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ABSTRACT

The Naz Foundation sponsors a project on HIV and AIDS education, prevention, and support among South Asian, Turkish, Irani, and Arab communities in Europe. As immigrants, ethnic minorities, and refugees, these people are not isolated from the societies in which they live, and are just as vulnerable as any other community to AIDS. A conference on AIDS in Berlin (Germany) in 1993 featured a roundtable on AIDS education and prevention among these minority groups. The roundtable opened with a discussion of the necessity for health education for immigrant and refugee peoples, and a call for culturally and linguistically appropriate services, including education. Defining the age groups to be targeted and the venues for education is a major concern for these ethnic communities. Five papers provide viewpoints about responses to AIDS in these minority groups: (1) "The Human Right of Movement and Asylum and Persons with HIV/AIDS" (Fernando Chang-Muy); (2) "Empowerment of Marginalised Communities To Develop Their Own HIV/AIDS Service Organisations To Provide Education, Prevention and Support Services" (Dima Abdulrahim); (3) "Development of Culturally Appropriate HIV/AIDS Education and Prevention Services for Ethnic Minority and Migrant Populations" (Ramazan Salman); (4) "Undocumented Immigrants Living with HIV in New York City" (Jairo Enrique Pedraza); and (5) "Report on the First European Information Exchange Meeting on Ethnic Minorities, Migrants and AIDS, Held in Blossin, Germany, May 1993" (Oonagh O'Brien). Attachments include declarations, issues, and recommendations from the roundtable and the entire conference. Recommendations for national and local AIDS service organizations are also made. An analysis of existing services leads to the call for culturally and linguistically sensitive services for these Muslim and Asian populations in Europe, including the provision of AIDS education in ways defined by the communities themselves. (SLD)

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The Naz Project

*an HIV/AIDS education, prevention and support service
for the South Asian, Turkish, Irani and Arab communities*

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1Xth International Congress on AIDS
Berlin, Germany
June 6th - June 11th, 1993

Ethnic Minorities and Migrant Communities

Report on the Round Table and Satellite Meetings

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INTRODUCTION

Shivananda Khan

HIV and AIDS is not prejudiced! It not only affects homosexuals, prostitutes and drug users. It affects everyone, whatever nationality, religion, culture, gender or sexuality. It is in every community.

But unfortunately this lack of prejudice is not necessarily true for the services that have been developed in terms of education, prevention and care.

As ethnic minority, immigrant, migrant and refugee peoples living in countries not of our origin, whether we are citizens of our country of residence, whether we are recently arrived, whether we are first, second or third generation, we are already on the edges of service delivery by governmental and more often than not, non-governmental agencies, whether it be housing, employment, or health. Marginalised because of colour, religion, ethnicity, the rising tide of racism adds further dimensions in terms of our safety, security and victimization. HIV and AIDS creates further challenges for us, as much for the national Governments and non-governmental organisations in the provision of services that are ours by right, as well as an urgent necessity.

But why an urgent necessity? Surely because of our cultural frameworks, our religious beliefs, our community strengths, HIV/AIDS actually has nothing to do with us?

THIS IS NOT TRUE!

We, as immigrant, migrant, ethnic minority and refugee peoples are not isolated from the societies we live in. We interact, socialise, form relationships, have sexual encounters. Our religious and traditional beliefs do not form some sort of protective barrier. We are just as vulnerable as any other community.

As citizens, residents, workers in any country, we have the right to any and all health services We have the right to knowledge, to information, to the facts.

But we also must recognize that we must also challenge our own communities to recognize this information, this knowledge, these facts.

In the process of such dissemination it is important to ensure that whatever the service, whether it be educational programmes, prevention programmes or care management services for those affected by HIV/AIDS, then these must be delivered in culturally and linguistically appropriate ways.

And in order to ensure that our communities take on board these issues, develop appropriate responses to the challenges of HIV/AIDS for ourselves, we as members of these communities must take the responsibility forward. We must stand up in our own communities and accept the responsibility that our position in our communities, or in our community organisations give us.

The 1Xth International Congress on AIDS in Berlin was an opportunity to address a range of issues that affect our lives in terms of HIV/AIDS service delivery, whether it was in legal status, education, prevention or health care. For the first time, in an AIDS Congress a space was created to explore these issues. Not only did we have a Round Table meeting with a range of speakers, but also we had a

Satellite meeting where minority peoples could come together and share the issues. This was not a gift from the powers that be. It had to be fought for!

This report then looks at the presentation of the Round Table and the discussions from the Satellite meetings, and also includes a range of reports and recommendations from other recent meetings for the ethnic minority, migrant and refugee communities.

These recommendations affect not only our communities, but also international bodies and funders, such as WHO Global Programme on AIDS, national AIDS programmes, and voluntary agencies, whatever the continent, nation, region, state, city, locality.

We not only have to challenge our own communities, we also have to challenge the host communities and the range of HIV/AIDS services they provide in order to ensure that racism and marginalisation is always confronted, and that we have adequate and appropriate access to services.

It is vital that we take this responsibility on. Vital to face the challenge now, before HIV infection takes a stronger hold within our own communities. Vital to stop AIDS now in our communities. For the sake of our children, our husbands and wives, our families, our friends, our lovers and partners, our sense of community solidarity.

The range of issues and concern that have been explored in the various meetings, seminars, conferences in the last year have included:

1. Education:

How will this education be delivered?

What images, language, context?

Can we be sensitive as well as factual?

Should HIV education be in schools, colleges, youth centres?

What is appropriate and sensitive to the different religions and cultural/linguistic dynamics?

2. Prevention:

a. sexual transmission through unprotected sex

b. through sharing unclean needles in intravenous drug use

c. mother to child through pregnancy

e. and in certain countries through inadequate health care, i.e. unsterilised equipment, infected blood, etc.

We need to recognize that members of our communities can be vulnerable to these processes. We are sexually active, some of us do use drugs and needles.

Questions raised thus include issues around condom promotion, issues around sexual behaviours, young people, homosexuality.

3. Community Response

How can our own communities deliver their own services around HIV/AIDS in conjunction with national and local programmes?

How can we ensure that our communities will deal with actual behaviours rather than the protective myths we often labour under?

How can communities develop sensitive, confidential and supportive systems for people within our communities who are living with HIV or with AIDS?

How can we deal with those within our communities whose behaviours may not have community approval?

How can we develop a compassionate and caring religious response towards those within our communities living with HIV/AIDS?

Major issues of concern include:

1. racism - legal, social and institutional responses, and their impact upon HIV/AIDS services for our communities
2. development of culturally and linguistically appropriate services and resources
3. ownership of HIV/AIDS services by the dominant community thus not addressing the needs of ethnic minority, migrant and refugee communities
4. legal and social harassment of our communities which disempowers members of our communities to utilise what services are available.
5. empowerment of our communities for the development of culturally, linguistically and community - owned HIV/AIDS services and resources.
6. economic, social and legal issues that marginalise and victimize our communities
7. human rights agendas
8. cultural and religious diversity within any specific country overshadowed by the dominant culture which leads to denial and invisibility

From the education and debates within these various meetings it is hoped that a International Forum and network will develop, whose specific brief is to take these issues forward, formulate policy and strategic planning, encourage programmes and services within our communities, develop skills training, networking and information exchange between our communities, groups and organisation globally.

1Xth International AIDS Congress, Berlin, Germany
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THE HUMAN RIGHT OF MOVEMENT AND ASYLUM AND PERSONS WITH HIV/AIDS

Fernando Chang-Muy

Physicians and scientists normally view HIV/AIDS as a purely medical disease. However, persons living with AIDS not only confront the medical disease, but the social consequences of the disease: violations of human rights as a result of having HIV/AIDS. This presentation will focus on three topics: the status of the AIDS pandemic, the definition of human rights, and two human rights in the context of HIV/AIDS: the right to move and the right to seek and enjoy asylum.

EPIDEMIOLOGY

The UN World Health Organisation estimates that a cumulative total of 13 million adults and one million children worldwide have been infected with the human immunodeficiency virus (HIV) since the beginning of the epidemic. The total of 13 million infected men, women and children includes approximately one million persons who were newly infected with HIV during the first six months of 1992. A little over two million of these adults and children have developed AIDS.

The regional distribution of cumulative adult HIV infections are as follows: sub-Saharan Africa has over seven million infections; North America and Latin America, (and the Carribean, have over two million; South and South East Asia have over one million; Europe, including the former Soviet Union countries), has over 500 000; North Africa and the Middle East have about 75 000; Australasia has over 30 000; and East Asia and the Pacific have approximately 25 000. These are figures reported and submitted by governments themselves. As a truly global phenomenon, AIDS demand a response that is no less sweeping. One of the critical ingredients of this global response is respect for human rights.

HUMAN RIGHTS

By human rights, I mean those universally accepted principles in the international system of declarations, covenants, and treaties. The Universal Declaration of Human Rights, adopted and proclaimed by the United Nations General Assembly on 10 December 1948 is a useful tool in analysing whether human rights are being violated or respected. These human rights are divided into two general areas: civil and political rights, and economic, cultural and social rights.

Some of the key civil and political rights are as follows:

Family. They are entitled to equal rights as to marriage, during marriage and its dissolution. The family is the natural and fundamental group and unit of society and is entitled to protection by society and the state.

Everyone has the right to own property alone as well as in association with others. No one shall be arbitrarily deprived of his property.

Everyone has the right to freedom of peaceful assembly and association.

Everyone has the right of access to public service in his country.

Everyone as a member of society, has the right to social security.

Everyone has the right to work, to free choice employment, to just and favourable conditions of work and to protection against unemployment.

Everyone has the right to a standard of living adequate for the health and well-being of the person and the family.

Everyone has the right to education.

THE HUMAN RIGHT TO MOVE AND TO SEEK ASYLUM

Against this backdrop of human rights, governments, as well as non governmental organisations which the government is unable or unwilling to control, violate the human rights of persons. In the context of the right to move and the right to seek and enjoy asylum persecution, governments violate the human rights of people with HIV/AIDS.

In some instances, governments restrict the movements of its own citizens, within the country, by quarantining people with HIV/AIDS in an "AIDStorium" or "SIDAtorium". This is a violation of the right to freedom of movement and residence within the borders of each state. The person with HIV/AIDS must reside in the location designated by the government.

The freedom to move is also violated when governments prevent foreigners with HIV/AIDS from entering their territory.

The right to seek and enjoy in other countries asylum from persecution is violated when governments do not permit refugees with HIV/AIDS from obtaining refuge in their territory.

CONCLUSION

It is to be hoped that as governments and citizens become Everyone is entitled to rights and freedoms without distinction as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Everyone has the right to life, liberty and security of person.

No one shall be subjected to torture or to cruel, or degrading treatment or punishment.

Everyone has the right to recognition everywhere as a person before the law.

All are equal before the law and are entitled without any discrimination to equal protection of the law.

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted by the constitution or by law.

No one shall be subjected to arbitrary arrest, detention or exile.

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal.

Everyone charged with a penal offence has the right to be presumed innocent until proven guilty according to law in a public trial.

No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence.

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon honour and reputation.

Everyone has the right to freedom of movement and residence within the borders of each state.

Everyone has the right to leave any country.....and to return.

Everyone has the right to seek and to enjoy in other countries asylum from persecution.

Some key economic, social and cultural rights are as follows;

Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a more aware of the disease, and the transmission of the disease, they will become more enlightened and not discriminate people living with HIV/AIDS.

As the former UN Secretary General stated, "We should fight AIDS, not people with AIDS".

EMPOWERMENT OF MARGINALISED COMMUNITIES TO DEVELOP THEIR OWN HIV/AIDS SERVICE ORGANISATIONS TO PROVIDE EDUCATION, PREVENTION AND SUPPORT SERVICES.

Dima Abdulrahim

“One of the major consequences of being in a minority in any society is that there is a tendency for others to identify one’s problems, as well as the ‘solutions’ which is thought appropriate and possible to provide”

1. MIGRATION IN CONTEXT

This presentation will focus on migration to the post-industrial ‘rich’ countries of the ‘North’ and will deal specifically with issues of ‘empowerment’ and the development by marginalised communities of their own organisations. These are complex and important issues that cannot be given their due in such a short space. This presentation will thus briefly look at some of the major issues, but will undoubtedly leave many untouched.

This round table focusing on ‘migration’ does, in fact, deal with migrants, asylum seekers and refugees in addition to citizens/subjects from minority ethnic groups. There are, of course, wide differences between these groups of people, in addition to cultural, national, socio-economic and many other variations. Of course, very important differences exist, resulting from the legal status of an individual in the country of immigration or Diaspora; the position of an asylum seeker in society is very different from that of the citizen. However within the Health for All entitlement, both have the right to health care.

Other differences also exist. People may vary in their volition to stay in the countries of immigration, and their legal ability to remain. However, the reality is that despite the ‘myth of return’ on behalf of the host states, very many will remain in the latter, as can be demonstrated by the case of Turks in Germany, Algerians in France or many other.

Thus, and unless the advent of an ‘ethnic cleansing’ campaign, minority ethnic communities will remain in host countries, and will form permanent parts of increasingly multi-cultural and pluralistic societies. Moreover, generations born or raised in Western countries are developing links with the countries of exile, different from those of their parents. Ethnic identities are being formed in the countries of ‘migration’ and are constructed by the presence of people in a minority/majority context.

I will therefore argue that the sole use of the term ‘migration’ utilised by the round table is misleading, partially because of its connotations of temporariness. Instead I will assert for the need to use the term minority ethnic groups, however unsatisfactory it also may be. This suggests the need for the strategic

and forward-looking planning and development of policy and HIV-related services that are equitable. In this text, the term majority ethnic group or majority society will be used concurrently with term 'host' society.

2. CULTURE AND POWER IN CONTEXT

Issues of HIV and migration or ethnicity undoubtedly raise issues of cultural appropriateness. It cannot be denied that within a minority/majority context, culturally differentiated groups have special and unique needs. However, the way these differences are dealt with by practice or research is very important. Over-emphasising them will in cultural stereotyping just as under-emphasising them will lead to cultural insensitivity.

It is argued here that HIV research, policy and practice should move away from the reductionist fallacy based on the myth that we can control or isolate cultural phenomena. 'Cultural' factors cannot be divorced from the socio-economic and political context in which they are located and the states and bureaucratic structures within which they exist. For a good knowledge of issues of HIV and ethnicity, it is impossible to understand cultural systems, meanings and notions such as 'risk', without locating them in the contexts of perceived and/or objective powerlessness, subjugation and marginalisation.

3. EMPOWERMENT IN CONTEXT

The 'empowering' process is an enabling mechanism, one in which conditions are provided to confer on to people skills, knowledge, and many other factors that will allow them to have an impact to change their environment, and have a greater degree of control over their lives. Of course, issues around HIV, migration and ethnicity raises questions about the provision of culturally and socially sensitive and appropriate services, developed with the active participation of minority ethnic people. They also raise questions around issues of equity and equal access. In light of the limited funding/cash available, this makes HIV, at least partially, a political matter, in as much as it involves access by marginalised minority ethnic groups to, and better usage of, power and resources. It thus is argued that in order to understand issues of HIV and ethnicity, it is essential to look at the concepts of culture and power as two concepts that are not separable.

Undoubtedly, HIV is not the primary concern of minority ethnic communities, refugees and migrants, even among groups with higher prevalence rates. On the contrary, evidence shows it generally falls low on their list of priorities. More pressing issues revolve around economic survival, employment, the right to work, racists attacks, fear of deportation and so on. In order to achieve empowerment over HIV-related issues, the need for a complementary strategy to enhance the lives ethnic minority people in general should be argued. Thus, empowerment over HIV-related issues cannot really be divorced from a general process of empowerment in matters of education,

employment, discrimination, prejudice and so on. The empowerment of minority ethnic groups over issues of HIV/AIDS requires, as a pre-requisite, the political will of host states, statutory authorities and majority society organisations to aim to eradicate marginalisation. It could be argued that it also requires the development and implementation of equal opportunities policies and legislation on discrimination.

4. EMPOWERMENT OF MARGINALISED COMMUNITIES AND THE DEVELOPMENT OF SERVICES.

Community and culture specific organisations play an essential role in the development of good quality and prevention services. Firstly, they play an important role in making issues of HIV/AIDS relevant to groups who do not feel concerned. HIV related work among all sections of society is often hindered by the fact that people in general often deny that AIDS affects them. Minority ethnic people often believe to be 'protected by their culture' as a study conducted among Chinese in London, for example, has shown. Many minority ethnic people still believe that HIV only affects gay men, injecting drug users and 'promiscuous' women. These are often perceived white phenomena, often resulting from a corrupt permissive society. They are the Other. For many minority (and majority) ethnic people HIV is a condition of Otherness, of the majority white society.

It is now acknowledged that prevention work among the various migrant or minority ethnic groups should be carried out with the active involvement of these communities. There is plenty of evidence that the use of members of these communities who would be seen as credible sources of information and would give rise to a sense of personal and communal relevance. Work among Vietnamese in the UK, for example, has shown that many assumed that information about HIV is fictitious and has been invented. They only believed it when a Vietnamese outreach worker was employed and started working within his 'community'.

The development of minority ethnic organisations dealing with issues of HIV/AIDS reinforces even more strongly the sense of personal and communal relevance of work. It is a clear message within these communities that some of their members (at least) have taken 'ownership' of the issue, outside the realm of the structures of the majority society. More than anything else, they purport to their own communities the point that 'AIDS affects us too' that it is not exclusively the concern of the majority white society and that it is not a condition of the 'Other'.

Undoubtedly, community-specific organisation are well placed to produce culturally appropriate and effective materials. I will not delve into that as it will undoubtedly be discussed elsewhere. They also provide safe environment in which sensitive issues and cultural prejudices can be discussed. They could thus have an essential role for empowerment by providing fora to resource communities to reassess outdated and possibly high-risk culturally specific beliefs, for example, the belief among African Caribbeans in the UK that no drug injectors are found in their communities, or that there are

no gay Indian men, or that Muslim women do not engage in pre-marital sexual activities and so on.

Community specific HIV organisation may also be the first point of entry of people living with AIDS with health and support services, especially if they are refugees or asylum seekers. There is much evidence that fear of deportation, the fear of jeopardising chances of being recognised as a persecuted political refugee and the right to remain in the country of exile discourages many from exposing their seropositive status to services directly or indirectly linked to the state. Culture and community-specific organisations also have an important role in the provision of care and support services that are culturally sensitive. Everyone working in the field knows the distress caused by serving pork to a Muslim or the inability to provide adequate religious/spiritual support. More importantly, they provide PWA contact with people who not only understand the language, but also the issues and matters that are important to them.

Community and culture specific organisations also have an important role to play with HIV agencies of the majority host society. They have significant capacity to challenge these organisations to target minority ethnic groups, or at least to provide equitable and accessible services and culturally and socially appropriate work. They have an important lobbying and awareness raising role. They can also challenge notions and concepts used and the essentialists and Euro-centric notions of homosexuality as indiscriminately applied to all men from minority cultures who have sex with them.

Community and culture specific organisations can also act as 'enablers' in as much as they provide support to majority society organisations and are used consultants/advisors over issues of HIV and ethnicity. They also have an important role in training. In addition to the development of culturally appropriate materials they act as central resources. These prevention materials could be used nationally, thus saving time and money. In the process of empowerment of minority ethnic groups over issues of HIV, the development of minority ethnic HIV organisations should by no means come at the expense of the development of culturally and socially appropriate work by the organisations of the majority society. On the contrary, minority ethnic groups should be at the core of the 'host states' HIV planning and must be on the agenda of senior managers, budget holders and policy makers. Generic organisations of the majority society should be accountable to take on board issues of HIV, race and culture on all levels of work and monitoring.

If a policy of total dependence on community-specific organisation is adopted, there is a real danger that absence of such organisations could be used as an excuse by the host country organisations to justify inactivity and to marginalise issues of culture and ethnicity. The justification that 'these people are not interested' is unfortunately much too often heard. Moreover, like others, minority ethnic people should have choice in accessing resources and support services. In fact, and because of the highly stigmatising nature of HIV it could be argued that many would prefer the use of majority society organisations, especially if they fear that their anonymity would be jeopardised if exposed in their own communities.

5. CONCLUSION

In conclusion, it can be argued that the development of community and culture-specific organisations is part of a process of empowerment. However, it is not sufficient on its own. On the contrary, multi pronged strategies should be developed by policy makers of the majority society to actively encourage the formation of these organisations on the one hand, while at the same time ensuring that all generic HIV services are equitable and appropriate to all. Finally, the empowerment of minority ethnic people over issues of HIV cannot be divorced from a general wide-reaching process empowerment. It is important to see racism, discrimination, marginalisation, poverty, educational deprivation, fear of deportation and insecure residence as they really operate: factors that impede changes in behaviour and propagate ill-health.

1. Malcolm Cross: Editorial *New Community* 17 (3) April 1991: 307
2. Quimby Earnest: *Anthropological Witnessing for African Americans: Power Responsibility and Choice in the Age of AIDS*. In Herdt G and Lindenbaum S (eds) *The Time of AIDS: Social Analysis, Theory and Method* Sage: Newbury Park, California 1992.

DEVELOPMENT OF CULTURALLY APPROPRIATE HIV/AIDS EDUCATION AND PREVENTION SERVICES FOR ETHNIC MINORITY AND MIGRANT POPULATIONS

Ramazan Salman (Ethno-Medical Centre, Hanover, Germany)

Firstly, I have to tell you a few things about my friend Mustapha. Mustapha has AIDS. He is a years old Turkish man and he was a drug user. He has 2 children and he is married. Mustapha will be dead in some weeks. The colleagues from "Betreutes Wohnen" which is a project from Deutsche AIDS-Hilfe called me three months ago because they needed help. Mustapha stopped any communication with them. It is nearly impossible to imagine how alone Mustapha is. Nobody from his family- his wife, his son, his daughter - is caring for him. They don't write to him, they don't telephone with him and they don't visit him. His car is parked in front of the house of his family but his son doesn't touch this car because he is sure that he can be infected. The family is so much in panic that they prefer to forget Mustapha. They don't know anything about HIV/AIDS because nobody taught them the language they are able to understand: the mother tongue. I am sure that Mustapha has no chance to hear words in his mother tongue in the last minute of his life, because there were no Turkish speaking man or woman in the institution where Mustapha is waiting for his death. So nobody will say Mustapha "seni seviyorum" (I love you), some sweet word from Mustaphas' mother culture. The colleagues in the institution where Mustapha waits for his death are not able to understand Mustapha. So I had to spend more time discussing with them, than time with Mustapha. This is a general problem. Mustapha is only one example. We have many Mustaphas' in Europe with the same problem as Mustapha has.

There are cultural problems in working with HIV/AIDS: the experts are nearly always from the ethnic majority. Members of the ethnic minority mostly haven't the chance for paid work in their own ethnic group. So my opinion is that we have to develop culturally appropriate HIV/AIDS education and prevention services for ethnic minority and migrant population. Services where migrants or members from ethnic minorities are able to work towards their own communities.

If we understand culture to be the opportunity that society offers its individual members to determine their own behaviour, thoughts and feelings, then it follows that the perception and treatment of health, sickness, sexuality and education are subject to culture-specific evaluation. This culture specific evaluation can only be understood by people from the same culture.

Every society develops techniques in the treatment of health, sickness, sexuality and learning, as well as ideas regarding the causes of sickness, sexual or educational problems. The resulting insights- the social norms of behaviour concerning prevention and resistance, and concrete measures for the treatment of people- are all culture-specific. Different cultures create different values in the field of healing, sexuality and education. Although several million people live as worker-migrants or refugees in Europe, these people, and their socio-cultural customs, have stayed for many members of the ethnic majority so far unknown.

The European health and education system is bedded in a scientific value system conditioned by local culture. The actors in this system are increasingly confronted with people from other cultural circles, who in matters of health, sickness, education and sexuality, as a result of insufficient background knowledge, they can only inadequately help. On the other hand, those seeking help cannot express their internalised attitudes and behaviours in questions of health, sickness or sexuality. They lack the appropriate socio-cultural terms of reference.

Between migrants or members of ethnic minority and the members of the ethnic majority 'helpers' there is precious little contact or dialogue concerning healing expectations and forms of treatment. This leads inevitably to misunderstandings and often inappropriate or inadequate health care and HIV/AIDS prevention of people from other cultures.

People from other cultures are also subject to specific stress factors that have their own origin in migration itself, and can lead to sickness. Here the reasons for migration (e.g. inability to secure life in homeland, fleeing) and the type of migration (e.g. with, or without, family) are decisive as the social conditions in our country, that determine the flexibility available to the migrant in his or her way of life.

In the European health and AIDS/HIV prevention system, people with illnesses derived from specific problems associated with migration find inadequate therapeutic care.

Comprehensive and, especially health care of the whole European population in psycho-social, psychiatric and psychosomatic areas can nowadays only be ensured in co-operation with ethnic specialisation.

HOW?

It is necessary

1. to highlight deficits in the health care of migrants, explore the causes in terms of cultural and migrational aspects, and prepare concepts for the solutions of these problems;
2. to contribute towards better medical care and AIDS/HIV of migrants in Europe, in the form of Model Projects, to determine new practical applications for ethnic-specific and migration specific concepts.
3. to contribute, on the basis of prepared model concepts towards better medical care of migrants.
4. to approach this task in a step-by-step manner, in which the opportunities open to us, in terms of the underlying concept, are constantly reappraised in line with practical experience and theoretical insights.
5. Health-care consultancy, with emphasis on preventative, curative and rehabilitative healing for migrants.
6. Helping health-service users to obtain maximum benefit from the current health system.
7. Intercontact and networking between institutions, facilities and staff in the health-service users.
8. Informing interested institutions/ facilities/ staff about ethno-specific aspects of their activities.
9. Development, co-ordination and conduct of vocational and further-training programmes for staff of social and health and AIDS/HIV services, with the aim of improving the health of migrants in Europe.
10. Research and documentation of deficits in the health care of migrants in Europe, with the aim of the highlighting future points of emphasis in the practical field.

UNDOCUMENTED IMMIGRANTS LIVING WITH HIV IN NEW YORK CITY

Jairo Enrique Pedraza

Me siento muy honrado en haber sido invitado a hacer esta presentacion. Quiero pedir disculpas a todas las personas hispanoparlantes que se encuentran en el publico por no hacer esta presentacion en castellano. El comite organizador me ha pido que tiene que ser en ingles.

Esta es una vez mas una muestra de como se nos excluye en vez de ser mas incluidos en estas conferencias internacionales. Hago mi presentacion en ingles, pero a la misma vez dentro de mi hay un sentido de protesta..

On August 28, 1987 HIV infection was added to the list of 'dangerous contagious diseases' that exclude a person applying for legal permanent residence in United States. In addition to meeting the long list of bureaucratic requirements to live in the United States, now an applicant also has to be HIV negative.

This not only affects people who are planning to migrate or to travel to the USA, but affects many undocumented people who are already residing in the USA and who otherwise would qualify for permanent residence status. HIV positive immigrants who are not eligible to obtain legal status face two inhumane choices: They can remain in the US undocumented and underground, without work authorisation or access to services such as counselling and medical treatment, or they can return to their home countries to face a bleak future of poor medical services, discrimination, persecution and possible early death.

The neighbourhoods immigrants live in are usually places where housing is deteriorating but the rents are somewhat more affordable. The scarcity of such housing leads many immigrants to share apartments and overcrowding is common fact in neighbourhoods of immigrants. Social services in these communities are minimal, The very few agencies providing services there have heavy loads of clients that have to wait patiently for long hours. Violent crime and drugs add to the problems of these areas which are made worse by police services that are deficient, racist, and in some cases, corrupt.

The general sentiment among Americans is that the new immigrants are outsiders who are coming to take the few jobs that are available in the US's shrinking economy. In fact, they work at jobs that no legal resident of the US would want to take for the actual wages paid to undocumented workers. Often they make their living by doing domestic jobs such as cleaning houses or selling flowers in the streets. They work long hours for small pay. For the undocumented immigrant social networks are of extreme importance as they help them sort out the many difficulties of life in the underground economy. The support provided by these networks is not only logistic but also emotional. Because of the fragility of their situation and the dangers involved in migrating without documentation,

individuals leave behind their families and other sources of support.

Most people are afraid to test for the HIV virus. Not only is it a frightening experience as for anyone but also the implications if one day they were to apply for permanent residence. Their lack of legal status means they are deprived of the medical services that citizens and legal residents can take for granted.

Immigrants migrate not only for economic reasons. Some are in search of a place in the world where they can lead fuller lives out of the closet and with less danger of violent homophobia. Once in the US they find that the dream of freedom is limited by a very real homophobia that impregnates most of this society. They also find themselves tied to their own ethnic communities. This offers them resources for survival, but at the same time reproduces the homophobia they hoped to escape from.

When AIDS strikes they are alone and without their families they are depending only on the support of a network of friends, often with very limited financial resources and minimal information on AIDS services. When they find themselves sick and alone their need for support increases this makes the distance from relatives and friends seem even greater. The high cost of travelling makes the idea of being with the loved one impossible. When family members can afford the expense of international travel they become caught up in a long and very discriminatory process that the American government has in place for granting visas. As a result many people die in hospitals alone or only with the support of those friends that they may have made. Friends that they had made.

Medical Attention:

Undocumented immigrants don't have access to adequate medical services. It is necessary to have legal permanent residence in order to receive complete medical care. The emergency rooms of city hospital are their only resource when it comes to their health care. Once medical care is accessed, it is very often difficult to find practitioners who speak the language of the patient. They are unable to communicate to their symptoms or the pain that they are going through. If an interpreter is used for communication this puts an immigrant in the vulnerable position of not only divulging their most intimate aspects of life to the doctor, but also to another stranger.

Some people in the different immigrant communities distrust the Western medicine. At times the side effects of the medications make people feel sicker not better. This confirms their doubts about the benefits of biomedicine. Immigrants with HIV sometimes feel more comfortable with therapies that include the use of herbs and other so called folk medicine. Immigrants distrust western medicine because of their unfamiliarity with it, and because they know that a contact with the medical system exposes them the being reported to the immigration authorities. This fear leads them to delay seeking medical help until the last stages of the illness. When their desperation is at such a point it overcomes their fears of deportation.

Because the services in communities of immigrants are few, everyone knows where the HIV related services are provided. People may be discouraged from seeking help because of the threat of stigmatisation.

The strategy of sharing a single dwelling among many individuals may cause medical problems. Malnutrition and an overcrowded situation is a hotbed for TB transmission. Tuberculosis is extremely dangerous to those infected with HIV, particularly now that the most used therapy strategies are proving to be ineffective.

The growing number of women infected with HIV presents an additional set of problems. There is a need to educate physicians who are not familiar with the characteristics of HIV when it attacks women and children. In addition, the social position of women in the particular communities to which they belong and how it may foster or preclude their seeking medical attention.

Social Services:

Undocumented immigrants do not have access to most social services. They do not qualify for any public benefits like cash assistance or food stamps. The complexities of the social service system makes it hard for this population to access the few services to which they are entitled. Even, when an immigrant with HIV obtains legal status, many social providers fail to recognise the documentation that the person may bring along and unfairly deny services.

When substance abuse is a problem, immigrants with HIV are confronted with another closed door. As with most services, they are only available to those who have other social services and therefore shut to undocumented immigrants. In New York, where only a quarter of those needing substance abuse services get them, immigrants with HIV have almost no way to deal with their addiction. The negative effects of drug use deepens the decay caused by HIV infection shortening their lives. It is also true that in some cases alcohol consumption may be misread as a problem. Social workers judge their client's level of alcohol intake according to the very strict standards of the USA, and penalise what otherwise would be culturally appropriate behaviour on the part of their clients.

There are few support groups that are open to immigrants with HIV, and support group therapy is not readily accepted among many ethnic minorities. The technique of group support emerged from the white middle class, and even Americans who are not white or middle class have problems with the idea that one can open up to a group of strangers. It is true that in some cases groups have provided some benefits to their participants, it is mainly when all of them are part of the same ethnic group and share similar problems. To the undocumented immigrant the idea of being part of a support group may be frightening because of their fragile legal situation that may be destroyed with a breach of confidentiality.

Legal Issues:

It is interesting to point out that in many cases the undocumented only come out of the secrecy in which they live as a result of their need for legal services with regard to their immigration status. In most cases they assume that they do not have any rights. But there are other ways in which an undocumented immigrant with HIV can be helped by a legal team. Issues like custody of children, testaments, discrimination, housing disputes, as well as the type of care a person wants for the last days of their life are some of the ways in which an immigrant can receive help from legal experts.

Undocumented immigrants must have access to medical services comparable to those available to any other person. These services should be provided in their native language and ideally be people who share their cultural background. The use of folk medicine should not be condemned if it is not causing the patient to be sicker. In fact it should be openly incorporated in the patient program for treatment. Such an attitude of the medical practitioner will foster trust from the patient, a trust that may translate in the compliance of Western medical procedures and medications. The different manifestations of HIV infections in females and children should be well known among services providers with an immigrant population. At every point a non-threatening environment should be provided and the patient should be reassured that taking care of their health at that particular site will not put them at risk with the immigration authorities.

It is very important that pharmaceutical companies that are profiting with the sale of drugs and treatments in the USA and Europe open up expanded access programs in developing countries. These programs would allow immigrants who want to go back to their home countries to consider the idea without fear of not receiving needed treatment.

Similarly social services need to be prepared to deal with the immigrant population. It is important that they speak the native language of their clients and that they are familiar with or share their culture so as not to misinterpret behaviours and values. Social workers should be very sensitive when conducting interviews that require the unveiling of more personal information, it is quite possible that their clients may have had a limited exposure to the idea of 'social work' and may react negatively. Social workers also need to be familiar with the rights of immigrants in order to provide for them all that they are entitled to. Substance abuse services should be made readily available when needed. It is important to have a clear idea of what organisations or cultural institutions are already in place in the community and to find ways in which they can be used for HIV prevention and for support to those already infected.

Legal services should begin by making immigrants aware of their rights and where to go if they feel that they have been denied them. They also need to be accurate and clear about the limits of the services they can provide so as not to create false expectations on their clients. Still legal services should be delivered in an atmosphere of friendliness and cultural understanding that would generate trust. Providers of legal services should know two things: that their services are a 'point of entry' for

many undocumented immigrants into the system of services and that their clients problems are more than legal. This means that they have a unique opportunity to outreach and that they should be prepared to do referrals for services that may not be legal.

I would like to conclude this presentation by condemning mandatory testing of HIV testing of immigrants and refugees which is blast example of the hypocrisy of the United States government. But this is not a problem solely confined to the borders of the United States. The United States mandatory testing program threatens every person with HIV on this planet.

THE WORLD UNITED MUST HOLD THE UNITED STATES AND ANY OTHER COUNTRY IMPOSING MANDATORY TESTING OF IMMIGRANTS AND REFUGEES ACCOUNTABLE FOR THIS ATROCIOUS VIOLATION OF HUMAN RIGHTS: We can not, we must not remain silent in the face of an insane policy whose only purpose is to further isolate, stigmatise and traumatise immigrants and refugees and persons living with HIV.

HIV is a disease that knows no borders.

I would like to dedicate this presentation to my clients, my fellow sisters and brothers activists that like me are fighting this virus, some of whom are sitting in the audience today.

Also to my true friend and lover ALFREDO, lets keep fighting ain't over yet.

ACT UP FIGHT BACK FIGHT AIDS,

not

IMMIGRANTS

Report on the First European Information Exchange Meeting on Ethnic Minorities, Migrants and AIDS, held in Blossin, Germany, May 1993.

Report by Oonagh O'Brien of Positively Irish Action on AIDS, London, UK

The first European meeting for the exchange of information on migrants and AIDS was held in Blossin, Germany, from the 7th-10th of May. It was organised by Deutsche AIDS Hilfe, Kultur ist Plural, VIA and EuroCASO, and was sponsored by the EEC and WHO. Participants were invited from a range of migrant and HIV/AIDS organisations in Europe. The organisers of the conference felt that it was important to hold the meeting during 1993, so that the results could inform the IXth International Conference on AIDS at Berlin in June 1993. It may be harder for migrants issues in Europe to be raised at the Xth International conference in Japan, because of the cost of travelling to Japan for migrants and voluntary groups based in Europe.

1. AIMS

A pre-conference planning meeting was held in Berlin on May the 6th. At this meeting it was agreed to change the name of the title from the original name of Migrants and AIDS, to Ethnic minorities, Migrants and AIDS. It was acknowledged that this title was not ideal as it did not reflect the wide range of situations which people are in when they move from one country to another, but could be used as a working title to refer to both settled, and recently arrived groups.

The aims of the conference were confirmed at the planning meeting as follows:

1. The establishment of a European network of the associations and groups active in the field of AIDS and migration.
2. The publication of the documentation of the conference and a directory of the associations and groups active in the field of AIDS and migration.
3. To draft a declaration for the IXth International AIDS Congress to be convened in Berlin in June, 1993, including a clear political statement against racism.
4. To benefit from sharing each others experiences.

2. STRUCTURE OF THE MEETING

The meeting was organised into two major formats; firstly there were presentations from organisations working with issues related to HIV/AIDS and migrant groups, such as the Project Migrants OFSP/IUMSP-ZH, in Switzerland, the Naz project for South Asian and Muslim communities, based in London, prevention projects with the Turkish community in Germany and Positively Irish Action on AIDS working with Irish people affected by HIV/AIDS in Britain. Secondly there were eight working groups on the following topics related to HIV/AIDS:

1. Social security and health systems for migrants.
2. Participation of governments, religious organisations and trade unions

3. Funds for the development of prevention programmes.
4. Migrant groups with special needs re HIV/AIDS information and care.
5. Programmes and services of HIV related care for migrants.
6. Creating a network structure for information and co-operation.
7. Ethical, legal and human rights for migrants affected by HIV/AIDS.
8. The situation of migrants living with HIV/AIDS.

Each workshop had two facilitators, and the reports are included in the conference documentation. The last workshop was charged with writing five declarations in the form of letters aimed at different audiences, which would be distributed after the conference. The audiences were as follows:

- a) - Religious organisations, trade unions and employers' organisations,
- b) - Migrants and ethnic minority organisations,
- c) - Government and non governmental AIDS service organisations,
- d) - Governments of host countries and all related governmental ministries and departments,
- e) - Global and European organisations such as the WHO and EEC.

Documentation of the results of the conference have been written up, and the original and full texts of the meeting documentation and letters are available from the offices of Deutsche AIDS Hilfe at the address above. In this presentation the general points which occur in all the letters will be summarised and then the specific points addressed to the different audiences will be briefly outlined. These points are all summarised from the text of the meeting.

3. TEXTS OF LETTERS - DECLARATIONS

General Points

All the letters started by referring to the Blossin meeting and explaining that it was the first meeting to bring together individual and community based organisations from migrant/ethnic minorities living in Europe, as well as representatives from both non governmental organisations and governmental AIDS service organisations (ASO's) and international organisations (EC, WHO). The meeting was a result of the concern among those working in the field that the needs of migrants and ethnic minorities were not receiving adequate attention in HIV/AIDS services. It was pointed out in the letters that the meeting had been very successful. A space had been created in which members of a diverse range of communities could learn, share and mutually support each other.

The letters clearly stated that, whether we are newly arrived migrants or 'guest workers' who are helping to build the economic strength of Europe, or permanent residents or citizens of European countries other than that of origin, we have the right to be treated equally, fairly and equitably as are all other citizens of Europe. This also means that any racist ideology, whether institutional or individual, is strongly challenged within existing or future services and respect accorded to different traditions, cultures and religious faiths.

These points should be clearly reflected in the institutional framework, laws and resources of community organisations. There is clearly a need to establish, strengthen and reinforce services and organisations which can provide a multi-cultural approach to HIV related issues within migrant communities and for members of ethnic minorities.

Migrants in Europe have to cope with many problems. The appearance of HIV in recent years has created additional problems. HIV does not distinguish according to origin, colour, religion or sexuality. Ethnic minorities/migrants are not affected by HIV/AIDS more than mainstream populations, however, if we are HIV+ or have HIV related illness we suffer a double stigma because of the status of being HIV+ as well being an outsider.

Europe is a multi-cultural society and must be recognised as such. This means that all people irrespective of where they live, where they originated from, their language, culture, religion, colour, social class, gender or sexuality, have the same rights to services as the mainstream population. Every person, no matter what country they are a citizen of or live in, is also a citizen of the world and as such has the right to prevention information and the financial means to protect him/herself from HIV infection, or to access care and support.

The specific points in the letters were as follows:

1) Religious Organisations, Trade Unions and Employers Organisations

It was pointed out that religious organisations of any faith, play a special role in maintaining links between migrant communities and their society of origin. Religious organisations have frequently developed social services which play a vital role in catalysing the participation of ethnic minorities. These may well include care and support for people who are HIV+. However, the specific elements regarding HIV infection have made the implementation of HIV/AIDS prevention programmes extremely problematic in this sector; sexuality has often presented problems within diverse theological institutions. The fight against AIDS and the fight for spiritual values are not necessarily in contra position to each other. At the basis of both is a respect for life. On the basis of this common denominator, we feel that it is important to support and sustain a continuing dialogue with religious leaders with an objective to finding a mutual means of support for the work we are engaged in.

Trade unions should:

1. Promote awareness regarding migrants issues.
2. Aim to abolish discrimination in employment.
3. Establish local monitoring of employers adherence to workers and human rights.
4. Promote specifically targeted health care activities.
5. Promote the establishment of services for sexual counselling.

2) Migrants and Ethnic Minority Organisations

In the letter to migrant and ethnic minority organisations, it was pointed out that they must take on board activities which include HIV/AIDS education of our communities. We must recognise that there are groups in our communities who are at risk of HIV infection. The only way to do anything to prevent HIV infection is a willingness to deal openly with the issue, and to demonstrate solidarity and care for those infected.

In order for such initiatives to be successful, individuals from our communities who have a position in religious organisations or politics, must not ignore the issue but support HIV/AIDS education and prevention.

3) Government and Non-governmental AIDS Service Organisations (ASO's)

The specific points made in the letter to ASO's were as follows:

ASO's have a particular responsibility to work with ethnic minorities and migrants on issues linked to HIV/AIDS, because they have direct access to target groups. They are also expected to do this as ASO's are highly sensitive to the discrimination of groups within the population as a result of the experience of working with gays, drug users and sex workers.

ASO's must realise that ethnic minorities and migrants are a group within the population which must urgently be included in primary, secondary and tertiary AIDS prevention and that ethnic minorities and migrants have to be perceived as a specific target group. This might require a special programme, such as an interpreter. Lack of confidence in mainstream services means that ASO's must provide advocacy for ethnic minorities/migrants.

4) Governments and Governmental Departments

The specific points made to governments and governmental departments were as follows:

Governments have a moral duty to set up intensive programmes against racism in their country. Adequate resources have to be spent on the research of knowledge, attitude and behaviour of migrants towards HIV/AIDS related issues in order to develop appropriate packages of prevention and care.

Migrants have to have access to information about HIV/AIDS. This information should be provided by governments, in collaboration with migrant groups.

Migrants affected by HIV/AIDS must have free access to social welfare, social security, sickness benefit and health care. All legislation should be established in accordance with fundamental human

rights, and opposed to any form of racism. Borders must not be closed to migrants affected by HIV/AIDS.

5) Global and European Organisations

The specific point made to global and European organisations were as follows: that the necessary legislative and monetary changes be made at international, national and local levels to ensure that migrants and ethnic minorities have equal and adequate access to the resources required by their communities. We specifically ask that supporting programmes and research which target migrants and ethnic minorities, are adequately considered and resourced by international organisations and national governments.

4. CONCLUSION

On behalf of all the participants of the conference, I would particularly like to thank the three organisers of the conference, Petra Narimani, Jaime Tovar and Ricardo Fonseca, and all the workers at DAH and Kultur ist plural, who worked very hard in order for the meeting to take place, and created an exceptionally friendly atmosphere. A great deal of work was done, and contacts made, which for example I have already used in my daily work with Irish migrants.

It is hoped that the initiative will continue. The Naz project are taking steps to establish a European resource centre in London, and a follow up conference is planned next year, to take the work initiated in Blossin, further. We must ensure that ethnic minorities, migrants, refugees and asylum seekers, whether black or white, male or female, gay or straight, mobile or settled are not forgotten in HIV/AIDS services.

For more information or full report on the meeting contact Petra Narimani, Jaime Tovar or Ricardo Fonseca at

Deutsche AIDS Hilfe at Dieffenbachstr 33, W-1000 Berlin 61, Germany.

Tel: Germany 030 - 690 - 08712

Declaration to those in positions of political responsibility in all the countries of Europe

In response to the recent events in Solingen, Germany, May, 1993, the II European Workshop "AIDS Prevention for the Turkish population in Europe" has issued the following statement:

We consider that the migrants and ethnic minorities living in Europe not only face social problems such as unemployment, poor housing, inadequate health care and other disadvantages, but a major threat also exist in Germany from groups of right wing extremists.

Those of us involved in HIV/AIDS prevention regard racism as a disease of the mind which presents an even greater threat than AIDS itself.

There has not yet been a firm and appropriate response to the attacks by right wing extremists in Germany.

The imposition of stricter regulations on asylum-seekers only seems to encourage right wing groups; it is no coincidence that the murders in Solingen were carried out shortly after the asylum laws were amended.

The following measures must be introduced at the earliest opportunity in order to protect migrants and ethnic minorities in Europe from further attacks, and to ensure their integration in the following areas of life.

1. Racism must be resisted at both international and local level
2. Specific anti-racist legislation, such as exists in the United Kingdom, should be introduced in Germany and other countries to ensure that effective penalties exist for institutional and individual acts of racism.
3. Racists laws must be expunged from the statute books of all countries. Authorities, including their organisational structures, must be examined to ensure that they are effectively resisting racism, and all racist employees must be expelled.
4. Organisations and projects should only be allowed to receive official funds if their objectives are clearly and firmly opposed to racism, and provided that migrants and ethnic minorities can make use of their services without fear or inhibition.
5. All right wing extremist organisations and parties must be strictly prohibited.
6. An anti-discrimination law must be introduced, prohibiting all kinds of discrimination and providing for suitable punishment.
7. The right to dual citizenship must be introduced.
8. Voting rights must be extended to the entire population.

In view of the inadequate provisions for information, prevention and care for those affected by HIV and AIDS, we call for the following measures to be implemented.

1. Migrants and ethnic groups are not particularly by endangered by HIV and AIDS, but they are exposed to additional hazards due to
 - inadequate information
 - language barriers
 - social disadvantages
 - discrimination
2. Therefore AIDS prevention should also include effective, subliminal messages aimed at migrants and ethnic groups.
3. An HIV antibody test should only be carried out voluntarily and under conditions of strict anonymity. Compulsory HIV testing of applicants of asylum or scholarships, and of immigrants must not be permitted.
4. Immigrants should not be expelled on the grounds that they are HIV positive.

It is time for action, in a wider sense.

The participants in the II European Workshop "AIDS Prevention for the Turkish Population in Europe.

Issues and recommendations arising from the Satellite Meeting held at the 1Xth International Congress on AIDS, Berlin, Germany, June 1993.

1. Invisibility of the specific needs of ethnic minority, migrant and refugee communities in National AIDS Programmes. The presence of peoples of different nationalities with different colour, religions, sexualities and languages, must be acknowledged within National AIDS programmes and specific HIV/AIDS services and resources.
2. The need for collaboration between ethnic minority, migrant and refugee communities and countries of origin in developing appropriate HIV/AIDS resources and materials.
3. Developing an international network of ethnic minority, migrant and refugee organisations working within the HIV/AIDS arena. This network would also include staff and volunteers of these communities working in statutory and non-governmental HIV/AIDS agencies.
4. Legal status of non-nationals in host countries need to be adequately addressed. The human rights of these people must be adhered to.
5. Informed consent is exactly that! All HIV anti-body testing must require informed consent within the fullest meaning of the term. This means that the test and its consequences must be explained to the person in their own language. Counselling that is linguistically and culturally appropriate must also be a part of this.
6. There are specific issues to do with internal migration from rural to urban areas of any country; with female migration and economics, and migration of people from Southern nations to the Northern nations, and also from South to South.
7. There are ethnic minority and migrant communities in all countries.
8. There must be an adequate and appropriate provisions of education, prevention and health care for all ethnic minority, migrant and refugee communities. The principles of equality and equity must be applied.
9. Any National AIDS Programme, governmental and non-governmental services, whether arising from the indigenous population or from the ethnic minority, migrant and refugee communities, must take on board issues of sexual minorities within these communities.
10. Racism must be challenged in all countries and at all levels. Racism has a dramatic effect upon the legal, social and political structures within a country and thus adversely affects the provision of welfare and health services for an ethnic minority, migrant or refugee person/community.
11. The human rights of all peoples, whatever race, colour, creed, gender, sexuality, economic class, caste, or ability must be adhered to and supported. These human rights will include reproduction rights.

Several actions that need to be taken were also addressed.

1. An International Ethnic Minority, Migrant and Refugee HIV/AIDS Resource Centre should be urgently developed. The responsibility of such a Centre would be to enable information and skills exchange, resources and materials exchange, materials development, networking.

Further, such a centre could also document human rights violations and abuse.

2. That we should seek funding to hold a specific international conference on HIV/AIDS for ethnic minority, migrant and refugee communities.
3. That issues concerning the legal status of people from ethnic minority, migrant and refugee communities in their host countries. This should include:
 - a. residency status
 - b. access to welfare and health care
 - c. human rights including reproduction rights
 - d. entry visas for visiting family and friends
4. There is also a demand that international bodies such as WHO, Amnesty International and others should put pressure on various governments to challenge racism and human rights abuse of ethnic minority, migrant and refugee communities.
5. All national governments should follow WHO Guidelines on testing, and there should be no discrimination in testing.
6. All people should have equal access to HIV/AIDS information and services that is adequate and culturally/linguistically appropriate to the needs of any person.
7. This means that appropriate levels of funding should be made available to ethnic minority, migrant and refugee groups/organisations to develop appropriate services and resources, and that indigenous organisations should be challenged to open up their services to members from our communities by making them more accessible and linguistically and culturally appropriate, whilst challenging any racism within them. This can be achieved by ensuring that funding regulations have such provisions within them before monies are entrusted to any organisation or service.
8. Ethnic minority, migrant and refugee organisations and individuals from these communities must be empowered to develop services for their own communities. Empowerment comes from equity and equality, through access to adequate funding, changing regulations and laws where appropriate, support of government institutions. These services should also be accessible to marginalised groups within our own communities, such as drug users, sex workers, men who have sex with men, women, etc.
9. Pharmaceutical companies must be challenged in their policies for testing new drugs upon people of Southern nations.
10. There has been a lack of research on HIV/AIDS impacts, sexuality and sexual behaviours, health, etc. on people from ethnic minority, migrant and refugee populations. Such research needs to be addressed if effective education, prevention and support services are to be developed for these communities. All institutions are urged to enable such research to be developed. It is vital however, that such research be conducted in culturally appropriate ways.

Challenge and Response

The First European Conference on HIV/AIDS for the Muslim and South Asian communities
London, United Kingdom
9th September - 11th September, 1992

sponsored by the:

Commission of the European Communities
Department of Health, UK
World Health Organisation, European Region

developed and organised by The Naz Project

The following is an abstract from the Conference Report published in November 1992. This report can be obtained from The Naz Project, Palingswick House, 241 King Street, London W6 9LP, UK. Fee: £5.00 (sterling) with post and packaging.

CONFERENCE STATEMENT

This Conference was the first attempt to bring together individuals and community based organisations from the Muslim and South Asian communities living in Europe, as well as representatives from AIDS service organisations both voluntary and statutory, at local and national levels to discuss, share and learn from each other.

It arose from the concerns of members of The Naz Project and others that the needs of the Muslim and South Asian communities of Europe were not being seriously addressed in terms of HIV/AIDS services.

With some rare exceptions, what services that did exist were either inadequate, not sufficiently resourced, racist, and imposed upon our communities. They were ineffective, and often increased the marginalisation of our communities within the European countries. Our communities are often vilified as the source and spread of HIV infection, rather than a part of the need to address community issues. The different religious, cultural, linguistic and traditional contexts are ignored. And all this does is to reinforce the stereotypical concepts both within the communities themselves, and without. Concepts that effectively block HIV/AIDS education and prevention and which marginalise treatment and care for those from our communities affected by HIV/AIDS.

This bringing together of our peoples was a tremendous success, a high point in a new initiative in terms of addressing the challenges of HIV/AIDS generally and specifically. A time was given to learn, to share, to mutually support each other, coming as we did from a diverse range of ethnic communities. A process of empowerment. A chance to state that "we are here in Europe to stay" and that "our human rights need to be recognized", and that "we are a part of the European Community too".

The Conference recognised the tremendous challenges that lie before us to ensure that the momentum generated by this Conference does not "wither away and die on the vine", that we had to remain in contact with each other, "exchange skills and expertise" and "join together for mutual solidarity and concern".

We state clearly that, whether we are newly arrived migrants or “guest workers”, “who are helping to build the economic strength of Europe” or permanent residents or citizens of the European countries, we have the RIGHT to be treated equally, fairly and equitably as any other citizen of Europe. That respect should be given to our different traditions, cultures and religious faiths. And that this should show itself clearly in the institutional frameworks, laws, and resources available for community action generally and specifically with reference to HIV/AIDS.

The recognition that Europe is now a multi-cultural society should be emphasised across the board and must be a part of any agenda on public health or other local/national/intergovernmental agenda. And based upon such recognition, the different communities of European countries must be drawn into the debate on policy and strategic development on HIV/AIDS. That communities must be consulted and listened to. That communities must be resourced to develop their own educational and prevention strategies. And that their skills must be effectively utilised and promoted in such developments. And where specific skills may be lacking, training should be provided to develop them.

All we ask is to be treated equally, with dignity and respected as any other member of the nations of Europe. That we are recognized as members of the European Community. And in that recognition we have a just and fair access to services and resources whether international, national or local, whether statutory or voluntary.

RECOMMENDATIONS

From the various discussions, workshops, working groups and other forums within the Conference, a series of specific recommendations emerged directed at the European Commission, WHO, national governments, city authorities, Health Authorities, voluntary organisations (whether national or local), and our own communities.

Recommendations for National and International Institutions

1. A new European network must be established for the “migrant” communities which can act as a resource and information base, especially in terms of consultancy, health promotion policy and strategic development, and advocacy.

It was also decided that there must be a further conference for 1993 to continue the work of this conference; and that this should also be financially supported by the European Commission and national governments.

It was strongly felt that this first conference was an initiatory process and that a second conference will expand the work and develop a skills training programme to enhance the range of experience and skills that the members of our communities will be able to offer in the development of community-based organisations working on HIV/AIDS issues, whether specifically AIDS services organisations, or as part of their broader agendas.

That if this initiative is not nurtured and supported to develop the network, then this will reflect not only the perceptions of the initiating delegates in terms of how seriously our communities are viewed by the European Commission and national governments, but will also reflect how seriously HIV/AIDS issues within our communities is viewed whether by government or by our own communities.

2. Such a network must be adequately resourced from the European Commission, WHO Global Programme on AIDS (European Region) and National Governments and will be empowered to work with the migrant communities in developing a response to HIV/AIDS.
3. This network must also work with existing networks such as EuroCASO, the Migrants Forum, AIDS and Mobility, Global Network of People Living with HIV/AIDS, in order to ensure that there is an exchange of information and skills, as well as ensuring that the issues of the "migrant" communities are taken on board by these other networks.
4. Action should be initiated by this network to encourage and urge "migrant" communities to develop their own community based organisations working on HIV/AIDS education, prevention and care to participate in local and national debates and structures on HIV/AIDS service delivery; to participate in the policy and strategic planning on HIV/AIDS.
5. European and other international forums, non-governmental organisations, National AIDS Commissions, local health boards and voluntary organisations should be challenged in their response to the needs of the "migrant" communities by this network and in this challenge they should be urged to take appropriate action in order that ALL communities have adequate, appropriate and accessible services.
6. Delegates expressed concern about the terminology of the debate with specific reference to the word "MIGRANT". What does this mean? There are some who are European descended "migrants" as they move from one European country to another. There are some who are descended from "migrants" from Southern nations and are born in the country of adoption. There are some who are political refugees.
7. Racism is endemic within the European nations and must be challenged at international, national and local levels. While Britain has specific laws with regard to racism, i.e. The Race Relations Act, all nations should be ensuring that effective legislation is available to challenge racism, both institutionally and individually, with effective penalties to eradicate this pernicious ideology. This means racist laws must be removed from the statute books, all services must be monitored to ensure that they will challenge racism within the organisations that deliver them, and all staff who are racist must be removed from their posts. Where organisations are funded from public budgets, such funding should not be targetted where such organisations do not implement effective race-awareness training programmes for their staff, where they do not make changes in policy and strategy with regard to ensuring that they are services are appropriate and accessible to members of our communities without fear and hindrance.

Further where:

1. Legislation that restricts services to members of our communities because of their residential status;
2. Members of our communities living in Europe who are affected by HIV/AIDS are deported;
3. Those whose lives are threatened by their HIV/AIDS status and/or their sexuality in their countries of origin, and who are living in European countries, but are not allowed asylum status;
4. Members of our families living in our countries of origin are not allowed visiting rights because of restrictive practices or legalities;

These should all be challenged and effective amendments made in law whether by national governments and/or by the European Commission.

In the context of the conference the issue was one concerned about the non-European descent communities known in Britain as the "Black and minority ethnic communities". We recognised the issues that surround those from Eastern Europe and the former Soviet Union. These have tended to be the latest migration into Western Europe. While there were commonalities between the the former and the later, there were also differences in terms of history, culture, tradition and religion. These differences must be recognized.

Within the British definition of Black and minority ethnic communities there are substantial differences between communities. We are not a homogeneous group of people. HIV/AIDS demands that these differences are recognized and accepted in order that effective services can be developed that adequately address the equality and equity of opportunities.

What this preamble asks for is for the development of terminology that addresses these issues. Such a development must involve the communities themselves to ensure that communities are not marginalised by language, and language does not determine the level and appropriateness of service delivery.

The above recommendations reflect the pan-European concerns of the Conference.

Recommendations for National and Local AIDS Services Organisations

1. It is very important that HIV/AIDS service delivery in terms of education, prevention and care not be imposed upon our communities. Generic education and prevention programmes are not reaching within our communities. Such programmes should be specific to the community in which they are operating.
2. Members of our communities should be encouraged to develop their own responses to the dilemmas of HIV/AIDS.
3. In order for this to effectively occur specific strategies should be developed where necessary, to incorporate the issues of HIV/AIDS into the priority agendas of our communities, i.e. housing, employment, immigration, racism. It may be possible to develop the debate in the context of viewing HIV/AIDS within sexual health parameters.
4. Such education and prevention programmes should be adequately resourced. Funding strategies should not rely upon annual funding but should be on a long term basis. Funding must be made available to develop effective services for our communities and which are managed by members from our communities.
5. In terms of treatment and care, front-line staff such as nurses, doctors, councillors must be trained in the cultural and religious issues of the different communities. They will also need training regarding the specific needs of people from our communities affected by HIV/AIDS (which are not necessarily the same as those from the white communities).
6. More staff from our communities must be recruited to deliver these services. More people from these communities must be employed in the mainstream services, rather than creating only "specialist" marginalised posts.

7. Muslim and South Asian Statutory and Voluntary agency employees should be provided with support and training opportunities to develop their expertise.
8. Statutory and Voluntary organisations must consult with Muslim and South Asian communities.
9. Funding must be made available to upgrade/or produce resource materials in community languages rather than have them translated into the language. Translators to be trained in issues around HIV/AIDS. Care must be taken to ensure that terminology, style and content is consistent with community language levels.
10. Appropriate imagery must be developed. For example, if a leaflet is developed around safer-sex for “gay men” then images must also be used that reflect the multi-cultural basis of European countries.
11. As far as possible such resource production should be given to the Community Based Organisations themselves to develop and produce.
12. Who are the educators talking to? Care must be taken to ensure that all sections of the various communities are consulted, and not just the “community leaders” .
13. Funding should be made available to do effective research in terms of language and terminology.
14. It is an assumption that everyone in our communities read in their community language. Other forms of audio-visual resources need to be developed.
15. There must be recognition that Western terminology around sexuality may not be appropriate within our communities. The constructions around sexual behaviour are perceived in different ways and arise from different histories and world views.
16. There must be effective monitoring of all service delivery to our communities and within our communities.
17. There must be determined efforts by national and local governments to tackle racism, both overt and institutionalised. Proper legal penalties must be available to deter such forms of racism. People from our communities are often doubly marginalised because of ethnicity and HIV status. Effective monitoring of services can ensure that racism and AIDS phobia within service delivery is challenged and penalties given. Human rights for all peoples, whatever, the race, colour, creed, gender or HIV status must have a full legal status.
18. The terminology around immigration populations should be reviewed. “Migrants”, “guest workers” etc, add to the sense of marginalisation. Some so-called “migrant” peoples and “guest workers” have been living in their adopted country for several generations.
19. More research is needed around issues of sexuality, sexual behaviours, condom usage, drug use, HIV status and so in terms of our communities. Much resource production is based on assumptions and mythologies about our communities. Some of this research also needs a historical analysis in

order to deter assumptions within our own communities (i.e. homosexual behaviour arises from Western "decadence"). Such research should be done by effective members of our own communities.

20. Cultural and community specific resources should be provided for members of our communities affected by HIV/AIDS in order to enable them to still feel a part of the community from which they come.

21. Recognition must be given to the fact that many members of our communities feel unable to utilise the "mainstream" services, because of their immigration status, distrust of the medical profession, fear of the police, and so on. Special services must be developed in order to cater for these fears. Such services must take into account the specific issues for women as well as men in terms of community beliefs and expectations. For instance, a large number of Muslim women prefer not to be examined by a male doctor.

Further recommendations addressed to governments, national AIDS commissions, local governmental, health bodies and AIDS service organisations.

Over the last few years there has been a series of recommendations concerning HIV/AIDS that have been developed for governments and AIDS Service Organisations that are concerned with people living with HIV/AIDS, drug-users, sex-workers, lesbians and gay men, and others.

These recommendations are all extremely valid for our own communities as well. I refer the reader of the report to the recommendations developed by:

1. The Report of the Fifth International Conference for People with HIV & AIDS "HIV and Human Rights - From Victim to Victor".
2. The Report of a Pan-European Consultation, "HIV/AIDS In The Context Of Public Health and Human Rights.
3. The "KHUSH" Report by Shivananda Khan

Recommendations for the Muslim and South Asian communities

1. Our communities must recognize that HIV/AIDS affects all people whatever their country of origin, race, colour, religious beliefs, sexuality and behaviour.
2. That in such recognition they must develop a sense of responsibility to educate members of our communities and prevent the spread of HIV infection amongst them.
3. And further to this they must develop systems of care and support for members of our communities affected by HIV/AIDS directly.
4. While we recognise that our communities face a host of issues that they may well get prioritised above HIV/AIDS, such as basic issues around employment, housing, racism, general medical care, and on, these must not be used as a means of denial that HIV/AIDS should also be placed on our communities agendas.
5. That while we recognize that in the pursuit of personal, familial and community affirmation sometimes community members may avidly deny specific issues around behaviours, most especially

around homosexuality, in the need to show a sense of perceived superiority to the white community, this particular stance ensures that people in need become fearful of rejection and isolation, if not actual violence, by members of our own communities and thus do not utilise the services that are already there and do not enable a community response to HIV/AIDS to develop. Such an approach actually increases the risk to members of our communities. There must be a recognition that sexual and other behaviours exist in our communities that put members of our communities at risk in terms of HIV infection and that we have duty to ensure that effective education and prevention campaigns exist within our communities that approach people with a sense of personal dignity and empowerment, rather than one of judgement and punishment.

6. That our communities must recognize that the source of our emotional support and well-being is within them, and that by the process of denial and invisibility, they can marginalise and hurt peoples within them.

7. We must become more aware of our own histories, and the affirmations of self and community that lie within them. We must make our sexualities and HIV status more visible without the fear and threats that most feel.

8. Religious leaders within our communities must recognise the compassionate and tolerant nature of the religions they profess and encourage their communities to provide support and care for our people affected by HIV/AIDS.

9. Community leaders must recognise that very often they do not represent their community but only their own particular prejudice and mythologies. Communities must also recognize that often people who speak on their behalf do not necessarily address their needs and concerns.

10. As communities we are already marginalised in the countries of adoption or residence. For those of us who express different sexualities, or are living with HIV/AIDS, we are doubly marginalised. Our sexuality or HIV/AIDS status does not make us less a member of the community. We need your support, you need our knowledge.

11. In all this our communities need to develop and must develop specific strategies for education, prevention and care, as well as developing community-based initiatives to promote them. If we do not, then all of us are abdicating our responsibilities to our families and friends, to our sense of community and well-being.

It is a challenge, and we must provide a response to this challenge.

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