

## HIV AND SEXUAL HEALTH SERVICES FOR ETHNIC MINORITY COMMUNITIES

## MINORITY PATIENTS DENIED FULL HIV CARE

Minority ethnic patients are not receiving full care for HIV/AIDS, according to patients and health workers in London. Minority patients say they feel mistreated and misunderstood by staff in the National Health system and unable to express themselves. Much of this appears to be down to poor communication.

"I don't think I'm imagining that there are two standards of treatment: one for the English and one for foreign HIV patients," says Marcos, 38, a Brazilian lawyer living in London. "In the clinic I observed that staff have more smiles and better dialogues with the English patients. Only one nurse, an Australian, treated me very well; she was the first to ask if I had remembered to take my HIV medicine."

An HIV consultant at Guy's and St Thomas' Hospital NHS Trust, David Lewis, admits that it is sometimes difficult to fully address the complex physical, emotional and psychological problems experienced by ethnic minority patients in a time-limited appointment. "At St Thomas', we allocate a full 30 minutes per patient because we believe it is important to give the patients enough time to discuss all their issues. However, for some non-English speaking minority patients with multiple issues this may still not be enough, and time pressures can occasionally result in a less than optimal holistic approach to patient care," says Dr Lewis. Some mental, sexual and family health issues, it appears, are not being adequately discussed.

To tackle these problems, Naz is continuing to expand its support services for minority HIV patients. And in the first six months of this



year, the organisation welcomed 60 new clients, exceeding its targets for the whole year. Naz helps these clients by providing interpreting and advocacy services.

### Language problems

"When I arrived, I couldn't even make an appointment in English..." recalls Marcos. "... When I did, the consultant looked blankly at my prescription from Brazil and told me to come back with an interpreter. When I did, he issued a new prescription, but mistakenly put it away in a file. He insisted he had handed it to me. On my third visit, I waited for hours until he found the prescription. Then he didn't apologise, and I never saw him again. If I spoke English, this might not have happened."

Communication is also a problem for patients with better command of English. "'Enough English to get by' is usually not enough English for HIV patients," says Parminder Sekhon, head of client services at Naz. "People need to be able to express themselves fully and freely. Clients often muddle their way through with

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## NAZ BOOSTS TRAINING SERVICES

Naz is boosting its training and consultancy services in an effort to help Government services cope with the growing and complex sexual health needs of minority ethnic communities.

Naz has begun to provide specific training packages for the health service, young people and voluntary organisations. By next year, Naz hopes to become a major training consultant for the Department of Health in this field. For years, Naz has been training professionals on sexual health for black and minority ethnic communities mainly on an ad-hoc basis.

"This is the first time we are comprehensively planning our services," says Manjit Rooprah, the training and consultancy team leader at Naz. "For me this is also a really exciting time

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## MINORITY PATIENTS DENIED FULL HIV CARE

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poor English, so doctors don't get a really insightful perception of their overall well-being. That is not good enough."

The real problem, says Ms Sekhon, is the failure of hospitals to routinely use interpreters. She recalls how one consultant assured her that the patient understood everything, when this was clearly not true. "I don't know if she's being stupid or deliberately trying not to understand," the doctor reportedly told Ms Sekhon. "He was very antagonistic. When I asked if he had thought of using an interpreter, he said she didn't need one. For many doctors, booking interpreters is just an extra hassle."

"In recognition of the importance of communication between patient and doctor, at St Thomas' we have taken the innovative step of employing a French interpreter to assist in both our HIV and genito-urinary medicine clinics. For other languages we rely on hospital interpreters who may sometimes be held up because of work with other clients; and on rare occasions we may have to use the telephone service which can sometimes slow down consultations," says Dr. Lewis

Naz believes doctors should use an interpreter whenever there's the slightest doubt about communication. If not, the doctor-patient relationship will suffer, the doctor will not understand the patient properly; and they will not provide holistic medical care. Doctors must not end up blindly writing prescriptions.

### Fine, but not really

And there are other difficulties. Minority patients often have a different concept of doctors than many English people. "Our clients tend to look up to, even revere doctors," says Ms Sekhon. "Many are very passive as patients. They claim to understand when they do not, or they limit their

answers to "Alright," "I'm fine," or "I've got a pain." Even if in their own languages, they have plenty more to say."

The clinic tells them to see a GP because their complaint is not specifically related to HIV. The GP, often untrained in HIV, sends them back to the clinic.

In contrast to minority HIV patients, gay English men appear to communicate more effectively with the doctors. They tend to be better informed, ask more pertinent questions or crack jokes with the consultants.

"We have very limited training on cultural and religious diversity. You learn

on-the-job in a multi-ethnic society," says Dr Lewis. He has learned to consider diets, marriage, sexuality, feasts, death rites, as well as the practical barriers facing each community, including high levels of stigma and the constraints of childcare, accommodation and the whole torturous process of seeking asylum.

### Patient ping-pong

One of the most common problems Naz clients face is being sent back and forth from HIV clinic to General Practitioner (GP). The clinic tells them to see a GP because their complaint is not specifically related to HIV. The GP, often untrained in HIV, sends them back to the clinic. And so the client is knocked from pillar to post, which is demoralising and demeaning.

Marcos, who now speaks more English, relates his experience. "Last month I had a high fever. The HIV doctors would not see me at first. Finally a doctor told me this was a problem for my GP, whom I had never met. I felt this was not very humane treatment. One of the nurses even said I was abusing the system, taking someone else's place."

"For me there was no difference between HIV and fever; I needed urgent treatment. I'd expect the doctor to say to me: 'look, here's something to treat your fever, but next time you have to see your GP!'"

## NAZ BOOSTS TRAINING SERVICES

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to pass on our special knowledge to the newly-established Primary Care Trusts and other organisations about the sexual health needs of their minority ethnic communities. Very few other organisations are doing the work we do," says Mr Rooprah.

According to a new leaflet designed to promote its training services, Naz says it can develop courses to meet the specific needs of its clients in the social, cultural, religious, sexual, gender and health issues affecting minority ethnic communities. "We also offer training on how to work with young people and pupils from Black and ethnic minority communities, including work to reduce teenage pregnancies in minority communities," says Mr Rooprah.

Naz has already provided a range of training modules for organisations around the country. Among its clients are the Ealing, Hammersmith and Hounslow Gay Men's Project, the Bradford Youth Service, Yorkshire Mesmac, the Trust for Adolescent Studies and Friends and Families of Lesbians and Gays. Thanks to grants from the Peter Moores Foundation, Naz has been able to share its expe-



# NAZ IMPLEMENTS NEW PLAN

rience with organisations outside London.

"All of them needed training in this area," says Mr Rooprah. "The evaluation and feedback have all been very positive. Some people were aware of the issues but did not know how to take things forward. Others had low awareness. Our training helped them to open a dialogue in an sensitive space, and to identify special areas of concern."

Prospective clients and participants can expect to come away with a greater awareness of minority sexual health issues, and ideas on how to make their own policies and procedures more inclusive and culturally sensitive. Myths and stereotypes about minority ethnic communities will be dispelled.

"Much of what we do is cultural awareness training, but it focuses on sexual health and behaviour. We break down stereotypes like the idea that all South Asians have arranged marriages," says Mr Rooprah. "It's also about dialogue: we share all our experience, anecdotal and otherwise. And we highlight the sexual health needs of Naz target communities, like the need for interpreters, problems of racism and non-attendance at sexual health clinics."

**N**az is implementing improvements to its work after a major review conducted last year, says the organisation's director. The Strategic Review concluded overall that Naz should concentrate on doing what it does best; it should consolidate and raise the professional level of all its work.

"We are well into implementing the Strategic Review. All of the 41 recommendations have been adopted by the Board of Directors," says Bryan Teixeira. "The review has really helped to focus our priorities. Producing the report was relatively painless, but now we are working hard to implement improvements. Thankfully, the Naz leadership is highly committed to this process, and the review's author, Tahera Anchawan, is being co-opted as board member in August."

Naz is doing more and better work in a range of areas - from developing new resources in Spanish, Portuguese, Arabic and Horn of Africa languages to improving client-based work. Both Spanish and Portuguese speaking caseworkers will now work more time each week. Naz is also stepping up its training and consultancy work.

The organisation is also looking to streamline its work in some areas. For instance, it has been reviewing all its work for South Asian Men who have Sex with Men (MSM) and evaluating its effectiveness. After ten years, some approaches clearly work better than others.

"We are also reviewing our work with young people," says Mr Teixeira. "The pilot project we have been doing with six schools in Camden

## ARABS IN DENIAL?

By Mubarak Dahir

**N**EW YORK - Ignorance and fear of HIV/AIDS are so widespread in Arab migrant communities that it is difficult to estimate how many people are infected. There could be anywhere between 3 and 7 million Arabs in the United States. How many of them may be infected with HIV remains unknowable. It is clear, however, that people are affected and the community may experience a growth in HIV infection. But before they can be reached for prevention work, they have to be counted. This remains a source of endless frustration for Arab activists in America on the frontlines of fighting AIDS.

Critically for HIV transmission, the population is a very young one. Almost half of all Arabs in America are under age 25, while only 6 per cent are over 65. New Arab immigrants are more dedicated to preserving their languages and heritages; so any effective AIDS education will necessarily be in Arabic as well as English. It will have to find a way to be sensitive to the traditionally conservative cultural and religious norms, and be aimed at the young and most vulnerable.

A New York City organisation called MENTORS - Middle East Natives Test-

ing, Orientation and Referral Service - is one of the few organisations in the United States that provides such services. Wahba Ghaly, its director, first began talking publicly about AIDS in Cairo in 1993. But in Egypt, there was still official denial that any AIDS cases existed in the country. Ghaly won grants to travel to the United States to learn how to set up an AIDS outreach and prevention programme.

Establishing what has now become the Center for HIV and AIDS Prevention in Cairo was not easy. "If I said, My message is condoms and safer sex, anywhere I went I'd be told, Get out!" explains Ghaly. "Such a direct approach would have alienated just about anyone in Arab society," with its conservative rules on sex, homosexuality, and drug use. He was forced to develop his own programme that took into consideration Arab cultural sensitivities. But he says he found people "hungry for information." Today, the Centre, which Ghaly continues to work with, has a staff of 13 professionals.

Despite inroads, denial in Egypt and other Arab countries about HIV remains supreme, says Ghaly. One problem is that most people who



# WORLD NEWS

and Islington is due to end in June. Since we don't have the resources to emphasise classroom work and direct student work, we are redirecting our efforts into training teachers, counsellors, nurses and youth coordinators at Primary Care Trusts (PCTs)."

A problem is that Naz has only two management workers to implement these changes. This puts an enormous strain on time and resources, especially at a time when 33 new PCTs are being set up. "Things seem chaotic so far," says Mr Teixeira. "PCTs do not seem to want to work with each other. All of them want to meet Naz, which is impossible for a small organisation."

The strategic review process, says Mr Teixeira, will be successful when Naz is recognised as a leading provider of sexual health and HIV services to minority ethnic communities

in the UK and when HIV clients feel genuinely welcome and get actively involved in service provision. "There will be improvements in what we do and how much we provide; and clients will experience these improvements. But ultimately they must be the judges of our services."

While Naz works to implement the 41 recommendations, however, another challenge will be to remain flexible enough to respond to the changing HIV epidemic. The organisation must remain a home for people in the emerging epidemic, which currently means Latin Americans, Africans, and South Asians in Britain. But the epidemic is also growing rapidly among Eastern Europeans and Naz will have to decide if and how it can respond to the needs of such communities.

are infected don't even know it until they are very sick and about to die. Testing is rare, even if a patient comes to a doctor with classic signs of opportunistic infections. Partly, says Ghaly, that is because so many people in Egypt wouldn't be able to afford the expensive AIDS drugs. But just as important, he says, is the continuing atmosphere of denial. "I'm really worried that in the Arab world, we are going to keep denying the numbers until its like a bomb that explodes, and then there is nothing we can do about it."

Last year in Detroit, home of the second largest Arab population in the United States, the Arab Community Center for Economic and Social Services (ACCESS) applied for state money to fund AIDS education, prevention and counselling programmes aimed at Arabs. But it was unable to provide the statistical data required to win state money for the kind of projects they hoped to set in motion.

Because Arabs have been classified as either whites, blacks or the vague "other" on AIDS surveys and research forms, statistics on Arabs with HIV simply do not exist, says Asyah Ali, the HIV and AIDS prevention coordi-

nator at ACCESS. "I know there are Arabs with AIDS," she says, "because I've held their hands and watched them die at hospitals."

The cornerstone of the MENTORS programme is an AIDS information book that "refers to specific verses of the Koran," explains Ghaly. He uses Koranic verses that promote good health and personal responsibility as an entree to discussing HIV. "If we don't use the Koran to support our work, people won't accept our information."

In the wake of September 11, prevention activists in Arab and Muslim communities need not only sensitivity and delicacy, but great reserves of patience. "Now more than ever, Muslims in the United States are trying to cultivate a cohesive community and a positive public image to outsiders," observes Faisal Alam, who heads up Al-Fatiha, a national gay Muslim group. "Even under the best of circumstances, we were in denial and didn't talk openly about AIDS. Now it's the worst of circumstances for Muslims in America. You can't expect AIDS to even be on the radar screen at this point." The aftershocks of September 11 have cast a pall over AIDS outreach efforts.

## Global AIDS Fund failing?

The Global Fund to Fight AIDS, Tuberculosis and Malaria, set up last year to wage war against HIV/AIDS worldwide, is failing. The Secretary-General of the United Nations, Kofi Annan, asked for \$7-10bn a year to meet commitments made by governments in June 2001. So far, governments have pledged a mere \$1.8bn. Private sector pledges remain paltry. A more equitable system would be for the the 48 countries that enjoy a 'high' standard of living by the UN's Human Development Index to contribute 0.035 per cent of their Gross Domestic Product. Under this system, the United Kingdom has contributed 44 per cent of what would be considered equitable. The United States and Japan have only contributed 13 per cent and 12 per cent. [Source: Tim France et al, April 21, 2002]

## HIV surges in Eastern Europe

HIV is surging in Eastern Europe and the former Soviet Union, according to UNAIDS' 2001 report on HIV. The epidemic there was initially driven by needle-sharing among drug users until it began to spread rapidly. The fastest-growing HIV epidemic in the world now is in Russia, where some 1 million of its 148 million citizens are infected, largely as a result of intravenous drug use. Ukraine has the highest regional prevalence of HIV, at 1per cent of its adult population. Tiny Estonia has nearly the same prevalence. Social and economic turmoil have stoked the fast-spreading epidemic in the region, the report says. A much larger and more generalised epidemic is now a real threat. Moreover, the rapid rise in HIV infections in Russia could lead to a TB epidemic too. An estimated 16 million people, or one in six, in Russia are already infected with TB. A 33-fold increase in HIV infections could propel the number even higher, Russian and American researchers said in a report in the Lancet (2001; 358). People whose immune systems are weakened by HIV are 30 times more likely to develop TB, which is a main opportunistic infection. The epidemic is still at an early stage, and preventive measures could still limit its spread. [UNAIDS, 2001; Reuters 02.11.01]

# UK NEWS

## Young people risk sexual infections

Sexually transmitted infections are still rising in Britain as young people fail to practise safe sex. According to a report published in February by the British Medical Association (BMA), sexually transmitted infections, including HIV/AIDS, gonorrhoea and syphilis, have soared by almost 300,000 cases between 1995 and 2000. The group most at risk now, say the BMA, are the 18-24 year olds who missed the AIDS scare in the 1980s and have seen the arrival of the antiretroviral drugs that keep people alive. Vivienne Nathanson, head of science and ethics at the BMA, said a public education campaign is needed to alert people to the dangers of their sexual behaviour. "We need to break the complacency," she says, arguing that careful sex education could begin in schools with children as young as seven. [Sources: *Guardian*, February 27, 2002; *Nursing Times* 7 March 2002]

## South Asian HIV epidemic in Britain

The sharp increase in HIV in the Indian subcontinent could be affecting Asian minorities in Britain. Few South Asians in Britain are using HIV services, so the epidemic gives the appearance of being contained. The Public Health Laboratory Service has found no higher rates in areas with high Asian populations. And while recent estimates suggest up to eight million people could be infected with HIV across the Indian subcontinent, most Asians in Britain are from rural areas where the epidemic is less acute. Naz, however, believes that HIV rates may be higher among British Asians than recognised. One HIV transmission risk is that arranged marriages often disregard the sexual history of potential partners, and negotiating safe sex remains very difficult and embarrassing for girls and boys going into arranged marriages, and for their families. Another risk is that married south Asian gay men could be concealing rising HIV rates. "They haven't been specifically targeted and it seems they aren't accessing services," says Suki Sandhu,

head of the male sexual health group for Naz South Asians. "I'm sure Asian men are putting themselves at risk in venues like saunas and gay bars, but out of the small group of positive men I know, there is little acknowledgement of HIV status." The Asian HIV explosion could hit Britain on a large scale, and services must be improved to respond to this. If not, many people may die because the services are not available. [Sources: *Positive Nation*; *Community Care* 7-13 February 2002]

## London Latinos at risk

Latin American gay men who flocked to London in the early 1990s remain a largely hidden community. An estimated 200,000 Latin Americans live in London, about half of them Brazilians. Although HIV rates are low in Brazil, the high percentage of gay men in London means rates are relatively higher. Gay men from Latin America have also come to London to escape the terrible stigma of HIV in the region. Feeling that they have come to a free country, Latinos may lack the confidence to negotiate safe sex and are likely at increased risk of infection. Levels of denial and stigma appear to be even higher among Portuguese-speaking Africans in London. [Source: *Positive Nation*]

## Ethnic gays lack HIV information

Minority ethnic gay men lack information about HIV/AIDS. Naz members told a yearly Gay men's survey that compared to White gay men they need more information on HIV. According to preliminary results from the 2001 National Gay Men's Sex Survey conducted by Sigma Research. Almost twice as many Naz members wanted information about HIV treatment than White men. And about another third wanted more information about safe sex. These figures come from a very small sample, but they appear to offer further evidence that ethnic minorities are losing out in efforts to inform people about HIV/AIDS and sexual health. [Source: *Naz Research*]

## Hepatitis C epidemic

A silent epidemic has infected some 500,000 people in Britain, and 170m worldwide, attracting hardly any attention. Hepatitis C, or HCV, can lay dormant in a carrier for up to 25 years, and health professionals fear it is a timebomb ticking away that will explode one day. Although commonly transmitted blood-to-blood, approximately a third of all cases come from an unidentifiable source. People infected require treatment that invariably leaves the patient suffering nausea and depression. The Royal Hallamshire hospital in Sheffield now employs a social worker dedicated to working with HCV patients. [Source: *Guardian* March 6, 2002]

## Forced marriage rules

The British Government has launched new police guidelines to help victims of forced marriages. The guidelines, it is hoped, will help make it easier for anyone who is victim of a forced marriage to approach the police. The Government stressed it is not against arranged marriages, but was working to put an end to forced marriages. "Forcing a young person to marry against their will is a breach of their fundamental human rights and the Government is working hard to put an end to this practice," said Home Office Minister Angela Eagle. [Source: [www.number-10.gov.uk](http://www.number-10.gov.uk) May 20, 2002]

## English prejudice profile

English people who are prejudiced against an ethnic minority are also twice as likely to be prejudiced against gay and lesbian people, according to a MORI poll. The research conducted among 1,183 adults revealed that 16 per cent of respondents feel less positive feelings towards three or more groups. This hard-core minority of prejudiced people, however, appears to be balanced by 36 per cent core of tolerant people who do not feel less positive towards any group. [MORI Poll, *Profiles of Prejudice in England*, 30 January 2002]

If you have a story that you think should appear here, please email [naz@naz.org.uk](mailto:naz@naz.org.uk) so that we can try to include it in our next issue

# NAZ DIARY

## Naz Latina Support Group

Grupo Amigos, a support group for Spanish-speaking Latin Americans infected by HIV meets every month. For further information, contact Naz Latina on 020 8741 1879, or call London Lighthouse, Wednesdays after 2:00pm on 020 7792 1200.

## DOST friends

Visit Naz's support group for South Asian, Middle Eastern and North African gay men and men who have sex with men. DOST is a safe, confidential and informal space to socialise and discuss sexuality, safer sex, drug use, marriage, culture and more. Meet first Wednesday of each month, 7:00pm, at Govinda's Restaurant, Soho St - near Tottenham Court Road station. Call Suki on 020 8741 1879 to find out more.

## Kiss group

The Kiss group is for lesbian and bisexual women of South Asian and Middle Eastern origin. Whatever your age, whether married or single, clear or confused about your sexuality, you will meet women like yourself. We provide friendship and support in a safe environment for women only. The Kiss group meets the last Thursday of every month at the Glass Bar in Euston (opposite Euston train station) from 7:00 - 9:30pm. Call Par-minder confidentially on 020 8741 1879. See [www.planetkiss.org.uk](http://www.planetkiss.org.uk)



## Club Kali

An authentic mix of South Asian spices with Bhangra and House, Hindi and Soul, Swing and Arabic flavours. Naz has a stall on the third Friday of each month, with information, advice and resources for your sexual health. Club Kali is on the

first and third Friday of each month, from 10:00pm- 3.00am. Venue: The Dome Nightclub, 1 Dartmouth Park Hill, London N19. Nearest tube: Tufnell Park.

## Masala

A friendly social support group for young gay and bisexual men, aged 16-25, from the South Asian community. It meets on the second Tuesday of each month, 7:00pm, at Govinda's Restaurant, Soho St, nearest tube Tottenham Court Road. For more information call Suki on 020 8741 1879.

## Naz Brasil

Naz Brasil offers advice and support on HIV, AIDS and sexual health for Portuguese-speaking people in London. Pau Brasil is the monthly support group for HIV-positive, gay men.

We are in the process of developing a support group for Portuguese-speaking HIV-positive heterosexuals. Contact Naz Brasil on 020 8741 1879 for more information.

## Horn of Africa drop-in

Find care at Akairah, the drop-in centre for Black people living with HIV/AIDS. The group can help you get access to a social or health worker, and give you advice on health, treatment, rights and housing. You can also contact support groups. Nutritious lunch and refreshments (Halal) are available at low prices. The Naz Horn of Africa worker will be at Akairah, at the River House Drop-In Support Service, on the first Thursday of every month from 12:00am - 4:30pm. For more information, call Bisrat (Mon, Tues, Wed) on 020 8741 1879 or Helen at River House on 020 8741 4772.

## Other events

### Wise Thoughts

The sexual minority issues-based arts group seeks new talent to join a Bollywood-style dance group to develop a dance performance (no experience needed). Or to join the Bollyqueens visual arts exhibition project (for drag artists). Find out more, call 020 8881 9696.

 Naz Project London

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