and utilise available resources.

The issue of HIV and migrants has the potential to become more prominent in Finland because at the time of writing this report, a case has emerged of a migrant living with HIV who has been accused of deliberately spreading HIV. How this case is handled in the mass media, law courts and streets will have a great impact on public perceptions of migrants living with HIV.

5. Recommendations for developing policy and practice

5.1 Need for the development of linguistically and culturally appropriate information directed specifically to meet the needs of migrants

The two migrants interviewed for this report stressed the difficulty of obtaining information on basic living issues such as social entitlements, immigration matters, and health and labour rights. Many of these issues are specifically related to the status of being a foreigner in Finnish society. The lack of basic knowledge of the availability of services in general has a direct influence on the ability to access services specifically related to HIV. Furthermore, the paucity of culturally and linguistically appropriate information developed by migrants for their own communities certainly has an impact on the level of knowledge about HIV among migrants in Finland as well as on help-seeking behaviour. The development of culturally and linguistically appropriate information should be a priority in HIV work in Finland. Both migrant interviewees also felt that there needed to be a liaison or social worker specialised in migrant issues related to HIV who could counsel and advise migrants.

5.2 Need for the development of comprehensive social care for migrants living with HIV

Finland is geographically a large country. People living with HIV who live far from metropolitan centres sometimes experience a higher level of social isolation due to the lack of local counselling centres. Migrants, however, tend to experience higher levels of social isolation in Finnish society in general due to the lack of a social network. The migrant interviewees emphasised the important role of the specialised health care personnel in managing their illness. Aurora Hospital in Helsinki was particularly singled out as a centre of excellence. Migrants found nurses to be the most significant source of information and care. However, there is a need to develop comprehensive social care to enhance the possibilities of migrants living with HIV to continue working, cope with social stressors and manage immigration-related matters.

5.3 Need for a meeting space for migrants living with HIV/AIDS

One of the migrants interviewed spoke at great length about the need for a space for migrants themselves to meet. He was very positive about the facilities and help provided by the Finnish AIDS Council and Body Positive, but felt that there should be a space just for migrants to meet and discuss issues that are specific to migrants. The development of a project which would empower migrants living with HIV to coordinate and facilitate counselling and discussion sessions would be an important step towards developing social network support and disseminating information about services in migrant communities.

5.4 More research is needed

The needs of migrants living with HIV have not been charted from a migrant perspective. Research on the information and service needs of migrants living with HIV should be the essential starting point of HIV policy and good practice development. It is difficult to imagine how these needs can be adequately addressed when there is a lack of information about the daily reality of migrants living with HIV and the challenges they face. Well-designed research is an efficient way of using resources because it indicates the most effective way to inform and support migrants living with HIV and prevent HIV in migrant communities.

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[12] This information was given by Bengt Lindblom, director of the Finnish AIDS Council, in an email message.

[13] The report, Welfare Research into Marginal Communities in Finland: Insider Perspectives on Health and Social Care, will be available from the University of Tampere, Department of Social Policy and Social Work as well as the Finnish Ministry of Social Affairs and Health.

6. References

Edubio, A. & Sabanadesan, R. (2001). African Communities in Northern Europe and HIV/AIDS. Report of Two Qualitative Studies in Germany and Finland on the Perception of the AIDS Epidemic in Selected African Minorities. Woerden: European Project AIDS & Mobility (NIGZ) & Tampere: University of Tampere, Department of Social Work and Social Policy.

Finnish Directorate of Immigration (2002). www.uvi.fi (accessed December 12, 2002).

Finnish national AIDS strategy (2002). www.stm.fi/suomi/eho/julkaisut/tyoryhmamuistio02_1/trm02_1.pdf (accessed December 6, 2002).

Helsingin Sanomat (October 29, 2002). Organised prostitution leagues amicably divide Finland into zones. www.helsinki-hs.net/news.asp?id=20021029IE17 (accessed December 13, 2002).

Institute of Migration (2002). Statistics on immigration (1973-2001). www.utu.fi/erill/instmigr/eng/e_15.htm (accessed December 12, 2002).

Kleinman, A. (1988). The Illness Narratives: Suffering, Healing & the Human Condition. New York: Basic Books.

National Public Health Institute (November 27, 2002). HIV/AIDS statistics. www.ktl.fi/ttr/hiv_aids.html (accessed December 7, 2002).

Pitkänen, P. & Kouki, S. (2002). Meeting foreign cultures: a survey of the attitudes of Finnish authorities towards immigrants and immigration. Journal of Ethnic and Migration Studies, 28, no. 1.

UNAIDS (2002) AIDS epidemic update: December 2002. www.unaids.org/worldaidsday/2002/press/update/epiupdate_en.pdf (accessed December 12, 2002).

7. Acknowledgements

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Greece

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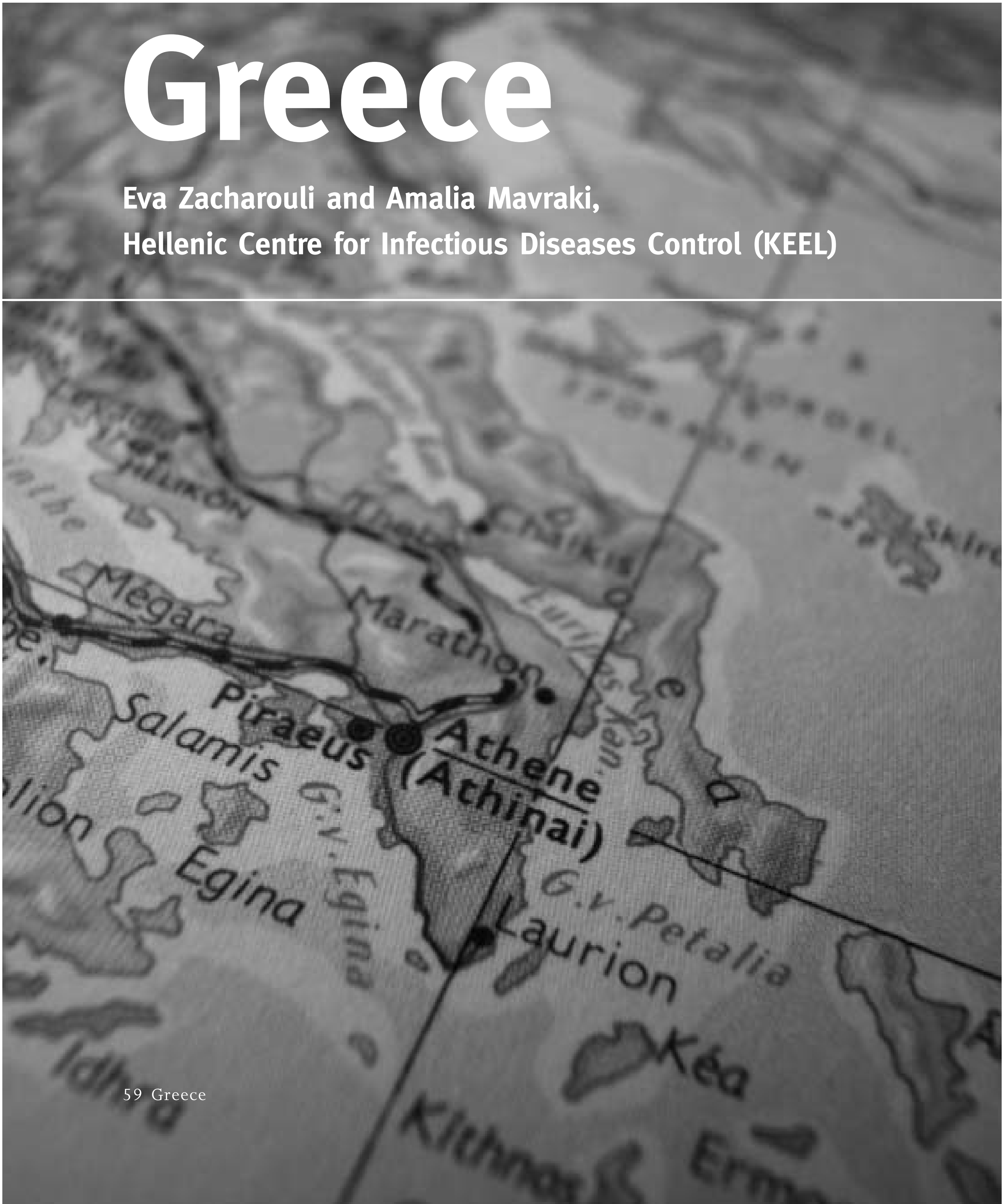

1. Introduction

Non-governmental organisations as well as the National Focal Point network have contributed significant experience, knowledge and ideas to this report. With the members of the national network we formed a working group to edit the final report.

The growing scope of migratory movements all over the world raises specific health problems in both sending and receiving countries. Migrants are particularly vulnerable to health issues. Due to their vulnerable situation and to cultural obstacles in host countries, they appear to be more exposed than the rest of the population. Given the inevitable interdependence between the health of migrants and their host countries' populations, this issue is of general concern and should be acknowledged as being highly important. The right to health associated with access to health care is one of the basic universal human rights and should be applied equally to all people including migrants, refugees and displaced persons.

The main reason why undocumented migrants do not contact health services is these people's fear of deportation. This creates enormous health risks both to undocumented migrants and people they encounter, because of the possibility of transmitting various untreated diseases. Treatment should thus be provided both for humanitarian reasons and to protect public health. It is particularly difficult for government agencies to address infectious diseases when they affect undocumented migrants. However, a number of NGOs have shown that they can readily access and work effectively with people without legal status in the countries in which they are living.

In many European countries there are migrants who fall outside the scope of existing health care and social services. In general, migrants are not provided with health services that are socially and culturally adjusted to their needs. Greece is among the very few countries that have developed comprehensive health policies concerning migrants.

2. The Hellenic Centre for Infectious Diseases Control (KEEL)

2.1 Overview

The Hellenic Centre for Infectious Diseases Control (KEEL) was established in Athens in 1992. Until July of 2000 it was called the Hellenic Centre for the Control of AIDS and STDs (KEEL); the name change resulted from the Centre's decision to broaden its activities to other communicable diseases besides HIV/AIDS. KEEL falls under the authority of the Ministry of Health and Welfare. The Centre monitors, coordinates and supports activities for the prevention and treatment of communicable diseases, primarily HIV/AIDS. It has been the National Focal Point for the European Project AIDS & Mobility since 1997.

KEEL has been successful at achieving most of the goals it has set by pursuing the following activities:

Surveillance, by means of collecting epidemiological data from individual cases and/or aggregated reporting forms for the diseases notified to the Centre
Prevention, by means of disseminating information at a national level to raise public awareness
Care (primary, secondary and tertiary), by means of therapeutic treatment, training programmes for health professionals, home care, hospice services and research programmes
Psychosocial support and legal counsel, by means of solving the varying problems arising from social, legal and ethical issues related to communicable diseases

International relations, by means of creating a direct network and cooperating with similar organisations worldwide
Training, by means of informing target groups about infectious diseases and educating personnel

2.2 The Mobile Populations Office

The Mobile Populations Office is KEEL's most important branch. In order to meet the needs of mobile populations, the office has designed the so-called 'Intervention in Emergency Settings'. This intervention is undertaken by the outreach work team of the Office, which includes specialised medical doctors, an interpreter who also acts as an intercultural mediator, and a psychologist. The outreach work team has intervened in many arrivals of undocumented migrants throughout the country. It drives out to locations where they enter the country to perform medical checks on them.

Since April 2002, KEEL has carried out the pilot programme 'Advocacy, Promotion of Health and Socialisation of Greek Gypsies'. KEEL has employed a team of medical doctors and administrative employees who cooperate closely with the Ministry of Health and Welfare. Interventions have been made to the residences of gypsies in Northern Greece, Western Peloponnisos and the prefecture of Viotia. Visits are paid three times per week from 08:00-17:00. These actions involve the participation of KEEL's mobile medical units (staffed by full-time personnel as well as volunteers) and local health services and authorities (prefectures, municipalities, the Greek Orthodox Church).

2.3 The AIDS Helpline and the Counselling Centre

Surprisingly, of the great number of calls received daily by KEEL's AIDS Helpline, only a limited number are made by individuals belonging to mobile populations. This is probably because many migrants find it hard to communicate by telephone with someone they don't share the same first language and the same cultural and religious background with.

Migrants make up only 3% of the total number of people who make use of KEEL's Counselling Centre. Most migrants who make use of the Counselling Centre are from African countries, a small number being from the Balkans or Asia. They may be divided into two groups. There are migrants who make use of the Counselling Centre for pre-testing counselling. Despite cultural differences, the characteristics of this group do not differ from those of the general population making use of this service. Then there are seropositive individuals. In contrast to the first group, this group is different from the general population in terms of needs, requests and referrals. More specifically, the majority of seropositive referrals are referred to the Counselling Centre by medical structures and governmental and/or non-governmental organisations. They ask for assistance in managing multiple cases on basic health issues.

Migrants making use of the Counselling Centre approach the service with hesitancy and distrust due to the extreme, sometimes traumatic experiences they had in their countries of origin. Also, they are often staying in Greece illegally and are afraid to get in touch with an organisation falling under the authority of a ministry. They insist on direct management of practical issues concerning health and living. The help they are given often seems to be unsatisfactory to them. It is hard for staff of the Counselling Centre to develop a trusting relationship with individuals from mobile populations due to linguistic and cultural differences and the lack of systematic cooperation with cultural mediators. Further, there is insufficient networking between the Counselling Centre and other services that migrants make use of for the same issues.

The Counselling Centre believes that cultural diversity could be incorporated into prevention campaigns and psychosocial interventions. Access to health/medical services for specific population groups (undocumented migrants, sex workers et cetera) could be facilitated. Interdisciplinary procedures could be regularised. The significant and often diverse characteristics and needs of the different subgroups that constitute the mobile populations could be recorded systematically.

In order to realise the abovementioned proposals, psychological services must be incorporated within an organised and efficiently coordinated framework of action. Such a framework, focused on the needs and demands of the mobile populations, will define the goals of each action, the procedure to be followed and the role of each participant.

The European Project AIDS & Mobility has created the opportunity for the Counselling Centre to exchange information and experiences and has initiated the coordination of a large number of services addressing mobile population issues.

2.4 Other activities of KEEL

In February 2002, KEEL was invited to participate in the 1st Meeting of the HIV/AIDS Advisory Group at the United Nations High Commissioner for Refugees (UNHCR) headquarters in Geneva. The primary roles of the Group, which is composed of United Nations agencies and NGOs from several countries, are advocacy, the promotion of partnerships and complementary collaboration, the provision of technical and financial support in terms of an agreed plan of action to be developed to meet the HIV/AIDS prevention and care needs of refugees, and the identification of potential support to refugees from already existing bilateral or multilateral aid. The Group will meet in regular time intervals.

KEEL has an NGO Committee which meets once a month to improve networking among Greek NGOs on the issue of migration and HIV/AIDS and other infectious diseases.

3. Epidemiology

Distribution of AIDS cases by country or region of origin reported in Greece by December 31, 2002

Origin	Number	%
Greece	2,145	90.97
Western Europe	53	2.25
Central Europe	18	0.76
Eastern Europe	7	0.30
Sub-Saharan Africa	55	2.33
South and South-East Asia	8	0.34
North Africa and the Middle East	9	0.38
North America	16	0.68
Caribbean	1	0.04
Latin America	11	0.47
Foreigner, region unknown	30	1.27
Unknown	5	0.21
Total	2,358	100

The cumulative number of HIV positive persons, including AIDS cases, reported in Greece up to June 30, 2002 is 6,088. Of these, 4,925 (80.9%) are men. The gender was not reported for some cases. Most of the data were collected retrospectively. From January to June 2002, 35 new AIDS cases were reported in Greece. Among them, 33 (94.3%) are males and 2 (5.7%) are females.

About 10-15% of HIV positive persons reported in Greece are non-Greek citizens. Taking into consideration that 10% of people living in Greece are non-Greeks, we can estimate that the prevalence of HIV is slightly higher among immigrants than among native people. Most HIV positive immigrants are from sub-Saharan Africa and Eastern Europe. Immigrants have access to services and facilities as soon as they are diagnosed. Even immigrants who reside in Greece illegally have access to services. They are not reported to the authorities. Practically, there is no other way to treat HIV positive immigrants.

4. Migrants and HIV testing

The Greek government had adopted fundamental principles for the protection of human rights and civil liberties (Ministry of Health Circular, Y1/3239/4.7.2000, Articles 49-56 & KEEL, C. Politis, 1995, 1996). These principles are a type of legislation. According to the principles:

Article 49. Examination for the detection of AIDS antibodies is not allowed as a condition for exiting a country regardless of the destination.
Article 50. Examination for the detection of AIDS antibodies is not allowed as a condition for entering a country regardless of the country of origin.
Article 51. Examination for the detection of AIDS antibodies is not allowed as a condition for providing residence permits, regardless of the country of origin.
Article 52. Deportation, unfavourable treatment or discrimination towards persons with AIDS is not allowed, regardless of the country of origin.
Article 53. Examination for the detection of AIDS antibodies is not allowed as a condition for equal treatment of foreign nationals or asylum seekers or refugees, the awarding of scholarship grants, admission to a university, etc, regardless of the country of origin.
Article 54. The diagnosis of an HIV positive person cannot negate the favourable legal stipulations of the previous article.
Article 55. Examination for the detection of AIDS antibodies is not allowed for asylum seekers and refugees.
Article 56. Asylum cannot be denied as a result of persons being diagnosed HIV positive.

According to Law 2955/2001, Official Gazette of the Greek Republic, A, 256/2.11.2001, Article 11E, ‘Free of charge nursing and medico-pharmaceutical care is offered to foreign economic migrants and refugees infected with HIV/AIDS and/or other infectious diseases, in case the former require appropriate health and pharmaceutical care which cannot be provided to them in their country of origin or in the country they may return to. While they remain in need of health care, foreign economic migrants and refugees are entitled to temporary residence and work status.’

5. Privacy and confidentiality

Data on HIV and AIDS cases are collected and managed by the HIV Infection Office of KEEL. Data collection is anonymous, confidential and required by law (A1/6122/19.9.1986). Due to this unique surveillance system for monitoring HIV infection, all insurance providers offer antiretroviral therapy to patients using a personal identifier (record). In this way, no personal information about the patient is revealed to the insurance agent.

6. European projects

6.1 The Mediterranean Network Listening to Women

KEEL is involved in the European project 'The Mediterranean Network Listening to Women'. Interdisciplinary groups were formed on the issue 'Mobile Population – Women and HIV Infection', aiming to record the problems encountered by professionals, exchange experience and form proposals. Other participating organisations are the Sida Info Service (France; project coordinator), FASE (Spain) and ABRACO (Portugal).

6.2 European Network Male Prostitution

The coordinator of the European Network Male Prostitution is the Netherlands Institute AMOC/DHV. KEEL has cooperated with the Network since 1999. In 2000, KEEL was selected as regional coordinator of the Southern European Group. KEEL took part in the following activities of the network:

- Editing a travel guide for (mobile) male sex workers listing health services offered in the EU countries (including Greece)
- Writing an edition of a leaflet regarding male prostitution status and existing social politics in EU countries (including Greece)
- Participating in several conferences, seminars and meetings regarding male prostitution issues
- Organising a training for agencies considering, planning or implementing services for male sex workers, which took place in Athens with the participation of six European countries in cooperation with the European Project AIDS & Mobility and the Dutch Schorer Stichting
- Doing research into the needs of male sex workers in Greece, Spain, France, Portugal and Italy
- Editing three newsletters with articles addressed to male sex workers
- Participating in an article entitled 'Models of Good Practices for Service Providers'

6.3 Immigrants from European Southern and Eastern Borders: HIV/Health Risks, Social Condition and Service Provision Re-orientation

This project started in September 2002 and is led by the Regional Centre for Health Promotion, Department of Health, Veneto Region, Italy. The project studies the socio-cultural and legal aspects of the situation of immigrants in the partner countries. Health and social services need to understand these aspects in order to understand the health needs of immigrants, in particular with a view to improving HIV/STD prevention. Data is to be collected and analysed at a national/sub-national level. The project already conducts qualitative research in the form of interviews and case histories. The research will comprise a combination of quantitative and qualitative techniques applied to both immigrants and services.

7. Cooperation of KEEL with NGOs and other organisations: their activities and stands

7.1 Médecins Sans Frontières (Doctors Without Borders)

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www.athens.msf.org

Médecins Sans Frontières – Greece (MSF-Gr) was founded in 1990. MSF-Gr is currently implementing development projects in Malawi, Zambia, Ethiopia, Palestine, Armenia, Serbia and Greece. Through the creation of Athens and Thessalonica polyclinics, MSF-Gr aims to provide free primary health care and referral of patients to the National Health Care System and to protect patients from exploitation. MSF-Gr has been operating a Legal Information Centre in Athens and Thessalonica since 1998, informing immigrants, refugees and asylum seekers about the legislation and the procedures they have to follow to receive legal status. MSF-Gr aims to create lobbying procedures to push the government to reinforce and in some cases change the legislation regarding these groups. Additionally, through the Public Health projects some interventions have been made to assess the living conditions of immigrants and to disseminate information about basic health problems (such as personal hygiene, dental hygiene, STDs, hepatitis, drug abuse, family planning, HIV/AIDS). MSF-Gr has distributed leaflets in various languages (English, French, Kurdish, Farsi, Urdu, Albanian, Bulgarian, Russian, Rumanian, Polish), has given some lectures in migrant communities (meeting points, churches, schools, entertainment venues et cetera) and has carried out informational activities (for instance on National AIDS day).

Regarding immigrants, refugees and asylum seekers and health care, Greece has taken a step in the right direction, but a lot of issues remain to be clarified. Some examples will follow.

An important net of protection of medically vulnerable aliens is offered by the new decree of article 44, paragraph 6 of law 2910/2001, which foresees that in cases of aliens under administrative expulsion the General Secretary of the District 'may' after application or even on his own initiative delay the expulsion 'when it is deemed necessary due to humanitarian reasons, or a crisis situation or public interest, like under exceptional reasons that regard the life or the health of the alien or of his family'. This decree is alarmingly incomplete, since it provides absolutely no clarification regarding the time and the qualitative frame of the temporary protection.

The decree of article 54, paragraph 2 of law 2910/2001, which obliged the managers of clinics and health facilities to inform the police or the immigration authority about the arrival and departure of the people they serve, was especially problematic. MSF Gr openly expressed its opposition to the decree, since it violates the fundamental principle of not distinguishing between people on the basis of national origin. This principle has been adopted de facto by the international human rights legislation. Moreover, the same decree was in violation of the constitution, as confirmed by the Authority of Personal Fact Data Protection in consultatory response.

Asylum seekers who have proof of asylum application (the 'pink card') and those who are recognised as refugees have a right to medical care free of charge, including antiretroviral treatment. Nevertheless, there is a large number of asylum seekers in Greece who do not have a pink card and for whom the Greek state does not provide free medical care.

There's also a legislative gap as regards financial support to seropositive aliens, their housing, (the existing facilities are not adequate) and their integration into the labour market through special projects.

Greece lacks an organised system of medical reception of immigrants and refugees. Depending on the case, their health care is taken up either by the facilities of the corresponding District Health System (PESY), by the Centre of Control of Special Infections (KEEL) or by NGOs. Since 2000, MSF-Gr has intervened in Mantoudi of Evia, on Zakynthos island and in Almyropotamos of Evia, by taking up the sanitation of the area, the construction of sanitary infrastructure and the medical screening of the population.

7.2 Hellenic Society for the Collective Support against AIDS

PO Box 10614, 54110 Thessalonica, tel. & fax +310243373, www.esyvsaids.gr

The Hellenic Society for the Collective Support against AIDS provides psychological support and information about HIV transmission to people coming from Africa, Central and Eastern Europe and Albania. The Society acts as an intermediate between these people and the AIDS Unit of AXEPA (State) Hospital to ensure that they are given appropriate treatment in case of HIV infection. The Society spreads leaflets about HIV/AIDS and provides financial support whenever possible.

The Society believes there should be a greater effort to secure equal rights for mobile populations regarding testing issues. Migrants entering Greece should no longer be tested for HIV without being informed.

7.3 Act Up Greece

Tel. & fax +2103224472

Act Up Greece cooperates closely with the Asylum Service (GADA) to facilitate the process of providing residence permits and access to public health services for HIV positive migrants. Also, Act Up Greece has a vaccination programme for tuberculosis and hepatitis B, available to both (infected) refugees and GADA personnel (who come in touch with infected migrants daily).

7.4 Centre for Inspirational Living

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The Centre for Inspirational Living, a non-profit NGO founded in November 1991, offers support and services for people living with HIV/AIDS. The centre works under strict confidentiality with volunteers who attend training seminars twice a year. The Centre favours the establishment of an organisation and services network that will cover a wide range of needs by undertaking – each organisation in its own field – specific action, such as provision of health services, legal services, social rehabilitation, psychological support and housing. The Centre further proposes informing and sensitising law enforcement about the needs and characteristics of mobile populations. This will be done by a multi-scientific group of doctors, psychologists, social workers, lawyers et cetera.

The Centre proposes the foundation of street work groups comprised of doctors, psychologists, social workers and lawyers who will approach and inform mobile populations in their own districts. The Centre is in favour of political asylum on humanitarian grounds for asylum seekers living with HIV, and of enlargement of the Piraeus hospital or extra housing. Due to the increase of mobile populations with serious health problems, the hospital's needs have multiplied.

Over the years, KEEL has funded many of the Centre's actions, such as the summer information campaigns, the participation in conventions and the employment of a social anthropologist. The Centre knows it can always apply to KEEL for financial and legal support for HIV positive individuals who have been released from prison, since communication with KEEL's Office for Psychosocial Support is perfect.

7.5 Synthesis

11, Kanari Street, 10671, Athens, tel. & fax +2108619348, www.hiv.gr

Synthesis is a grassroots, community-based association committed to action to help end the AIDS crisis. Thanks to the joint efforts of KEEL and NGOs, the situation of HIV positive people in Greece is remarkably good. Access to care and medication is guaranteed quickly and effectively for everyone who is diagnosed, whilst confidentiality is safeguarded. There is room for improvement, however, particularly in terms of supporting HIV positive people with information packs.

In contrast with this, Greece is seriously lagging behind in terms of prevention. Given the absence of sexual health education in Greece and an almost complete lack of governmental HIV/AIDS awareness campaigns, Synthesis has focused on safer sex and sexual health campaigns, with particular emphasis on men who have sex with men.

Another chief focus of Synthesis is supporting HIV positive people with information on medication, side-effects, adherence issues, et cetera.

7.6 Médecins du Monde (MDM)

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mdm@alas.net

MDM has worked extensively with migrants and asylum seekers arriving massively in Greece over the last years. Although one would expect that the intensification of the phenomenon would have resulted in a comprehensive national plan of action, securing quality facilities, quality services and access to basic rights, this has not yet been the case. Experience form the field shows that so far, control of sexually transmitted and other communicable diseases is rather occasional.

Although there exist a number of public and non-governmental services dealing with these controls, there is often an overlap due to a lack of coordination and the scarcity of follow-up procedures. Vaccination, treatment, epidemiological surveys and statistics are also segmental. The situation has deteriorated when taking into account conditions and services provided in ad hoc established reception centres in North Greece (Evros) and the islands. The picture does not differ much in the capital and other urban centres. Medical checks for legal migrants consist of a simple clinical check and a chest X-ray. There is no systematic provision for the control of sexually transmitted and communicable diseases. In addition, diagnosis of STDs relies mainly on blood tests rather than saliva tests. The latter is a more suitable and cost-effective method for the diagnosis of STDs when it comes to large population samples. There is no difference in procedures followed when it comes to other socially excluded populations with inhibited access to the National Health System, such as the Roma tent-dwellers, victims of trafficking, drug addicts, the homeless and the poor. Among MDM proposals are the following:

- Improved services and a right to health for all aliens present in the Greek territory, irrespective of their legal status
- Common practices for producing statistics for all partners involved
- An improved communication/information strategy involving all protagonists, to reach as massively as possible the general audience and high-risk population categories

7.7 Greek Helsinki Monitor

PO Box 60820, GR 15304, Glyka Nera, tel. +2103472259, fax +2106018760,
www.greekhelsinki.gr

The Greek Helsinki Monitor, member of the International Helsinki Federation, is an NGO dealing with human rights. Individuals from mobile populations such as refugees, immigrants, Roma people, and sex workers contact the Monitor asking for support and/or legal advocacy. The Monitor is active in the field of AIDS policy and is in close contact with KEEL.

7.8 UNHCR in Greece

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fax +2106726417, www.unhcr.gr

For the period 2002-2003, the two implementing partners under UNHCR – the Social Work Foundation and the Greek Council for Refugees – report that there were a total of seven cases of HIV positive refugees. Six of them were granted humanitarian status and one has Convention refugee status. The agencies had intervened in these circumstances in order to speed up the procedure of obtaining asylum seeker status (pink card) and therefore access to health care.

Due to their humanitarian status, these refugees cannot apply for a welfare benefit from the Welfare Department of the Athens Prefecture. Also, it is difficult for them to seek formal employment since, because of their illness, they are not eligible for a work permit from the Athens Labour Office of the Athens Prefecture. Due to the acute vulnerability of such cases they had been supported financially by the two mentioned UNHCR implementing partners in order to cover their immediate needs. These cases are responding well to treatment.

8. Recommendations

Successful prevention and care programmes for migrant populations are those developed with and supported by migrant communities, involving substantial community mobilisation. These programmes should ensure access to care and be integrated with other local and national infectious diseases programmes.

Countries receiving migrants need to adopt health policies and practices that will remove economic, administrative and linguistic barriers to migrants' access to health. Such policies and practices should include all migrant groups, among them the most vulnerable ones such as undocumented migrants.

In most countries, migrant and mobile populations tend to have less access to reproductive health and STD services than non-mobile nationals. Planning and implementing appropriate programmes for migrant and mobile populations should therefore receive urgent attention in almost all countries.

Further recommendations by KEEL:

To examine national laws and policies regarding the health of migrants and refugees with a view to developing a comprehensive harmonised approach in all member states of the European Commission and member countries of the AIDS & Mobility Network.

To organise exchanges of experience and information on the subject between the member states, with the participation of the appropriate government agencies and NGOs, including migrants' and refugees' associations

To create new arrival centres and upgrade the existing ones according to regulations imposed by the European commission

To instruct the appropriate KEEL committee to develop, in consultation with the relevant governmental and non-governmental organisations, guidelines to be addressed to the member states on the health conditions of migrants and refugees in Europe

To foster the standardisation of health screening to migrants
To review policies for the protection of migrants in the face of occupational risks

To set up a European system (among the National Focal Points of the European Project AIDS & Mobility) for the systematic collection and sharing of health care statistics concerning migrants (a database)

Moreover, National Focal Points should be encouraged:

- To develop specific information programmes for migrants covering their rights in the field of health care
- To help migrants associations promote health educationm by financing the provision of educational documentation, through the training of staff recruited from migrant communities
- To encourage migrants to get actively involved in both national and local health care and disease prevention programmes
- To examine more closely the problem of cultural obstacles complicating access to health care, including the difficulties of translation/interpretation
- To establish programmes to train health care providers to be more sensitive to the needs and backgrounds of migrants

'The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social conditions.' (World Health Organization Statute, 1946)

9 References

AIDS & Mobility (1998). AIDS & STDs and Migrants, Ethnic Minorities and Other Mobile Groups. The State of Affairs in Europe.

AIDS & Mobility (2002). HIV/AIDS Care & Support for Migrant and Ethnic Minority Communities in Europe.

European AIDS Treatment Group (2000). AIDS and Public Health Policy. European Parliament meeting report.

European Women's Health Network (2000). Country Report Greece.

Hellenic Centre for Infectious Diseases Control (1996). AIDS: Fundamental Principles for the Protection of Human Rights and Civil Liberties. Athens: Ministry of Health.

Hellenic Centre for Infectious Diseases Control (2002). HIV/AIDS – Public Health & Human Rights.

Hellenic Centre for Infectious Diseases Control (2002). HIV/AIDS Surveillance in Greece. Half-yearly edition. Data reported up to June 30.

Human Rights Watch (2001 & 2002). World Report: Greece. www.hrw.org.

UNAIDS (2000). Migrant Populations & HIV/AIDS.

UNAIDS (2001). Migrants' Right to Health.

UNAIDS (2001). Population Mobility & AIDS.

UNAIDS (2002). UN Entrenches Human Rights Principles in AIDS Response. Press release. www.unaids.org.

World Health Organization (2003). Health and Human Rights of Migrants. www.who.int.

Politis, H.T. (2003). Blood Security & Public Health Protection. Athens.

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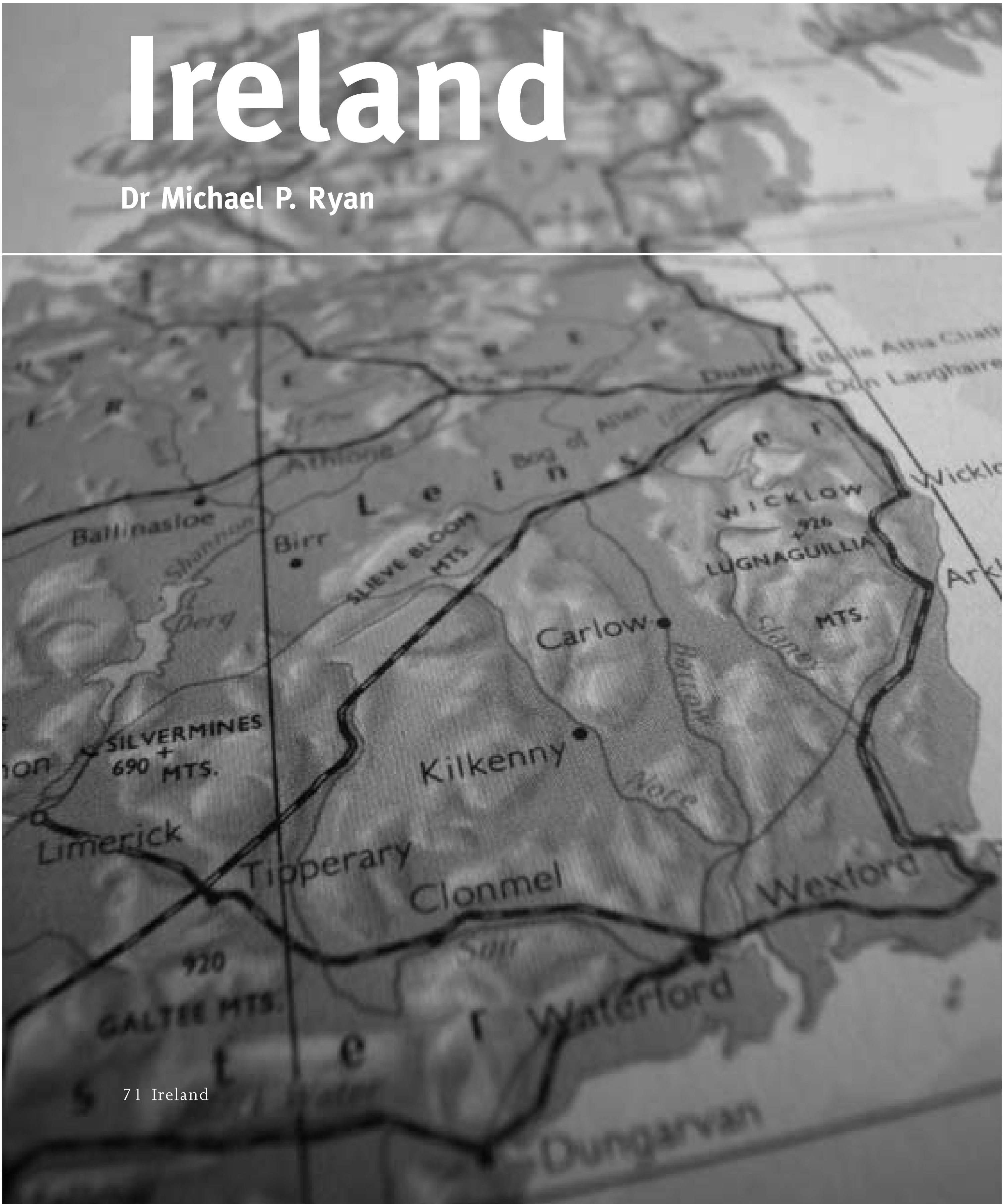


1. Introduction

Ireland has been part of the AIDS & Mobility network since 1997. The author of this report took over the task of coordinating the network from Dr Patrick O' Sullivan and is now the Irish National Focal Point. This report has been prepared using data provided by the Irish National Disease Surveillance Centre, the AIDS & Mobility network of organisations providing services to migrants in Ireland, and data from media sources.

2. Access to treatment

Compared to many other countries Ireland does not have a severe AIDS problem. This is fortunate, because many years of underfunding have led to the term 'health care crisis' being frequently used in news headlines, and an inadequately funded health care system would have difficulty coping with the extra demands required to provide adequate therapy for large numbers of individuals living with AIDS. The system is having difficulty coping with providing an acceptable level of care for the general population. There are long hospital waiting lists for basic procedures. Despite these problems, the level of access to health care services provided to migrants is excellent, with culturally appropriate formats provided, counselling, voluntary HIV testing, outreach programs, accommodation, financial help and peer education programs. The availability of these services is largely due to the contributions of the various members of the AIDS & Mobility network which was put together and coordinated by Dr Patrick O'Sullivan, the National Focal Point over the past five years. The members of the AIDS and Mobility network outside Dublin deserve special recognition for their response to the sudden influx of migrants following implementation of the Dispersal Policy.

Not all of the following services are available at all centres. In general, however, the level of services is excellent.

1. Health care information packs have been translated into culturally appropriate formats in ten different languages.
2. Translators have been used where needed.
3. Outreach workers have been used in an effort to disseminate health care information.
4. Free condoms have been distributed.
5. Counselling services have been made available for migrants.
6. Health care services are available for those who require or wish to access them.
7. All centres, especially those working in dispersal areas, report an increasing demand for their services. Some agencies deal with this by setting up education programmes for migrants in order to empower them to help themselves.

2.1 Other services

1. Some groups provide such services as hospital, home and prison visits.
2. Drop-in centres
3. Legal advice
4. Financial assistance
5. Peer training
6. Cultural integration
7. Voluntary HIV screening programmes
8. Advice on HIV/AIDS support groups
9. Respite weekends are provided by at least one refugee centre
10. Medications are available for HIV/AIDS patients under the government-sponsored health care scheme.
11. Gender and sexual preference specific support groups

3. Migration patterns in 2002

With the expansion of the European Community, there is an increase in migrant traffic, some legal, some illegal. This trend is worrying to public health care providers. Countries with a colonial history in Africa and South America are particularly affected by this increase in legal and illegal migrant traffic, as citizens of present and former colonies turn to the colonising country for help in obtaining treatment for HIV/AIDS. Some of the receiving countries have declared that they are not prepared to become 'hospitals to the world'. For some countries, 'therapeutic migration' has become one of the push/pull factors in migration patterns. A therapeutic migrant is an HIV/AIDS migrant who relocates in order to gain access to affordable AIDS therapy. Since at present AIDS can not be cured, only controlled, therapy must continue for an indefinite period. This will be expensive for the host countries.

Prior to 1997 Ireland did not attract many migrants. In fact, the trend was for large numbers of Irish citizens to leave the country because of its poor economy. Ireland enjoyed a brief period of prosperity during the years of the 'Celtic Tiger'; Ireland's significant economic growth in 1998-2001. An expansion of the European Union coincided with a significant increase in migrant workers and asylum seekers from more disadvantaged countries. Initially this was a novelty for Ireland, and the migrants were provided with accommodation, food, laundry, pocket money, as well as all other social benefits.

The increasing numbers of immigrants settling in Dublin, approximately 1,000 a month, caused a problem for an already competitive housing market. This was addressed by the introduction of a Dispersal Policy which sought to disperse immigrants around the country. Many caregivers serving the designated dispersal locations were presented with challenges they were ill-equipped to deal with, as most of the specialist units dealing with HIV were in Dublin. However, through the work of many dedicated individuals and agencies and the coordinating efforts of the former National Focal Point, Dr Patrick O'Sullivan, this situation has been largely remedied by improving the range of services available to migrants in various centres outside Dublin.

4. HIV and AIDS in Ireland in 2001

In 2001 there were 299 newly diagnosed HIV cases in Ireland, compared to 290 newly diagnosed cases in 2000. There was a 36% increase in the heterosexual group. Present strategies for injecting drug users and men who have sex with men are proving to have the desired effect, namely a reduction or stabilization of HIV incidence. Among men who have sex with men there was no significant increase. Among injecting drug users there was a 54% decrease largely due to an effective government programme combining methadone maintenance and HIV screening. The majority of new cases (59%) were among heterosexuals. Of the 82 new heterosexual cases, 74% were from sub-Saharan Africa. Seventy-four percent of cases from this region were women, and 15% were less than twenty years old. In 2001, 88 children were born to HIV positive mothers. Of these, only three children were HIV positive.

5. Changes in policy

The attitude towards asylum seekers found in certain sectors of the general public has changed. There have been media reports of incidents of verbal and physical assault directed against migrants, and one politician was censured for what were deemed to be racist remarks. Legislation has been enacted to impose penalties on those found guilty of verbal or physical attacks on migrants or any indigenous or visiting member of any minority group. This has resulted in a significant reduction of incidents of this type.

The government is involved in a thorough review of its policies. Asylum applicants from EU accession states and Romania, designated as 'safe', are to be fast tracked with the presumption that their claims as refugees fleeing persecution are manifestly unfounded. This would eliminate many of the claims clogging up the system, and would lead to applicants with a well-founded fear of persecution having their applications processed rapidly so they can live and work permanently in Ireland.

5.1 Changes in policy for pregnant asylum seekers

A new antenatal centre for pregnant asylum seekers has been set up in Dublin. There has been a report in the Irish Times in which government officials said that some 80% of women of childbearing age are visibly pregnant when they lodge their application for refugee status. This was because any child born in Ireland was given Irish citizenship and usually the parents were given residency status. Many non-EU nationals availed themselves of this legal method of getting residency status. Because of perceived abuses of this legal loophole, the government no longer grants residency status to parents of Irish-born babies. All cases are now considered on an individual basis. Many of these pregnant applicants come from high HIV prevalence areas, and risk transmission of HIV to the baby unless diagnosed in a timely manner. With early diagnosis and treatment the outcome is better for mother and child.

5.2 Changes in policy regarding illegal migrants

There is a marked increase in the government's efforts to locate and deport illegal immigrants. Because employers have exploited illegal immigrants, in some cases quite ruthlessly, new legislation will impose fines of € 250,000 or ten years in jail for employers of illegal immigrants.

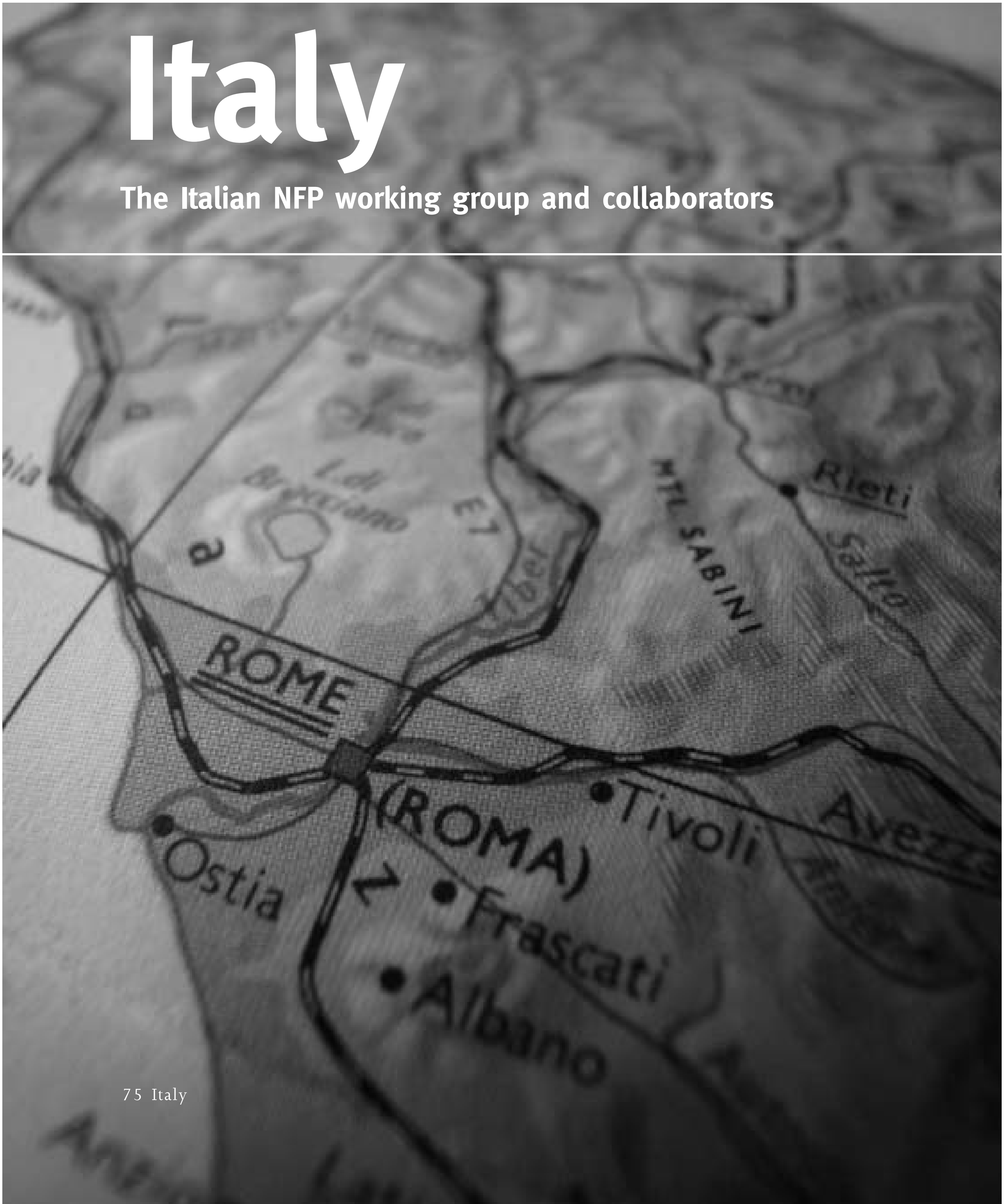
Fears of links between international terrorism and illegal migration have led to a general increase in worldwide security measures over the past few years. This has made life more difficult for many migrants. Many legal migrants recently got caught up in a government security operation aimed at arresting illegal migrants.

6. Recommendations

There have been significant changes in the demographics of new HIV cases in Ireland recently. Indications are that the Irish AIDS & Mobility network must now refocus its efforts towards the heterosexual and school age populations. The fact that the majority of new HIV cases were heterosexuals from sub-Saharan Africa suggest a re-focusing of our strategies is needed in order to address the medical requirements of this group. Since most of these cases were diagnosed as part of an antenatal screening programme, it is probable that there are many more cases of HIV positive individuals. Early diagnosis leads to earlier therapy and limitation of transmission to family and friends. The development of voluntary screening programmes for all those coming from high prevalence areas such as sub-Saharan Africa should be encouraged.

Italy

The Italian NFP working group and collaborators



1. Migration patterns

For some years the industrialised countries of the Mediterranean area have been affected by constant migratory flows of people who, driven by precarious living conditions in their countries of origin, embark on often risky journeys in the hope of obtaining conditions of greater well-being and freedom. Italy has changed from a country of emigration into a preferred migratory destination and has been forced to address the problems that arise from permanent, temporary and seasonal immigration.

According to the official data of the Ministry of Internal Affairs, the number of foreigners legally residing in Italy as of December 31, 2001 was 1,362,630 – equal to approximately 2.8% of the Italian population, while estimates of the presence of illegal or clandestine immigrants range from 15 to 30% of immigrants as a whole. The most numerous immigrant communities are those originally coming from: Morocco (158,000), Albania (144,000), Rumania (75,000), the Philippines (64,000), China (56,000) and Tunisia (46,000).

2. Epidemiological developments

This migratory phenomenon has given rise to a series of political, economic, social, sanitary and health problems. With regard to health care, although a gradual administrative decentralisation is taking place in this field, immigration will remain under state control. However, official data for evaluating the health of the immigrant population are not available since Italy does not yet have a national epidemiological observatory. The sources of information on the types and characteristics of diseases suffered by immigrants are therefore the case histories of public and voluntary structures that provide psychosocial health assistance to immigrants throughout the country.

Available data show that, generally speaking, immigrants are in good health at the time they leave their own countries but their health deteriorates during both the journey and their stay in Italy. The diseases most frequently suffered by immigrants in Italy are the non-infectious ones developed in the host country, typical of the hardship in which most immigrants are forced to live. The National AIDS Register of the Istituto Superiore di Sanità shows a significant increase in the proportion of cases of AIDS reported among immigrants: from 1.7% in 1993/94 to 8.9% in 2001/02. The majority of cases concerned persons from Africa, South America and Eastern Europe.

Although Law 40/98 regulates health care to foreigners residing in Italy, whether legally or illegally, it often happens that foreigners, especially illegal residents, do not make use of the services of the National Health System. Fear of contact with public structures and a lack of correct information about HIV/AIDS (particularly about the test) mean that immigrants are reluctant to undergo the clinical examinations aimed at timely diagnosis and adequate, well-monitored pharmacological treatments, with the result of late diagnosis. Indeed, for many immigrants there is only a small lapse of time between their first test for HIV antibodies and the diagnosis of AIDS, if the events are not actually simultaneous.

Therefore, steps must be taken to improve the quality of services of prevention, care and treatment for foreign populations and strategies need to be adopted for promoting a transcultural form of medicine, willing to recognise cultural diversity. An adequate, concrete response to the health needs of foreigners must necessarily entail an examination of their needs and an analysis of demand, plus a reorganisation of services based on the specific requirements of the target group, planning new strategies and approaches characterised by flexible services, technical and relational training of personnel, a multidisciplinary approach (teamwork) and an integrated collaboration between public services, NGOs and voluntary associations (network activities).

2.1 New diagnoses of HIV in the post-HAART era. Comparison of Italian and foreign populations

Many recent studies show that Black and Latino persons are more likely to receive late HIV diagnosis, late adequate treatment and late support. Recent advances in HIV treatment underscore the need to increase the early knowledge of HIV serostatus. In Italy, access to heath services, HIV testing and treatment are free of charge. Over the last few years, the number of immigrants attending the outpatient clinic for HIV/AIDS of the Istituto Nazionale per le Malattie Infettive L. Spallanzani in Rome, one of the largest centres for the diagnosis and treatment of HIV in Italy, was seen to grow. We set out to describe the epidemiological and clinical characteristics of persons newly diagnosed with HIV and to compare these characteristics for the Italian and foreign populations (persons from non-EU countries).

The study included all adults attending the outpatient clinic and diagnosed as HIV positive between January 1997 and December 2001. A total of 463 HIV positive persons – 358 Italians and 105 immigrants – were observed. Forty percent of the immigrants were Africans, 40% were Latinos from Central or South America and 20% were from Eastern Europe or North Africa. Over the years there has been an increase in the number of HIV diagnoses observed, while the proportion of immigrants among those diagnosed has also grown (from 8% in 1997 to 36% in 2001).

The immigrants were less likely to have had a previous negative HIV test result; they were more likely to test as a result of antenatal screening. Sixty-four percent of immigrants compared to 43% of Italians contracted HIV through heterosexual intercourse, while 2% compared to 10% reported intravenous drug use.

Our data show that, during the HAART (Highly Active Antiretroviral Therapy) era, immigrants accounted for an increasing proportion of the new diagnoses of HIV. There were significant differences in epidemiological characteristics between the populations studied. More than 40% of the persons with a new diagnosis of HIV had the disease in a relatively advanced stage. No differences emerged between immigrants and Italians with regard to the clinical stage. This can be explained by the fact that we did not consider the inpatients in this report, but only patients seeking HIV testing at an outpatient clinic: it is possible that they may have had greater access to appropriate services or a greater awareness of their status. Strategies to give foreigners the opportunities, information and motivation necessary for being tested must be improved.

3. Legislative policy: recent modifications and additions

On the subject of immigration, the political criteria set by the legislature in force have been characterised by the firm intention to stress legality within the democratic system. In pursuit of this objective, the government's programme has aimed at giving all foreigners residing in Italy a well-defined legal status by implementing legislative measures designed to legalise illicit work, to set clear-cut and severe rules as regards the expulsion of clandestine immigrants and foreigners guilty of serious crimes, to tie residence permits to the length of job contracts, to strengthen official administrative structures and to make administrative and criminal sanctions harsher. At the same time the parliament also passed legislative measures designed to:

- favour all humanitarian organisations engaged in the promotion of social development activities;
- make it possible to facilitate and revise bilateral cooperation and aid programmes for non-humanitarian initiatives in favour of non-EU member countries that collaborate in the prevention of flows of illegal migration. These countries also participate in the fight against criminal organisations engaged in clandestine immigration, trafficking in human beings, exploitation of prostitution and drugs and arms traffic. They carry out law enforcement activities to prevent the return of foreign citizens who have been expelled.

For a comprehensive view of the aforementioned regulations, reference must be made to Legislative Decree no. 286 of July 25, 1998, with the force of law, containing the Consolidated Act of the measures regarding immigration and the regulations governing the status of foreigners, with the result that practically all the legislation currently in force on the subject is consolidated in a single text. In the case of applicants for refugee status, article 1 of Law no. 39 of February 28, 1990 remains in force, though it has been extensively modified and supplemented by the recently passed Law no. 189 of July 30, 2002 (known as the 'Bossi-fini-Giovanardi Law'). The most significant innovations introduced in Legislative Decree no. 286 of July 25, 1998 by the aforementioned Law 189/02 can be summed up as follows: November 30th of the preceding year was fixed as the deadline for setting quotas of foreign immigrants to be accepted in Italy; entry visas may be refused for reasons of security without giving the reasons; criminal punishment may be inflicted if an application for an emigration visa made to the diplomatic delegation or consulate in the country of origin is accompanied by false statements; photographs and fingerprints are to be taken of foreigners applying for residence permits; residence permits for work are only to be issued if a contract of residence for a permanent job has already been signed; the duration of the residence permit is to be limited to the duration of the employment contract; severe penalties are to be inflicted on persons who falsify entry visas or other deeds or documents regarding residence in the country; the employer must guarantee lodging; the employer must make a formal commitment to pay the immigrant's repatriation costs; the period of residence required for obtaining a residence card is increased from five to six years. The measures against clandestine immigration contain more severe administrative and criminal penalties than previously. Specifically, adequate measures are contemplated for expulsion, escort to the border by the police; in addition, expulsion orders are to be adopted as an alternative punishment to imprisonment.

The immigrant's right of defence is confirmed, although it is not clearly defined in specific cases. The services designed to provide access to employment, provided for under the previous regulations, are replaced by the so-called 'pre-emption right' granted to potential immigrants who attend professional training courses in their countries of origin under programmes financed by the Italian government.

As regards applicants for refugee status, a clear legislative reference is now contained in the abovementioned Law no. 189 of July 30, 2002. In short: a temporary residence permit is issued which is valid until the necessary background investigation for the granting of refugee status is completed; the administrative procedures for handling the application are simplified; the system of protection and safeguard for applicants for asylum and refugees is guaranteed. All the abovementioned provisions, as well as those issued under Legislative Decree no. 195 of September 9, 2002, which contains urgent provisions regarding the legalisation of illicit work by 'non-EU immigrants' and was converted with amendments into Law no. 222 of October 9, 2002, will be supplemented by implementation regulations and government provisions.

3.1 Health policies and immigration: the impact of the new law on immigration

The Bossi-fini-Giovanardi Law came into force on September 10, 2002. It met with heated reactions. The government's attempt to make the measure less drastic by permitting the regularisation first of family assistants and then of illegal workers (Legislative Decree no. 195 of September 9, 2002) did not succeed in softening the tone of the discussion.

The presence of immigrants in Italy is a great occasion and opportunity: not so much in economic and job-related terms – though this is certainly the case – but in the light of cultural and social considerations and, as a result, organisational consequences as well. Immigrants bring with them a kaleidoscope of cultures; they have varied expectations and a different perception of their bodies, health and illness; and they belong to a variety of social situations with different legal statuses. This has led to a closer examination and a questioning not only about these developments, but also about our own attitude and approach as health workers, the way the services are organised and the relationship that each of us manages to establish with others, be they Italians or foreigners. This process necessarily involves a reciprocal adjustment to one another's cultures. It involves forms of integration that enrich a society and an organisation petrified by too much affluence and by budgets frequently designed for a culture of desires, appearances and virtual worlds rather than for essential needs and a standard of living that takes into account human relations and the feeling of belonging to a community. No law or regulation can determine this process, but it can certainly acknowledge and attempt to regulate this phenomenon in terms of integration and respect even by establishing severe rules, provided that they are justified by manifest conditions that everyone, both Italians and foreigners, must observe.

Limiting the reflection on the new law to topics related to health care, we cite the remarks contained in the final document of the 7th Consensus Conference on Immigration held in Erice, Sicily in May 2002, an event where approximately 250 health operators working in the public or private social services and in voluntary associations came from all over Italy to exchange ideas and examine the available scientific data on the health of immigrants and on health policies. The final resolution of the Consensus states: 'the fact that the residence permit is tied to employment casts foreigners in a utilitarian light, reducing them to nothing more than a work force, with the risk of exposing them to blackmail and harmful exploitation by employers (in fact, being fired would have far more serious consequences than simply losing a job); it also makes it impossible for workers to make durable plans. Furthermore, by creating obstacles to legalisation (in particular the "abolition" of sponsorships) it encourages illegal situations, which have been found to represent a significant risk factor for health. The restrictive criteria for family reunification impede the formulation of long-term projects and the emotional stability of the immigrants, with resulting damage to their psychological and physical well-being. The adoption of a simplified procedure for asylum, combined with the abolition of funding for the National Asylum Programme – resulting in a sudden cessation of assistance for asylum seekers and refugees, many of whom find themselves without housing or even the most elementary assistance – will produce (and is already producing) significant damage to the health of these persons, who are the weakest among the immigrants.'

Starting from the very first days of implementation, we have noticed an effect that gives serious cause for concern. Many health service operators believe that the health regulations guaranteeing access to services both to legal immigrants and, even more importantly, to clandestine immigrants have been abrogated and so they refuse to provide assistance. Nonetheless, everyone holding a long-term residence permit must be registered with the National Health Service, while illicit and clandestine immigrants are guaranteed essential, emergency, preventive and permanent care and it is forbidden to report them to the police if they are hospitalised or cared for. In confirmation of this, some regional governments more or less promptly issued comments/memorandums confirming not only that the right of immigrants to health care remained unchanged, but that foreigners in the course of regularising their situation (those who had submitted a request to bring their 'illegal' jobs onto the legal labour market) had obtained the right to register with the National Health Service.

The new law on immigration has increased the cultural gap, the fears, suspicions and reciprocal prejudices existing between Italians and foreigners; at a time when the provisions of the national legislation regarding health care for foreigners should be put into effect at the local level through initiatives that could make the system truly accessible.

4. Campaigns for the prevention of HIV/AIDS for mobile populations

As part of the prevention campaigns organised by the Ministry of Health during the period 2001-2002, the Ministry has gone on with the distribution of materials designed for the migrant populations and produced in the course of the 6th Informational-Educational Campaign on AIDS. In 2002 the procedure for a call for tenders to select the agency to handle the information campaign for 2003/2004 was completed. The programme chosen includes the production of multilingual brochures, along with multilingual posters on public transport vehicles and a varied sports programme that has recently attracted a good deal of interest from young foreigners living in Italy.

5. Research and training activities of the Italian NFP (2001/02)

5.1 Research activities of the Italian NFP

During the period 2001/02, the Italian National Focal Point (NFP) – coordinated by the Istituto Superiore di Sanità (National Institute of Health), which has experts belonging to public structures, NGOs and voluntary associations – proposed and implemented two projects in Italy.

The first is the project 'Creation of a national network of the non-governmental psychosocial health structures that work with immigrant populations suffering from problems related to HIV infection or sexually transmitted diseases (STDs)'. The general objective of this study, coordinated by the Istituto di Ricovero e Cura a carattere Scientifico L. Spallanzani, is to provide an updated overview of the actual situation in Italy with regard to NGOs and voluntary associations that work with mobile populations and AIDS/STDs. This is being done in order to favour collaboration among the different services while facilitating access by foreign citizens to the structures in question.

The second is the project 'Arianna – a pilot study for the creation of a multi-centre training network for linguistic-cultural operators and mediators, to be utilised in initiatives of information and prevention of HIV infection and sexually transmitted diseases targeted to groups of immigrants at risk of exclusion from psychosocial health services: clandestine and illegal immigrants, foreign prostitutes and drug addicts'. The objective of the study, coordinated by the Istituto di Ricovero e Cura a carattere Scientifico San Gallicano, is to provide specific training to linguistic-cultural mediators and to operators working in psychosocial health centres accessible to foreign users.

5.2 A training experience proposed by the Italian NFP

Among the many actions designed to safeguard the health of migrant populations, the Italian National Health Plan for 2002-2004 stresses the need for initiatives that facilitate access to services and make them easier to use, including providing specific information that takes the cultural diversity of the target group into account. In October of 2002, the Istituto Superiore di Sanità organised a 'Training course designed for psychosocial health operators in order to achieve an integrated multi-professional approach to the health of immigrants'. The training process was designed for the staff of the National Health System, of NGOs and of voluntary associations. It was designed to stimulate, through an analysis of the current situation, reflection on the need to pursue a transcultural health approach aimed at recognising the 'diversity' of others and making the most of their human and cultural heritage. The course tried to improve teamwork and network activities, so as to increase the effectiveness and quality of the services supplied to foreign citizens. The subjects dealt with included:

- the epidemiological situation of HIV among migrant populations;
- particularly high-risk infectious pathologies among immigrants;
- health policies and legislative aspects regarding mobile populations;
- communication and relational aspects within a transcultural framework.

6. Availability of services and access to medical treatment: past experiences of public structures, NGOs and voluntary associations belonging to the Italian NFP (2001/02)

6.1 Telephone counselling on HIV/AIDS within a transcultural framework

Between November 29, 1995 and December 31, 2002 the Telefono Verde AIDS (TVA) of the Istituto Superiore di Sanità received a total of 1,682 calls from foreign users: 493 (29.3%) from citizens of the Americas; 484 (28.8%) from citizens of African countries; 262 (15.6%) from citizens of non-EU countries; 253 (15.0%) from citizens of the European Union; 174 (10.3%) from citizens of Asian countries and 4 (0.2%) from citizens of the countries of Oceania. In the case of 12 users (0.7%), it was not possible to identify their origin.

The groups of users were:

- persons who had heterosexual intercourse and were not drug addicts: 1,041 (61.8%)
- subjects who did not engage in risky behaviour: 341 (20.3%)
- HIV-positive persons: 151 (9.0%)
- homosexuals or bisexuals: 111 (6.6%)
- drug addicts: 15 (0.9%)
- persons who had received blood transfusions: 6 (0.4%)
- not indicated: 17 (1.0%)

Most questions concerned information on the test. Among the other topics discussed were modes of transmission, psychosocial topics, misinformation, prevention, symptoms, and therapies and research. The telephone proves to be a particularly useful tool in the prevention of HIV/AIDS, not only due to the rapid access offered but also because its anonymity facilitates discussion of the illness and helps overcome the uneasiness felt with topics regarding the sexual sphere.

In replying to the questions asked by the callers, the counsellors of the TVA must keep in mind a series of psychological, social and cultural factors that have a great influence on the outcome of the informative message, making the counselling process highly complex.

This is particularly true in the case of foreign citizens who, in addition to the language difference, have different socio-anthropological and religious customs. Therefore the TVA not only represents a rapid and economical instrument for supplying ‘personalised’ scientific information, but also a privileged observatory for evaluating the information needs of the general public and for planning more effective prevention actions.

6.2 The San Gallicano Institute – Department of Preventive Medicine for Migration, Tourism and Tropical Dermatology

The services of the San Gallicano Institute in Rome are aimed at clandestine and illegal immigrants, Gipsy people, refugees and asylum seekers, immigrant and Italian transsexuals and homeless people, among other groups. Since 1996, San Gallicano’s Department of Preventive Medicine for Migration, Tourism and Tropical Dermatology has availed itself of the help of linguistic-cultural mediators. Over the last few years the City Council of Rome has given significant encouragement to a policy of health promotion ‘without exclusion’, through projects coordinated by its Health Promotion Policies Department. This Department has engaged in a number of social promotion activities aimed at supporting disadvantaged homeless people with health problems, in collaboration with a medical institution that can offer scientific reliability and cultural awareness from its experience in the field. In July 1999 an agreement was made between the City Council of Rome, the Health Promotion Policies Department and the San Gallicano Institute for the purpose of developing social and health services for homeless and resident people and immigrant and Gipsy groups in Rome. This has resulted, among other things, in the use of linguistic-cultural mediators specially trained for work with the homeless, and to experimentation with a social administration service that offers referrals and establishes connections between the homeless who seek aid from the San Gallicano Institute, the public structures and the social private centres operating in the field.

6.3 Access of immigrants to the AIDS Operational Unit of the Local Health Care RM/E, Rome

The law of 1998 finally extended access to health care to immigrants without residence permits. As a result, this population was able to deal with its health needs in those cases where the legislation was applied. With the passing of the law, the AIDS Operational Unit of the Local Health Care RM/E (Rome/District E), for years one of the landmarks for the local immigrant community in terms of HIV prevention, became a centre of standard health care for immigrants too. Patients attending the outpatient unit are not only people who wish to be tested because they have been exposed to the risk of AIDS, but also groups of immigrants with health problems under way. When the requirements are met, immigrants are issued an identification card and a health care number, and are offered basic health care with a medical examination, prescription of treatment for the diseases found and prescription for more examinations by a specialist.

Everyone is informed of the possibility of being tested for HIV free of charge, with pre- and post-test counselling. A number of observations can be made on the basis of the experience of past years. A large part of immigrants who have attended the service suffer from diseases that have long been neglected or have become chronic. The offer of the test was quickly accepted by nearly all the patients, who expressed their satisfaction with being able to overcome their lack of information, up to that point, on the procedures for carrying out the test, as well as their embarrassment over asking about it. During the counselling, most patients expressed significant concern, primarily with regard to the potential risks faced by spouses from whom they were separated for lengthy periods. The counselling has proved to be a useful personalised intervention that provides an opportunity for reflection on HIV infection, the risks and the adoption of safer behaviours. In addition, it gives the psychologist working at the clinic an important chance to learn about patients' uneasiness, problems and psychological symptoms. The patient learns that there is a psychologist who can be contacted in times of need. Contacts with patients often uncovers psychological problems that have long been neglected. The experience of the AIDS Operational Unit, though limited, together with the follow-up studies carried out in Rome District E, show the efficacy both of testing and counselling in promoting safer behaviours. Nevertheless, the actions need to be adjusted to reflect factors, such as language, culture, religion, sexuality and cognitive and behavioural problems, that influence the quality of communication and the therapeutic relationship.

6.4 Activities of the Committee for the Rights of Prostitutes

As in previous years, the majority of the women engaged in prostitution are foreigners, primarily coming from Nigeria, followed by those coming from Eastern Europe and Latin America. Recently, Chinese women have been found working in a number of large cities. There has been a significant drop in the number of Albanian women, while the number of women from Rumania has increased. The newly arrived women know very little about STDs. A Help Line against violence was established in 2002 (a DAFNE VIP project of the European Commission) and a survey on the telephone calls received reporting instances of violence was carried out. Apart from serious cases of attacks and robberies, a significant amount of violence emerged by clients who abuse the women, preventing the use of condoms.

The law on immigration (Law 40/98) was amended and is now much more restrictive and penalising for non-EU foreigners who wish to enter Italy. The effects of this law on people who practise prostitution are extremely serious, given that many of them have not only entered Italy clandestinely but have already been subject to expulsion orders and either disobeyed the measures or returned illegally for a second time; other prostitutes are forced by those who exploit them to carry false papers. All these circumstances result in immediate arrest and imprisonment. Persons caught by the police for the first time are either immediately escorted to the border and expelled or placed in special centres that differ only slightly from jails. Every day a large number of women are caught during police round-ups. As a result of the repressive measures, there is less prostitution on the street but a rise in prostitution in homes.

The law on immigration made no changes in art. 18 regarding the fight against the trafficking of persons for the purpose of sexual exploitation, but the repressive practices make it almost impossible for the women involved to be informed of their rights and succeed in requesting aid in entering social programmes. Nevertheless, more than fifty projects have been started up in Italy to support the victims of such trafficking. Given the slow pace of the Italian court system, at the moment it is not possible to obtain figures on how many traffickers have been sentenced, though there can be no doubt that charges have been brought against many. In the past, 10 billion lire (5 million euros) were allocated each year in support of the law against trafficking in persons. At present there are plans to reduce this expenditure by 50%, a cut that will prevent many social and prevention projects from going on.

The 'clean streets' campaign recently launched by the government, though designed to meet the requests of citizens for a greater security, has not addressed the trafficking of persons, as shown by the fact that no funds have been allocated for these victims. Though the law upholds the right to medical care and preventive treatment for infectious diseases for illegal immigrants as well, there is the risk that the new law will make it increasingly difficult for persons who practise prostitution to gain access to health services. At present, the women are hesitant to access health services or centres for immigrants because they obviously fear the potential consequences; in addition, the operators find it increasingly difficult to arrange for the health services to provide care and treatment. During the last two years the national campaigns on AIDS prevention have not taken into account the target group of prostitutes and their clients. The government has proposed that a new law be passed on prostitution, calling for obligatory medical examinations for prostitutes.

6.5 Activities of the Lila CEDIUS (Human Rights and Public Health Centre) during 2002 in the field of immigration

Lila CEDIUS (Human Rights and Public Health Centre) is a non-profit organisation based in Milan. In the course of 2002, its activities in the immigrant health sector were mainly carried out as part of a research project co-financed by the Istituto Superiore di Sanità. This project focused on primary and secondary prevention, as well as on treatment of HIV and STDs among immigrant patients. The objective was to evaluate the ethnic-cultural, psychological, linguistic and religious difficulties faced by health personnel, foreign users and cultural mediators, in order to draw up communication strategies designed to optimise the quality of the services already accessible in the sample cities. This objective was to be achieved by creating and trying out a working protocol designed to overcome the difficulties that hinder proper communication between health personnel and immigrant patients.

Many studies have been carried out in order to understand the problems of immigrants, and ad hoc training programmes have been implemented for immigrant communities and cultural mediators, but nothing has been done to learn about the obstacles encountered by physicians while interacting with immigrant patients and providing assistance, treatment and information. A point highlighted by an initial analysis of both groups involved in the research (users and operators) is the difficulty in communicating and the misunderstandings caused by language, which are seen as the single greatest obstacle to obtaining access to health structures. Next come problems related to bureaucracy: from the perspective of the users, these consist of difficulties in gaining access to structures, in not knowing the procedures to follow, the documents to be submitted or which structures to go to (for example, they may go to the emergency room for services that are not urgent and are therefore turned away). As far as the operators are concerned, the greatest difficulties are caused by a lack of information/training on the legislation regulating immigration and on the approach to immigrant users, since the cultural approach is not a subject included in any type of official training provided to physicians or nurses. The operators themselves say that they would like to receive more information and take part in training courses. They stress the importance of having information material to distribute to immigrants so as to favour better access.

A more in-depth, comparative analysis of the data demonstrates that behind the apparent language barrier there are further difficulties due to the lack of a shared conceptual framework: it is the operators themselves who, though they initially state that cultural differences are of little importance, go on to express the need for the presence of cultural mediators, not merely for the purpose of translation but as a liaison between the two cultures.

The working group that met to discuss and plan possible communication strategies aimed at optimising health services identified three possible approaches to be developed by the structures responsible for treatment. The first is introducing ECM (Permanent Medicine Education) courses, within those already started, organised by the local health units and coordinated both by persons working in these same structures as well as by others from the private social sector, regarding the topics of legislation, health care and interpersonal relations. The second approach is permanent updating on regional enforcements and memoranda. The third approach is the distribution and publication of existing ministerial guides in different languages.

7. Conclusions

The long-term experience acquired by the individual members of the Italian NFP in activities involving health care and treatment for foreign users has made it possible, in the course of the last year, to carry out two research projects (see 5.1), as well as a training course for operators engaged in services meant for foreign citizens (see 5.2). The shared objective of these initiatives was to identify conditions that can favour easier access and more effective use of the psychosocial health services, considering that the existence of public or voluntary services and the right to access (guaranteed by the laws in force) do not always guarantee the basic levels of assistance for vulnerable persons, such as immigrants.

The National Health Plan for 2002-2004, as part of a series of initiatives designed to safeguard the health of migrant populations, among other things emphasises the need for projects that facilitate access to the services and that improve their utilisation. What is more, as has been observed for some time now, the multifaceted nature of migratory activity in Italy, in terms of ethnic and language make-up, age and the various goals of migrants, calls for the identification of easy-to-use access points able to overcome the rigidity of deadlines and procedures. In addition, there is the need to train people who can be recognised by foreign citizens as resources meant to favour a matching of the immigrants' need for health with the services offered. At the same time, psychosocial health operators must have access to training courses on the elements of law, medicine and interpersonal relations that come into play during interaction with foreign users.

Accessibility to the psychosocial health structures, meaning the possibility for the user to benefit from the necessary service on a timely basis, represents the top priority for those working to promote the health of the migrant population. The end goal is to ensure the highest possible levels of service.

8. Bibliography

Belpiede, Cacciavillani, Di Bella, Goussot & Palidda (March 2002). Pratiche di mediazione interculturale. Animazione sociale, no. 3.

Bestetti, G. (Ed.) (2000). Sguardi a confronto. Milan: F. Angeli.

Bianchini, C., Marangi, M., Meledandri, G. & Morrone A. (Eds.) (2000). Medicina internazionale. Rome: SEU Editore.

Burgio, A. & Silvestri, I. (2001). Caratteristiche dell'ospedalizzazione degli immigrati provenienti dai Paesi a forte pressione migratoria per la salute riproduttiva delle donne straniere. In Atti 'Seminario Internazionale di Geografia medica – Salute e Migrazione'. Verona.

Burns, F.M., Fakoya, A.O., Copas, A.J. & French, P.D. (2001). Africans in London continue to present with advanced HIV disease in the era of highly active anti-retroviral therapy. AIDS, no. 15, 2453-55.

Campsmith, M. & Burgess, D. (2001). Race/ethnicity and gender differences in late HIV testing. Abstract n° 540, 2001 National HIV Prevention Conference, August 12-15.

Caritas di Roma (2001). Immigrazione: Dossier statistico 2001. XI Rapporto sull'immigrazione. Rome: Edizioni Nuova Anterem.

Castiglioni, M. (1997). La mediazione linguistico-culturale. Franco Angeli.

Centro Operativo AIDS. Istituto Superiore di Sanità (2002). Aggiornamento dei casi di AIDS notificati in Italia al 30 giugno 2002. Rome: Ministero della Sanità.

Donati, S., Spinelli, A., Grandolfo, M.E., Baglio, G., Andreozzi, S., Pediconi, M. & Salinetti, S. (1999). L'assistenza in gravidanza, al parto e durante il puerperio in Italia. Annali dell'Istituto Superiore di Sanità, 35, no. 2, 289-96.

Geraci, S. (Ed.) (2000). Approcci transculturali per la promozione della salute. Argomenti di medicina delle migrazioni. Rome: Anterem.

Geraci, S. & Martinelli, B. (July 2002). Il diritto alla salute degli immigrati. Scenario nazionale e politiche locali. Rome: Anterem.

Girardi, E., Sampaolesi, A., Gentile, M., Nurra, G. & Ippolito, G. (2000). Increasing proportion of late diagnosis of HIV infection among patients with AIDS in Italy following introduction of combination antiretroviral therapy. Journal of Acquired Immune Deficiency Syndromes, 25, no. 1, 71-6.

I diritti delle donne migranti (2001). Supplement to Diritto Immigrazione e Cittadinanza, no. 2. Franco Angeli.

ISTAT (1998). La presenza straniera in Italia negli anni '90. Informazioni 61. Rome: ISTAT.

McFadden, J. (Ed.) (1999). Transcultural Counselling. Alexandria: ACA.

Ministry of Health (2001). Assistenza sanitaria agi stranieri immigrati: guida partica alla normativa vigente.

Ministry of the Interior, Department of Public Security (2001). Rilevazione dei dati statistici sugli stranieri in Italia al 31 dicembre 2001. Roma.

Morrone, A. (1999). L'altra faccia di Gaia. Salute, migrazioni e ambiente tra Nord e Sud del Pianeta. Rome: Armando

Morrone, A. (2001). Dermatologia delle popolazioni mobile. Rome: SEU Editore.

Morrone, A. & Mazzali, M. (Eds.) (2000). Le stelle e la rana. La salute dei migranti: diritti e ingiustizie. Milan: Franco Angeli Editore.

Morrone, A., Mazzali, M. & Pistolese, A. (Eds.) (1999). Oltre il colore della pelle. Italia crocevia di migranti e culture. Rome: Bagatto Libri.

Morrone, A., Mazzali, M. & Tumiati, M.C. (Eds.) (2000). La babele ambulante. Parole intorno ai mondi che migrano. Dogliani: Sensibile alle foglie Editore.

Moya, A. & Vegni, E. (2000). La visita medica centrata sul paziente. Milan: Raffaello Cortina Editore.

Nadir, I-CAB (Italian Community Advisory Board) (Ed.) (January 2001). Introduzione alla terapia combinata.

Pagliani, S. (March 2002). Qui la malattia ha diritto di Asilo. Occhio clinico, no. 3.

Palmer, S. (Ed.) (2002). Multicultural Counselling: A Reader. London: SAGE Publications.

Porter, K., Wall, P.G. & Evans, B.G. (1993). Factors associated with lack of awareness of HIV infection before diagnosis of AIDS. BMJ, 307, 20-3.

Report on the implementation of the law containing the rules and regulations for the social safeguards involving maternity and abortion (final figures for the year 2000, preliminary data for the year 2001). Presented by the Minister of Health (Sirchia). Chamber of Deputies. Parliamentary Proceedings of the 14th Legislature. Doc. XXXVII No. 3. 2002. www.camera.it (www.ministerosalute.it).

Rozzi, E. (Ed.) (March 2002). I minori stranieri non accompagnati. Save the Children (newsletter), no. 1.

Sestetti, G. (2000). Sguardi a confronto. Franco Angeli.

Specific Needs of Migrants, Ethnic Minorities and Refugees in the field of HIV/AIDS. Satellite Meeting held at the 3rd European Conference on the 'Methods and Results of Social and Behavioural Research on AIDS', Amsterdam 2000. www.aidsmobility.org.

Spinelli, A., Baglio, G., Donati, S., Grandolfo, M.E., Andreozzi, S., Geraci, S., Baljozovic, V., Scassellati, G., Ciminelli, P., Pollastrini, L. & Marzano, P. (1998). Gravidanza, parto, puerperio: una ricerca su donne immigrate. Proceedings of the Convention 'Immigrati e salute sessuale riproduttiva: le risposte dei servizi', November 26-27, p. 35-9. Milan.

Spizzichino, L., Casella, P., Zaccarelli, M., Rezza, G., Venezia, S. & Gattari, P. (1998). HIV infection among foreign people involved in HIV-related risk activities and attending an HIV reference centre in Rome: the possible role of counselling in reducing risk behaviour. AIDS Care, 10, 473-80.

Spizzichino, L., Zaccarelli, M., Rezza, G., Ippolito, G., Antinori, A. & Gattari, P. (2001). HIV infection among foreign transsexual sex workers in Rome. Prevalence, behaviour patterns, and seroconvertion rates. Sexually Transmitted Diseases, 28, 405-11.

Tertio millennio ineunte: migration, new scenarios for old problems. A Consensus Conference (VII) in collaboration with SIMM, May 19-22, 2002, Erice.

UNAIDS (2000). Migrant Population and HIV/AIDS. www.unaids.org.

United Nations Development Programme (1999). Human development report. New York, Oxford: Oxford University Press.

United Nations High Commissioner for Refugees and others of concern to UNHCR (1999). Statistical overview. www.unhcr.ch/statist/90oview/toc.htm (accessed January 20, 2001).

United Nations Office of the High Commissioner for Human Rights (2001). Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Geneva.

Voluntary Advisory Group on AIDS-related Problems (Ed.) (2001). Manuale di informazioni pro-positive. Ministry of Health.

WHO (2000). The World Health Report 2000. Health systems: Improving Performance. Geneva.

WHO (2002). Poverty and health – Evidence and action in WHO's European Region. Copenhagen: WHO Regional Office for Europe (EUR/RC52/8).

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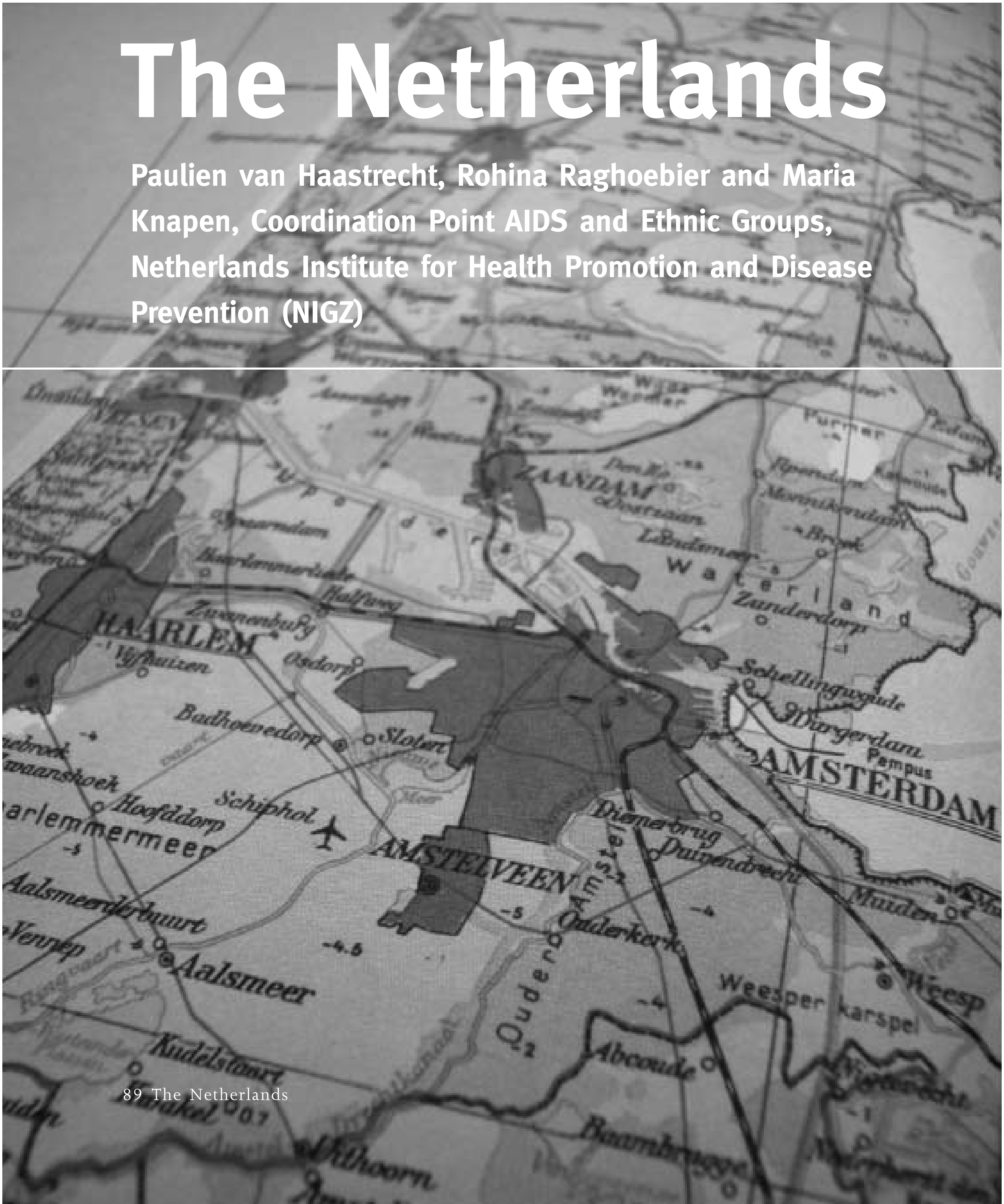

1. Introduction

1.1 Procedure

This report was written in close cooperation with the Dutch Network for HIV/AIDS Prevention, Care and Support for Migrants. It is an overview of the situation in the Netherlands regarding the accessibility and quality of care and support for migrants and members of ethnic minority communities living with HIV/AIDS. Information is given about epidemiological data and Dutch national policy on health care. Specific information is presented about the situation of subgroups such as women, children and undocumented migrants. This report also updates the Dutch country report for AIDS & Mobility about these subjects from 2000.

We have used official statistics, literature and documents of various organisations in the preparation of this report. We gathered information about the developments since 2000 during two expert meetings in March and October 2002. The first, about the situation of asylum seekers, refugees and undocumented migrants, was attended by thirty experts: health care workers, policy makers, researchers and members of community-based organisations (CBOs). The second meeting, about (the possibility and necessity of) cooperation between statutory/professional organisations and CBOs, was attended by 25 experts of similar backgrounds.

This report focuses mainly on problems, because they are most often the subject for discussion. Of course, this does not mean that the health care situation for people from ethnic minority communities living with HIV/AIDS is always problematic. However, the problems that do occur are usually complex and have a large impact on both the person living with HIV/AIDS and the health care provider.

This report is based on discussions held at the expert meetings and on working documents which have been discussed at meetings with the members of the Dutch Network for HIV/AIDS Prevention, Care and Support for Migrants. This Network is coordinated by the Coordination Point AIDS and Ethnic Groups, based at the Netherlands Institute for Health Promotion and Disease Prevention (NIGZ). It encompasses the following institutions: the Netherlands Aids Fonds, the Dutch Foundation for STD Control, the Schorer Foundation, the Pharos Foundation, the African Foundation for AIDS Prevention and Counselling (AFAPAC), the Project for AIDS Prevention and Care for people from Surinam, the Antilles and Aruba, and the Dutch HIV Association.

1.2 HIV/AIDS problems never come alone

This report looks at health, treatment, medication and possibilities for (social) support. One of the main arguments is that care for affected members of ethnic minority groups should be far more holistic or ‘system-oriented’ rather than based on the person living with HIV/AIDS as an individual. The problem of HIV/AIDS for members of ethnic minorities never comes alone. Usually it is accompanied by problems like a taboo or stigma within the personal environment; if a person is undocumented there are problems with treatment but also housing, money etc; if the person living with HIV/AIDS is a child, there is also always a parent living with HIV/AIDS; and most people living with HIV/AIDS from endemic areas are anxious about the situation back home, where family members may have HIV/AIDS as well. A holistic approach which includes both the individual and his or her environment, and which addresses both health and socio-economic aspects, is the most appropriate way to deal with these multifaceted problems.

2. Developments and changes in the last two years

2.1 Developments in the target population

Migrants have been coming to the Netherlands for many years and for various reasons. As in most Western European countries, the main migration movements consist of people from former colonies, labour migrants, asylum seekers and refugees. People from the former colonies – Indonesia, the Moluccas, Surinam and the Netherlands Antilles – have migrated to the Netherlands since World War II. Since the 1960s, migrant workers have come to live in the Netherlands. Most of them come from Mediterranean countries such as Italy, Spain and Portugal. In later years, large numbers of migrants have come from Turkey and Morocco. Currently, these last two groups form the largest migrant populations in the Netherlands, apart from the Surinamese. finally, asylum seekers from various countries (Iran, Iraq, Vietnam, Sri Lanka, Somalia, former Yugoslavia, Central and sub-Saharan Africa, etc) have come to the Netherlands requesting refugee status. The number of asylum seekers has increased enormously since the 1980s. An average of 30,000 refugees per year applied for a residence permit in the late 1990s. Recently the number of annual refugees has dropped dramatically by about 50%. This is due to a new Aliens Act becoming effective in 2001, which is very strict compared to the former act. However, as long as the political landscape remains rather unstable, so will the characteristics and size of refugee groups. The war in Iraq for example may change the composition and size of the group of asylum seekers.

Table 1. Numbers of the largest ethnic groups living in the Netherlands per January 1, 2002 (including first and second generation)

Ethnic group	Population
Total population	16,105,000
Dutch	13,140,000
Turkish	331,000
Surinamese	315,000
Moroccan	284,000
Antillean/Aruban	125,000
Former Yugoslavian	75,000
Iraqi	41,000
Chinese	36,000
Former Soviet	35,000
Afghan	31,000
Spanish	31,000
Somali	29,000
Iranian	27,000
Cape Verdian	19,000
Ghanaian	17,000
Portuguese	16,000

Source: Centraal Bureau voor de Statistiek (Statistics Netherlands, CBS), 2002

Various definitions are used when describing migrants, asylum seekers, refugees and other mobile groups. In this report, these groups will be referred to as ‘ethnic minorities’. The main reason for this is that people from the former colonies and the offspring of the migrant workers do not consider themselves to be migrants any longer.

2.2 Epidemiological trends

In the Netherlands, newly diagnosed cases of HIV are not registered. Only data about people diagnosed with AIDS has to be reported. These figures are categorised by nationality and transmission route. The percentage of people living with AIDS from Asia, Africa and Latin America has recently increased compared to the percentage at the beginning of the AIDS epidemic. In 1988, 79% of people living with AIDS were of Dutch origin; 21% were of non-Dutch origin. Over half of those of non-Dutch origin were from Western countries (Western Europe, Canada and the US). In 1998, 66% were Dutch nationals and 34% were of non-Dutch origin. However, the non-Dutch AIDS cases are now found mostly among people originating from non-Western endemic areas. This trend has continued. As of 2000, 60% of the people living with AIDS are Dutch and 40% are of non-Dutch, mainly non-Western origin.

In total, 5,441 people have been registered with AIDS as of December 31, 2001 (source: Inspectie voor de Gezondheidszorg, Dutch Health Care Inspectorate). It is estimated that about 17,000 people are living with HIV/AIDS in the Netherlands (RIVM, National Institute of Public Health and the Environment, 2002).

In general, compared to the 1980s, more people who are currently diagnosed with AIDS have acquired HIV through heterosexual contacts and fewer through homosexual contacts. Research has shown that the recent increase in incidence among heterosexuals is caused by the disproportional number of people living with AIDS from sub-Saharan Africa and the Caribbean (Termorshuizen, 1997).

Recently, a study found that there is an increase in the number of HIV cases among children: between 1982 and 1994, 74 children were reported as HIV positive, while 43 children were reported between 1995 and 1997. The majority of these children have parents who originate from outside the Netherlands (during the last period this was the case for 91% of the children), often from HIV-endemic countries (De Kleer, 1999). In 2000-2001, 86% of the children came from HIV-endemic areas and no child had two parents with a Dutch background (NSCK registration in: RIVM, 2002). In 1998-1999, paediatricians reported 33 new cases; in 2000-2001 they reported 24 new cases (numbers for 2001 were still incomplete at the time of writing). The slight decrease in the number of new cases of children with HIV/AIDS is most likely the result of the active HIV-screening among pregnant women. See also 2.3.

At the moment there is no registration system of STD/HIV incidence where people's country of origin is taken into account. However, a new registration system for HIV and STD surveillance is being prepared by the National Institute of Public Health and the Environment (RIVM), so hopefully we will be able to present better figures in the near future.

An important development in Europe is the rapidly increasing incidence of HIV and syphilis in certain Eastern European countries. Due to the mobility between Eastern European countries and the Netherlands – a result of drugs and prostitution migration, among other things – the results are measurable in terms of a rapid increase of STDs and HIV among Eastern Europeans living in the Netherlands. (Inventarisatie, 2002).

2.3 Changes in national policy

Both the national government and the local municipal councils are responsible for developing health and welfare policy. Municipalities are free to set their own priorities and allocate budgets. Most large cities in the Netherlands have a specific welfare policy for ethnic minorities.

In general, the policy aims are that all health care and welfare institutions in the Netherlands should supply services for the entire population, including ethnic minorities. All staff should be able to work with all target groups. In practice, however, the statutory Dutch institutions are not always fully accessible to ethnic minorities, partly because of communication problems (language and cultural barriers) and partly because of a lack of knowledge among the staff about the specific needs, habits and behaviour of various ethnic minority groups. Moreover, not all facilities are fully used by all members of the ethnic minority groups because they are not always familiar with the Dutch health care system.

In recent years several CBOs have set up activities for people from the same country or cultural background. They work alongside the statutory Dutch institutions. These CBOs receive some financial support from the Netherlands Aids Fonds. Some organisations focus on subgroups such as men who have sex with men. Others offer services for the specified target group in general. In addition to offering support and information, these organisations play an important role in reporting misunderstandings and other frictions experienced by members of the specific target group in relation to care providers.

Specific policy on care for people living with HIV/AIDS is developed by the Netherlands Aids Fonds and the Dutch HIV Association. In 1998, a policy paper was published that discussed both testing policy and related treatment programmes (Netherlands Aids Fonds and Dutch HIV Association, 1998). The main reason for the changes proposed in the policy paper was the introduction of new medication requiring early detection of HIV and strict compliance to the treatment. The policy strives to improve the care for people living with HIV/AIDS by focusing on their needs and linking all providers, including both professional and informal caregivers, such as buddy support. This enables a more coordinated and multidisciplinary approach – in short, care tailored to the specific needs of individuals.

In order to adequately carry out the policy, it is necessary to have sufficient information about the specific needs of those affected by HIV/AIDS, and also to be able to provide the necessary treatment and support. Because these conditions are not always available for members of ethnic minorities, policy makers consider them as a target group in need of specific attention.

This policy was discussed and accepted by all relevant institutions, and is now being put into practice step by step. The first step is focused on changing the policy on testing. At the beginning of the epidemic, testing was not encouraged because no cure was available. With the introduction of combination therapy, this has changed. It is important to start with this medication as soon as possible and therefore the Gezondheidsraad (Health Council) considers it useful to promote testing more actively. This advice is aimed especially at people who belong to the so-called risk groups: people who have (had) a partner living with HIV, injecting drug users, people who have lived in or originate from an HIV-endemic country, and people who have (had) a large number of sexual partners. As a start, the policy is being implemented for pregnant women in order to prevent vertical transmission. As of January 1, 2003, the Municipal Health Service of Amsterdam decided to screen every pregnant woman on HIV. HIV screening for all pregnant women in the Netherlands is expected to start at January 1, 2004. By then, the HIV test will be standard procedure for pregnant women, but there will be a so-called ‘opting out’ option. If women refuse, they will not be screened. It remains very important to provide good information to pregnant women about the implications of an HIV test.

3. Developments in access to health care and social support

In principle, health care is available to all, including people living with HIV/AIDS from ethnic minority communities who have legal status. Many health care institutions have taken special measures to provide care for people from these groups. For example, health care providers are trained in working with people from different cultures and a free interpreter system is available.

In addition to the restrictions related to people's legal status, accessibility can be limited in practice due to a lack of knowledge among ethnic minorities about the health care system and the way this system is structured in the Netherlands. As a result, in some situations, members of ethnic minority communities still do not profit fully from all available care. For instance, both research and information from the working field has shown that people from ethnic minority communities living with HIV often do not get into contact with health care providers until they have developed full-blown AIDS and are very ill. Therefore, they do not benefit from the treatment options that are now available.

Not only the lack of information, but also the idea that AIDS does not affect them is a reason why members of ethnic minorities do not take an HIV test.

Behind many of these problems is the fear of stigmatisation. Due to the stigma and taboo surrounding AIDS there is a great fear among members of ethnic minority communities who live with HIV/AIDS to talk openly about their disease. They tend to keep their HIV positive status a secret and are often too afraid to inform their family or even their partner.

This secrecy can lead to health problems. For instance, compliance with combination therapy becomes almost impossible. Furthermore, these people can be very lonely, dealing with all the psychosocial problems by themselves, too afraid to seek support from others who live in the same situation. Several CBOs have set up support groups, but not everyone dares to use such services.

Section 3 of this report focuses on the factors that ultimately limit the accessibility of care and influence its quality. Although these factors do not apply to the majority of people living with HIV/AIDS from these target groups, it is clear that the consequences often create complex problems and have a large impact on both the person affected and the health care provider. In section 4 we will focus on some recent projects and developments that may contribute to solutions.

3.1 Legal aspects

First of all, accessibility is connected to health insurance. Anyone who has a legal residence status is entitled to insurance. This includes asylum seekers who are awaiting a decision on their application. People who do not possess a valid residence permit and are residing in the Netherlands illegally cannot obtain health insurance. This group includes asylum seekers who have not been granted refugee status, labour migrants who have not applied for a permit and migrants who entered the country with a temporary permit and have overstayed their visa. This report uses the term 'undocumented persons' to refer to this group.

In order to make sure that undocumented persons are excluded from social benefits, including health care facilities, the Dutch government introduced the so-called Koppelingswet (Linkage Act) in 1997. This Act requires all administrative data about residence permit, social security and taxes to be linked. Only those people who can demonstrate compliance with all regulations have access to social benefits. There is an exception to this exclusion: if undocumented persons are seriously ill and treatment is considered necessary from a medical point of view, the illness must be treated. In the working field different interpretations of this regulation are reported. Whether treatment is considered necessary depends on the view of an individual doctor. The new law has enforced stricter guidelines for dealing with undocumented persons and health care workers consider the responsibility of deciding on treating persons from this group a very heavy burden.

According to the new law, the costs of primary health care are to be paid by the government; the costs of hospital care have to be paid by the hospitals themselves. This may explain the reluctance of some hospitals to treat people who are not insured.

In practice, we see that people who have no health insurance and are seriously ill with HIV/AIDS usually do get treatment in hospitals. Problems occur when they are well enough to leave the hospital. Although medication should be made available to them according to the new regulations, this is still not always the case, demanding a lot of persistence from the care providers and CBOs involved. Because of the high costs, which undocumented people living with HIV/AIDS cannot afford to pay on their own, combination therapies may cease to be available to them so that it becomes impossible to continue their medical treatment.

3.2 Lack of information

Access to health care can also be limited due to ethnic minorities not being well-informed about the Dutch health care system. This applies mostly to services like buddy support and psychosocial support services. Furthermore, ethnic minorities are not always well-informed about the advantages of early detection of HIV.

There are several programmes aimed at the distribution of information among ethnic minorities. These programmes generally provide information about AIDS prevention. The information is given by peer educators in community centres, schools and other places that are easily accessible and often frequented by ethnic minorities. Annually, more than 10,000 people are reached this way. Furthermore, information is disseminated by the migrant media (radio and TV) and by telephone help lines. Special educational materials explaining the HIV test have been developed, including materials aimed specifically at informing pregnant women. These materials are widely distributed. In the first two years, over 140,000 booklets were handed out to the target groups.

There is still a great need for adequate medical information for members of ethnic minorities who are already living with HIV/AIDS. There is hardly any information in the native languages of these people, or information connected to their needs. CBOs play an important role in informing people living with HIV/AIDS and their relatives and friends. However, their possibilities are limited because they are mainly small, voluntary organisations. Moreover, not all members of their target group are familiar with their services or are willing to use them, because of fear of revealing their seropositive status.

3.3 Differences in language and culture

Communication is often limited due to language problems. In the Netherlands, health care workers are entitled to a free interpreter service, either by telephone or in person. However, this service is not always used because it is considered too time-consuming to arrange. Furthermore, health care workers who do use the service point out its limitations when dealing with the issue of HIV/AIDS. The interpretation is limited to technical information: it is not possible to translate emotional support. Furthermore, due to the fear of stigmatisation, many people refuse the help of interpreters who belong to the same ethnic group.

People living with HIV/AIDS have noted that it is not only the difference in language but also the medical terminology used by the doctors that presents a problem.

Additionally, cultural differences influence the relationship of health care workers with people from different ethnic minority communities and can lead to communication problems. Health care workers find it more difficult to establish a trusting relationship with them. Coping with different beliefs about illness and dying is also indicated as a problem. Although several trainings for medical staff have already taken place, there is still a great demand from health care workers to receive additional information about intercultural aspects of health care.

In the interviews mentioned in the introduction, most people said they would like support from someone who is familiar with their cultural background, beliefs and habits. Some people participate in support groups with others from their own ethnic group. Although they say they are initially fearful of this contact, they are generally very happy about being able to share their problems and fears with people who speak the same language and live in a comparable situation.

3.4 The structure of the health care system

Not all members of ethnic minority communities are familiar with the structure of the Dutch health care system. As a result they do not always use all facilities that are available. By and large, facilities that provide psychosocial support are not widely used.

There is a rather strict division between prevention and care facilities. In practice we see that the needs of ethnic minorities often span across both territories at the same time: there is a demand for information, care and support. Secondly, several specialists are involved in the care for people living with HIV/AIDS. These services are not always well coordinated and as a result the care is ‘scattered’. Moreover, there is no close cooperation between the formal health care services and the ‘informal’ services, such as those offered by CBOs. Among the reasons for this lack of cooperation is the fact that these services are not always known by health care workers, or they do not know what to expect of the services.

Many health care workers work under the stress of time pressure: there is not enough staff, and an efficient use of time is crucial. This means there is not enough time to cope with people who in fact need extra time because of communication problems and other problems. Recently, an internal specialist of the Amsterdam Medical Centre showed how the situation has changed in about ten years (Dr J. Prins MD, April 2003): the AMC treated over 600 people living with HIV/AIDS in the early nineties, 20% being of non-Dutch origin. Nowadays the AMC treats over 1200 people living with HIV/AIDS, 40% of whom are of non-Dutch origin. Not only has the caseload grown to four times as many people, but it has grown almost exponentially: many people living with HIV/AIDS who are of non-Dutch origin deal with a multiplicity of problems and need a broad spectrum of support.

Case management is an important (but also time-consuming) answer to this situation. In short, it means that the service or care provider does not focus exclusively on the health problems of the person affected, but that the person’s social, economic and legal situation, family relation and other relevant aspects are addressed as well. The care provider is in touch with a variety of services – social, housing, justice etc – to which the person in question can be referred. An example is the initiative taken a few years ago to start with case management in the department of obstetrics in several hospitals specialised in treating children living with HIV/AIDS. Case management has many advantages for those affected: one staff member can be contacted for all of the different problems; this staff member is well-informed about someone's specific situation and needs. Furthermore, it is easier to establish a relationship based on trust between the person affected and the care provider.

3.5 Specific target groups

In this section we will describe the specific problems of women, children, asylum seekers, refugees and undocumented persons, and (where possible) actions aimed at solving these problems.

3.5.1 Women and children

The total numbers of women and children living with HIV/AIDS in 1999 were estimated at 2,500 and 100 respectively (source: RIVM). It is not known how many of these women belong to an ethnic minority group. It is estimated, based on information from the working field, that at least 50% of the cases concern women from ethnic minority groups.

In the Netherlands almost all affected children have parents who belong to an ethnic minority community. Research has shown that 39 of the 43, or 91% of the children living with HIV who were diagnosed from 1995 on, have at least one parent who belongs to an ethnic minority community. In 27 cases (63%), both parents did. Most parents (77%) originate from HIV-endemic countries, such as in sub-Saharan Africa and the Caribbean. Of these parents, 44% came to the Netherlands as refugees, seeking asylum (De Kleer, 1999).

The problems encountered by women living with HIV/AIDS are generally complex. These women have very individual needs: they have different questions, different symptoms and face different problems because their illness has a direct impact on family life. All these factors are more prominent among women from ethnic minority communities because they are afraid to discuss their status with their family or partner. As a result they do not receive support and have to cope with all of these problems by themselves. Furthermore, some of these women are dependent on their husbands for a residence permit. Many problems are reported by the working field and CBOs in the relationships between women and their partners.

Often, HIV is detected during the first trimester of pregnancy as a result of the new testing policy for this group. This leads to a difficult situation. The mother finds out that she has HIV, which will have a large impact on her life. Also, she worries about the health of her baby. She might consider abortion and often will feel guilty if her child also has HIV. In general the problems of women living with HIV and children living with HIV are very much related. Often, in one family, both the woman and child(ren) are affected.

Children living with HIV have specific problems as well, compared to adults: compliance to medication or a diet is much more difficult. Other specific problems that occur for the parents are when and how to inform the children about their status, while at the same time secrecy is considered very important. Moreover, an increasing number of problems are reported as children get older, particularly during adolescence.

Recently, policy makers and health care workers have focused increasingly on the family as a whole, instead of on women and children separately. There are several reasons for this change. firstly, if a mother and/or a child are affected this has broad consequences for the family: special care is needed, the partner and other children need to be informed and the problems they may have with the situation are reflected in the family. Furthermore, it is to be expected that, in the future, fewer children will acquire HIV through vertical transmission because of the new policy of offering an HIV test to pregnant women. Consequently, specific care for newly infected children will no longer be necessary. Care and support will need to be directed more at older children, with their specific needs.

3.5.2 Asylum seekers and refugees

Asylum seekers live in reception centres during the period that their applications are investigated. Due to these living conditions, they do not have much privacy, which has a strong impact on those living with HIV/AIDS. It is very to keep the illness a secret while complying with the medical treatment, receiving mail from health care institutions, etc.

Furthermore, asylum seekers, who do not (yet) have a residence permit, are in an especially vulnerable situation. Although officially HIV status plays no role in either the acceptance or refusal of an application for refugee status, many asylum seekers worry about this. They are not always well-informed about official regulations because of communication problems. Additionally, HIV is just one of their many problems: their main concern is to obtain a residence permit. Refugees, who do have a residence permit, do not feel that HIV/AIDS is the only problem. Many of them suffer from psychosocial problems or war trauma.

3.5.3 Undocumented persons

Undocumented persons, who have no residence permit, do not have access to health insurance. They do have access to care facilities, if they are able to pay for these themselves. An exception is made when medical care is considered necessary from a medical point of view. Whether treatment is considered necessary is decided by the medical staff.

The exact number of undocumented persons living in the Netherlands is not known. It is estimated that about 100,000 people have no residence permit. This group mainly consists of labour migrants and refugees who have not applied for a residence permit or who have been refused.

It is even more difficult to assess how many undocumented persons are living with HIV/AIDS. A ‘Servicepunt illegalen’ (support office for undocumented persons) was set up by the Dutch HIV Association and the Netherlands Aids Fonds in 1998. It charts problems within this group and when possible refers health care workers, people living with HIV/AIDS and their relatives to appropriate services. During 1999, about a hundred cases were taken care of.

In general, we can see that members of ethnic minorities who are not insured and are living with HIV/AIDS do have access to hospital care. Problems occur when they are discharged from the hospital and become outpatients. Due to the high costs, medication is not available to them, nor do they receive the necessary counselling.

Health care workers find it very difficult to decide whether or not to start these people on combination therapies. As long as they are not sure that the person affected will (be able to) remain living in the Netherlands, they tend to refrain from starting the medical treatment. Pregnant women, however, are usually treated in order to prevent infection of the baby. Some health care workers and support groups (such as CBOs) try to help undocumented persons living with HIV/AIDS, for instance by trying to obtain free medication. Sometimes a new or renewed request for a residence permit – on medical grounds – is put forward. This is only applicable if the person affected comes from a country where medical treatment for HIV/AIDS is not available. Often, the decision on this request takes a long time. During that period the person affected has no right to treatment or other social services.

3.6 Improvements and deterioration

Unfortunately there are some points of deterioration. first of all there is a new Aliens Act, effective since April 1, 2001.The result of this renewed act is that many asylum seekers are turned down in their request to get asylum in the Netherlands. As a result many rejected asylum seekers stay in the Netherlands ‘underground’. There are no official figures yet, but there are strong indications that the number of undocumented persons is growing rapidly due to this new act.

Secondly, the political climate in the Netherlands is changing. Although it is difficult to analyse exactly what is going on, there seems to be a more critical attitude towards ethnic minority groups since the attacks in the United States on September 11, 2001. This has had an effect on the social and political situation in the Netherlands. For example, there always used to be a tolerant policy towards undocumented persons. But nowadays it seems to be ‘fashionable’ and accepted to rout undocumented persons, for example by sweeping prostitution or drug areas. As a result of such actions, providing aid to (possibly HIV positive) drug users or prostitutes becomes extremely difficult.

On the positive side, we can mention two developments, both concerning the intention of closer cooperation between organisations in the Netherlands in the field of HIV/AIDS and ethnic minority groups. A website allowing organisations dealing with these issues to introduce themselves, www.allagainstaids.nl, has been available since 2001. The website contains project descriptions, announcements of activities and relevant documents. Further, a joint programme was initiated in 2002 by both statutory and community-based organisations about AIDS control among ethnic minority groups. The programme deals with information and prevention on the one hand, and care and support on the other hand. The call for such a comprehensive programme came especially from CBOs, which experience in daily practice that prevention cannot be seen separately from care and support.

4. Projects and interventions related to access to treatment

4.1 The ethnic care consultant/AIDS consultant

In order to provide tailored information and support for members of ethnic minorities living with HIV/AIDS, a pilot project – called Sadi – was set up in the city of Rotterdam to reach people from sub-Saharan Africa, Surinam and the Netherlands Antilles in November 1999. This service is carried out by an AIDS consultant who shares the affected person’s ethnic background and works as an intermediary between them and the statutory health institutions. The AIDS consultants cooperate closely with these institutions. The main aims of the project are to offer information and social and emotional support in people’s native language, in addition to the care offered by the statutory health care institutions. People are referred to these institutions or come on their own initiative. The first objective is to create a safe environment in which they are not afraid to make their problems known. The project is financed by the Netherlands Aids Fonds. When the project period ended, the organisations employing the care consultants decided to continue the project using their own funds. It is still unclear whether similar projects will be set up in other cities.

4.2 Cooperation between statutory organisations and CBOs

In recent years we have seen closer cooperation in the Netherlands between CBOs and 'white' organisations active in the field of AIDS control. A concrete example is the cooperation between the Schorer Foundation (the Netherlands' expertise centre for lesbian and gay specific health care) and Sida Vida, a self-help organisation of Spanish-speaking people living with HIV. Since 1997, the Schorer Foundation has worked on (inter)national exchange and cooperation with Latin-American and HIV/AIDS organisations that want to start a buddy project. The Dutch HIV Association cooperates with and supports both Sida Vida and PAMA (Positive African Mutual Aid).

4.3 Network of organisations caring for undocumented persons

In the last years, quite a lot has been done to make an inventory of cases where undocumented migrants with HIV/AIDS did not receive appropriate care, and to create local platforms to find solutions for these people. There is a great need among health care workers to have centralised information and unambiguous guidelines about how to deal with uninsured people. At this moment the Coordination Point AIDS and Ethnic Groups at the NIGZ is initiating the development of a network of organisations involved in care and support for undocumented persons and their close environment.
Two things need to be done:

1. Every health care worker needs to know what the possibilities are for giving the best possible care and support to undocumented persons.
2. Undocumented persons who receive treatment in the Netherlands need to get permission to stay in the country as long as they are in need of medical treatment. To this end, the possibilities for regulations on a medical or humanitarian basis should be investigated.

4.4 Improvement of conditions for CBOs

One of the most important conclusions of the programme on AIDS control among ethnic minority groups is that the position and working conditions of CBOs must be addressed. We are clearly beyond the stage of inventories now, and it is time to take a real step in terms of improving their situation. To improve the quality of care for people from ethnic minorities, especially when there are communication problems due to language or cultural differences or complicating situations like an undocumented position, optimal cooperation between statutory care facilities and CBOs is necessary. So is strengthening the position of CBOs and improving the relations and cooperation between statutory and community-based organisations. The challenge for the near future is to make this possible, for example by investigating whether the activities of CBOs can be financed by health insurances. By helping each other, CBOs could help to strengthen their position. Especially the more 'established' CBOs could support other CBOs in starting up.

5. Conclusions and recommendations

5.1 Conclusions

According to Dutch health policy, all health care facilities are provided to all inhabitants, including ethnic minorities. Specific measures, such as free interpreter services and intercultural training of medical staff, have been taken in order to guarantee access for ethnic minorities.

However, health care is not accessible to undocumented migrants, unless such care is considered necessary from a medical point of view. As a result, outpatient care and medication are generally not sufficiently available to them.

Accessibility and the quality of care can be limited due to cultural and linguistic barriers and a lack of information. The quality of care is also influenced by the structure of the health care system: the care is compartmentalised and many different specialists and institutions are involved.

The taboo surrounding AIDS plays a restricting role: due to the fear of stigmatisation, many members of ethnic minorities living with HIV/AIDS are afraid to talk openly about their illness and to seek support. The taboo also makes people reluctant to seek out information and hesitant and fearful about testing.

Epidemiological figures point out that in the near future relatively more and more people living with HIV/AIDS will come from ethnic minority communities. This group requires specific care and attention. Although it is clear that specific subgroups within this group – such as women, children and refugees – require even more specific care, some general conclusions can be drawn. first of all, coordination between the different services is needed. Secondly, living conditions as a whole – including cultural, social and economic factors, as well as different lifestyles, the family situation and the community – must be taken into consideration.

There are several initiatives seeking to solve these problems. The initiatives involve health care workers, lay health advisers and CBOs.

5.2 Recommendations

In order to improve the accessibility and quality of care the following steps should be taken:

- More must be found out about the incidence and prevalence of HIV/AIDS as well as other STDs among several ethnic minorities. There is also a need to know more about sexual patterns, levels of knowledge, attitudes and behaviour with respect to AIDS and STD among these groups. At this point we have some knowledge about the largest ethnic minorities in the Netherlands (Turks, Moroccans, Surinamese, Antilleans), but very little is known compared to the body of knowledge about, for example, men who have sex with men. Especially as regards other ethnic minorities than the largest four we lack a lot of important information.

- It seems to be very important to monitor the consequences of a larger European Union for AIDS and STD control on a national and European level.

- Undocumented persons living with HIV/AIDS should have access to the necessary care and support. Clearer guidelines about the availability and financing of treatment for them are needed, both for them and for the health care workers.

- It is necessary to look into the possibilities for a medical or humanitarian residence permit for undocumented persons or asylum seekers whose temporary permit to stay in the Netherlands may not be extended.

- Adequate information and support must be offered, connected to the real needs of these people. For instance, medical information and information about the Dutch health care system should be available in the native language of the person affected. In order to produce this kind of information and support, more background information is necessary about the specific needs of members of ethnic minorities living with HIV/AIDS.

- CBOs can play an important role in tackling several problems: they can set up support groups closely related to the cultural background of the target group. It is clear that strict confidentiality needs to be guaranteed for these kinds of support groups. They can also provide support for relatives of affected people from their communities. Furthermore, CBOs can assist health care workers from statutory institutions. They can provide information about people's cultural background and needs, and can assist in solving communication problems. CBOs should be better equipped and receive more financial support so they can actually carry out these services. In order to improve the working relationship between CBOs and statutory health care institutions, it is important that there is a clear division of tasks and responsibilities.

- Health care workers need more background information about cultural differences and how to deal with them. In addition to training on how to deal with people from different cultures, specific training sessions about the situation of members of ethnic minority communities living with HIV/AIDS could be set up.

- Case management can be an answer to the various care institutions and specialists that are involved now. People living with HIV/AIDS should have one central care provider who is able to arrange the necessary care. The experiments with case management that have recently been set up could serve as an example that could be implemented in more institutions.

- In general, data needs to be collected from the several initiatives and pilot projects in the Netherlands that have been set up to improve health care for people from ethnic minority communities living with HIV/AIDS. Wherever possible, these projects should be implemented more widely and in close cooperation with members of the target groups.

6. Services in the field of HIV/AIDS (NGOs and CBOs involved in the National Network)

Netherlands Aids Fonds
NGO. Since 1985, the Netherlands Aids Fonds has striven for a world without AIDS. The Fund works for everyone living with, or vulnerable to, HIV/AIDS and its consequences. Support for people with HIV/AIDS and advocacy on their behalf are two of its most important tasks. Most of its resources come from fundraising activities and are spent on scientific research, education and information, help and care, vaccine development, and international projects.
Keizersgracht 390-392, 1016 GB Amsterdam
aidsfonds@aidsfonds.nl
www.aidsfonds.nl

Dutch HIV Association (HVN)
The Dutch HIV Association is a national, volunteer NGO that promotes the interests of people with HIV in the Netherlands. HVN offers 'Checkpoint', a testing facility for rapid HIV testing.
P.O. Box 15847, 1001 NH Amsterdam
info@hivnet.org
www.hivnet.org

Netherlands Institute for Health Promotion and Disease Prevention (NIGZ)
The NIGZ is a nationwide institute for health promotion aimed at various population groups and addressing a variety of health issues. The NIGZ hosts the National Coordination Point AIDS and Ethnic Groups. The main areas of the Coordination Point are prevention, care and support for ethnic persons with

HIV/AIDS. The focus of NIGZ policy is fortifying the position of CBOs and stimulating the cooperation between NGOs, care providers and CBOs.
P.O. Box 500, 3440 AM Woerden
allagainstaids@nigz.nl
www.allagainstaids.nl

Pharos

Pharos is an NGO that functions as a national knowledge centre. It concentrates on developing, analysing and conveying knowledge, always practically applicable, related to health and health care for refugees.
P.O. Box 13318, 3507 LH Utrecht
pharos@pharos.nl
www.pharos.nl

Netherlands Foundation for STI Control

The Stichting soa-bestrijding (Netherlands Foundation for STI Control) is an NGO concerned specifically with (the quality of) prevention and control of sexually transmitted infections. It informs the general public as well as specific target groups such as young people and prostitutes.
P.O. Box 8198, 3503 RD Utrecht
info@soa.nl
www.soa.nl

Schorer Foundation

The Schorer Foundation is an NGO active as the Dutch national expertise centre in the field of health care for gay men and lesbian women. Its mandate is to ensure a suitable range of services to gays and lesbians throughout the Netherlands, and one that shows both an appreciation of and respect for the way they live.
P.O. Box 15830, 1001 NH Amsterdam
helpdesk@schorer.nl
www.schorer.nl

Mainline

The Mainline Foundation is an NGO promoting the sexual health of drug users in general. Drug users of ethnic origins have the specific attention of Mainline.
P.O. Box 58303, 1040 HH Amsterdam
info@mainline.nl
www.mainline.nl

Muhabbat/Tjandu

The Muhabbat Foundation and the Tjandu Foundation are both CBOs/NGOs working for the Moluccan community. Both give information on HIV/AIDS and support affected Moluccans.
Oranjesingel 26, 6511 NV Nijmegen
info@muhabbat.nl
www.muhabbat.nl

PASAA

PASAA is a CBO working in the field of AIDS prevention and counselling for Surinamese and Antillean/Aruban people, and others originating from the Caribbean area. PASAA also promotes the expertise of care providers concerning people from ethnic minorities.
c/o Maassluisstraat 180, 1062 GK Amsterdam
pasaa@club.tip.nl

AFAPAC

The African Foundation for AIDS Prevention and Counselling is a CBO working in the field of AIDS prevention and counselling for people from sub-Saharan Africa and their personal environments. AFAPAC provides information and support to Africans with health issues, HIV/AIDS in particular. AFAPAC develops methods and activities that fit in the world of Africans.
Daalwijk 29, 1102 AA Amsterdam
1.afapac@wxs.nl
www.afapac.nl

PAMA

Positive African Mutual Aid is a CBO that supports and promotes the interests of HIV positive Africans. PAMA works together with the Dutch HIV Association.
1e Helmersstraat 17, 1054 CX Amsterdam
asg@hivnet.org
www.hivnet.org

Sida Vida

Sida Vida is a CBO that supports and promotes the interests of Spanish and Portuguese-speaking people with HIV/AIDS and their relatives. Sida Vida works together with the Dutch HIV Association and the Schorer Foundation.
1e Helmersstraat 17, 1054 CX Amsterdam
sidavida@hivnet.org

Mission (im) Possible

Mission (im) Possible is a CBO that provides care and support for people with HIV/AIDS in the Netherlands and in Surinam. The foundation works mainly for HIV positive women and their children. It facilitates contacts between fellow patients.

Beeklaan 400A, 2562 BH Den Haag
mission_im_possible@hotmail.com
www.geocities.com/stichtingmission

Stichting Dominicana "Santo Domingo"

The Dominican Foundation Santo Domingo is a CBO providing information about HIV/AIDS to Dominicans and other Latin Americans in the Netherlands.

Kleiburg 32, 1104 EA Amsterdam
sdsdnl@hotmail.com
www.fundaciondominicana.com

Sadi

The Sadi Foundation is a CBO providing care and support to sub-Saharan Africans and Capeverdians in Rotterdam living with HIV/AIDS. Sadi works with ethnic care consultants and facilitates contacts between migrants living with HIV/AIDS.

Ron Wichmanhuis,
Westersingel 103, 3015 LD Rotterdam
info@sadi.nu
www.sadi.nu

7. References

Centraal Bureau voor de Statistiek (2002). Allochtonen in Nederland 2002 (Migrant people in the Netherlands). Voorburg: CBS.

Netherlands Aids Fonds and Dutch HIV Association (1998). Hiv-test en behandeling. Gecoördineerde aanpak van integrale aids-bestrijding en actieplan (HIV test and treatment. Coordinated approach to comprehensive AIDS control and action plan). Amsterdam.

Kleer, I.M. de, et al (1999). Toename van gemelde HIV-1-infectie bij kinderen in Nederland, 1982-1997: meer verticale transmissie en groter aandeel van allochtone kinderen (Increase in registered HIV-1 infection in children in the Netherlands, 1982-1997: more vertical transmissions and a larger share of migrant children). Nederlands Tijdschrift voor Geneeskunde, 143, nr. 33, 1696-1700.

Netherlands Aids Fonds (January 2003). Inventarisatie Aidsbestrijding onder Allochtonen in Nederland (Assessment of AIDS Control among Migrant People in the Netherlands). Amsterdam.

NIGZ (March 2002). Werkdocument Aidsbestrijding onder asielzoekers, vluchtelingen en illegalen in Nederland (Working document on AIDS control among asylum seekers, refugees and illegal aliens in the Netherlands). Woerden.

NIGZ and Netherlands Aids Fonds in cooperation with OAM (November 2002). Programma Aidsbestrijding Allochtonen 2003-2005 (Programme for AIDS Control among Migrants 2003-2005). Woerden.

NIGZ (March 2002). Verslag werkbijeenkomst Aidsbestrijding onder asielzoekers, vluchtelingen en illegalen in Nederland (Report of a meeting on AIDS control among asylum seekers, refugees and illegal aliens in the Netherlands). Woerden.

Op de Coul, E.L.M. et al (December 1, 2002). HIV en AIDS in Nederland (HIV and AIDS in the Netherlands). RIVM rapport nummer 441100017/2002. Bilthoven.

Termorshuizen, F. et al (1997). Aids-epidemie in Nederland: recente ontwikkelingen naar transmissieroute, leeftijd en nationaliteit (The AIDS epidemic in the Netherlands: recent developments in route of transmission, age and nationality). Nederlands Tijdschrift voor Geneeskunde, 141, nr. 40, 830-5.

Portugal

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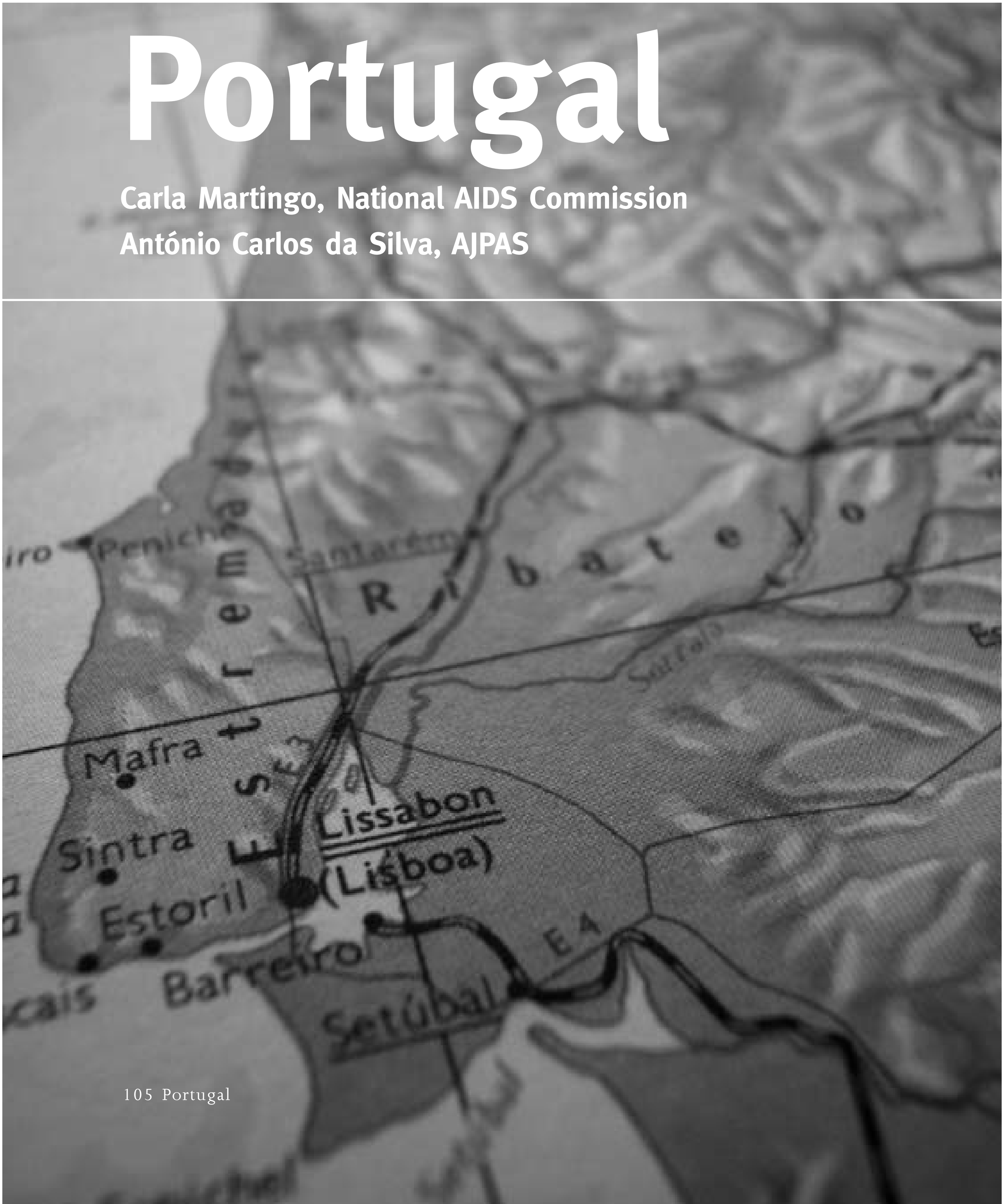


1. Introduction

This report deals mainly with the changes in legislation regulating foreign citizens' entry into and stay in Portugal, and their departure and expulsion from the country. The new law's impact on migrants, particularly on undocumented migrants, has been the subject of much discussion, even before it was passed. It has been presented by the Portuguese government as an inevitable consequence of the European legislative trend towards a more restrictive and controlling policy regarding migration fluxes.

Being a governmental organisation, the National AIDS Commission (the Portuguese National Focal Point) has chosen an NGO as partner in writing for the report. The Associação dos Jovens Promotores da Amadora Saudável (Association of Young Health Promoters of the Healthy City of Amadora; AJPAS), has a very long and rich experience working with legal as well as undocumented migrants. It was considered a very reliable source for the point of view of migrants. AJPAS works from a communitarian perspective, aiming to promote health in general, and intervening along with the persons targeted by the organisation. Since the beginning, AJPAS has worked directly with specific groups, such as migrants and the socially disadvantaged who face exclusion from society.

We gathered official information from institutions and organisations such as the High Commissioner for Immigration and Ethnic Minorities, the Foreigners and Borders Service, the National Statistical Institute of Portugal, the Portuguese Refugee Council and the Surveillance Centre for Communicable Diseases. We also used the testimony of HIV positive people who participated in a conference cycle in January-June 2003 entitled 'Being positive in the fight against discrimination'. This conference cycle addressed discrimination against HIV positive people in the workplace and in the fields of health, insurance and education. The last meeting was held in the National Parliament, with the conclusions and recommendations being discussed by politicians and policy makers.

The meetings were held against the background of the UNAIDS theme for 2002-2003, 'Stigma and discrimination'. Measures against discrimination are essential to create a world where people don't have to hide behind a mask in fear of losing their family, friends and jobs.

2. Migration patterns

In recent years, migration fluxes to Portugal have changed: non-EU migrants are of more diverse geographical origins; there is a major increase in the migration wave coming from some of the Eastern European countries; the educational level of migrants has gone up, with a more significant number of newcomers having medium and high academic degrees; and migrants are spread over more areas in Portugal.

According to the Foreigners and Borders Service, 190,896 foreign citizens lived in Portugal on December 31, 1999: 109,965 males and 80,931 females. Between 1998 and 1999, a growth of the foreign population by 12,759 people was registered. Until 1999, the most representative nationalities were Cape Verdean, Brazilian, Angolan, Guinea-Bissau, UK and Spanish. The African Portuguese speaking countries, and former Portuguese colonies, provided, until that time, the highest numbers of migrants. Data from November 31, 2002 about residence permits indicates that 235,627 foreign persons were legally living in the country: 131,448 males and 104,179 females. The Portuguese African former colonies provided 122,550 citizens, Europe provided 71,383 citizens (65,393 from the EU and 5,990 from other European countries), Central and South America 32,269, North America 10,463, other African countries 6,217 and Oceania 545.

The possibility of getting a special residence permit led to an additional 169,953 migrants from 2001 to 2002. Unlike migration fluxes until 1999 mentioned above, this new picture shows a more significant number of migrants coming from Eastern European countries: 60,310 from Ukraine, 11,746 from Moldavia and 10,089 from Romania. Brazil still remains in the second place with 33,820 citizens.

Data from the Portuguese Council for Refugees shows that in 2002, 180 people applied for asylum, 65 of them being family members of asylum seekers. In first place comes Sierra Leone, with 34 citizens, followed by Angola with 33 and Poland with 14. The fourth place is shared by Cuba and Russia with 9 citizens.

Refugees as defined by the Geneva Convention are entitled to an identity card for the period of five years, which can be annually renewed after evaluation. They are also entitled to work, education and health.

Migrants represent at least 4% of the resident Portuguese population and 8% of the active labour force. These numbers are often mentioned by trade unions and migrant associations. They argue that the share of migrants in the labour force is vital in view of the proportional increase of the ageing population. Eurostat's last report states that Europe will need 44 million additional migrants until 2040.

3. Immigration policy

3.1 The new immigration law

The new government coalition formed by Social Democrats and the Popular Party (Christian Democrats) at the beginning of 2002 brought several changes in all fields, including health and immigration. Immigration policy addresses the need, defended by the new government, for a rigorous control on the entry and stay of foreign citizens in the country, towards an effective integration into society. A new immigration law (Decree Law n. 34/2003, February 25) was approved and implemented in March. It is based on three main principles:

1. Promoting legal immigration in view of the country's labour force shortage
2. The integration of immigrants
3. Combatting illegal immigration

The new law established annual immigration quotas and abolished permanence permits (permits valid for one year which could be renewed), allowing only the granting of visas or residence permits. The new law leaves room for those who submitted their files towards legalisation under the old law to have their application considered according to the old law.

In order to assess immigration quotas, the government produces a biannual report in collaboration with several organisations, such as the High Commissioner for Immigration and Ethnic Minorities, the trade unions, the employers' organisations and the municipalities. The criteria followed will be economic and social, based on the capacity of each region to effectively integrate the newcomers and on the employment needs in each economic activity.

In order to improve the integration of migrants, those who are in the country within the family reunion regime are now allowed to have a job. Also, a new working permit has been introduced, enabling migrants to undertake a scientific research activity or other activity that requires highly technical knowledge. This last point will allow the presence in Portugal of migrant scientists and highly specialised technicians.

The time it takes for foreign citizens to obtain a residence permit has been reduced. According to the government, this enables the legalisation of all migrants who are integrated into Portuguese society.

In the fight against illegal migration, the procedures were shortened towards the quick expulsion of undocumented migrants. The penalties for recruiters of undocumented migrants or those who facilitate this kind of activity have become more severe. This is the result of applying European guidelines to Portuguese law.

The new law still provides for access to social protection, education and health services already established under the old law. It is still possible to obtain a visa for medical treatment in the country, for the maximum period of one year. When a foreign citizen has a disease necessitating long-term medical treatment and returning to their own country would endanger their health, a visa is not required for obtaining a residence permit. Therefore, migrants living with HIV can obtain a residence permit, even when they are undocumented.

The new immigration law has been criticised on several counts: the virtual inability for undocumented migrants to become legal, a very restrictive annual migration quota, the fact that it is the government which selects the employees (causing some migrants to be more privileged than others depending on their country of origin, according to critics), the fact that migrants cannot move around within the national territory but are obliged to stay in the area where they are working, and the fact that expulsion is now easier and quicker.

3.2 The High Commissioner for Immigration and Ethnic Minorities

Immigration policy has changed and so have its representatives. The High Commissioner for Immigration and Ethnic Minorities was nominated, among other reasons, for his wide experience in working with Eastern European migrants and his humanistic views. However, his Jesuit priesthood has elicited protest since he is responsible for a commission that has to deal with many nationalities and beliefs. The High Commissioner has drawn up a strategic plan for 2002/2003 setting out major guidelines: a Social Pact and National Plan for Immigration, a national information network for migrants, a national migrant support system and a migration Observatory. The High Commissioner’s office publishes a newsletter, online information, leaflets and brochures in several languages and is preparing a ‘cyberbus’ which will visit migrant districts and provide information materials and Internet access.

A telephone line, SOS Immigrant, was activated, with the number 808 257 257. Migrants and migrant organisations can call it for all issues of concern to them. The line is available in Portuguese, English and Russian and can be reached at the cost of a local call. It is open from Monday to Friday from 10:00 AM to 10:00 PM and on Saturdays from 10:00 AM to 5:00 PM. The SOS Immigrant team is made up of two shift coordinators and six contact points staffed by migrants.

On a final note, the High Commissioner is setting up a National Immigrant Support system made up of National Support Centres in the country's two major cities, Lisbon and Porto; Regional Support Centres in the district capitals; and Local Support Centres for smaller cities and villages. Social Security Centres, the Foreigners and Borders Service, all ministries and many other services will have bureaus in these centres, which will be providing information to migrants.

4. The professional integration of migrants

An integration success that merits a special mention is the project 'Professional support for immigrant medical doctors', initiated in 2002. Resulting from a protocol signed by the Calouste Gulbenkian Foundation (a public institution promoting education, science, welfare and art) and the Jesuit Refugee Council, the project was started with the objective of creating conditions for highly qualified migrants to work in suitable professions according to their academic abilities, providing not only their integration in Portuguese society but also overcoming the need for more highly qualified professionals than the existing Portuguese ones.

The project targets medical doctors from Eastern European countries who live and work legally in Portugal. As their university degrees are not recognised in Portugal, they work in other fields, for example civil construction.

Medicine books, subsistence allowance during the project period and payment of the registration in the Medical Doctors College are some of the forms of support provided. Within this project around two hundred medical doctors form Eastern European countries are working in Portuguese health facilities.

5. Epidemiological developments

Epidemiological data reflecting the situation up until February 28, 2003 reveals that there have been 21,587 HIV/AIDS cases in the several stages of infection: 9,812 asymptomatic HIV positive persons (9,346 alive and 466 deceased), 1,933 AIDS-related complexes (1,593 alive and 340 deceased) and 9,842 AIDS cases (4,489 alive and 5,353 deceased). The expression 'AIDS-related complex' is directly linked with the Centers for Disease Control and Prevention (Atlanta) classification and includes Groups III and IV.

Most AIDS cases (79.5%) affect people between 20 and 44 years of age. Women represent 19.9% of the cases, which, considering similar data until December 31, 2002, constitutes a 3.3% increase. Injecting drug use accounts for 49.8% of the cases, followed by heterosexual sex (29.1%) and in the third place homosexual or bisexual sex (14.8%).

Epidemiological data about AIDS-related complexes and asymptomatic HIV positive persons covers the period from 1983 to December 31, 2002. Asymptomatic HIV positive persons, meaning persons who are HIV positive without showing any symptoms, are notified between age 20 and 44 in 82.8% of the cases, with particular incidence in the 25-29 interval. Injecting drug use accounts for 52.7% of the asymptomatic cases, followed by heterosexual sex (32.4%) and homosexual or bisexual sex (8.5%). Importantly, a change in the epidemic trend was observed from 2000 to 2001: there was a decrease in injecting drug use cases and an increase in cases of heterosexual sex. The same patterns are observed in the cases of AIDS-related complexes, but here the proportion between injecting drug use and heterosexual sex is less significant than in the other stages of the epidemic (44.1% injecting drug use and 32.2% heterosexual sex).

Considering HIV-2, data from December 31, 2002, shows 370 AIDS cases, which is 3.6% of the total number of AIDS cases officially notified. For this type of virus, the major transmission category is heterosexual sex (73.3% of cases), followed by 16.5% presumably due to blood transfusions. Only 3.8% of the cases stem from injecting drug use.

One of the possible measures to fight the undernotification of HIV/AIDS cases is to classify HIV/AIDS as an obligatory notification disease. This possibility, which has led to heated debate in Portugal, could be a way for people living with HIV/AIDS to have access to medicines to fight opportunistic infections, since antiretroviral medication is already free of charge.

6. Access to health

Regarding access to health care, the Portuguese constitution and Portuguese legislation proclaim equality, non-discrimination and health protection. Foreign citizens have the same rights and duties in accessing the National Health Service. Their access is established in the Health Ministry Dispatch n. 25.360/2001 from December 12. It's necessary to obtain a 'user card' and, for that, foreign citizens must present a document proving the legality of their stay in the country. If they don't have such a document, they can also obtain a user card by proving with a certificate provided by the municipality that they have lived in the country for ninety days or longer.

The cost of using the health services is in accordance with the official price charts unless a foreign citizen can prove, through a social security certificate, that they live in great social and economic need. In the case of a transmissible disease threatening public health, such as HIV/AIDS and TB, services are provided free of charge. Services are also free of charge in maternal and child health vigilance and family planning.

Any person present on national territory, when feeling sick, in an emergency situation, has the right to be assisted in a hospital or health centre, regardless of their nationality, economic status and legal status. In case they are refused treatment they must immediately report this to the User Office (where people making use of the National Health Service can obtain information and file complaints) or to the High Commissioner for Immigration and Ethnic Minorities.

Although immigration law has changed, the law regarding asylum seekers and refugees remains the same (Law n. 15/98 from March 26). Asylum seekers living in social and economic need are provided with social support by the Portuguese state. They are also granted medical and therapeutic assistance according to the Health and Internal Affairs Ministry's decree n. 30/2001 from January 27. Asylum seekers and their direct family have access to health care services after they are granted a provisional permanence permit. They then have the same access as national citizens. Free access including diagnosis and medication is provided not only in urgent situations, but also in primary health care services. Although, according to the decree, access to the National Health Service ceases with the final decision on the asylum procedure, it can be prolonged if the medical evaluation of the asylum seeker's health status justifies it.

Portugal's political scenery has been marked not only by changes in the immigration law, but also in a new management vision developed by the Health Ministry, opening the management of health units to the private sector. This has sparked controversy between the government and medical staff. Migrants and human rights organisations also fear that this new regime will make it even more difficult for migrants to access the National Health Service. They fear that health care will become more expensive when privatised and people with higher incomes will have priority access to health care. According to the government, these fears are unfounded.

7. General AIDS policy

The incidence of HIV/AIDS in Portugal makes it clear that this continues to be a major concern for health policies in the country. In order to fight the epidemic in a broader way, the National AIDS Commission established priorities in a strategic plan for 2001-2003. Besides carrying out studies into HIV/AIDS in order to have a clearer picture of the country's situation, prevention and training are of utmost importance. Networks like Combined Therapeutic Centres (HIV and TB medication along with substitute drugs taken with clinical and psychosocial support), Centres for the early detection of HIV/AIDS (with voluntary, confidential and free of charge HIV testing) and the nationwide network for extra-hospital support for HIV positive persons are also priorities for the National AIDS Commission.

At this stage there are thirteen HIV screening centres throughout the country providing voluntary, confidential and free of charge HIV tests, but also pre and post test psychosocial support. Media campaigns were held advertising the centres in order to convince people to determine their HIV status, to prevent not only new cases but, also and not least important, reinfections.

8. HIV and discrimination

One of the main problems which were publicly disclosed at one of the meetings is the unethical HIV screening people undergo not only before they get a job but also when they already have one. There is yet a long way to go towards an ethical policy respecting people's constitutional protection from discrimination on the ground of health problems or physical disabilities.

HIV positive persons have the right to work under the same conditions as any other person suffering from a chronic disease. This principle is not often observed, since the stigma of HIV/AIDS makes the affected persons victims of discrimination. The fear of losing their jobs makes them even more vulnerable.

HIV positive persons in Portugal have the right to a retirement allowance granted by the social security service. Unfortunately, it is very low and insufficient for them to live normal, independent lives. The law concerning this allowance says that a person cannot receive it and meanwhile receive an income from working. This has led to dramatic situations with people not having enough money to live in dignified conditions, worsened by the fact that medicines use up a great part of the allowance.

9. Conclusions

Portugal is engaged in controlling the migration fluxes into the country and in creating conditions to receive and integrate migrants into Portuguese society. Legal migrants, if they are taxed for social security, have the right to social protection, unlike undocumented migrants. The situation of undocumented migrants is getting worse, since they don't have any official support.

The lives of migrants have always been and always will be the subject of heated political debate, regardless of the host country. There will also always be a segment of the population who understand the problems of migrants and a segment who will blame the country's problems on their presence. Especially at a time like this of national and international economic recession, the massive presence of migrants can be perceived as a threat to the Portuguese-born citizens, since they are competing for jobs while unemployment rates are rising.

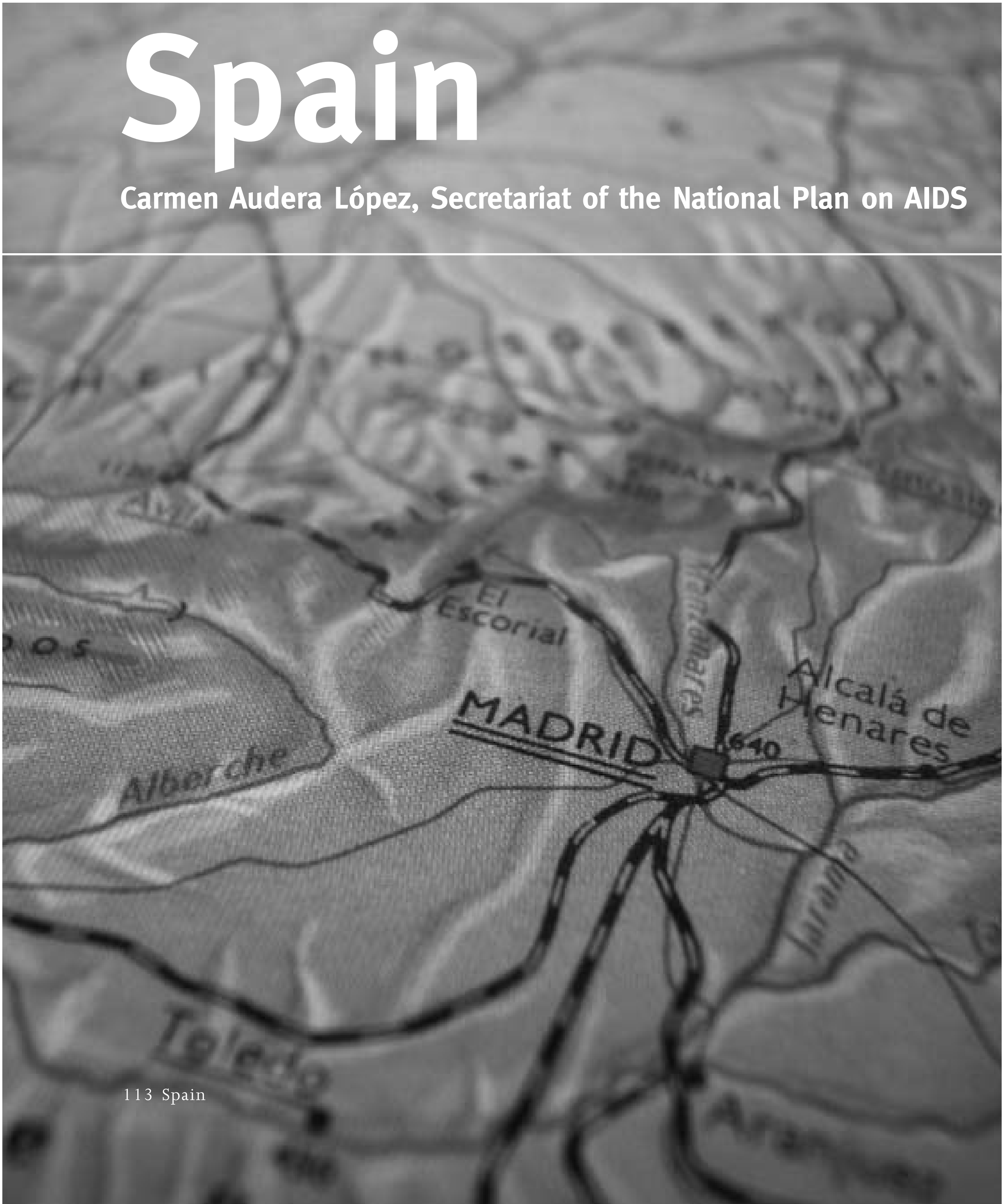
From the point of view of migrants, there is no real health policy for migrants. What can be observed is the existence of projects implemented by NGOs to see to needs that are not looked after by the state, as for instance homecare support for undocumented HIV positive migrants. Often these solutions are provided in restricted geographical areas, so there is a limited number of beneficiaries. If there were a health policy for migrants, nationwide measures could be implemented in an integrated way involving all the ministries.

Twenty years after the discovery of AIDS, HIV positive people still fear that if they disclose their health status they will lose their jobs. Their retirement pay isn't high enough to allow them to live economically independent lives. People who want to buy a house exceeding a certain price are obliged by banks to take life insurance, which entails an HIV test. The situation is worsening for migrants, and particularly for undocumented migrants who often have no family support or any source of income to face health needs.

The existence of services to inform migrants and to help them integrate can be seen as a good measure. But the immigration law, although it relieves the situation of legal migrants, does not allow undocumented migrants to regularise their situation, leaving them in tragic living conditions. Also, the government's intention of opening the management of health units to the private sector is regarded with concern by migrants.

Spain

Carmen Audera López, Secretariat of the National Plan on AIDS



1. Basis for the preparation of this report

This report is based mainly on the contents and results of the 4th National Work Meeting on HIV/AIDS in Migrants and Ethnic Minorities, which took place in Madrid in December 2002. Migrant associations, NGOs working in the field of HIV/AIDS and government institutions working in HIV/AIDS prevention and treatment in Spain were represented at the meeting. The Secretariat of the National Plan on AIDS (SPNS) has been the National Focal Point for Spain in the European Project AIDS & Mobility since 1998. The SPNS is a governmental department that was created in 1983 within the Ministry of Health and Consumer Affairs, with the task of coordinating the various governmental institutions in the fight against HIV/AIDS.

Since 1998, Spain's migrant population has been a priority concern for the SPNS. The strategy followed so far by the SPNS has been not to create special HIV/AIDS prevention or care programmes for migrants but to ensure that migrants have adequate access to, and are able to benefit from the existing national prevention programmes and health care system. For this to be possible, these programmes and health structures have to be adapted to the specific needs of the different migrant populations. Although the provision of adequate prevention programmes and health care for everybody is the responsibility of governments, the adaptation mentioned above requires close collaboration between government institutions and civil society.

The cultural, social and legal barriers that migrants face when accessing the existing health structures and the question of how to adapt these structures to their needs were addressed in two roundtable discussions at the National Work Meeting. The first discussion was about the interaction and cooperation between migrant associations and NGOs working in the field of HIV/AIDS. The second discussion was about access to prevention and treatment, from the community setting to the hospital level. The outcome of these discussions has been the material used for the elaboration of this report. The report also uses the discussion of the other topics presented at the meeting, such as SPNS activities regarding HIV/AIDS and migrants, characteristics of immigration in Spain and epidemiological surveillance data of HIV/AIDS among immigrants.

2. The growth of migrant populations in Spain

Spain has been, until very recently, a country of emigration and not a recipient of immigrants. The few foreign people who came to live in Spain before the 1990s were mainly from Northern European countries and came to enjoy their retirement. The number of people coming to live in Spain from countries other than the Northern European countries – mainly from developing countries – has greatly increased over the past few years. Four times as many people from developing countries currently live in Spain as was the case in 1995. According to the Ministry of Internal Affairs there were 1,243,919 foreign residents in Spain in 2002 (about 3% of the total population). Of these, 388,217 come from developed countries and 871,892 come from developing countries. About a quarter of foreign people living in Spain come from the European Union, another quarter come from Africa and another quarter from South America.

Around 170,000 foreigners who have already obtained Spanish nationality and about 400,000 more people who are at present illegal but in the process of legalising their situation have not been included in these figures. The estimated number of foreign people living in Spain is, therefore, around 1,813,919 (4.5% of the overall population).

This marked increase in the number of foreign people coming to live in Spain over the past few years has provoked alarm and xenophobia among certain segments of society. However, if compared to the rest of Europe and taking the estimated 5%, Spain has not surpassed the European average and we are far behind countries such as Luxembourg, Austria, Germany and Belgium.

3. Demographics of migrant populations

Age distribution of the migrant population in Spain varies according to the country of origin. Migrants from developed countries are older, about half of them being over 45. Migrants from developing countries are much younger, the bulk being in the age range of 25 to 45. Overall, 55.6% are males but this percentage varies according to the country of origin. Among Western Europeans and North Americans the proportion of men and women is equal. Among South Americans there is a marked predominance of females (56%). Among Africans there is a marked predominance of males (69%). The majority of migrants who are of working age are employed and have a health status above average. Approximately 75% of their income is spent in Spain and about 25% is sent to their countries of origin. A study carried out by the Colectivo IOE found that when asked about perceived discrimination, migrants stated that looking for a place to live ranked in the first place followed by access to work. When asked which official structures they trusted, the public health system came in first place followed by the educational system.

4. Epidemiology of HIV/AIDS among people with a country of origin other than Spain

Spain's National AIDS Registry collects data on people's country of origin. This is the only variable that we can use to estimate the AIDS incidence in migrants and mobile populations. The cumulative number of reported AIDS cases in Spain since the beginning of the epidemic up to June 2002 is around 65,000 people, 1,457 of whom reported countries of origin other than Spain. Of these, 568 (39%) came from Europe, 392 (27%) from America (34 from the United States and the rest from Central and South America), 307 (21%) from sub-Saharan Africa, 127 (9%) from North Africa, 49 (3%) from Asia, 4 from the Australian Continent and 10 were not specified.

The annual incidence of AIDS cases in persons whose country of origin is not Spain has undergone great changes since the beginning of the epidemic. From 1993 to the present time there has been a continuous increase, in contrast with the decline in the number of new cases in the total population of Spain (figures 1a and 1b). This upward trend is observed in people coming from all regions except Asia (figure 2a). Within Europe, people whose county of origin is Portugal account for the greatest increase in the past few years and within Africa, the greatest increase stems from persons from sub-Saharan countries (figure 2b). In 2002, 9.6% of new AIDS cases occurred in persons whose country of origin is not Spain, compared to 1.2% in 1992 (figure 3). In spite of this increase in the proportion of new AIDS cases in persons coming from other countries, Spain continues to be the European country with the lowest proportion of cumulative AIDS cases in migrant people since the beginning of the epidemic (2.7%). The AIDS epidemic in Spain has always been considered an autochthonous epidemic.

The rate of new AIDS cases in the overall Spanish population clearly went down in 1996 with the introduction and universal availability of highly active antiretroviral drugs. It has continued to decline gradually since then. The rate among persons with a country of origin other than Spain has not declined and seems to remain the same as in previous years (although these rates must be interpreted cautiously since the denominator, which takes official numbers, is not always accurate for migrants) (figure 4). One of the reasons why a proportionally higher number of migrants have AIDS compared with native Spaniards could be that a high proportion of HIV positive migrants are not benefiting from treatment before the appearance of AIDS. Among migrants diagnosed with AIDS, 69.9% of migrants from developing countries and 48.2% of migrants from industrialised countries were diagnosed with HIV less than a month before their AIDS diagnosis, compared to 34% of native Spaniards diagnosed with AIDS.

The distribution of AIDS cases according to infection mechanism in migrants diagnosed with AIDS in Spain does not differ from that in their country of origin except among persons from North Africa, where about half of all cases occur in injecting drug users and that practice is not common in their country of origin (figure 5).

There is no national HIV registry in Spain. An HIV surveillance system has been set up in three Autonomous Communities (administrative divisions of Spain). All HIV positive persons attending any medical centre for any reason will be registered. HIV diagnosis in persons whose country of origin is not Spain remained below 10% until 1997. In the past years, however, a marked increase both in percentage and absolute numbers of new HIV diagnoses in people with a country of origin other than Spain has been observed, reaching 25% of all new HIV diagnoses in 2001. Sixty-four percent of these HIV-diagnosed migrants acquired HIV through heterosexual practices and 27% were bisexual or homosexual men. Data analysed for the first semester of 2002 points towards an even higher percentage for this year.

5. Activities of the SPNS concerning HIV/AIDS and migrants

Here follows a summary of the activities related to migrant populations carried out by the SPNS since 1998.

- The SPNS has carried out an epidemiological surveillance of HIV/AIDS in subjects with a country of origin other than Spain and has published the results.
- The SPNS has transferred additional ear-marked funds to Autonomous Communities and has elaborated guidelines for prevention priorities. These guidelines cover immigrants and ethnic minorities.
- The SPNS has provided technical and financial support to HIV/AIDS prevention projects for immigrants. Every year, the SPNS issues a public call for grant applications by NGOs or migrant associations for nationwide HIV prevention. Since 1998, the SPNS has prioritised projects aimed at or including migrant populations presented by migrant associations or NGOs. NGOs working in the fields of AIDS, sex work, injecting drug use, and so on, are encouraged to adapt their existing programmes to the specific needs of migrant communities. Although only five of the fifty-three projects financed by the SPNS in 2002 directly targeted migrants, other financed projects from AIDS-related NGOs include migrants in their target groups.
- The SPNS has carried out campaigns for the prevention of HIV/AIDS in different languages targeted at migrant populations. The first campaign was initiated two years ago. Materials were distributed nationwide in French, English, Arabic, Portuguese and Spanish. In 2002, the same materials were reissued and were also made available in Chinese, Russian and Polish. The materials consist of pamphlets, bookmarkers, calendars, stickers, postcards and posters.
- The SPNS has strengthened national and international networks of organisations of peo-

ple working in HIV/AIDS prevention among immigrants and ethnic minorities by acting as National Focal Point for AIDS & Mobility, organising national meetings, financing exchange visits between migrant associations and AIDS-related NGOs to encourage cooperation between them, etc.
- The SPNS has published reports and books and has run a webpage about HIV/AIDS among migrants.

6. Legislation with regard to immigration and HIV/AIDS

In principle there is no law restricting immigration to Spain as a measure to protect public health. However, in some instances a medical insurance has been a prerequisite for obtaining a visa in the country of origin and for this medical insurance some insurance companies require an HIV test. If the HIV test result is positive, the insurance company does not cover that person and the visa is denied. Spain does not issue a stay permit in case of proof that a treatment that is required for a life-threatening condition is not available in the country of origin. Although legally it would be an offence to discriminate against an HIV positive person applying for a job or looking for a place to live, the possibility exists that this would happen.

7. Health issues among migrants in Spain

Traditionally, migrants have been considered as young, healthy people. Although this is true for the majority of newly arrived immigrants, the situation may change with the length of their stay as well as with the arrival of family members coming to join them. Moreover, immigrants cannot be considered as a homogeneous group. This means that although some interventions can have similar approaches, these strategies will need to be adapted to the different needs. There are, however, a number of common aspects shared by members of different communities.

- They may present a number of specific pathologies, such as tropical diseases, that require specialised medical assistance.
- There is an increased vulnerability to certain physical or emotional pathologies caused by the migration process.
- There are a number of interrelated factors such as an illegal situation, poor working conditions, a low income, poor living conditions and so forth which enhance the risk of social exclusion and could generate a number of health problems.
- The need to solve immediate first-need situations puts health issues in a non-prioritised position.
- In many instances migrants lack understanding of the health system in Spain, which is often very formal compared to the health system in their countries of origin. The latter is often based on hospital and emergency assistance rather than on primary care and prevention programmes. There are also different ideas about health in different cultures, with different attitudes towards seeking health care.

8. Access to the Spanish health care system

Neither Spanish civil society nor its institutions were fully prepared for the growing number of immigrants to Spain since the start of the 1990s. In view of the increasing relevance of the issue of immigration in Spain, the Ministry of Labour and Social Affairs created the Institute for Migration and Social Services (IMSERSO) in 1997. Health issues became more and more important, not only for migrant communities, but also for governmental institutions and their legislative representatives. A new Law on the Rights and Liberties of Foreign Citizens was proposed and approved by Parliament. The current Law on the Rights and Liberties of Foreign Citizens, approved on December 22, 2000, states the following:

1. Foreign citizens living in Spain and registered in the census of the town where they live have the right to health care under the same conditions as Spanish citizens.
2. Foreign citizens have the right to emergency health care and follow-up till discharge independently of the cause of the accident or medical condition.
3. Foreign citizens under the age of 18 living in Spain have the right to health care under the same conditions as Spanish citizens.

HIV/AIDS testing in Spain is confidential and free of charge for anybody demanding it. Antiretroviral treatment as well as all the diagnostic tests performed for an appropriate follow-up are also available free of charge for every person requiring it. The only requirement for migrants to have access to free health care is to register in the town census. Migrants do not need to have formalised their legal situation in order to register. They will be asked to present their passport and the contract for rent of the house where they live. If they are not renting the house they will need signed acceptance from the person renting or owning the house. There are a number of NGOs such as Medicos del Mundo (Doctors of the World) and the Spanish Red Cross that help migrants through the process of registering and accessing the public health system.

Although this new law has theoretically enabled many migrants to benefit from free HIV/AIDS treatment and care, there are still a number of unsolved barriers to adequate health care.

9. Barriers to adequate health care

Barriers to adequate health care are not exclusive to the immigrant population. There are internal and external barriers. Internal barriers may arise during the process of decision making in a person seeking health care. Depending on the perception of health and disease and what is considered normal, the decision of whether or not to seek care may be different from what the health authorities consider as necessary. These differences in perception are more evident among immigrants but also occur often among Spanish people. It can also happen that someone does not seek health care because there is a lack of information on what the health system offers. In the case of migrants, the decision of not seeking care could be a consequence of fear of being identified when using government institutions if they have an illegal status in Spain, fear that it will cost them money that they don't have, fear of losing jobs if medical visits are within working hours, fear of being unable to understand treatment or to communicate, etc.

Once people decide to seek health care, they may run into external barriers. These may be administrative barriers, when people have insufficient knowledge about the Spanish public health system and administrative procedures. They may be legal barriers, if people have not registered in the town census and applied for their health card. They may be communication barriers, arising from differences in language but also from different sexual standards and a lack of written material in different languages. They may be cultural barriers, when there is no culturally adequate health care environment and when advice given by health professionals conflicts with cultural prescripts. They may be barriers resulting from the type of relationship between health professionals and affected people; the length of time spent with affected people to listen to them and to be able to explain the diagnosis and treatment properly, xenophobic attitudes, and so on. Mutual understanding between affected persons and health professionals is vital given the length and complexity of antiretroviral treatment regimes and the inherent difficulty of adherence. External barriers may give rise to 'secondary internal barriers': internal barriers arising from the experience of external barriers.

In order to circumvent these internal and external barriers, interventions should take place at both the community level and the health care system level. At the community level, interventions will be aimed at those people not benefiting from HIV/AIDS prevention programmes and the health care system. At the health care system level, interventions will be aimed at reducing the external barriers and avoiding secondary internal restrictions.

10. Employing migrant community members as health mediators

Both civil society and government institutions have identified the need of trained people to act as links between migrants and the health care system. The activities of these professionals, ideally from ethnic minority origins, should take place both at the community level and in health care centres (primary health care, hospitals, etc). Their role would be to supply clear information about prevention and access to the health care system, accompany migrants in the process of accessing the health care system, act as interpreters, provide health professionals with information about the situation of the migrant, support HIV positive migrants at the community level so they are not rejected by community members, support them in their adherence to treatment, and provide or help provide appropriate psychological and family support. There are already some examples of initiatives in which migrant community members are being trained to act as mediators at different settings. We will present some of these initiatives, which were discussed at the 4th National Work Meeting on HIV/AIDS in Migrants and Ethnic Minorities.

10.1 HIV/AIDS prevention in migrant populations: Health promotion strategy based on peer education. An example of health mediation with migrant populations

The objective of this project is to design, implement and evaluate a community work strategy based on peer education, that is training migrants to educate other migrants, which would be useful in HIV/AIDS prevention in different migrant communities in Madrid. Target populations are communities from Morocco, the Dominican Republic and sub-Saharan Africa. The migrant educators follow a training programme in which they are taught about subjects including infection mechanisms, risk behaviours, prevention, diagnosis, treatment, counselling and support, STDs, sexuality and gender inequalities. The training also addresses techniques for identifying appropriate places for intervention and the question of how to plan different activities. From January to June 2002 a total of 184 individual interventions took place and group interventions reached 501 persons. The methodology has proven to be effective in reaching a large number of people. The information given is received positively, since everything takes place within the community and in an everyday environment.

10.2 Training course on social health intercultural mediators for citizens of foreign origin and ethnic minorities

The town council of Madrid has also created a series of training courses for people in disadvantaged situations (migrants, young people and women) to help them pursue a professional career. One is a 300-hour course entitled 'Social health intercultural mediators for citizens of foreign origin and ethnic minorities'. The objective of this course is to train people to act as social health mediators for migrants at health centres. The mediators support health professionals who treat people from other countries, accompany foreign people accessing the health system, inform them about the different services available, help with paperwork and administrative issues, act as interpreter and translator, coordinate with the external social services and facilitate the approach between native Spaniards and people of foreign origin. Sixty people are currently enrolled in the course, which has just started.

10.3 Community health agent programme

In Barcelona, a group of health professionals at the Tropical Medicine Centre Drassanes have incorporated community health agents into their clinic and are advocating a similar approach for other health centres. Although Drassanes has a very high proportion of migrants seeking health care for STDs, the community health agent programme will not be focused exclusively on HIV/AIDS but will cover all aspects of health. A community health agent is preferably a member of the community who becomes part of the health team. The agent acts as a link between the health system and the community in order to improve the flow of information about initiatives and resources in both directions and to promote and implement health promotion actions from each side or in combination. Community health agents share certain similarities with other professionals such as cultural interpreters, translators and health promotion agents. However, their role goes beyond these activities. Their job includes three dimensions: socio-cultural, health and community. The socio-cultural dimension includes translation, interpretation, cultural mediation, analysis of the structure and practical issues of health services (place, working hours, administrative procedures), analysis of health promotion programmes in order to detect aspects that could pose problems to the community, etc. The health dimension includes activities aimed at improving health information and at helping people develop skills to reduce individual and community vulnerability to HIV/AIDS. The community dimension includes activities aimed at strengthening community networks in order to reduce the vulnerability of community members. The experience with community health agents in Drassanes, although still too recent to have produced measurable results, is proving satisfactory and many other primary health centres are supporting the initiative and show an interest in incorporating community health agents into their staff.

11. Conclusions and recommendations

Although Spain has been the European country affected the most by the HIV/AIDS epidemic, and has had for many years the highest prevalence (only recently surpassed by Portugal), the epidemic curve reached its peak in 1996. There has since been a decline both in the number of AIDS cases and in the number of new HIV diagnoses. The smaller number of AIDS cases was a clear consequence of the availability of highly active antiretroviral therapy. The smaller number of new cases is due mostly to the fact that the main infection mechanism in Spain, injecting drug use, is no longer a popular practice here. Credit must also go to the various prevention campaigns and healthy sexual behaviour promotion programmes that have taken place. However, this epidemic pattern is not observed among migrant populations. In the past years an increase in the total number of AIDS cases among migrants has occurred.

There are a number of possible reasons for this increase: an increase in the number of immigrants; an increase in the proportion of immigrants coming from countries with a high HIV/AIDS prevalence; the situation of social and economic disadvantage which most migrants suffer at least upon arrival; the adoption of risk practices that they did not engage in in their country of origin (such as prostitution and injecting drug use); the lack of adequate access to prevention programmes, to early diagnosis and to treatment of STDs.

Both government institutions and civil society are concerned with the current situation of the HIV/AIDS epidemic among migrants in Spain, and although a series of activities are already being carried out, we cannot claim that the epidemic is under control. Much more needs to be done. The main areas of concern that were brought forward during the 4th National Work Meeting on HIV/AIDS in Migrants and Ethnic Minorities were the following:

1 Migrant associations and other NGOs claim that the Spanish immigration law needs to be reviewed so that the process of regularising the administrative situation becomes clearer, working permits are granted more easily and working conditions for immigrants are improved. This improvement in legal status would automatically translate into an improvement in living conditions and health.
2 Although the AIDS epidemic in Spain has been, up to now, an indigenous epidemic and AIDS has not been associated in a negative way with the immigration phenomenon, measures must be taken to prevent this from happening.
3 The information gathered by the national HIV/AIDS surveillance system is useful to identify possible needs for interventions. However, care must be taken to avoid misuse of data about HIV/AIDS among migrants. The Spanish HIV/AIDS surveillance system lacks some important variables, such as ethnic background, thus missing information on HIV/AIDS among Spanish Roma people. The system doesn't record the possible country of infection or the date of arrival in Spain, either, so it is not easy to determine whether infection occurred before or after a person came to live in Spain.
4 Migrants should be able to benefit from existing HIV/AIDS prevention structures rather than having to rely on parallel systems. For this to happen, HIV/AIDS prevention programmes need to be adapted to the situation of the different migrant populations. The information needs to be culturally appropriate and available in different languages for those who have recently arrived and do not speak Spanish yet. The role played by social/cultural/health mediating services, which are being gradually set up in some big cities, is essential in detecting specific needs in the communities and situations of special vulnerability.
5 Similarly, educational programmes for children and adolescents at schools need to speak to the culture and beliefs of immigrant children with examples of situations from different cultural settings. The programmes should be the same for all children in order to avoid discrimination. At the same time, they should give Spanish children the opportunity to learn about the cultural backgrounds of their classmates.
6 Although the vast majority of migrants have access to free health care irrespective of their legal status, migrant populations make insufficient use of the health care system or use it in the wrong way. Trained professionals acting as mediators have proven to be essential for improving access to HIV/AIDS-related existing structures. They help migrants resolve their doubts, help them dispel their fears regarding identification and, ultimately, they can refer migrants to those centres or facilities where they can be assisted. Moreover, they have an important task in raising awareness among health professionals of the reality of migrant situations, which will favour mutual understanding. The need for mutual understanding is particularly pressing for those people living with HIV who are accessing the antiretroviral treatments, due to the complexity of the drugs administration regime.
7 Interventions to improve the access of immigrants to HIV/AIDS prevention and treatment should be a result of collaboration between government institutions and civil society (NGOs, migrant associations, community-based associations, etc). NGOs should not take over the government's responsibility to provide adequate HIV/AIDS prevention programmes and health care to migrants, but should collaborate with the government in planning and implementing the strategies. The role of migrant associations in the

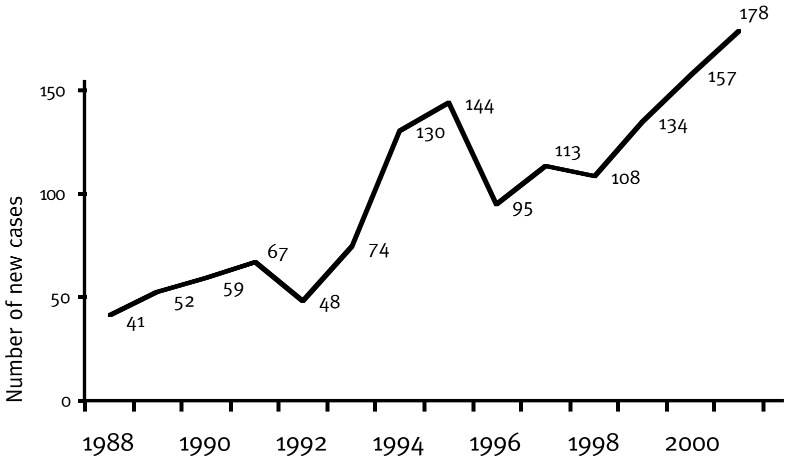
design and implementation of HIV/AIDS prevention programmes is essential for adapting the different programmes to the needs and the reality of migrant populations and for finding mechanisms to deliver health information. A close collaboration between migrant associations and HIV/AIDS-related NGOs is highly encouraged by the SPNS, although this is not always easy to achieve as became clear in the discussions held during the work meeting. Migrant associations claim that they are underestimated by NGOs working in HIV/AIDS and that they are only called when needed for very specific themes but not for an ongoing collaboration. NGOs, on the other hand, claim that they often try to involve migrant associations in their projects but do not receive a response from them.

8 Lastly, there is a need for research into new approaches and strategies to improve access to information about HIV/AIDS prevention and care.

12. Acknowledgements

Thanks to all the participants in the 4th National Work Meeting on HIV/AIDS in Migrants and Ethnic Minorities, especially those who presented their work at the meeting: Jesus Castilla (SPNS), Colectivo IOE, Anna Rodes (SPNS), Maria Jose Belza (SPNS), Thomas Holbrook (Comisión Ciudadana Antisida de Bizkaia), Norberto Masa (Asociación Cultural Colectivo de Inmigrantes Independientes), Cristina Menoyo (SPNS), Marisa Martínez (Instituto de Salud Carlos III), Andrés Hervás/Delvis Juan Ramírez (Itinerario Integrado de Inserción Socio Laboral, Ayuntamiento de Madrid), Concha Colomo (Area de Salud y Consumo Ayuntamiento de Madrid), Carme Ollé (Centro de Asistencia Primaria Drassanes), Elena del Cacho (Servicio de Farmacia Hospital Clínico de Barcelona), Jesús Edison Ospina Valencia UMTIVI-ACSAR. Special thanks to Cristina Menoyo and Monica Suarez for their critical reading of the document.

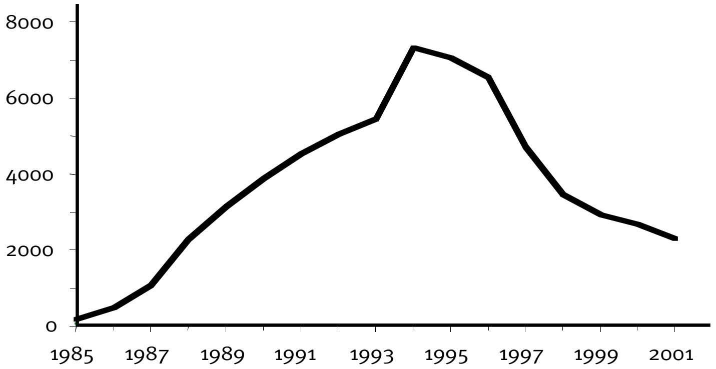
Figure 1a. Number of new AIDS cases in persons whose country of origin is not Spain



	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Number of new cases	15	28	41	52	59	67	48	74	130	144	95	113	108	134	157	178

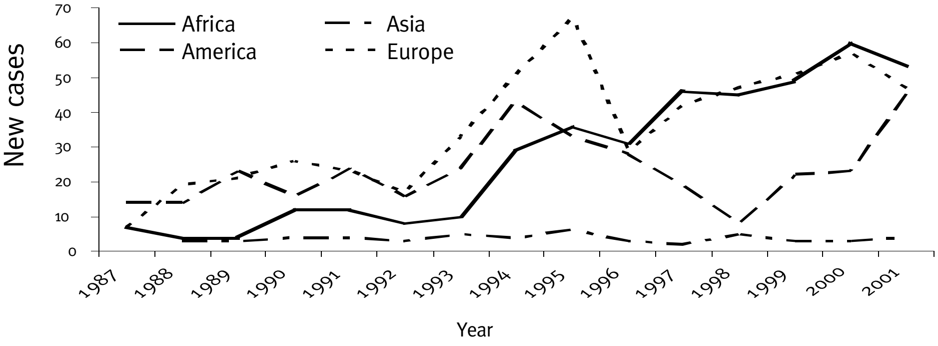
Source: National AIDS Registry, Centro Nacional de Epidemiologia, Madrid

Figure 1b. Number of new AIDS cases in Spain



Source: National AIDS Registry, Centro Nacional de Epidemiologia, Madrid

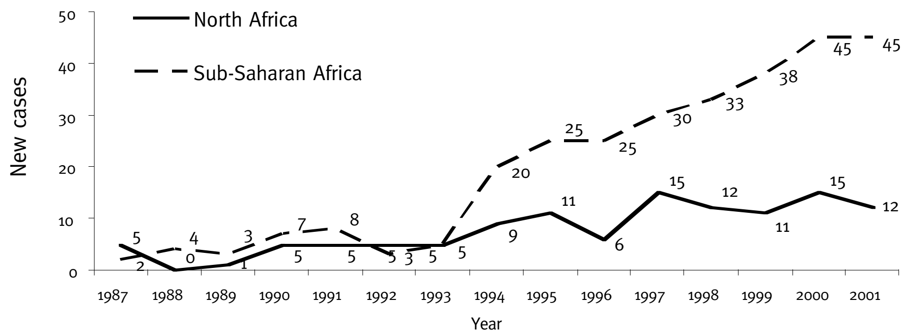
Figure 2a. Trend in AIDS cases according to region of origin



	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Africa	3	7	4	4	12	12	8	10	29	36	31	46	45	49	60	53
Asia			3	3	4	4	3	5	4	6	3	2	5	3	3	4
America	5	14	14	23	16	24	16	24	43	33	28	19	8	22	23	45
Europe	7	7	19	21	26	23	17	33	51	67	29	42	47	51	57	47

Source: National AIDS Registry, Centro Nacional de Epidemiologia, Madrid

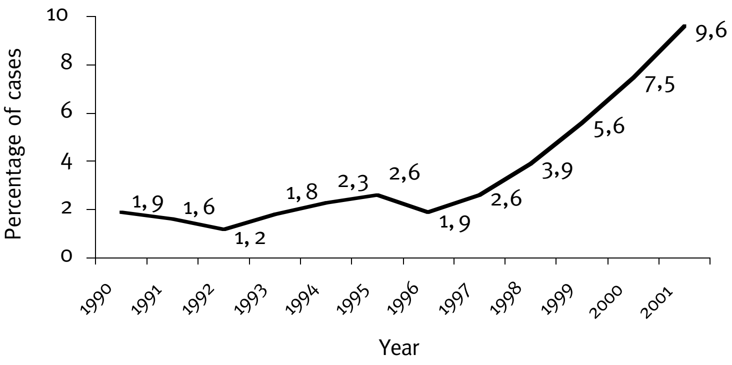
Figure 2b. Trend in AIDS cases in persons with a country of origin in Africa



	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Africa	3	7	4	4	12	12	8	10	29	36	31	45	44	41		
North Africa	1	5	0	1	5	5	5	5	9	11	6	15	12	11	15	12
Sub-Saharan Africa	2	2	4	3	7	8	3	5	20	25	25	30	33	38	45	45

Source: National AIDS Registry, Centro Nacional de Epidemiologia, Madrid

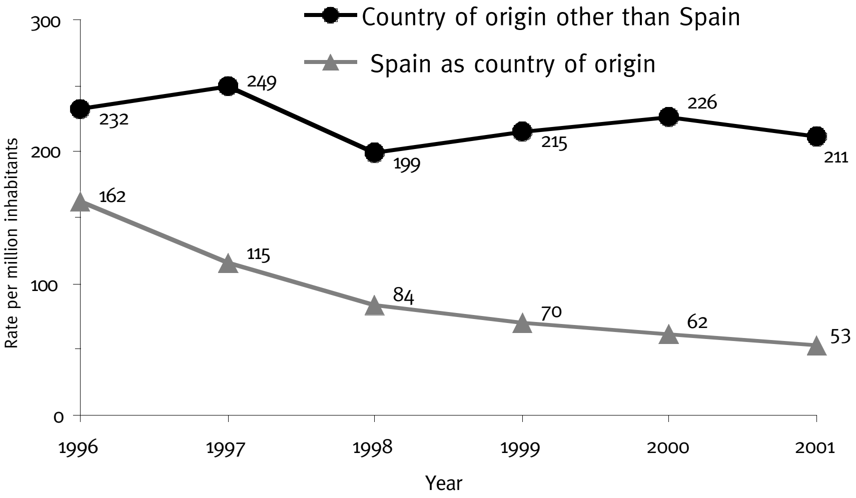
Figure 3. Percentage of AIDS cases in Spain in persons with country of origin other than Spain



	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
%	3.2	2.8	1.8	1.8	1.9	1.6	1.2	1.8	2.3	2.6	1.9	2.6	3.9	5.6	7.5	9.6

Source: National AIDS Registry, Centro Nacional de Epidemiologia, Madrid

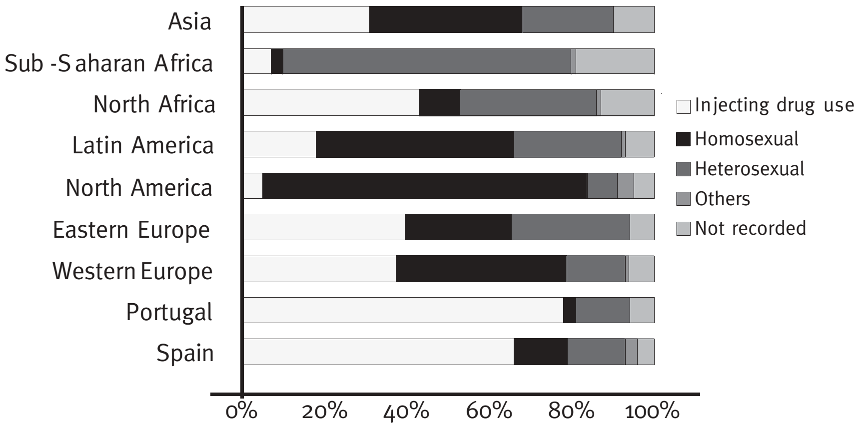
Figure 4. Trends in AIDS rates among persons with a country of origin other than Spain



Year	Country of origin other than Spain	Spain as country of origin
1996	232	162
1997	249	115
1998	199	84
1999	215	70
2000	226	62
2001	211	53

Source: National AIDS Registry, Centro Nacional de Epidemiologia, Madrid

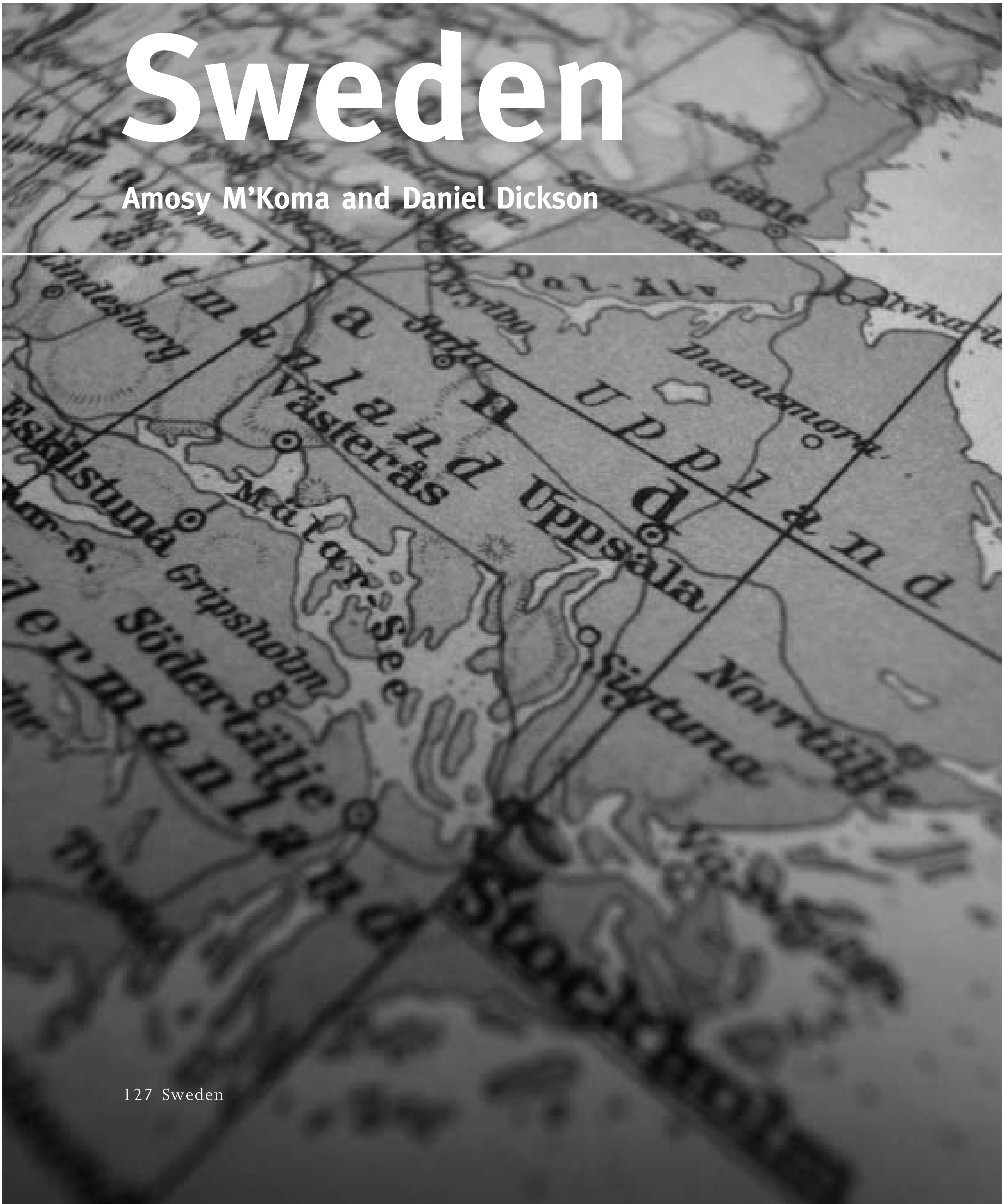
Figure 5. Infection mechanism according to country or region of origin



Source: HIV/AIDS Epidemic 2001, Centro Nacional de Epidemiologia, Madrid

Sweden

Amosy M'Koma and Daniel Dickson



1. Background

This report was written with references from governmental and non-governmental organisations, municipalities, county councils, educational institutions and immigrant associations receiving funds from the National Institute of Public Health for HIV/AIDS prevention targeting immigrants and refugees. HIV positive migrants were closely incorporated. Epidemiological data was taken from the Swedish Institute for Infectious Disease Control (SMI).

The report was written by Dr Amosy M'Koma from the NGO the African Health Team and Mr. Daniel Dickson, consultant, at the request of the National Institute of Public Health (the Swedish National Focal Point). The authors are responsible for the content of the report.

2. Migration patterns

Immigrants from highly endemic areas came to Sweden during the 1990s mainly from war zones of sub-Saharan Africa (Uganda, Somalia, Ethiopia and Eritrea). In 2001, asylum seekers in Sweden came mainly from Iraq (6,206 asylum seekers), the Federal Republic of Yugoslavia (3,102), Bosnia-Herzegovina (2,775), Russia (840), Iran (780), El Salvador (618) and Afghanistan (593).

3. Epidemiological data

Table 1. Total number of HIV notifications in Sweden per year up to 2001, by route of transmission and gender

Likely route of transmission	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	Total
Sex between males	704	184	159	141	113	110	100	118	100	88	70	77	89	59	73	66	2,251
Sex between males and females	73	101	88	109	170	176	209	231	120	118	114	112	120	113	122	143	2,119
Males	43	60	45	54	102	76	109	110	61	61	58	61	57	49	61	58	1,065
Females	30	41	43	55	68	100	100	121	59	57	56	51	63	64	61	85	1,054
Injecting drug users	345	98	45	45	44	30	27	26	29	19	22	26	17	16	16	38	843
Males	240	77	28	32	33	19	16	16	23	13	15	17	14	13	14	27	597
Females	105	21	17	13	11	11	11	10	6	6	7	9	3	3	2	11	246
Blood/blood product	166	11	8	5	1	3	2	2	2	4	2	2	2	4	3	1	219
Males	130	8	5	5	0	1	2	2	1	0	1	1	0	0	1	1	158
Females	36	3	3	0	1	2	0	0	1	4	1	1	2	4	2	0	61
Mother to child	1	4	2	0	4	8	6	3	6	7	6	4	4	3	7	0	65
Males	1	2	0	0	2	6	4	1	4	3	1	2	2	2	1	0	31
Females	0	2	2	0	2	2	2	2	2	4	5	2	2	1	6	0	34
Others/unknown	1	0	2	5	3	0	5	8	1	12	10	19	17	16	21	22	142
Males	1	0	1	4	2	0	4	6	1	7	5	8	6	10	9	13	77
Females	0	0	1	1	1	0	1	2	0	5	5	11	11	6	12	9	65
Total	1,290	398	304	305	335	327	349	388	258	247	224	240	249	211	242	271	5,639
Males	1,119	331	238	236	252	212	235	153	190	172	150	166	168	133	159	165	4,179
Females	171	67	66	69	83	115	114	135	68	76	74	74	81	78	83	106	1,460

Source: Swedish Institute for Infectious Disease Control (SMI)

A total of 271 cases of HIV were reported during 2001, an increase from the average yearly number of cases from the 1996-2000 periods (234). The increase seen during the second half of 2000 and the first half of 2001 did not continue during the second half of 2001. A total of 5,639 cases of HIV have been reported since 1985. Of these, 4,179 were males and 1,460 were females.

3.1 Sex between males

In 2001 a total of 66 new cases of HIV were reported where sex between males was cited as the route of acquisition. A total of 2,251 persons in this category have been reported as HIV positive until 2001, representing 40% of all the reported cases. Of these, 1,002 have developed AIDS and 742 have been reported dead [11, 12].

3.2 Sex between males and females

In 2001, 143 persons were reported to have contracted HIV through heterosexual contact, of whom 58 were males and 85 were females. Of these, 59 persons (42%) were of African descent [7, 11, 12]. Until 2001, a total of 2,119 persons (1,065 males and 1,054 females) have been reported as having acquired HIV through heterosexual activity. Of these, 1,199 persons (57%) came from Africa, especially from the highly epidemic sub-Saharan countries. A total of 452 persons (267 males and 185 females), have developed AIDS, and 204 have been reported dead [11, 12].

3.3 Injecting drug users

Thirty-eight injecting drug users (27 males and 11 females) were reported to have contracted HIV during 2001, compared to an average of nineteen cases per year reported during the past five years. The majority of these (25 persons) were reported from Stockholm. A total of 843 persons have been reported to have acquired HIV via injecting drug use, or through sex among injecting drug users. Of these, 597 were males and 246 were females. Among them, 201 have developed AIDS and 150 have died.

3.4 Age

The mean age at the time of diagnosis has remained stable for persons who have acquired HIV through heterosexual activity (35 years), for injecting drug users (38 years) and for persons who have acquired HIV through homosexual activity (36 years).

Table 2. Total number of AIDS notifications in Sweden per year up to 2001, by route of transmission and gender

Likely route of transmission	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	Total
Sex between males	78	51	61	89	91	86	78	91	108	94	69	25	23	24	21	12	1001
Sex between males and females	3	7	13	12	22	23	23	48	41	63	51	31	30	36	26	24	453
Males	2	6	8	7	12	14	17	30	27	38	32	14	12	22	13	14	268
Females	1	1	5	5	10	9	6	18	14	25	19	17	18	14	13	10	185
Injecting drug users	0	0	5	5	7	20	19	32	27	27	24	10	8	9	3	5	201
Males	0	0	3	4	6	15	16	24	16	22	18	9	6	4	2	4	149
Females	0	0	2	1	1	5	3	8	11	5	6	1	2	5	1	1	52
Blood/blood product	0	10	15	14	9	6	5	3	3	9	4	4	0	0	0	2	84
Males	0	7	11	10	9	6	5	3	2	3	2	2	0	0	0	1	61
Females	0	3	4	4	0	0	0	0	1	6	2	2	0	0	0	1	23
Mother to child	10	1	2	1	0	1	0	0	0	2	7	2	0	1	0	0	27
Males	9	0	1	0	0	1	0	0	0	0	4	2	0	1	0	0	9
Females	1	1	1	1	0	0	0	0	0	2	3	0	0	0	0	0	9
Others/unknown	0	0	0	1	1	1	1	1	2	3	1	5	2	4	4	4	30
Males	0	0	0	1	1	1	0	1	2	2	1	4	1	4	4	3	25
Females	0	0	0	0	0	0	1	0	1	1	0	0	0	0	0	1	4
Total	91	69	96	122	130	137	126	175	182	198	156	76	62	74	54	47	1,795
Males	89	64	84	111	119	123	116	149	155	159	126	56	42	55	40	34	1,522
Females	2	5	12	11	11	14	10	26	27	39	30	20	20	19	14	13	273

Source: Swedish Institute for Infectious Disease Control (SMI)

In 2001, 47 persons were diagnosed with AIDS in Sweden, of whom 34 were males and 13 were females. This is the lowest number of cases reported during the past ten years. Of these, nine persons were diagnosed with HIV and AIDS at the same time, which is not an increase over previous years.

Table 3. Total number of HIV notifications in Sweden by country of transmission between 1985 and June 2002

Likely country of transmission	Males	Females	Total	Share (%)
Sweden	2,384	495	2,879	50
Rest of Scandinavia	137	10	147	3
Rest of Europe	380	77	457	8
Africa	746	728	1,474	26
Asia214	133	346	6	
America	302	44	346	6
Oceania	9	1	10	0
Unknown	90	14	105	2
Total	4,262	1502	5,764	100

Source: Swedish Institute for Infectious Disease Control (SMI)

3.5 Other routes of transmission

Isolated cases of HIV acquisition by blood products have been notified each year, but since 1985, none of these persons have been reported HIV positive in Sweden. In 2001, no case of vertical transmission from mother to child has been reported either. In four HIV positive cases reported in 2001, it is impossible to establish whether the contraction of HIV occurred through sexual activity or through the medical services in these persons' countries of origin. Of the 26 persons with an unknown route of acquisition, three come from Sweden.

3.6 HIV screening of pregnant women

In 4 of the 21 Swedish counties there is selective HIV screening of pregnant women in high-risk groups. Generally, HIV testing is applied in the other counties, which represent 88.4% of the population (February 2001) [7, 11]. A total of 171 HIV positive women have been identified in this screening since the screening programme started in 1987. These 171 women had not previously tested positive for HIV. Ninety-nine women came from high epidemic areas in Africa. Thirty-four of the women were of Swedish origin. Of these, four were injecting drug users, one acquired HIV via blood transfusion, and 29 acquired HIV through heterosexual activity.

In 2001 nine women were identified as HIV positive in the screening. None of them were of Swedish origin; six came from sub-Saharan Africa and three from Asia [7, 11].

3.7 Swedes contracting HIV abroad

An increasing number of Swedish citizens are going abroad for work, studies or leisure. According to the Swedish Institute for Infectious Disease Control (SMI), in recent years a large proportion of Swedes who have contracted STDs or HIV heterosexually were infected abroad. This trend is likely to continue. People working for Swedish companies, institutions and NGOs receive education and information about HIV, especially when they are sent to highly endemic areas. The National Institute of Public Health has distributed brochures through vaccination centres and other channels. A few mass media campaigns have been targeting people travelling abroad.

4. Interventions and policies related to prevention and treatment

4.1 The National Action Plan for STD/HIV prevention

A coalition (National Action Plan for STD/HIV prevention in the period 2000-2005) [7] led by the National Institute of Public Health [7, 8] with AIDS experts from various governmental organisations, NGOs, foundations and institutions was launched to give greater attention to HIV/AIDS. The available statistics show that migrants are the next worst affected after men who have sex with men. The coalition calls for a multisectoral approach to preventing HIV/AIDS involving foundations, health actors, NGOs and community-based organisations (CBOs), since HIV can cause major complications both for the affected individual and for society as a whole.

The coalition is expected to coordinate the national efforts to reduce the rate of infections, to promote care and support for those affected by HIV, to reduce stigma and discrimination and to mobilise and empower communities, governmental organisations and NGOs (including organisations for people living with HIV/AIDS). The coalition is also to mobilise the private sector to respond effectively to the epidemic.

The National Institute of Public Health and a special Committee of inquiry into HIV/AIDS

(S 2002:11) are committed to HIV/STD prevention and health promotion among the migrant/refugee population living in Sweden.

Other important targets of the national policy include the reduction of HIV transmissions from mother to child, the reduction of HIV/STD prevalence among people aged 15-24, and general access to education, information and services. The initiative focuses on resource mobilisation, research and advocacy.

4.2 HIV testing policy

Since 1985, it has been possible to test persons for HIV. Testing is compulsory for blood donors and partners of HIV positive people, but is also readily available for anyone else wishing to be tested [1-3]. The health care system has encouraged testing and made it very easy for people to come on their own initiative. The test is free of charge and can be taken anonymously. HIV testing is also offered routinely at places such as STD clinics. Injecting drug users are within certain projects offered HIV tests when in custody or jail. All refugees and asylum seekers are offered a health check at asylum seeker centres or at health clinics where they are given the option to take an HIV test. The National Board of Health (Socialstyrelsen) [2] recommends HIV testing and counselling to be offered selectively to people coming from high epidemic countries and to people who have a history of sexual abuse. HIV testing is offered to all groups mentioned above, informed consent must be given, and participation in testing should be voluntary.

In 1986, Swedish STD clinicians decided on a national policy of offering HIV tests routinely to all their patients. From July 1986 through December 1994, 224,722 tests were performed [14]. HIV tests for one or more specific reasons were carried out on 7% of the patients and 20% requested the test solely because of anxiety. The remaining 73% accepted the test as part of the clinical routine without giving any specific reason. Of those offered a test, 54% had been tested at least once before. Twenty-three percent did not accept the test. Among those tested, 373 persons (0.2%) were found to have a newly detected HIV infection. Contact tracing was the reason for testing in 11%, 32% were tested for other specific reasons, 29% requested testing for no stated specific reason and 28% had been tested as a routine. Of all the tested men who reported sex with men, 7% proved to be HIV positive. The 373 persons with a newly detected HIV infection constituted 14% of all newly detected cases in Sweden during the period in question.

4.3 Information dissemination

The communities and/or social organisation networks of migrants are important sources for information dissemination. Community leaders are contacted for opinions and they help to organise their members for discussions on HIV/AIDS. Long-term work, for instance through schools, youth centres and NGOs, is of great importance.

Several persons, usually a group within an organisation where outreach has been carried out, are involved in discussions. Focus group discussions allow in-depth discussion on sensitive issues. Normally, the members are people of the same educational background, age, sex and/or religious belief.

Lively discussions are held on the radio in easy-to-understand language. Experts are invited to take part in the discussions. They involve interviews, where listeners can call in with their questions or comments. This kind of broadcast intervention is very effective and has been successful in some CBOs, such as the Arab Information and Cultural Centre (AICC) and The Gambian organisation.

Easy-to-understand pamphlets and folders with pictures on AIDS/STD issues are distributed by NGOs and CBOs. The brochures are specially designed for certain groups, for example young people, religious people, ethnic groups and the general public. These brochures are an important source for education and information.

There are also several governmental institutions and NGOs that produce information materials for migrants, among them the National Institute of Public Health, The Swedish Board of Health and Welfare, the Social and Welfare Office of the Malmöhus County, Stockholm City and the Stockholm County AIDS Prevention Programme (LAFA).

Besides the above activities, Community Youth Education (CYE) and sports clubs are also organised as a means to promote AIDS/STD education and awareness. Performers in drama/theatre, traditional singing and music are encouraged to inform audiences about HIV/STD and to distribute condoms. The most active group in organising CYE and sports to promote HIV awareness is the Somali Health Team in Rinkeby, a heavily populated migrant area north of Stockholm.

4.4 AIDS counselling

The provision of effective counselling for migrants regarding HIV/AIDS is an important goal in AIDS care. Health institutions offer pre-test and post-test counselling and advice to a large number of people. In some occasions they are complemented by migrant organisations (including the African Health Team, the Federation of Chilean Associations in Sweden, the Portuguese Immigrant Women's Organisation (PIKO), the National Organisation for Migrant Women and the National Federation of Immigrants in Sweden). Issues covered in counselling include how to cope with HIV positive or HIV negative status and with problems in interpersonal relationships. These talks can include almost anything: psychosocial, medical, religious, cultural and sexual issues.

With government grants, migrant organisations have developed three main forms of counselling services: (i) the chain method; linking seropositive people with each other to share experiences and support each other, (ii) the family arbitration method; using social and family issues as a means of discussing problems affecting HIV positive persons with their family and other relations and (iii) self-care activating support; using the experiential knowledge of seropositive persons and professional expertise to tackle psychosocial, medical and other problems connected with HIV infection.

4.5 Reaching migrants

CBOs reach their target populations through the following four means: (i) their members' participation in exclusively migrant cultural activities such as name-giving ceremonies, funerals and migrant-oriented festivals, (ii) contacts with migrant social organisations, churches and shops, (iii) the use of official channels such as refugee centres, hospitals, other health institutions and adult education institutions (information about sex and cohabitation issues, including HIV/AIDS, is integrated in the Swedish for immigrants adult training programme), and (iv) contacts with migrant-oriented Swedish aid organisations.

4.6 Access to treatment for asylum seekers

Asylum seekers are granted medical treatment only if it cannot be delayed. There are no general rules for what kind of treatment that is considered, but it is decided at the physician's discretion. However, according to the Communicable Diseases Act [1-4], treatment and medication for HIV and some other diseases are offered when it is appropriate. Asylum seekers younger than eighteen have the same right to medical care as Swedish citizens. This also applies to children visiting the country as tourists or undocumented immigrants. Adult tourists and undocumented immigrants do not have the right to check-ups or health care free of charge.

5. Undocumented immigrants and access to treatment

The number of undocumented migrants in Sweden has increased due to the large number of refugees whose request for asylum has been rejected as well as more people emigrating from Eastern Europe. Undocumented immigrants are vulnerable because they depend entirely on casual friends and acquaintances for help. In order to survive, many of them engage in activities that expose them to a high risk of contracting HIV. Undocumented immigrants of course have no health insurance, so their access to health care services is very limited.

It is not easy to reach undocumented immigrants because of their fear and mistrust for authorities and the uncertain circumstances under which they live. However, some NGOs have developed approaches that facilitate access to undocumented immigrants, including contacts with leaders of self-help or ethnic organisations and members' participation in exclusively migrant-oriented ceremonies such as name-giving and cultural festivities. An interesting insight NGOs have gained is that if an organisation wants to help undocumented immigrants it must be willing to provide better services to legal immigrants. Many legal immigrants have acquaintances who are in Sweden illegally, and the latter are likely to take seriously any recommendation made by the former.

HIV positive undocumented immigrants have developed AIDS because they were not entitled to antiretroviral triple therapy. They have been admitted to hospital on an emergency basis through NGO initiatives. The Federation of the county councils has discussed this issue and has recommended that each county council make a decision that antiretroviral treatment can be prescribed to undocumented immigrants with severe AIDS diagnosis.

5.1 Legal barriers

Hospitals usually have difficulties in treating seropositive people without a residence permit because treatment is only available to them in the case of acute illness. Occasionally NGOs arrange for physicians to attend to such individuals on an emergency basis. Apparently there is an ongoing discussion between politicians and hospital staff in different regions to find a common solution to avoid current ethical dilemmas regarding access to treatment for undocumented individuals. Some medical staff have encountered political constraints in their work because of migrants entering and living in Sweden illegally. For example, the African Health Team has to spend a good deal of time convincing local and national authorities that as far as HIV/AIDS prevention is concerned, the needs of this (undocumented and therefore non-existent) category of migrants have to be addressed as much, if not more, than the needs of other migrants.

Most CBO/NGO members see undocumented immigrants on a daily basis. CBOs dealing with undocumented immigrants provide counselling and refer them to other organisations and/or institutions which can offer them voluntary counselling and testing and treatment for STDs. But no official funding is available for this treatment. Several CBOs have shown immense capabilities in mobilising and engaging various individual CBOs/NGOs in the country.

Advocacy is an important aspect of counselling. CBOs fight for the rights of migrants of various ethnic origins regarding problems they face with house doctors and at hospitals. The fear and mistrust felt by undocumented immigrants and refugees towards authorities and the uncertain conditions under which they live make them vulnerable and eventually prone to contracting HIV and other diseases. Various CBOs have been able to reach unregistered immigrants and HIV positive people because their members participate in the activities of close-knit immigrant communities. The increase in the number of immigrants and Swedish institutions that NGOs have had contact with signifies the acceptance of the organisations among the migrant communities and the institutions.

5.2 Intermediary role

Statutory health institutions are complemented by CBOs, which serve as a bridge for migrants by referring them to doctors, midwives and other institutions where medical care can be offered. They can also promote communication and interaction between migrant CBOs and health institutions. In some cases, some personnel of CBOs must accompany patients to the hospitals to help improve communication between the doctor and the patient.

6. Conclusions

The National Action Plan for STD/HIV prevention in the period 2000-2005 accepted in Sweden evolved in accordance with the WHO directives for stopping the spread of infection. This is a national response and action towards the implementation of the Declaration of Commitment on HIV/AIDS.

The action plan includes multidirectional activities: training of staff; diagnostic facilities and research units; prevention of infection by sexual transmission, blood, needles and syringes. The action plan stresses development of prevention strategies directed to different vulnerable groups and human rights, care and support for HIV positive persons and people affected by HIV. Much attention is given to health education for vulnerable groups and for the population in general, especially adolescents. Health education is connected with prompting for the serological testing of HIV antibodies, which is principally voluntary.

Immigrant communities in Sweden have special health care needs, since they are experiencing language barriers, cultural differences and economic difficulties. Health care providers should be alert to these needs. Appropriate resources are required to address these issues in a timely fashion.

7. References

1. The Communicable Diseases Act SFS 1988:1422. Revised version SFS 1995:1315.

2. Strandell, A. & Dreber, A. (1995). Swedish National public health policy for STDs/HIV: Basis and principles. Stockholm: National Institute of Public Health.

3. Sylvan S., Gustavsson, M. & Christenson, B. (1999). Evaluation of the law of communicable disease control: Compulsory isolation can reduce the high-risk behaviour of HIV positive individuals. The Journal of Swedish Medical Association, 96, no. 28-29, 3244-7.

4. Hellström, L. (1992). Experiences with the new communicable diseases act: The limited obligation to report and demand for anonymity make protection against communicable diseases more difficult. The Journal of Swedish Medical Association, 89, no. 11, 881-2.

5. Declaration of commitment on HIV/AIDS. Global crisis--global action (2001). IAPAC Monthly, 7, no. 7, 209-16.

6. Reichman, L.B. (2001). Declaration of Commitment against HIV/AIDS. Lancet 358, no. 9295, 1818.

7. Rådö, G. (Ed.) (2001). The Swedish National Action Plan for STI/HIV Prevention 2000–2005. National Institute of Public Health.

8. Hansson, E.-M. (Ed.) (2003). Samlevnad och Sexualitet. Handlingsprogram för att förebygga aborter och sexuellt överförbara sjukdomar 1998-2003 (Relationships and Sexuality. Action Plan to prevent abortions and sexually transmitted diseases 1998-2003). National Institute of Public Health, Kalmar County Council.

9. World Health Organisation (1999). HEALTH21: the health for all policy work for the WHO European Region. European Health for All Series No. 6. Copenhagen: World Health Organisation, Regional office for Europe.

10. Berglund, T. (2000). Preliminära data från projektet "Epidemiologisk uppföljning av HIV-patienter" (Preliminary data from the project "Epidemiological follow-up of HIV patients"). Cooperation between the Swedish Institute for Infectious Disease Control and the National Institute of Public Health.

11. Swedish Institute for Infectious Disease Control (2002). Smittsamma sjukdomar 2002 (Infectious diseases 2002). Annual report from the department of epidemiology.

12. Dickson, D. & Forssman, E. (Eds.) (2001). Insatser mot STD/HIV: Projektkatalog 2001 (Measures against STD/HIV: Project specification 2001). National Institute of Public Health.

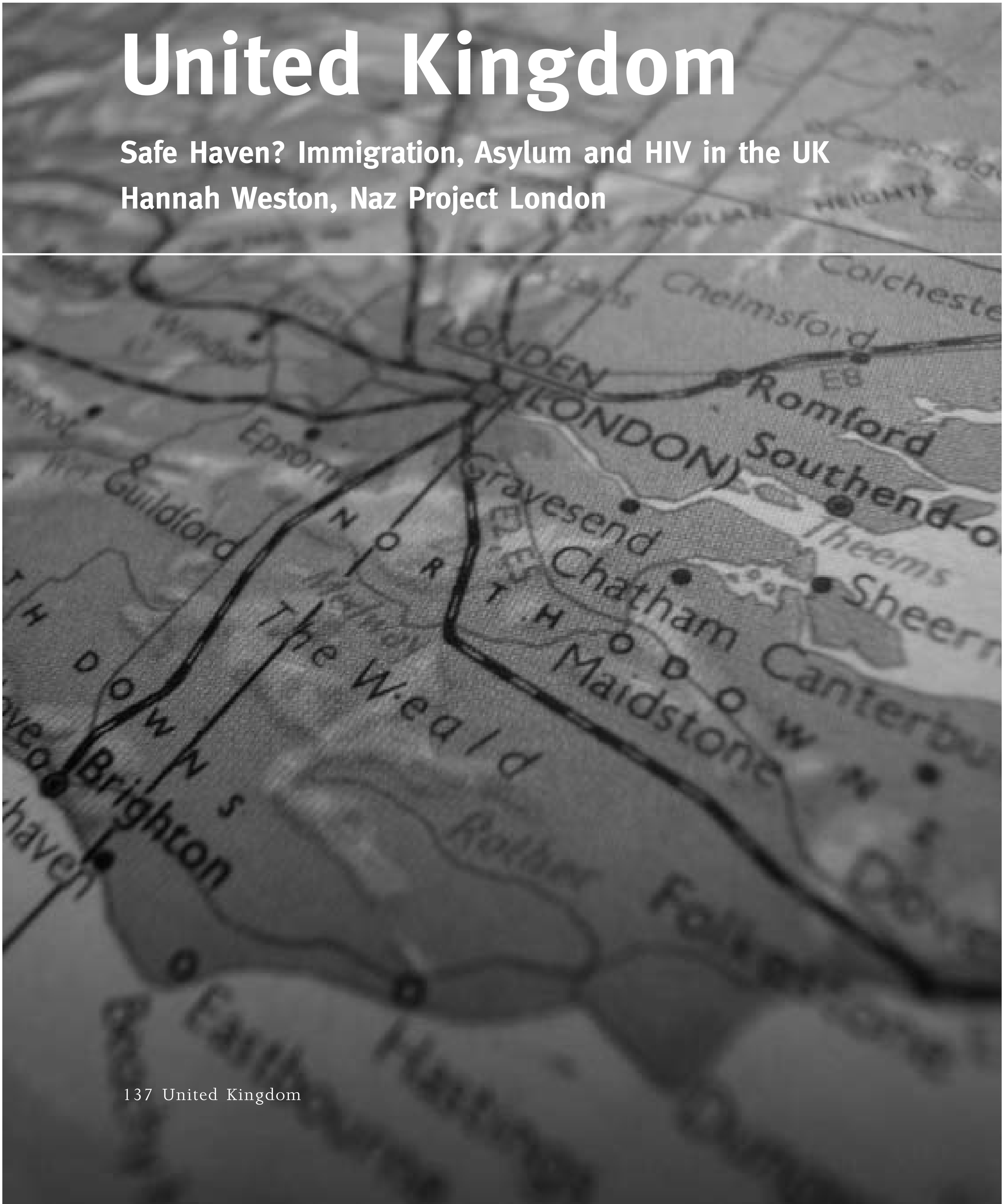
13. Herlitz, C. (2001). HIV/AIDS and society – Knowledge, attitudes and behaviour, 1989-2000. Stockholm: National Institute of Public Health.

14. Anagrius, C., Ruden, A.K. & Sandstrom, E. (1998). HIV testing in Swedish STD clinics 1986-1994. International Journal of STD & AIDS, 9, no. 8, 457-62.

United Kingdom

Safe Haven? Immigration, Asylum and HIV in the UK

Hannah Weston, Naz Project London



1. Introduction

1.1 The production of this report

This report draws substantially on the proceedings of a conference entitled 'Safe Haven: Immigration, Asylum, Human Rights and HIV' organised by the Naz Project London in collaboration with the European Project AIDS & Mobility. Held in London on January 17, 2003, the conference brought together practitioners from health and social care services, policy planners, care providers, clinicians, legal advocates, human rights activists and service users to address the critical issues facing people with insecure residency status living with HIV in the UK. The aim was to promote understanding and collaboration between these various groups of professionals from the voluntary and statutory sectors. Presentations and discussions at the conference explored the impact of recent legislative developments on the treatment and experiences of migrant communities living with HIV. Current issues in the clinical care of migrant populations were also examined. HIV positive migrants were involved in the conference through a series of client case presentations and as participating delegates.

This report is also based on literature produced by a wide range of NGOs and statutory organisations currently working with asylum seekers and refugees in the UK (see the table below for definitions of these terms). These include the Refugee Council, the British Medical Association, the Medical Foundation for the Care of Victims of Torture, the Joint Council for the Welfare of Immigrants, Asylum Aid, Naz Project London and the African HIV Policy Network. Information on the current legislative position has been taken from Department of Health and Home Office information sources. The Communicable Disease Surveillance Centre (CDSC) of the Public Health Laboratory Service (PHLS) has provided epidemiological data.

1.2 The focus of this report

This report focuses mainly on issues of access to clinical health care for asylum seekers and refugees living with HIV in the UK. Factors affecting access to HIV testing, primary care and antiretroviral treatments are therefore explored in depth. Access to psychosocial care and support is considered more briefly. The broader issues of access to adequate nutrition, housing and financial support are addressed in the light of the changing system of asylum and immigration in the UK. This report concentrates mainly on the issues faced by asylum seekers and refugees whose socio-cultural and linguistic background is significantly different from the majority of the population of the UK.

2. The changing accessibility of treatment and health care

2.1 The current situation

Since the last UK country report (Gardner, 2000) the issue of asylum seekers and refugees has rarely been far from the British political and media agenda. The public attitude towards asylum seekers is generally negative and refugees are regularly stereotyped in the media as 'bogus', 'scroungers', 'terrorists' and 'disease carriers' (Burnett and Peel, 2001a). The United Nations High Commission for Refugees has expressed its concern at the atmosphere of hostility towards even legitimate asylum seekers created by UK newspaper coverage of events arising from terrorist attacks around the world (BBC Online, 2003). This has been exacerbated by controversy over the Sangatte refugee camp in France, violence against refugees living in the UK and the election of several British National Party candidates in local elections in the North West of England. It was within this hostile climate that the ‘Nationality, Immigration and Asylum Act 2002’ became law on November 7, 2002 (Home Office, 2002). This is the fourth major piece of asylum legislation to be passed in the last nine years, and the second review of asylum policy to be undertaken by the current Labour government. This new legislation, designed to reduce the number of refugees seeking to enter the UK and to accelerate the process of considering asylum claims, has significant implications for all refugees and asylum seekers and especially for those who are living with HIV and AIDS (the implications are discussed in detail in section 2.4 below).

The UK is signatory to the Geneva Convention which defines a refugee as any person who ‘owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear is unwilling to return to it’ (see Table 1). Since 1996, when legislative changes reducing the entitlement of refugees to social security benefits reduced the number of annual asylum applications by one third to 30,000, asylum applications to the UK have risen significantly year on year. The conflicts occurring in Sri Lanka and the Federal Republic of Yugoslavia, and the repressive regimes operating in Iran and, until recently, in Iraq were significant in generating refugees over this period. By 2000 the number of applications had risen to 80,000 which then fell slightly to 72,000 in 2001. By the third quarter of 2002 applications had reached record levels due to a marked increase in applications from Iraq, Afghanistan and Zimbabwe. Of 118,195 application decisions made during 2001, 26% enabled the applicant to remain in the UK (Justice, 2002).

Table 1. Definitions of refugee status in the UK (Source: Burnett and Fassil)

Asylum seeker	Claim submitted for protection under the Geneva Convention. Awaiting Home Office decision
Indefinite leave to remain	Given permanent residence in Britain for an indefinite period (ILR). Eligible for family reunion only if able to support family without recourse to public funding
Refugee	Under Geneva Convention, given leave to remain in the UK for four years, can then apply for settled status (ILR). Eligible for family reunion with one spouse and all children under eighteen
Refusal	Refugee status has been rejected but the person has the right to appeal within strict time limits

2.2 The epidemiology of HIV/AIDS in the UK

Asylum seekers and refugees may be particularly vulnerable to HIV/AIDS for three reasons. firstly they may have experienced situations of risk in areas of high HIV prevalence (Burnett and Peel, 2001c). The CDSC has identified the ‘large and increasing impact of migration from high prevalence areas’ as one of the five main public health challenges of HIV/AIDS in the UK (PHLS, 2002). In recent years the UK has received many asylum seekers and refugees from regions experiencing HIV/AIDS epidemics, most notably Asia and sub-Saharan Africa. Migrants from Somalia and Sri Lanka comprised the third and fourth largest groups of immigrants to the UK in 2001 (respectively 6500 and 5545 individuals) (Justice, 2002).

The CDSC estimates that at the end of 2001 there were 41,200 adults living with diagnosed or undiagnosed HIV in the UK. The CDSC does not record the immigration status of individuals in its data collection procedures, so there are no figures available for the prevalence of HIV or any other disease among asylum seekers entering the UK. New cases of HIV acquired through sex between men and women continue to rise both numerically (by over 40% between 2000 and 2001) and proportionally (from 31% of the total new cases in 2000 to 36% in 2001). These cases have outnumbered new diagnoses among men who have sex with men in the UK since 1999. The majority of individuals who acquired HIV through heterosexual sex probably did so outside the UK, the majority in sub-Saharan Africa. In 2001, 71% of heterosexually acquired HIV cases diagnosed in the UK were in people from Africa or were associated with exposure there.

In the early 1990s, cases of African-acquired HIV diagnosed in the UK were mostly associated with Uganda, but more recently an increasing number have been associated with the growing epidemics in Southern, South Eastern and Western Africa. New diagnoses in black Caribbean people predominantly attributed to acquisition in the Caribbean have also shown a significant increase in the last few years, forming 4.3% of new HIV diagnoses in the UK in 2001. As yet, the growing HIV epidemic in the Indian sub-continent seems to have had little impact in the UK. HIV diagnoses among individuals of Indian, Pakistani or Bangladeshi ethnicity formed just over 1% of new diagnoses in 2001 (PHLS, 2002). The current status of the HIV/AIDS epidemic in the UK is illustrated in Table 2. This shows the current total of HIV cases differentiated by probable route of acquisition and ethnic group.

Table 2. Probable route of acquisition and ethnic group of people diagnosed with HIV reported as seen for HIV-related treatment or care in England, Wales and Northern Ireland during 2001 (Source: PHLS, 2002)

Ethnic Group	White	Black/ Caribbean	Black African	Black Other	Indian, Pakistani, Bangladeshi	Other/ mixed	Other Asian/ Oriental	Not known	Total
Probable route of acquisition									
Sex between men	10,220	256	160	166	74	538	99	1,043	12,556
Injecting drug use	745	7	18	2	6	57	3	44	882
Sex between men and women	2,203	372	5,680	192	165	192	123	240	9,167
Blood or blood products	345	6	51	3	14	10	6	19	454
Mother to infant	98	14	609	2	11	106	2	14	856
Not reported or unknown	544	50	406	23	31	40	12	182	1,288
Total	14,155	705	6,924	388	301	943	245	1,542	25,203

Secondly, asylum seekers and refugees may be particularly vulnerable to contracting HIV because of the experiences which caused them to leave their country of origin. Many experienced massacres, detention, beatings and torture, rape and sexual assault, destruction of homes and property, forced conscription, harassment and other abuses of their human rights. Incidence of HIV has been shown in many countries to be particularly high amongst military personnel, who may often perpetrate sexual violence. The largest group of asylum seekers to the UK in 2001 was from Afghanistan (9,190). Many of these individuals reported instances of physical and psychological abuse, which may well have put them at risk of acquiring HIV.

Thirdly, the experience of becoming a refugee can increase an individual's risk of contracting HIV. Refugees and asylum seekers may be exposed to poor living conditions, malnutrition and lack of personal protection. While unable or legally prevented from working, they may resort to sex work in order to survive. The stress and isolation, which often accompany the experience of seeking asylum, may contribute towards depression and psychological distress. Two thirds of refugees in the UK have experienced anxiety or depression (Carey-Wood et al, 1995), which can cause low self-esteem. This has been shown to increase rates of risk taking, which may include sexual risk taking.

Since the development of triple combination therapies in the mid-1990s, clinical care for HIV in the industrialised world has changed dramatically. The provision of palliative care to those dying of AIDS has been replaced by management of HIV as a chronic relapsing condition. In the industrialising world however, the inadequate and sporadic availability of antiretroviral drugs often means that HIV positive individuals with access to these drugs are intermittently exposed to a number of different therapies. As a consequence of this erratic treatment, such individuals often arrive in the UK with some form of drug resistance. They may be reluctant or unable to detail their past treatments to health care workers in the UK, which can cause difficulties in their treatment, particularly if they have presented late for clinical attention.

2.3 National policy on HIV/AIDS

The first National Strategy for Sexual Health and HIV (NSSHH) was produced by the Department of Health (DoH) in 2001 (DoH, 2001). The main aims of the strategy are to reduce the transmission of HIV and the prevalence of undiagnosed HIV in the UK. The strategy identifies asylum seekers as a 'group at special risk' for whom information and advice on matters of sexual health need to be provided. Targeted prevention work with African communities is identified as of particular importance in light of the fact that 'An estimated 60% of all new HIV diagnoses in the UK in 2001, and over 80% of those heterosexually acquired, were recorded as probably acquired abroad, mainly in sub-Saharan Africa' (DoH, 2001). The NSSHH does not, however, mention any initiatives or set any targets with regard to improving access to health care for asylum seekers and refugees.

One particularly significant consequence of the NSSHH has been the removal of the 'ring-fence' around funding for HIV prevention in the UK. HIV prevention allocations now form part of mainstream National Health Service (NHS) funding and health care commissioners will no longer be compelled to actually spend this portion of their money on HIV prevention. Agencies seeking funding for HIV prevention work with vulnerable minorities such as asylum seekers and refugees now have to compete directly with other more mainstream health needs (Teixeira, 2002). The existence of community organisations, which have played an important role in encouraging HIV testing among black and minority ethnic groups in the UK, is threatened by this change in funding. Paradoxically, the success of these organisations in promoting testing increases their financial difficulties by increasing their client numbers.

The NHS is also undergoing a restructuring process, which is likely to have significant consequences for the prevention and treatment of HIV/AIDS in the United Kingdom. The creation of Primary Care Trusts is intended to devolve needs assessment and service commissioning to a local level, bringing decision-making processes closer to local communities. Sexual health service providers however, have expressed concern that government performance assessment targets for Primary Care Trusts do not as yet include any sexual health objectives, and that therefore funding for sexual health may become a low priority in the newly devolved system (Pickstone, 2001). Due to their increased local accountability, Primary Care Trusts may also be less willing to provide services to groups on the margins of 'mainstream' society, such as asylum seekers and refugees (Bradford, 2002).

2.4 National policy on asylum and immigration

2.4.1 Migration patterns

Countries from which high numbers of asylum seekers originate are influenced to some extent by their historical links with the UK. The dominant influence on migration patterns to the UK at any given time however is the political climate in countries of origin. In the first quarter of 2002, for example, the top three applicant countries were Iraq (2,840), Afghanistan (2,350) and Zimbabwe (1,495), reflecting the current political instability of these countries.

2.4.2 Entry procedure

In the course of normal immigration procedure, a diagnosis of HIV or AIDS is not in itself sufficient to justify refusal of entry to the UK if the person otherwise qualifies under immigration rules. Individuals living with HIV/AIDS are allowed to enter the UK specifically in order to seek treatment provided that they can show they can afford the treatment, the treatment will be finite and they intend to leave the UK after its completion. Immigration officers may exclude an individual suffering from a serious illness (including HIV) if it is thought they would be unable to meet the costs of any treatment they might require. Individuals can also be excluded if it is felt they pose a significant risk to public health.

2.4.3 Applications to remain in the UK

Individuals who do not otherwise qualify to remain in the UK may apply for asylum on the basis of a well-founded fear of persecution on various grounds. However, section 55 of the new Immigration and Asylum Act which came into force on January 8, 2003 denies the right to claim asylum to individuals who fail to apply 'as soon as is practicably possible' after their arrival in the UK. Anecdotal evidence suggests the legislation could be interpreted very harshly, with a delay of even two days being grounds for refusal. The Refugee Council claims that this will leave thousands of asylum seekers destitute (2002). This could be particularly dangerous for those who are HIV positive. Various human rights and refugee organisations are preparing legal challenges.

HIV positive status can be used to justify an application for leave to remain in the UK on compassionate grounds in a very limited range of circumstances. If it can be shown that there is a complete absence of treatment facilities or social support in the applicant's country of origin, which could result in their imminent or lingering death and which would be very likely to cause them acute mental and physical suffering, then leave to remain may be granted (D vs. the UK). In these circumstances, returning the applicant to their country of origin would be judged to amount to 'inhumane or degrading treatment', engaging the UK's obligations under Article 3 of the European Convention on Human Rights. The number of individuals applying to remain in the UK on the basis of Article 3 is not documented, although the number of people seeking legal advice on this matter is reported to be increasing.

The Home Office can use the existence of any service provider in a refugee's country of origin to refuse an asylum claim made on the basis of HIV positive status. This is regardless of the financial or physical accessibility of the service provider for the individual in question. The existence of a single facility hundreds of miles from the applicant's home is considered grounds for the refusal of an asylum claim, even if the individual would be unable to finance their treatment at that facility. Given the minimal standard of service provision required by the Home Office to justify returning an applicant to their country of origin, the number of countries considered capable of providing care and support is rapidly increasing. At the same time the number of asylum cases brought solely on the basis of HIV positive status is decreasing given the limited likelihood of their success.

Under the Nationality, Immigration and Asylum Act 2002, all asylum seekers will be sent to induction centres run by the National Asylum Support Service (NASS) on arrival in the UK. Basic health screening will be offered at these centres to enable the early identification of health needs. After remaining in induction centres for 1-7 days, asylum seekers who do not require support will move to an agreed address while others will be dispersed to accommodation centres located around the UK (including the 'fast track' processing centre at Oakington). This policy of dispersal is designed to relieve pressure on health and social services in the Southeast of the UK. Newly arrived refugees are moved away from the area which, due to its proximity to continental Europe, has historically received the majority of asylum seekers and refugees. The accommodation centres, which are currently being established, will provide healthcare and other services. They will accommodate applicants until a final decision has been made and any appeal has been resolved.

The nature and extent of the health care and counselling services that accommodation centres will provide are as yet unclear. The British Medical Association has expressed concerns that services will be minimal and argued that accommodation centres are not the solution for meeting the longer term health needs of asylum seekers and refugees, such as those who are living with HIV. Detention facilities have also been observed to cause distress to asylum seekers, particularly those who have been previously detained in their own country.

The policy of dispersal has generated widespread controversy, not least among health care providers. It has been suggested that the implications of dispersal for HIV positive asylum seekers have not been adequately considered. One report found that insufficient resources have been allocated to the NHS in dispersal areas to meet the special health care needs of asylum seekers, who have been left marginalised, isolated and impoverished by the dispersal process (Woodhead, 2000). Dispersal seems likely to increase feelings of insecurity among asylum seekers and to discourage them from testing for HIV in contradiction of the stated aims of the NSSHH.

Clinicians have reported that the policy of dispersal often disrupts the continuity of care provided to asylum seekers, making follow-up procedures impossible. If refugees have suffered painful experiences it is not therapeutic for them to have to repeatedly rehearse their life history with a series of different health care providers. It is far better for them to establish a trusting personal relationship with a few individuals than to endure repeated interruptions in their treatment regime.

The policy of dispersal has proved particularly problematic in the case of pregnant women who are HIV positive. In some cases it has been reported that women have suddenly been dispersed just prior to giving birth, disrupting plans to give them prophylactic drugs, which would reduce the transmission of HIV to their babies. Clinicians have also complained about the lack of any system to inform hospitals when people have been dispersed away from the area. Asylum seekers undergoing treatment often ‘disappear’ without warning due to dispersal. Unfamiliarity with the area of dispersal can lead to late presentation at health facilities in these locations. Continuity of care for asylum seekers living with HIV is non-existent in these instances.

Under the Immigration and Asylum Act 2002, the status of ‘Exceptional Leave to Remain’ (ELR) which used to enable refugees with a ‘strong reason’ not to return to their country of origin to remain in the UK for up to four years has been abolished. HIV positive status was often accepted as grounds for ELR. It remains unclear how the replacement category ‘Humanitarian Protection’ will be applied, but it seems likely that it will involve more regular reviews of individual cases, taking into account the changing treatment conditions in countries of origin. In light of the growing speed of asylum decisions (designed to work through the substantial existing backlog of cases), it seems increasingly unlikely that arguments for special needs on the basis of HIV positive status will be able to be made.

2.5 Access to health care

Asylum seekers, individuals given refugee status and those granted indefinite leave to remain in the UK are all entitled to receive free medical treatment under the National Health Service in the same way as an ‘ordinarily resident’ UK citizen. Many asylum seekers and refugees however are unaware of their entitlement to treatments in the UK, which may be unavailable in their home countries. Health and social care workers are often ignorant of the rights and entitlements of these groups. As a result, the care provided to asylum seekers and refugees is in practice extremely inconsistent and varied across the UK. Many, particularly young, single, homeless individuals, find it impossible to register with a general practitioner or are given only temporary registration which disqualifies them from health checks, screening and immunisations. Only undocumented migrants who have ‘overstayed’ their visa or entered the UK illegally have no entitlement to health care beyond emergency treatment. Differing interpretations of whether antiretroviral therapy constitutes emergency treatment currently lead to inconsistencies in their provision to this group.

To date, clinical health care workers report that they have not been called to justify their provision of health care to asylum seekers and refugees in any systematic way. Regardless of theoretical entitlements, clinicians have been able to provide care on the basis of clinical need rather than residency status. Given the expense of antiretroviral therapies, this situation may change in the future if rates of HIV acquisition in the UK continue to rise and resources remain limited. Some clinicians have reported increasingly rigorous hospital trust policies on the treatment of overseas visitors. For the moment, confidentiality requirements mean that the provision of health care to asylum seekers and refugees cannot legally be monitored by hospital trusts or the Department of Health.

2.5.1 Access to testing

The only disease for which routine screening is currently conducted at the port of entry is tuberculosis. In practice, screening occurs in only a small proportion of cases (Burnett and Peel, 2001b). There is no policy of mandatory HIV testing for individuals seeking asylum in the UK. In the second half of 2002 however, the former head of the PHLS and an ex-president of the BMA responded to new statistics on the rise of TB and HIV in the UK by calling for the introduction of mandatory HIV tests for asylum seekers and refugees. In the past, calls to restrict the movement of people living with HIV across international borders have been justified on the grounds of protecting publicly funded health and social services. At the time, the minister for public health rejected these calls on the basis that compulsory medical tests could drive people with diseases underground.

Clinicians and other individuals working with asylum seekers have expressed concern that in the future this issue may return to the political agenda. Such fears were heightened in early 2003 by the publication of a government consultation paper which proposed that doctors and nurses recruited from overseas to work in the NHS should face mandatory HIV tests. The clear consensus among professionals working with asylum seekers is that mandatory testing of refugees would be entirely counterproductive and have no public health justification. HIV testing of potential immigrants should only be carried out with the voluntary consent of the individual concerned if the need for a test is indicated by a general health examination. Testing must always be accompanied by thorough pre-test and post-test counselling, which may be problematic if there are linguistic issues to be overcome. Mandatory screening is also against WHO guidelines.

Asylum seekers and refugees may fail to seek information about HIV and treatment for HIV infection for a range of reasons. In the UK, screening and health promotion programmes have been shown to have a particularly low rate of take-up among refugee women (Burnett and Peel, 2001b). More urgent concerns arising from their uncertain residency status often take precedence over health matters. Economic factors, racism, language difficulties, physical access issues, illness, lack of childcare, and time constraints may all limit the ability of migrants to access health care. Denial is one of the most significant factors deterring individuals in all cultures from testing for HIV. The children and grandchildren of immigrants who have no direct experience of the impact of HIV in their countries of origin are particularly unlikely to perceive themselves as being at risk of contracting HIV. The African HIV Policy Network has expressed concern that work by community organisations to encourage testing among black and minority ethnic communities may increase the marginalisation of these communities if they are perceived to have particularly high rates of HIV.

Routine voluntary antenatal HIV testing provides a valuable route for the identification of HIV positive women, but there is a lack of options for men seeking an opportunity to test. Men are hence more likely to present late with opportunistic infections, often in Accident and Emergency hospital departments. Management of HIV is often more difficult at this late stage, which can lead to poor chances of survival. Immigration-related fears and lack of community support for HIV positive individuals may also discourage testing. Concern has been expressed that diagnoses of HIV in children may be missed if HIV is not routinely included as a possibility in differential diagnoses. The consequences of such omissions can be serious, as children tend to progress more rapidly.

2.5.2 Access to clinical treatment

Migrants who do manage to access clinical care for their HIV infection may face particular difficulties in adhering to their drug regimens. The physical side effects of therapies often make an HIV diagnosis very visible to an individual's community and the resultant stigma can sometimes discourage individuals from continuing with treatment. HIV positive mothers may be reluctant to bottle-feed their babies in communities where breastfeeding is the universal norm. Lack of privacy in shared accommodation can make it hard for individuals to follow complex drug schedules, particularly if they are trying to disguise their diagnosis from other residents. Managing symptoms such as diarrhoea may be problematic if bathroom facilities are shared. Limited income (currently set at 70% of the income support level for UK citizens) can make it difficult for asylum seekers to achieve the optimum nutrition recommended for those living with HIV. In the long term many people undergoing treatment to manage their HIV infection experience therapy fatigue and there is a need for adherence support groups to assist them.

Concerns about confidentiality and stigma and mistrust of interpreters may discourage some asylum seekers and refugees from accessing HIV treatment. Problems with maintaining confidentiality have arisen in some small clinics outside large cities. As a consequence of the policy of dispersal, some clinics have recently seen a substantial rise in the number of asylum seekers accessing their services. Where clinic services are limited it may be difficult to prevent people from encountering other members of their community while accessing these services.

At the moment, the highest standards of clinical care continue to be available to everyone in the UK without rationing. The rising number of HIV diagnoses in the UK is inevitably putting increasing pressure on the resources available for care and support. If the current rise in diagnoses continues as predicted, it is likely that in future years these resources will need to increase accordingly. This is particularly so for primary care providers and general practitioners in London and the Southeast of England where resources are already strained. In the future, increased resources will be required to treat the side effects generated by long-term antiretroviral use as well as primary health needs.

2.5.3 Access to psychosocial support

In some cases, clinicians feel that pressure on resources has caused the availability of psychosocial support for HIV positive asylum seekers and refugees to suffer. The need for effective psychological and social support to accompany clinical care is well established. There is a general lack of appropriate agencies to provide such support to asylum seekers and refugees in the UK, particularly in the areas to which they are now being dispersed away from London and the Southeast.

3. Projects and interventions related to access to treatment

Voluntary and community organisations can do invaluable work supporting and advocating for refugees. Their information and service provision can often reduce the isolation experienced by many refugees. In light of the government's dispersal policy it is regrettable that the overwhelming majority of such organisations are located in London and South-eastern England. Asylum seekers and refugees dispersed away from this area may be denied social support, opportunities to interact with peers and the chance to build valuable links with the host community. The provision of separate health and educational services for asylum seekers within accommodation centres, though relieving pressure on local resources, may serve to increase the isolation experienced by many refugees.

The African HIV Policy Network (AHPN) is an umbrella organisation which brings together many of the African community-based organisations working on HIV and sexual health issues in the UK. Many of these smaller organisations provide primary services to asylum seekers and refugees of African origin in the UK. AHPN works to develop the skills and services provided by these organisations. The network provides a collective and representative voice to enable these organisations to influence government policy, funding and community activities (www.ahpn.org).

A range of information, resources and reports relating to access to treatment for migrants in the UK are available from the British Medical Association (BMA, www.bma.org.uk) and the King's Fund (www.kingsfund.org.uk). The BMA is the main trade union and professional association for doctors in the UK. It is a central point of contact for refugee doctors and organisations helping them. Together with the Refugee Council, the BMA holds the voluntary database of refugee doctors, and sends out a regular newsletter to doctors on this database. The BMA offers a package of services to refugee doctors who are working towards General Medical Council registration, including help with exam fees. The King's Fund is an independent charitable foundation which works to improve health in the UK with a particular focus on London. The Fund conducts health-related policy, research and development work, provides research grants and offers training to health professionals.

HARPWeb (Health for Asylum seekers and Refugees Portal) is a website which brings together a range of resources for both professional and voluntary agencies working on health issues with asylum seekers and refugees (www.harpweb.org.uk).

The Joint Council for the Welfare of Immigrants provides advice, information and representation for people with immigration or nationality problems. It is an independent national voluntary organisation, campaigning for justice in immigration and asylum law and policy and aiming to combat racism. The JCWI provides a free advice telephone line, casework, training courses, and a range of publications (www.jcwi.org.uk).

Language Line is a commercial telephone translation service providing interpretation in a wide range of languages. It is contracted by a number of health authorities and trusts (www.languageline.co.uk).

Medact is an organisation which provides seminars for all health workers supporting or working with refugees and asylum seekers. Their aim is to share experience and information and build supportive networks for both experienced practitioners and newcomers to this area. The seminars include practical primary care information and advice on current policy. They also aim to build networks among professionals involved in this work (www.medact.org).

The Medical Foundation for AIDS and Sexual Health (MedFASH) is currently managing a project to support the Department of Health in achieving its strategic objectives on HIV service standards and networks across the UK. The project aims to develop updated standards for NHS HIV services and to disseminate learning about managed networks and how obstacles to their development might be overcome. These guidelines have been submitted to the Department of Health following consultation with national organisations and local HIV service providers. Although the standards are not to be formally monitored as yet, they are likely to be endorsed by the Department of Health and the British Medical Association, establishing them as the minimum acceptable level for HIV service provision in the UK (www.medfash.org.uk).

The Medical Foundation for the Care of Victims of Torture (MFCVT) provides services for victims of torture and other forms of organised violence. Centre staff carry out casework, counselling, advice regarding welfare rights, physical and mental health care, individual and group therapy, complementary therapy, family therapy and child and adolescent psychotherapy. They also give advice and help with access to statutory health care. MFCVT staff run training sessions and workshops for professional groups working with refugees and survivors of torture and can discuss issues with health care workers (www.torture-care.org.uk).

The Naz Project London provides a number of black and ethnic minority and migrant communities with HIV/AIDS support services. These services include specialised information and confidential advice, advocacy and referral services, drop-in space, support groups, interpreting, training and consultancy work and volunteer services (www.naz.org.uk).

The Refugee Council runs a range of direct and indirect services for asylum seekers and refugees in the UK. The main services include a One-Stop advice service in Brixton, south London and day centre services. They also have an informative website (www.refugeecouncil.org.uk).

4. Conclusions and recommendations

4.1 Research

A great deal more research is required to explore issues surrounding asylum seekers, refugees and HIV and how services can best be made accessible to these groups. There is currently an absence of comprehensive and accurate demographic data on asylum seekers and refugees arriving in the UK. The BMA has identified the need for research to establish the health status of immigrants, the health impact of immigration controls and dispersal, the impact of immigration on general practitioners and the cost effectiveness of the new immigration legislation. Without such information the assessment of needs and planning of local health services will continue to be very difficult.

The epidemiology and biology of HIV are constantly and rapidly changing, and models of clinical care therefore need to keep pace. Almost all clinical research carried out so far has been on subtype B of HIV-1, which represents 5% of HIV diagnoses worldwide. Very little research has been done on the non-B HIV subtypes, which have so far been geographically distributed in the industrialising world. An increasing number of non-B type infections are now being seen in the UK. Laboratory tests for the monitoring of viral loads which are validated for type B virus may differ in accuracy for non-B type infections. It is possible that disease progression may also be affected by subtype. The majority of clinical research has been carried out on men. Possible differences in the opportunistic infections, effectiveness of drugs and side effects experienced by women are little understood.

4.2 Networking

There is a need for greater networking between voluntary, statutory and professional bodies in order that specific issues of importance to asylum seekers and refugees can be identified and acted upon. This is particularly so in the light of ever-reducing budgets for all work on HIV/AIDS and the removal of the ring-fence around prevention budgets. Cooperation is likely to increase the weight of individual stakeholders' contributions to policy debates and enhance the likelihood that the formation of future legislation can be influenced. The forthcoming government inquiry led by the Cabinet Office into the impact of immigration on public health is one example of a forum to which contributions could be made. Individuals can also affect such inquiries by approaching their local Member of Parliament.

Networking could also help individuals and organisations to remain up to date with the rapidly changing clinical and legal situation with regard to asylum seekers and refugees. It is essential for general practitioners and other health and social care workers to be well informed about the rights and entitlements of individuals whose residency status is uncertain. Keeping these grass roots workers up to date with legislation and information about the issues facing individuals seeking asylum in the UK is likely to reduce prejudice against these groups and facilitate better informed care and support. Collaborative working may also facilitate better planning, enabling organisations to anticipate and prepare for future epidemiological trends such as the likely future impact on the UK of the rapidly growing Caribbean epidemic. This could allow organisations to carry out proactive prevention work with communities who are likely to be affected in the future rather than always working reactively in the wake of the epidemic.

4.3 Attitude change in the general population

Some studies suggest that the health status of immigrants to the UK may actually worsen in the first two to three years after their entry into this country (London Health Observatory, 2002). Such conclusions are particularly worrying in light of the generally negative public attitudes towards asylum seekers and refugees. These attitudes continue to hinder efforts to improve their health and social welfare. Analyses of ‘the immigration problem’ frequently fail to appreciate the cultural diversity, economic wealth and skills which immigrants have historically brought to the UK and which could potentially be contributed by current arrivals. The prevailing negative attitude needs to be replaced by an understanding of asylum seekers and refugees as a very vulnerable group who are seeking asylum in the UK in the hope of improving their lives.

4.4 Attitude change in black and minority ethnic communities

For migrants living with HIV/AIDS, discriminatory attitudes towards refugees and asylum seekers in the UK are often compounded by the stigma surrounding the virus within migrant communities. Further work needs to be done to combat this, particularly with young people and in Caribbean and African communities. With the policy of dispersal in operation, such work needs to be carried out across the UK and not just focused on London.

4.5 Standardisation of clinical and social care

Existing geographical differentials in the quality and availability of clinical services and social support for asylum seekers and refugees are unacceptable. The standardisation of these services needs to be implemented and monitored as a matter of priority. Unfortunately, the Department of Health’s recent devolution of health service commissioning to the more local level of Primary Care Trusts may make this more difficult. Voluntary sector organisations need to maintain pressure on Primary Care Trusts to deliver standardised clinical and social services to asylum seekers and refugees wherever they are in the UK. Services for HIV positive migrants need to be particularly prioritised if the policy of dispersal is not to contribute to rapidly rising rates of HIV and TB among asylum seekers and refugees.

4.6 Antenatal health care

Antenatal health care for asylum seekers and refugees should be developed to include the father rather than just the foetus and the woman. This will provide men with routine opportunities to test for HIV which are not currently available to them. The Family HIV Unit at St. Mary's Hospital in London is an innovative example of such a family focused facility.

4.7 Information provision

There is a need for more information to be provided to refugees who may not have received effective education about HIV/AIDS in their countries of origin. Linguistic problems may need to be overcome in the provision of such information. In combination with social support this is likely to encourage them to seek voluntary testing, care and support services for HIV. There is a clear need to normalise HIV testing in the UK by routinely offering it to all those whose behaviour could place them at risk of contracting the virus.

4.8 Global issues

It is important that those working with asylum seekers in the UK develop and maintain an appreciation of the wider global issues around HIV. This can help them to maintain a perspective on the problems faced by individuals in the UK as well as to develop an understanding of the impact which global movements such as treatment access campaigns will undoubtedly have in the UK. For example, differential-pricing legislation will affect the movement of antiretroviral drugs between the countries of the 'south' and the 'north', influencing the availability of drugs in industrialising countries and probably increasing the likelihood of smuggling. Increased availability of drugs in the 'south' is likely to increase the number of individuals arriving in the UK with some form of drug resistance already established, making their treatment here more difficult. Treatment access debates are likely to be discussed at the G8 summit in 2003.

5. Bibliography

BBC Online (January 18, 2003). Refugee agency criticises UK media. http://news.bbc.co.uk/1/hi/uk/2671179.stm (accessed January 29, 2003).

Bradford, M. (2002). Moving on; a review of progress on gay men's HIV prevention in Enfield and Haringey and Barnet 1996-2001 (commissioned by the former Barnet, Enfield and Haringey Health Authority).

Burnett, A. & Peel, M. (2001a). Asylum seekers and refugees in Britain: What brings asylum seekers to the United Kingdom? BMJ, 322, February 24, 485-8.

Burnett, A. & Peel, M. (2001b). Asylum seekers and refugees in Britain: Health needs of asylum seekers and refugees. BMJ, 322, March 3, 544-7.

Burnett, A. & Peel, M. (2001c). Asylum seekers and refugees in Britain: The health of survivors of torture and organised violence. BMJ, 322, March 10, 606-9.

Burnett, A. & Fassil, Y. Meeting the health needs of refugees and asylum seekers in the UK: An information resource pack for health workers. NHS, DoH.

Carey-Wood, J., Duke, K., Karn, V. & Marshall, T. (1995). The settlement of refugees in Britain. London: HMSO.

Department of Health (2001). The National Strategy for Sexual Health and HIV: Implementation Action Plan. London: Department of Health.

Gardner, L. (2000). United Kingdom. In K. Clarke & G. Bröring (Eds.). HIV/AIDS care and support for migrant and ethnic minority communities in Europe (pp. 157-72). Woerden: NIGZ.

Home Office (2002). Nationality, Immigration and Asylum Act 2002. London: HMSO.

Justice (2002). Refugees and asylum-seekers, changes in the law. London.

London Health Observatory (2002). Health of Refugees and Asylum Seekers. www.lho.org.uk/hil/refugee.htm (accessed January 29, 2003).

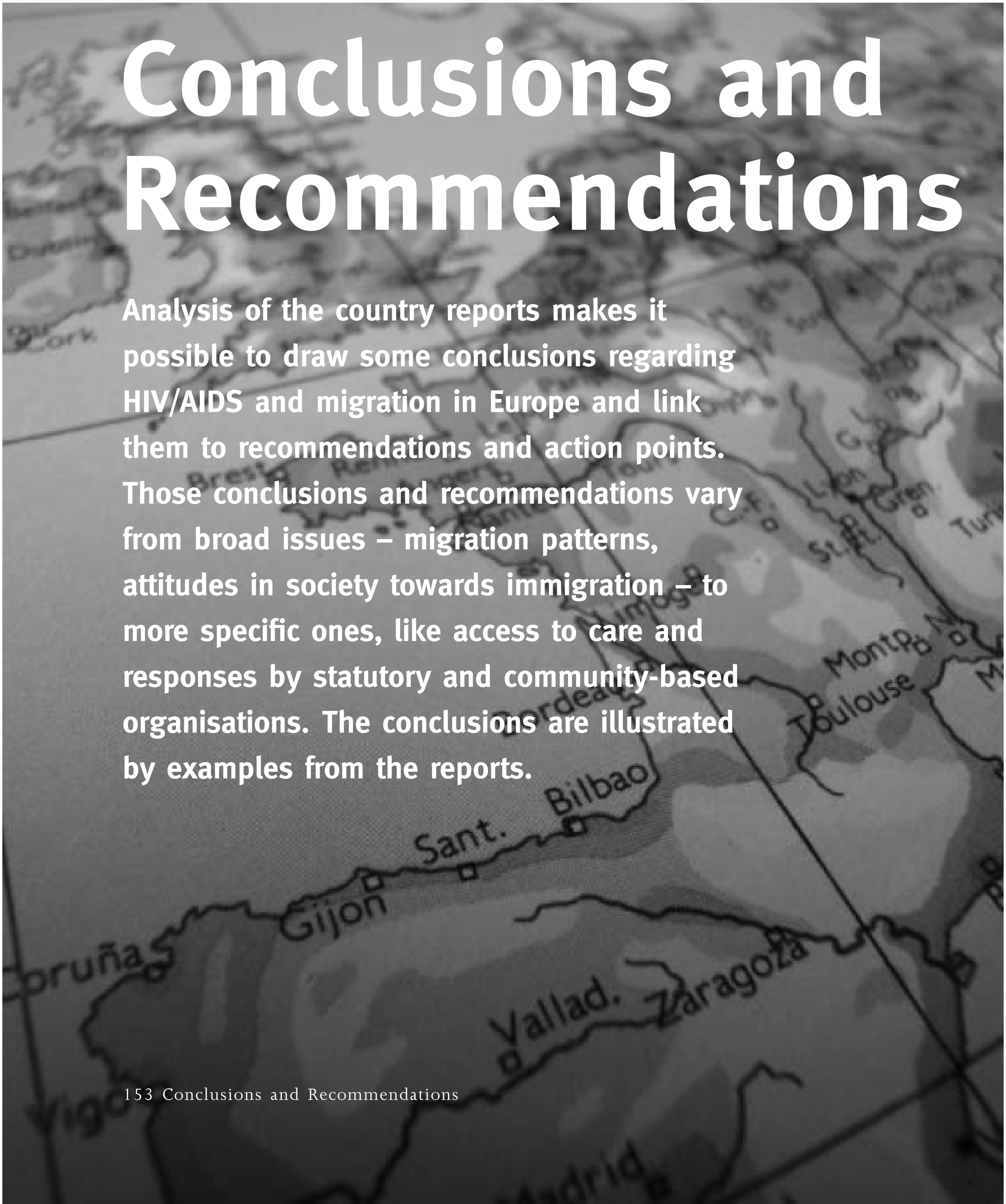
PHLS Communicable Disease Surveillance Centre, ICH (London), SCIEH (2002). HIV and AIDS in the UK in 2001: An Update: November 2002. London.

Pickstone, T. (2001). National disappointment; has the National Strategy for Sexual Health and HIV been worth the wait? Agenda, no. 25, p. 1. Manchester: George House Trust.

Refugee Council (2002). Briefing: 'Response to Secure Borders, Safe Haven: Integration with Diversity in Modern Britain (Government White Paper, February 2002)'.

Teixeira, B. (2002). Funding for sustainability in the United Kingdom. A&M News; biannual newsletter of the European Project AIDS & Mobility, no. 3, 14-5.

Woodhead, D. (2000). The Health and Well-Being of Asylum Seekers and Refugees, Kings Fund.



Conclusions and Recommendations

Analysis of the country reports makes it possible to draw some conclusions regarding HIV/AIDS and migration in Europe and link them to recommendations and action points. Those conclusions and recommendations vary from broad issues – migration patterns, attitudes in society towards immigration – to more specific ones, like access to care and responses by statutory and community-based organisations. The conclusions are illustrated by examples from the reports.

1. Migration patterns

1.1 Summary and conclusions

Migration as a global phenomenon needs to be seen as a reality: people will continue to migrate for all kinds of reason, to all kinds of places and at all times. Not surprisingly, the migration patterns and the populations involved vary widely throughout Europe. A main distinction can be made between those countries that have a colonial history and those that do not. Former colonial powers – like Belgium, the Netherlands and the UK – have a longer history of immigration and more cultural diversity in their societies. Other countries – in particular in Southern Europe – used to be emigration countries and have started to accommodate new populations only in the last decade or two.

Geographical factors also play a role. Neighbouring countries to the Baltic States and to countries of Central/Eastern Europe – like Finland and Austria – report considerable mobility between the East and the West. The Portuguese report refers to immigration from Eastern Europe. The East-West mobility is largely labour migration, but there are also mobile drug users and sex workers. In addition to migration to Europe from the south or the east, mobile populations exist within countries, such as the Roma in Greece.

While almost all reports speak about increasing immigration, the Dutch report mentions a decrease. This change has set in after a long period of increase due to immigration from the former colonies, labour migration, family reunification and asylum procedures. Stricter laws and regulations appear to have made access to the country more difficult.

The health situation in countries of origin – such as access to HIV treatment – is playing an increasing role. Health seeking migration may be a critical issue in the future.

1.2 Recommendations

1. From a public health perspective, the political focus should not be on how to influence migration and mobility, but how to reduce the health risks for the individual and for society at large.

2. Health promotion and HIV prevention interventions need to be flexible to respond to the diversity of the mobility and the populations involved.

3. Improvement of the situation in the countries of origin and the development of better health systems in countries/regions with a high HIV prevalence are of great importance. European institutions need to intensify their efforts to support developing countries to provide appropriate health care services. There needs to be more extensive and better collaboration between EU institutions – for instance Directorates for Development and Directorates for Health.

4. Countries with more or longer experience with migrants and ethnic minorities should support countries that have just started to develop policies and interventions.

5. The EU accession countries of Eastern Europe need specific attention in the future. Research into the public health impact of mobile populations in Central and Eastern Europe is called for, as are health promotion interventions for these groups. Interventions need to be tailored particularly for mobile drug users and sex workers.

2. Responses by society at large

2.1 Summary and conclusions

Most reports confirm that migration is a hot issue in the country in question. Attitudes in society towards migrants and ethnic minorities are part of a wider political climate, to which various factors contribute: the economic situation, unemployment rates and events like the attack on the World Trade Centre in New York in September 2001 and the so-called 'War on Terrorism'. All these factors may contribute to tensions between migrants and ethnic minorities and indigenous populations: it is not easy to single out one specific factor. The Spanish report draws attention to the fact that Spanish society was not prepared to change so quickly from an emigration to an immigration country, and that both authorities and citizens have to adjust to the new situation.

Discrimination (most commonly on the basis of ethnic background, sexual orientation or HIV status) can be observed in society at large but also in connection with the provision of health services. The important role of civil society in this connection is stressed in the Spanish report. The phenomenon of immigration is still rather recent in Spain, and the indigenous population as well as organisations and structures in the country need to adapt to the new situation. Insufficient representation and participation of migrants and ethnic minorities in society and social life is reported by various countries; the Finnish report even speaks about the 'invisibility of migrants'.

2.2 Recommendation

The various actors in society, such as governmental and non-governmental organisations, should increase efforts to achieve better representation and participation of migrants and ethnic minorities.

3. Policy and politics

3.1 Summary and conclusions

In the area of (health) policies for migrants and ethnic minorities, the authors describe a wide range of insufficiencies and inconsistencies. In general, immigration policies are becoming stricter, like in Belgium and the Netherlands. Dispersal policies – like in Ireland and the United Kingdom – make access to care and support services more difficult for asylum seekers with health problems in general and with HIV in particular.

Several authors complain that the rights of people and standards regarding access to care are unclear. Many care and support services operate in a grey area. And in those countries where clear regulations on access do exist, like Greece and Italy, there is a gap between policy and practice. For instance, many health workers are not aware of opportunities to support migrants with HIV.

The way in which HIV testing is carried out among asylum seekers and the standards of communication and information about testing are far from satisfying. Consequently, asylum seekers are frequently unable to make a conscientious decision about testing. Also, they may not be aware of the impact of a positive result on their asylum procedure.

Despite some positive trends, like the HIV anti-discrimination law and comprehensive access to health care for young migrants under eighteen in Spain, general rights-based access to services and appropriate standards are still missing in most European countries.

The expulsion of undocumented migrants with HIV remains a sensitive point. The fact that anti-retroviral therapy has become more widely available in more countries leads authorities to expel people under treatment more easily, even though continuation of treatment is often only theoretically available, and cannot be effectuated after expulsion. Authorities in the host country only look into the availability of drugs, and the representatives of the countries of origin (often embassies) may paint an overly positive picture of the situation. In addition to availability (is anti-retroviral therapy available at all in a given country?), one also has to investigate accessibility (how many people are in treatment programmes, what are the preconditions, are care services close to the home of the person in question) and affordability (what are the costs and can they be covered by the person in question) in countries of origin.

The Portuguese report mentions the concern of migrants and human rights organisations about the negative effect of the privatisation of health care especially on migrants and ethnic minorities. The increasing importance of private insurances and patient contributions, which can be observed in many European countries, is particularly affecting those who live on the margin of society and who were not able to save up money. Gaps in health insurance regulations for migrants are also reported from Austria.

Finally, some countries – for instance Finland and Portugal – draw attention to the fact that heath policies taking migrants and ethnic minorities into account are insufficient or entirely missing.

3.2 Recommendations

1. National health policies should address and include the specific needs of migrant and ethnic minority communities.

2. There is a pressing need for clarity about the rights of (migrant) persons with HIV. Legislation must provide satisfactory access to prevention, care and support, and expulsion must not take place unless treatment in the country of origin is available in practice.

3. Consistency is needed regarding testing procedures for asylum seekers and appropriate information and communication about these procedures.

4. Dispersal policies and a decentralised approach, which often land asylum seekers in poorly facilitated areas, must not have a negative impact on access to HIV treatment and support services.

4. Migrant and ethnic minority communities

4.1 Summary and conclusions

The populations described in the country reports are characterised by a diversity of social, economic and legal backgrounds and by a diversity of needs. The main distinction made by the authors is that between the more traditional migrants (from former colonies, labour migrants etc) who are fairly integrated into society and the 'new arrivals' (asylum seekers, undocumented migrants) who often live in precarious conditions.

An interesting point is raised in the Swedish report, which mentions that in many cases, migrants with residence and working papers have links with undocumented migrants.

They can play an important role as intermediaries to reach out to those who are not in touch with health services.

Scepticism about and mistrust of (health) authorities is found in many migrant communities due to a variety of factors, such as inappropriate treatment by immigration offices or health care providers in the host country or traumatic experiences before and during migration.

Stigma is mentioned in several reports. Stigmatisation of migrants and ethnic minorities by the host society is mentioned, as well as stigmatisation within communities. HIV positive members of ethnic minority communities may hide their seropositive status from relatives. When accessing health care, they may refuse interpreters from their own ethnic background. When sharing accommodation, they may encounter difficulty adhering to their drug regimen because they do not want other residents to learn of their diagnosis.

Migrant organisations and health care providers are increasingly paying attention to the situation of young people and families. The Belgian and Dutch reports call attention to the situation of children who were born to HIV positive mothers and who have grown into adolescents: specific assistance must be provided for them.

finally, some reports stress the link between migrant and ethnic communities in Europe and the situation in their country of origin. The economic and political situation there, but also health-related matters, like the development of the AIDS epidemic and the availability of treatment, have an impact on the communities here.

4.2 Recommendations

1 Health care providers should make use of the knowledge and expertise of migrant communities and take advantage of existing links to reach out to undocumented migrants.

2 Health care providers, but also schools and youth organisations need to take the issue of children/youth and HIV on their agendas.

3 Migrant organisations should tackle stigma and taboos within migrant and ethnic minority communities in order to improve the situation of migrants living with HIV/AIDS.

5. Epidemiological developments

5.1 Summary and conclusions

Almost all authors provide some epidemiological data. The prevalence of HIV in migrants depends to a great extent on whether the main populations originate from endemic areas. Austria, for instance, has a much lower HIV prevalence in its migrant community (predominantly from Eastern and Central Europe) than Belgium (with a high percentage of sub-Saharan Africans).

Some reports highlight the need for better epidemiological monitoring of the different HIV subtypes, better and more comparable ethnic monitoring, and a better insight into heterosexual versus homosexual transmission. The Swedish report also looks into the phenomenon of Swedes acquiring HIV abroad. Possible changes in the epidemic should be taken into account, such as a stronger influence of infection through injecting drug use due to increased East-West mobility.
A worrying phenomenon that is repeatedly reported is the epidemic split between

migrant and indigenous populations. While in the general population, many people with HIV do not develop AIDS due to good monitoring and treatment, this is often not the case for HIV positive migrants and individuals from ethnic minorities. This is particularly ascribed to the fact that the latter cannot access testing and treatment facilities as early and effectively as the general population.

5.2 Recommendation

1. The main recommendation about epidemiology to be drawn from the reports is the need for getting accurate and consistent epidemic data both nationally and on a European level in order to understand trends and processes in migrant and ethnic communities. This better understanding should be applied to achieve well-designed and focused prevention and care interventions.

6. Access to care

6.1 Summary and conclusions

A major theme of the reports is the disadvantaged position of migrants and ethnic minorities compared to the general population as far as access to care and support services are concerned. However, distinctions between different migrant communities need to be recognised. The more 'traditional' migrants and ethnic minorities, who are fairly well integrated into European societies, generally do not encounter legal obstacles to accessing services. For them, the barriers are mainly due to culturally inappropriate services or complicated bureaucratic procedures.

Undocumented migrants have many more difficulties to access HIV care and support. They are often excluded from health services and receive medical treatment only in emergency situations. The Dutch 'Linkage Act' establishes a link between a residence permit and access to all kinds of services (housing, work, health). It is an example of a high threshold policy that is preventing undocumented migrants from accessing services.

Another obstacle mentioned by various authors is the low priority of health issues for many members of migrant and ethnic minority communities. Coping with economic, social and cultural problems is often seen by them as a more immediate need. Further, the complicated structure and procedures of the health sector are identified as a major problem hampering access to services (for instance in the Belgian report). In the same line of thought, the Finnish report opposes the idea that everybody can be integrated into one and the same (health) system. The country reports stress the need for linguistically and culturally appropriate information about HIV/AIDS and health care structures and services.

The reports offer solutions to overcome some of these obstacles and improve access to services. A holistic approach that combines health issues with socio-economic and cultural aspects is one of the possibilities. A good example is found in the Netherlands, where 'case management' strives to address various problems of the care seeker, from housing to social support and HIV treatment.

6.2 Recommendations

1. Legal regulations need to be developed to achieve rights-based access to services for those whose lives are at risk.

2. Efforts need to be made in the field of communication, in order to provide better understanding of health services and health care structures. Information needs to be available for intermediaries/health care providers and for the migrant populations.

7. Statutory and community-based responses

7.1 Summary and conclusions

Governmental and non-governmental organisations both play an important role in the field of migration and HIV/AIDS. The country reports all stress the need for good collaboration and communication between both sectors. There are some significant differences between countries. Those countries with a longer history of immigration have a rather well-established network of community-based migrant organisations dealing with health or HIV/AIDS. The Finnish report states that specific projects for migration and HIV are non-existent.

The capacities of community-based organisations may vary: some work with volunteers, others also have paid staff. Almost all face a pressure on resources.

Most authors stress the rewards of collaboration between different organisations. The Belgian report mentions the positive effect of involving Doctors Without Borders in activities seeking to improve access to care for undocumented migrants. The collaboration between community-based organisations and statutory organisations is considered valuable: while the first may have access to (knowledge about) the communities, the second may have access to necessary (financial) resources.

Community-based organisations may have a valuable input in the training of health professionals. Communication between governmental or municipal health services and migrant communities can be facilitated by associations and organisations that are close to these communities. Especially where multiple issues need to be addressed, combined forces can lead to greater effects.

Some authors suggest that collaboration between community-based and statutory organisations can also be applied on an international or global scale, and that networks like AIDS & Mobility need to play a role in facilitating between the statutory level and communities.

7.2 Recommendations

1. Health care providers – both community-based and statutory – need to ensure that theoretically available services are accessible and affordable in practice. Training for health personnel and the involvement of cultural mediators from community-based organisations has to be encouraged to achieve this aim.

2. Statutory and community-based services should increase efforts to reach out to undocumented migrants. Their access to and contact with services is not only important for the health of the individual, but also for public health in the respective country.

3. Specific interventions, for instance culturally appropriate communication regarding HIV testing, need to be developed to address the problem of late presentation of migrants with HIV.

4. Since multiple health and social issues have to be addressed, a holistic approach providing support at different levels must be stimulated. Specific attention needs to be paid to young people and families. Community-based organisations should have a crucial position in this approach, as they may have the best access to the respective population.

8. Research

8.1 Summary and conclusions

The reports from Finland and the United Kingdom in particular stress the importance of gaining better insight into issues such as the daily reality of migrants living with HIV and the health impact of immigration controls and dispersal. According to the Finnish report, HIV policy for migrants should be based on their actual needs as determined by research. Epidemiological research needs to pay more attention to migrant issues (e.g. different HIV sub-types in Europe). The results of comprehensive research which takes into account the social and health needs of migrants and ethnic minorities, should lead to better collaboration between service providers.

8.2 Recommendations

1. Research into migrants and ethnic minorities needs to incorporate social sciences, epidemiology and clinical research. It should address different HIV subtypes, different sexual transmission routes, gender etc.

2. The involvement of migrants in research projects – at all stages – may provide vital information.

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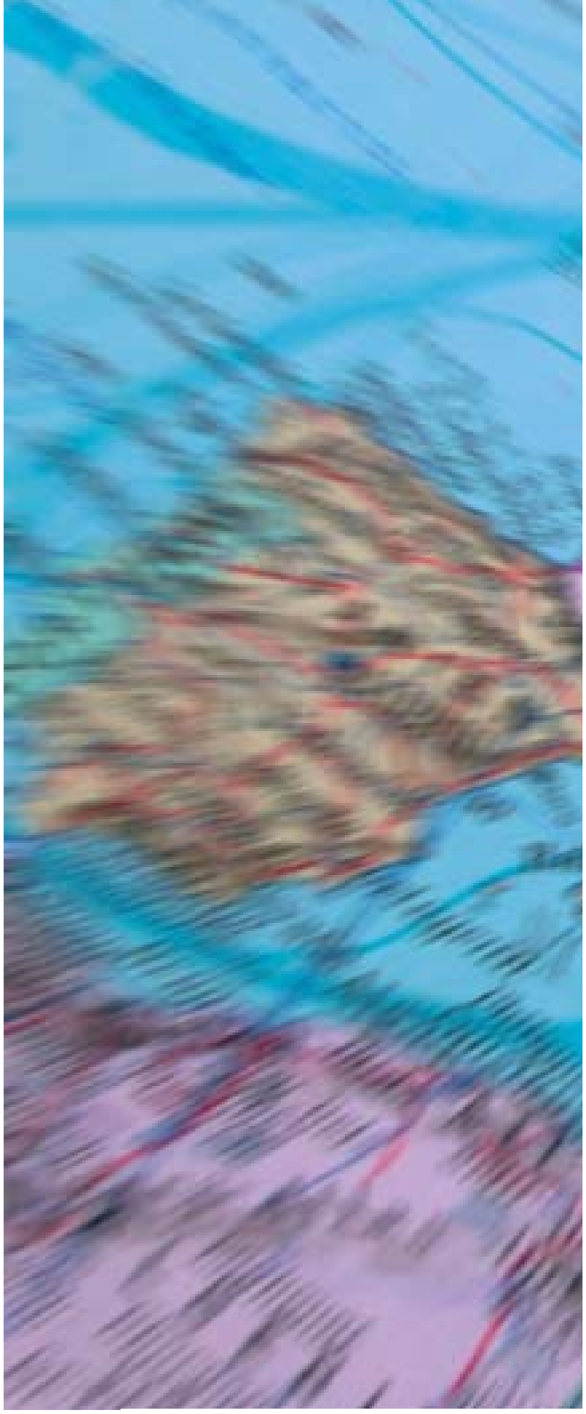

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