

The impact of HIV-related restrictions on entry, stay and residence: personal narratives



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International Task Team on HIV-related Travel Restrictions.
For information about the Task Team and to access its report,
see www.unaids.org.

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Introduction

1. It appears that 59 countries, territories and areas deny entry, stay or residence to HIV-positive people based on their HIV-positive status only. Of these, 26 deport people when their positive HIV status becomes known; seven bar entry to HIV-positive people based solely on their status; and six deny entry even for short-term stays.¹ Many of these restrictions were imposed in the early days of the epidemic, when there was a great deal of ignorance, fear and prejudice surrounding HIV and people living with HIV. For many governments, such restrictions were an attempt to “protect the public health” and/or avoid the potential costs of care and support that some HIV-positive people might incur, though they have been deemed ineffective and discriminatory since their introduction by experts and advocates.² Since that time, much has changed, with HIV present in all countries, much greater knowledge regarding effective HIV prevention, the introduction of antiretroviral treatment, which has extended the life and productivity of people living with HIV and made HIV a manageable health condition, and major commitments by governments to attaining universal access to HIV prevention, treatment, care and support and to protecting the human rights of people living with HIV, including the right to non-discrimination.
2. In early 2008, the Joint United Nations Programme on HIV/AIDS (UNAIDS) established the **International Task Team on HIV-related Travel Restrictions** as an advisory/technical group whose role was to galvanize attention to such restrictions on national, regional and international agendas, calling for and supporting efforts toward their elimination. The Task Team, co-chaired by UNAIDS and the Government of Norway, was made up of representatives of governments, international and intergovernmental organizations, the private sector and civil society, including representatives of networks of people living with HIV.
3. In the report of its Findings and Recommendations, the Task Team reiterated and went beyond what others before it had said: that HIV-specific restrictions on entry, stay and residence that are based on HIV status do not protect the public health, are discriminatory, may result in other human rights violations, and if applied in a blanket manner do not rationally determine those who might become an undue burden on public monies.
4. In its work, the Task Team detailed how the enforcement of such restrictions can violate human rights and curtail important life activities of people living with HIV. In particular, medical ethics and the rights to privacy and health appear to be routinely violated through mandatory HIV testing conducted without informing people of the test or its results, without providing counselling or maintaining confidentiality, and without connecting people to HIV prevention and treatment services. Such restrictions also appear to prevent HIV-positive people from uniting with families, doing business

¹ For further details, see *Mapping of restrictions on the entry, stay and residence of people living with HIV*, available at www.unaids.org, and/or visit the *Global Database on Travel Restrictions*, www.hivtravel.org

² See for example World Health Organization (1987), “Report of the Consultation on International Travel and HIV Infection”, Geneva, 2-3 March 1987, WHO/SPA/GLO/87.1; World Health Organization (1988), “Statement on screening of international travellers for infection with Human Immunodeficiency Virus”. WHO/GPA/INF/88.3.

or studying abroad, migrating for work, participating in international humanitarian and development efforts, serving in consular services, seeking or receiving asylum, attending conferences, or vacationing abroad. Furthermore, they appear to have a particularly devastating impact on labour migrants, who often use all their resources to finance the migration and when their positive HIV status is discovered are deported, resulting in both serious financial loss and return to a community where they may face discrimination and rejection due to their HIV status.³

Personal narratives: experience of restrictions on entry, stay and residence

5. The Task Team felt strongly that the true story of HIV-related restrictions on entry, stay and residence could not be told, or understood, without highlighting the human face and the human cost of such restrictions, as an important form of evidence and an important part of efforts to eliminate them. Therefore it asked the International AIDS Society (IAS), in its capacity as Secretariat to the Task Team, to collect personal narratives as examples of some of the impacts that HIV-related restrictions on entry, stay and residence have on the lives of people living with HIV and their families.⁴
6. The IAS developed a document to explain the objectives and process of collecting the personal narratives and a template to guide people and interviewees in preparing their contributions. Two teleconferences (in English and Spanish) were organized to present the Task Team's work and to encourage civil society organizations to reach out and gather narratives from their networks and communities. Partner organizations appealed for personal narratives on their web sites and electronic mailing lists. Individuals were invited to disclose their names and other personal information, but it was also made clear that testimonies could be submitted anonymously and that privacy and confidentiality would be fully respected. Consent was obtained from those people who indicated that their testimonies could be published or otherwise made available.
7. By June 2008, 19 personal stories, which are presented on these pages, had been collected. The stories give a voice to those people directly affected by HIV-related restrictions on entry, stay and residence. The experiences documented also informed the development of the Task Team's findings and recommendations. These stories clearly convey that restrictions on entry, stay and residence based on HIV-positive status only, and carried out without regard for the health and well-being of those involved, do not achieve valid objectives and must be overturned.
8. The narratives presented below are arranged alphabetically by name (most often a pseudonym⁵), with a short description of the context in which each person was travelling or migrating and the impact. The case studies have been edited for clarity and brevity. The facts and assertions presented in the narratives have not been independently verified.

³ For more complete discussion on these issues, see *Report of the International Task Team on HIV-related Travel Restrictions: Findings and Recommendations*, available at www.unaids.org

⁴ *Ibid.*

⁵ Stories are presented under a pseudonym to protect confidentiality.

Andrei

Working illegally to avoid mandatory HIV testing

Summary of personal impact

Every three months, “Andrei”, a person living with HIV of Ukrainian nationality, has to travel back to Ukraine in order to be allowed to stay in the Russian Federation with his partner. Andrei works illegally because he is HIV positive and chooses not to buy a forged medical certificate that would likely enable him to enjoy a stable life in the Russian Federation. If he were to be tested for HIV, as required to obtain a visa, the results would be given to the immigration authorities and would prevent any future application for residency or citizenship. HIV tests are required for longer-term stays (more than three months) in the Russian Federation. Foreigners found to be HIV positive are reported to be expelled. Foreign employees have to submit to an annual test to prove that they are not HIV positive.

Andrei fell in love with a Russian woman, and in 2004 the serodiscordant couple decided to live together. He moved from Ukraine to the Russian Federation. Citizens from the Commonwealth of Independent States can enter the Russian Federation without visas, but they are required to register in their city of residence if they plan to stay for more than three months. Registering as a resident, or applying for a work permit or Russian citizenship, involves “passing” an HIV test. All results are communicated to the immigration authorities.

Andrei travels to Ukraine every three months in order to avoid disclosing his HIV status to the authorities. This return trip allows him to remain in the Russian Federation legally. Usually he crosses the border and returns within an hour. Some customs officers know him well, know his situation, and stamp his passport without asking him for the reason for his regular short “stays” in Ukraine.

Compulsory HIV testing does not prevent the entry of foreign nationals living with HIV, Andrei says. They are forced into illegal employment and economic activities to stay in the country. Many people living with HIV reportedly buy forged medical certificates to enjoy a stable life in the Russian Federation and avoid deportation. Andrei will not buy one of these certificates as he wants to respect the law, but he is forced to work illegally because he is unable to prove that he is seronegative. Lack of residency status also means he cannot access medical insurance in the Russian Federation.

Anna

“Chance and pure luck” bring home adopted Ethiopian child living with HIV

Summary of personal impact

“Anna” and her husband adopted “Sara”, an Ethiopian child living with HIV. Only through “chance and pure luck” were the couple able to bring their daughter home. In a long, traumatic and expensive wait, Anna had to fly back and forth between continents and deal with a very slow bureaucracy, all because their child was HIV positive. During this time, Sara was not receiving necessary treatment in an orphanage in Ethiopia. A special application form for a waiver on the grounds of “inadmissibility” has been required for

foreigners requesting a visa for the United States of America if they have tuberculosis, HIV or certain mental health conditions.

Anna and her husband began their adoption of Sara, an eight-year-old Ethiopian child with HIV, in 2006 and sponsored her care at an orphanage for HIV-positive infants and children in Ethiopia. Sara's parents had died in 2005, both from AIDS-related illnesses. In March 2007, an Ethiopian court legally declared the couple as Sara's parents. By early April, families whose cases had been approved in court travelled home with their HIV-negative children. "Although they could file their Orphan Petitions in Ethiopia, we were required to file ours in the USA," Anna says. According to Anna, most *United States Citizenship and Immigration Services* (USCIS) Orphan Petition approvals take a day to process at the United States Embassy in Addis Ababa, but they can take several weeks, even months, to process if filed in the United States of America.

Anna described numerous and costly procedural barriers. The State USCIS office claimed it did not have adequate information to ascertain their daughter's orphan status and asked for death certificates for Sara's parents, which Anna says are "quite rare in Ethiopia". So, she travelled to Ethiopia in May 2007 to file the petition in person at the United States Embassy in Addis Ababa. If the petition was approved, she could then file the 1601 HIV waiver, which would take more than three months to process.

"The expense was daunting. By having to make two trips, I spent most of the money we had saved for Sara's first year of medical treatment. This seemed ironic, since USCIS requires proof of financial capability for adoptive parents, yet also requires many financial sacrifices through the expensive fees (\$545 for the waiver alone) and multiple trips to Ethiopia, due to the Orphan Petition and HIV waiver processing difficulties."

While the visa waiver form claims that it should take 60 minutes to complete, this does not take into account the supplemental documents—not listed in the instructions—that are expected from adoptive parents, including letters from doctors, health officials, insurance carriers and the adoptive parents themselves. Anna and her husband calculated that it took 15 hours to collect these documents. The 1601 waiver fee is an extra burden on the adoptive parents of children with HIV. Sara adds that in most cases the waiting children, who have lost their first parents to AIDS, are not receiving treatment. "They remain in orphanages surrounded by tuberculosis, chickenpox, influenza, parasites and many other conditions that are life-threatening for an untreated HIV-positive child." Meanwhile, the adoptive parents have completed a home study addressing the particular needs of an HIV-positive child and have health insurance and medical experts waiting to provide treatment.

Anna travelled to Ethiopia with many unknowns. "Would our Orphan Petition be approved? Could I push the 1601 HIV waiver through in the three weeks that I was able to stay in Ethiopia? Would the 1601 be approved at all? What was our daughter's state of health? Would she be able to handle it emotionally if I had to return to the USA without her?"

"The orphanage would not let Sara stay with me because they believed I would not be successful in getting the 1601 approved... This was traumatic for both of us as I returned her to the orphanage each night and tucked her into bed. She was covered in molloscum and ringworm, had a raging ear infection, severe tooth decay and pneumonia and had lived her entire life without HIV treatment, causing her system to be revved up, fighting the disease with all she had."

Meanwhile, Anna says, many waiver cases were sitting on a desk, waiting to be reviewed. “They had been there for 12 to 14 weeks... The waiting families would hope to simply receive a call one day saying their child’s visa was approved and they could travel to pick them up.” She says her family’s story ends well “only by chance and pure luck”. She was able to bring Sara home because her family was able to find an advocate in Washington, DC, to expedite the process. “Sara’s waiver was processed in two weeks, the fastest one ever. Other families who had been waiting for several months received news of their approvals at this time also.”

At the time of providing this testimony, Sara had been home for several months. “She began ARV treatment a month ago and is doing well,” Anna says. “Although her CD4 count records from Ethiopia were accurate, the clinic there was not able to test her viral load. When she arrived in the USA, her viral load was 750 000, 7.5 times the recommended standard in the USA to begin paediatric treatment. Her viral load will likely be undetectable soon and, due to an amazing new group of HIV drugs, it is predicted that she will live a normal lifespan.”

“Sara is in school now, learning English at warp speed; she is creative, affectionate, giving and remarkably resilient. Had we not found an advocate who pushed for her US visa approval, she might still be at an orphanage in Ethiopia struggling through another year with an untreated HIV infection.”

Anucha

Hiding HIV status to avoid stigma and deportation

Summary of personal impact

“Anucha”, a Thai national living abroad, fears he would be deported if his HIV status became known. Anucha lives in the Republic of Korea on a tourist visa rather than a work visa, which would require an HIV test. The financial strain of hiding his status is high; however, Anucha has heard that names of foreigners found to be HIV positive are given to the immigration authorities, resulting in swift deportation. He has decided to leave the country in which he has invested his time, energy and skills to avoid that possibility.

Anucha has lived in the Republic of Korea for more than six years. His work has ranged from teaching kindergarten children to developing human resource materials for large companies. “I speak Korean quite well, and feel that I have done a good job of accustoming myself to Korean culture and the Korean way of life,” he said.

When he found out that he was HIV positive in 2005, HIV testing was not mandatory for teachers in the Republic of Korea. However, today he feels like his options of living and working peacefully in the country as a teacher no longer exist, with stories of hospitals and clinics disclosing names of HIV-positive people to the immigration authorities, leading to deportation. “I live every day here in fear that the day when I get deported will be the next,” he says. He can understand the possible backlash that he could face if he were requesting free medication. “But I am in good health... I do not need medication to live, and I do not pose a threat to those around me.”

The financial impact is high. Anucha spends about US\$ 1000 every six months to go to Thailand for a range of medical tests. Every three months he leaves the country to renew his tourist visa. With the rising cost of fuel, each trip costs up to US\$ 1000. “I am no longer eligible for health insurance, so even a common cold can cost me US\$ 100 to US\$ 150 to treat. Anything major would put me under.” Working without a visa also has its costs, and recently Anucha was fined US\$ 300 for teaching a private lesson. Friends and students ask him why he is moving away this year; he tells them that he wants a change. “If they knew the truth—that I am leaving because I can no longer live and work in the Republic of Korea because I am HIV positive—I wonder if their views would change... Based on conversations I have had with people ...and their views of people with AIDS as ‘disease-ridden parasites’, I wouldn’t be surprised if I were suddenly ostracized because of my status.”

HIV stigma is a fear for many foreigners in the Republic of Korea. “Therefore, instead of tackling the problem head on, they bury it, don’t get tested, and act as if it does not exist.” According to Anucha, Korean men who have sex with men don’t get tested at all. “The fear that is instilled in people here about the stigma attached to being positive in Korea scares me more than the disease itself.”

Dr Jim

Media brands HIV-positive traveller a “gatecrasher”

Summary of personal impact

“Dr Jim”, a visiting scholar to Taiwan, China, disclosed his HIV status at a photo exhibition being staged to raise awareness about the epidemic. The media branded him as a “gatecrasher” for daring to enter the country. Officially, an HIV test result must be presented for stays longer than 90 days in Taiwan, China. However, people living with HIV are reportedly denied entry even for short-term stays.

In April 2002, Dr Jim went to Taiwan, China, as a visiting scholar to speak at a university and open a *Positive Lives* photographic exhibition. At the exhibition launch, he spoke openly about his HIV status. “The next morning,” he says, “it was all over the newspapers. Journals were asking how I got into the country when Magic Johnson had been barred from entry.” The headlines were along these lines: “Dr Jim, Australian Researcher Gatecrasher.”

The next day, while en route to a lecture he was delivering on “women and HIV” at a university outside Taipei, he was asked to give several press conferences. That evening, he appeared on many TV stations. Reporters followed him into his lecture and filmed part of it. “It was massive coverage, and I was back in the paper the next day. Fortunately, this was the day I was leaving the country. I don’t like fame.”

Guillermo

Traumatized by abrupt discovery of HIV status during visa application

Summary of personal impact

“Guillermo”, from the Dominican Republic, discovered that he was HIV positive when he applied for a visa to emigrate to the USA in 1997. Guillermo was aware that to secure such a visa he would have to undergo a medical examination. However, the visa would not be granted. Tested without counselling, Guillermo was traumatized by the blunt way he learned of his HIV status. Moreover, he would not be reunited with his family in the USA. Today, although Guillermo is active in the movement to defend the rights of people living with HIV, he has to decline invitations to participate in many HIV-related events outside his country as he cannot travel into or through the USA, affecting his professional development.

The doctor had just told Guillermo that he would not be granted a visa because he was HIV positive. “He also asked me if I had slept with other men,” he recalls. “From that moment on, everything was a blur... I don’t remember leaving the clinic. All I know is that some time later I was walking along the seafront... I could feel the tears streaming down my face.”

It was barely 9 a.m., and Guillermo said he did not come to his senses until that evening. “Because of the stigma attached to being HIV positive, and the fact that I didn’t understand the disease, I could only imagine the worst possible outcome; I didn’t even know if that was death.” He had to tell his family and friends, including his mother and family who were looking forward to being reunited with him, why he was denied the US visa. “All of my neighbours and some friends knew that I had applied for the visa. You can imagine what going to live in the USA meant in those times... it’s very traumatic for people who are diagnosed with HIV, precisely because they will be denied the possibility of experiencing the famous ‘American dream’.”

Guillermo heard about REDOVIH+, the Dominican Network of People Living with HIV, in 1998, and helped to organize support groups and defend the rights of people living with HIV. He joined the Greater Involvement of People Living with HIV/AIDS (GIPA) initiative of the United Nations in the Caribbean, and with time began taking on leadership roles, collaborating with the *regional network of people living with HIV*, and supporting community-based monitoring of sexually transmitted infections in his country.

Guillermo continues to work in the area of HIV and AIDS support, but he sees how travel restrictions are affecting his professional development. He cannot participate in events in the USA, or travel through the USA en route to other destinations. The International Federation of Red Cross and Red Crescent Societies attempted to support Guillermo’s participation in the United Nations General Assembly Special Session on HIV/AIDS in 2001, held at the United Nations Headquarters in New York, but his visa to enter the USA was denied. Last year he was invited to participate in an AIDS workshop in Colombia, but was not able to attend as it would have required transit through the USA.

Harjeet

After an expensive journey, tested, jailed, deported, destitute

Summary of personal impact

“Harjeet”, an Indian migrant worker, was jailed and then deported from Saudi Arabia when a blood test required for the conversion of his tourist visa to a work visa showed that he was HIV positive. HIV tests are required as part of the application for a work visa in Saudi Arabia, and HIV-positive people are deported. Harjeet was left destitute after a futile journey that he would not have undertaken if his doctor in India had told him that he was tested for HIV and that his test was positive. Harjeet tried to hide his “social blemish” following his return. He did not seek treatment and became seriously ill. His family disowned him when they discovered his HIV status.

Harjeet, a chauffeur, had been working in Dubai, United Arab Emirates, for five years. When his visa expired in 1994, he returned to his village, where the few jobs that were available were poorly paid. Harjeet applied for a job as a driver in Saudi Arabia; holding a job in the region enhances one’s social status in his home region. To facilitate the visa application process, Harjeet found an agent in Mumbai, India, and paid a commission of 20 000 Indian rupees (approximately US\$ 400).

In Mumbai, his agent took him to a medical centre for the tests required for the visa application. He paid 300 rupees. The doctor told Harjeet that there was “something wrong” with his blood test results, but offered to change his medical certificate for a “commission” of 2000 rupees (approximately US\$ 40). On the advice of his agent, Harjeet handed over the money. Perhaps, he thought, he had diabetes or anaemia—he had heard stories about people with such problems. He put in an application for a visitor’s visa. His agent promised that it would easily be converted to a work visa on arrival in Saudi Arabia.

Harjeet borrowed money from friends and family to fly to Saudi Arabia. It took him 20 days to find a “sponsor” to help him convert his visitor’s visa to a working visa. Harjeet went for the medical tests required for the visa, and worried about his blood test. He was told to wait for his sponsor, who entered the centre, glared at Harjeet, and then left. Not long after, Harjeet was escorted to a cell in the medical centre. He could not understand why he was being “jailed” for failing a medical test. He spent a day there. “They would give us food, but as if we were some wretched animals,” he says. “They would just throw food inside the room as if we were stray dogs.”

In court the next day, the judge ruled that Harjeet should be taken for a second medical test. Confused, he asked a medical staffer to explain what was happening. The person informed Harjeet that he was HIV positive. Harjeet realized that this was why he was isolated in the jail; he remembered that no one accompanied him in the back of the van while going to court. All he could think about was the hearsay he knew about HIV, that it is “a dreadful disease” and “one would die in two months”, he explains.

Harjeet felt cheated by the Mumbai doctor and agent. If they had told him the truth, he would not have been subjected to this humiliation. Apart from the shock of learning about his HIV status in this way, he was distressed by the financial loss he would incur from this futile journey. Two days later, policemen took Harjeet to the airport. “Deported” was stamped in his passport. Before taking a bus from Mumbai to his village, he tore up his

passport and visa documents. Fraudulent visas and deceitful agents were common stories in his village—Harjeet told the same story. He did not reveal that he had been deported or that he was HIV positive.

Depressed, Harjeet found himself drinking more and more, and eventually he became an alcoholic. He tried to hide his HIV status, even avoiding going to hospital. However, he developed tuberculosis and his family took him to a hospital for a blood test. Only then did Harjeet's family learn that he was HIV positive. As they regarded HIV as a social blemish, his family ostracized him, his wife left him, and his two children were taken away from him. His family placed him in a care centre, but no relatives would visit him. In his depression, Harjeet stopped taking his tuberculosis medication; he just wanted to die. He began having seizures "five to six times a day", which paralysed one side of his body.

However, Harjeet's situation began to change, and with support at the care centre he eventually recovered from his paralysis and his tuberculosis. Having regained his strength, Harjeet decided to devote his services to the centre for nine months, and following that secured a place in a centre run by a priest who provides care and support to people living with HIV. Harjeet is a HIV-positive speaker today and works with people living with HIV.

Huang

A denied student visa shatters academic dreams

Summary of personal impact

"Huang" was denied a visa to study for his PhD in Australia. He was offered a conditional visa that he believed would have jeopardized the chances of completing his studies. His right to privacy was compromised in the visa application process and the "fallout" forced Huang to leave his work and home in Singapore. He believes his career development has been irreparably damaged.

In 2005, Huang, an educational researcher, was living in Singapore and had been HIV positive for three years. He underwent regular check-ups and his condition did not require treatment. He applied to study in Australia in September 2005, and was delighted when a university awarded him a fully-funded three-year President's Scholarship for a PhD programme. While he had heard that Australia denied long-term visas to people living with HIV, nobody had ever said that HIV status was relevant to a student visa application. Set to travel to Australia in April 2006, Andrew did not renew his contract as an educational researcher.

In November 2005, Andrew went to a clinic for the medical tests required for student visa applicants. "I was rather anxious because I had heard rumours that Australia denied long-term entry visas to people living with HIV. Though a HIV test was not a requirement for a student visa, I decided to disclose my status anyway." In an e-mail, an Australian immigration official told Huang that his application had been declined: "You do not meet the health requirements for the grant of this visa." It did not say that he was rejected due to his HIV status, but, for Huang, this was the only logical ground. He was informed he could appeal, however.

In the appeal, a doctor who assessed Huang stated that he would not be a burden on Australia's health system; his condition was stable, and if he became ill he would seek treatment in Singapore. On this basis, the Australian immigration authorities granted him a renewable two-year visa, but on the condition he register with a doctor selected by the immigration authorities and undergo screenings every three months. After careful consideration, Huang decided not to go to Australia. "What if, after two years of hard work, I was denied an extension? I would then not be able to write up my research and defend it."

The "fallout", as Huang puts it, had just begun. "I had to withdraw my resignation letter from my employer, thus forcing my disclosure to my professors and colleagues in a social climate where even being openly gay, much less HIV positive, made it virtually impossible to be a teacher, trainer or researcher working with children and adolescents." Huang also had to explain to his family why he would not pursue his PhD dream.

The psychological burden and sense of loss of future career development weighed down. "The situation became so untenable that I left my job and my life in Singapore and fled to Europe, hoping to start my life afresh and leave the past behind." Huang is now an educator of people living with HIV.

Jean, Katiana, Suzette, Danielle

Georgetown Human Rights Action students document harsh effects of restrictions applied to Haitians living with HIV

Summary of personal impact

Georgetown Human Rights Action student research activities in Haiti gathered stories from people living with HIV that illustrate the harsh effects of HIV-related restrictions for positive people seeking to reunite with family abroad. In addition to families being kept apart, people reported being tested without consent or counselling and discovering their HIV status through reading embassy papers.

Georgetown Human Rights Action, a student-led mission funded by Georgetown University (Washington, DC, USA), completed fact-finding trips in 2008 to Miami and New York in the USA and Port-au-Prince in Haiti to investigate the impacts of US immigration policy on people living with HIV. Its activities included visits to AIDS clinics and interviews with human rights lawyers and immigration officials, as well as interviews with those personally affected by HIV-related restrictions on entry, stay and residence. The following are the stories of some of the people interviewed in Haiti. Names have been changed to protect privacy.

JEAN and his three children went to a doctor in Port-au-Prince in December 2006 to be medically examined, as required for the USA visa application. "My children and I hoped to join my father, who was already living in the USA," he says. The doctor produced medical reports for the children, but said that he would deliver the results of Jean's examination to the embassy because "there was a little problem". Jean reported to the embassy for the meeting, paid the immigration fees for his family and brought the required paperwork. He was informed, however, that his medical report hadn't arrived. He returned later to the embassy and was told, "The medical report has a problem; you can't leave."

“Then I was told that I was HIV positive,” Jean says, “and that I would need extra papers from several doctors before I could continue with my application process. They [the embassy officials] told me nothing about what the disease did to people or what I could do to treat it. I thought I was going to die soon... I was sick. I didn’t want to eat or do anything and couldn’t think of anything but death. I cried all day, every day.” Jean received no counselling.

“I returned to the embassy with information from three different doctors in the USA agreeing to treat me when I arrived in the USA, but each doctor was refused because the embassy ‘doesn’t trust them’. I then gave up. It was a very sad time for me.”

He sought support from the Haitian Group for the Study of Kaposi’s Sarcoma and Opportunistic Infections, a PEPFAR-funded organization in Port-au-Prince. “I began treatment for the first time and saw people living with AIDS who are still strong and leading productive lives.... Although being HIV positive will always be difficult, getting information from the clinics made me realize I could live with the disease. I did not feel this way after visiting the embassy.”

At the time of providing his testimony, Jean was still waiting for word from the embassy about his waiver. At one point he had a lawyer, but he can no longer afford to retain such expensive services.

KATIANA is trying to join her brothers, mother and stepfather in the USA. “The embassy contacted me in April 1998 and told me everything was okay, my papers were okay, and I should make an appointment.” Once at the embassy, however, they told Katiana that they had lost her application and that “it might be in Miami”. The file re-emerged after a month. “I didn’t know anything about HIV until I was forced to get tested as part of the application process. When I found out I had HIV, I was afraid to tell my family. When my mother found out, she decided that my youngest brother should come to Miami so that he wouldn’t have to find out. I was so depressed and embarrassed that I terminated my visa application.”

She says that in Haiti, HIV-positive people are treated as if they are dead. “Even the people at the embassy are always rude to people with HIV, and anybody who works at the embassy knows that you have HIV/AIDS because you will come on Wednesdays or Fridays, the days for people with health problems.”

“I feel I have lost 10 years of my life waiting.... I am lucky to have a mother who is willing to fly to and from Haiti to help with my application process, but I am embarrassed because I am an adult and my mom still has to support me. If I were in the USA, I could support myself and my mom wouldn’t have to send money to Haiti.” Katiana’s mother returned to Haiti and took her to a community organization for treatment. Here, she found out about the HIV waiver, and in December 2007, “reactivated her file”. She sat in the embassy waiting room for a day, but her name was not called. Katiana discovered, by talking to another woman who was waiting for a meeting, that the embassy staff only met with HIV-positive applicants on Wednesdays and Fridays. She returned to the embassy on Friday.

Katiana was told that since so much time had elapsed, she would need a letter from her mother agreeing to sponsor the application. Her mother flew from Miami to Haiti with a notarized letter, but Katiana’s name had been misspelled and the letter was rejected. Her stepfather sent another letter to her; twice, Katiana tried to take the letter to the embassy, but she was too sick. Eventually, embassy staff told her that the letter was not adequate because it did not say that she was HIV positive, although she had not been told that this had to be

included. The embassy eventually accepted the letter, but then told her that she needed to provide an additional, handwritten letter. At the time of providing her testimony, Katiana was working on obtaining this letter.

SUZETTE went to a doctor, as required by the visa application process, in 1995. "The doctor told me nothing and sent me to the embassy," she says. At the embassy, Suzette was given a piece of paper with information about HIV. "I returned to the doctor to ask what was going on. He told me I was HIV positive. It was the worst day of my life."

Suzette filed her papers with the embassy, but was refused a visa. However, in December 2007 she was finally granted an appointment at the embassy. "Here, I was given additional papers. I brought a letter saying I was getting treatment and I went to my clinic and had them sign it. The embassy would not accept it."

Suzette's parents found a doctor in the USA who said he would help with her treatment there. "But the embassy only told me to come back in another three months. On 1 March 2008, I returned to the embassy but was told that the required paperwork had not yet arrived from the USA... My mother, father, brother and two sisters are all already living in the USA. For eight years, I have been the only one in my family still living in Haiti. Why don't they want me?"

When Suzette discovered her HIV status, she was referred to private doctors who told her to fill their prescriptions at expensive, private pharmacies. The doctors did not tell her about the free clinics, nor did they provide her with counselling. Since finding out about the Haitian Group for the Study of Kaposi's Sarcoma and Opportunistic Infections, Suzette has been receiving free treatment and support.

DANIELLE began the visa application process in 1994, hoping to join her mother, husband and eight siblings in the USA. She went to a doctor for the medical examination required for the visa; he told her that she should go straight to the embassy. She did so, but the Embassy staff gave her papers and told her to go back to the doctor.

She received a form from the embassy. "On it, below my name and identification information, there was a large check mark in a box next to some text which read, " *Votre test est positif pour le Syndrome Immunodéficientaire Acquis (SIDA)*". I knew then I had HIV. I had no one to tell. If I told my friends and family, they would not want to see me again. I was so scared. No one helped me."

She called her husband in the USA, who accused her of having an affair. "I have not heard from him since... I asked my mother if she would sponsor me. She said no. I was now completely alone in Haiti. I terminated my application. Why would Americans, after giving so much money for AIDS medicines, not let people with HIV or AIDS come to the USA?"

Having found out that she was HIV positive through her embassy paperwork, Danielle was not referred to counselling of any kind. She managed to find POZ (Promoteurs Objectif Zero SIDA), which provides health care, medicine and counselling to people living with HIV. Through POZ, she learned of the HIV waiver process and decided to re-open her file in 2003. Her mother is also coming to terms with Danielle's HIV status and has agreed to be her family sponsor.

Jorge

Evading restrictions by posing as a “cancer patient”

Summary of personal impact

US immigration officials interrogated Jorge when they found his antiretroviral medication in his hand luggage while in transit to AIDS 2006 in Toronto, Canada. To avoid being denied transit, he told the officials he had cancer. As a result of this experience, Jorge avoids travelling to or through the USA.

As the head of an advocacy organization representing elected officials involved in the AIDS response, Jorge flew from Europe via the USA to attend AIDS 2006 in Toronto. US immigration officials searched Jorge’s hand luggage and found his antiretroviral medication. Jorge has been HIV positive for more than 20 years. “If I had told them about my illness... I would have risked not being able to go to the conference... so I lied by claiming that I had cancer,” he says. The officials did not believe Jorge and proceeded to interrogate him. “Despite their insistence, I continued to claim that these treatments were intended for my cancer. I could, after an hour, finally board. Resting in the plane, I thought: ‘Was I guilty for being ill? Had I committed a crime? Surely not!’”

“I have never been ashamed of my illness; I revealed it publicly and, as a politically-elected representative, it was not an easy thing to do.” Jorge says that he “does not dare to go to the USA anymore”. He stated that the US consul in his country indicated in response to an interview with Jorge that HIV-positive people who lied about their condition would be on a permanent blacklist and forbidden entry to the USA.

“I learned that by being ill—affected by a transmissible, though non-contagious illness—one could be treated as a threat to public order, and worse, as a terrorist,” Jorge says.

Lara

Residence restrictions based on HIV status keep apart a couple in love

Summary of personal impact

“Lara”, a citizen of Switzerland, is prevented from obtaining a US resident’s visa because she is HIV positive. This means she is not permitted to live in the USA with her partner. Even visits have their complications. When she goes to the USA, she ships her antiretroviral medication to the country before travelling to avoid having it with her when she goes through customs. Lara has learned that she would possibly be allowed to live with her partner if they married, but would still have to endure long formalities and an uncertain outcome.

Lara discovered that she was HIV positive in 1996. “I first thought that it was a death sentence, and my main concern was to know how long I could expect to live, followed closely by the fear of passing this on to someone else,” she says. “But I didn’t have the slightest idea then that it would also one day affect my freedom.”

She gave up her job, and focused on art and travels. In “the East”, Lara recounts, she met a man, an American citizen. The relationship deepened, and Lara decided to tell him about her HIV status. Although it took some time for her partner to digest the fact, “he did not run away or make me feel like I was tainted or rotten, as had happened on other occasions.”

When Lara visits her partner in the USA, she ships her antiretroviral medications before travelling, to avoid the risk of having them on her as she passes through customs. The relationship has deepened further and in March 2008 the couple made the decision to live together, bridging at last the many kilometres. They chose to make the USA their home. However, as they began making plans they made a shattering discovery: “I would never be allowed to join him in his country because of my HIV condition, despite the fact that I am not and will not be a threat to public health nor a financial burden for the public purse.”

“After lengthy searches, and with the help of some competent people at my local HIV association, we did find out that there might still be some hope for us if we got married, but that even if we did, we would still have to go through long and fastidious formalities, answer lots of questions, and hope for the best, leaving the final outcome in other people’s hands.”

Lara says the process is still under way. She adds, “It is hard for us to think that in a world that is supposed to be a free world, and in countries that have high ideals of personal freedom and democratic values, it is possible still for governments to interfere in people’s lives and take away from them the possibility of choosing the course of their own lives.”

Maria

Deported and stigmatized due to HIV status, but now educating others

Summary of personal impact

Maria was deported from Singapore after testing HIV positive during the renewal of her working permit. With no counselling and support—only the scorn and judgement of the doctor who diagnosed her—she feared what her family would think when she returned home unexpectedly. Since her diagnosis, Maria has remained in good health and wants to work overseas again, but worries that mandatory HIV testing will prevent her from securing employment or the necessary permits. Today she is increasingly involved in efforts to educate women about HIV before they depart for overseas employment.

Maria, a citizen of the Philippines, was employed in Singapore for four years as a domestic worker. Upon completion of her contract with her Singaporean employers, she was hired by an American and had to undergo medical testing in order to process her new working permit. After a two-week wait, her employer told her that they had to go to the diagnostic clinic together to get her results. This was how Maria found out that she was HIV positive.

Although Maria’s new employer wanted her to stay on in Singapore and work for him, the Singaporean authorities required her deportation. The doctor who diagnosed Maria said she had to go back to her country immediately because it was “migrant workers like her who spread diseases like HIV in his country”. She did not get any pre- and post-test counselling related to HIV, but she was advised to contact the Philippine Embassy if she needed help. However, after the initial reactions she received from the doctor, she did not contact the embassy—she could only imagine what type of reaction might await her there.

Since it was the holiday season and flights were fully booked, Maria was not able to leave Singapore right away. However, her employer made sure that she was taken care of during her two remaining weeks in the country. Recognizing Maria’s state of complete shock and deep despair, her employer expressed his worry that she might be suicidal. Maria found the force to

survive this difficult time and prepare for her departure. When she got home to the Philippines, she did not know how to explain to her family her sudden return to the country. She also did not know where to go for support and counselling, until she happened to hear an ad on a local TV station about HIV and noted down the telephone number of a counselling hotline.

It is several years since Maria's diagnosis with HIV, and she remains strong and healthy. Except for occasional bouts of flu and a skin condition called psoriasis, she has not had any significant illness. Maria has not told anyone in her family about her HIV status for fear that they might throw her out of the house and disown her. Her mother has since died without knowing the real reason why Maria would not leave again to work abroad.

Maria feels strong and wants to seek work abroad, but because of mandatory HIV testing she worries she will be disqualified for overseas employment. At present, she lives off of what she earns running a small retail store in her neighbourhood. While she has kept her HIV status confidential, she has become increasingly active in advocacy and education related to migration and HIV and has collaborated with some government institutions. She is also involved in providing HIV orientation seminars to outgoing migrant workers, as well as through a support group of women living with HIV.

Pat

HIV-positive delegate to the United Nations High-Level Meeting on AIDS denied visa

Summary of personal impact

Pat O. Matemilola was initially denied a visa to enter the USA to attend a preparatory meeting that preceded the 2006 United Nations High-Level Meeting on HIV/AIDS on the grounds of his positive HIV status. After the embarrassment of this rejection, Pat applied for a waiver available to people living with HIV to attend the meeting itself. Embassy officials appeared to not be aware that such a waiver existed.

Pat was nominated to be part of the Nigerian Government delegation to the United Nations High-Level Meeting on HIV/AIDS at the United Nations Headquarters in New York, USA. He filled in and submitted the US visa application form and was given a date on which to be interviewed at the US Embassy in Lagos, Nigeria, for his proposed visit. He paid the necessary fees and waited to be interviewed.

The interview lasted barely 15 minutes. "At the end of it, the embassy staff simply told me I cannot obtain an entry visa because of my HIV status," Pat recalls. "Fortunately, I had knowledge of the fact that a general waiver had been made for people living with HIV proposing to attend the meeting. So I mentioned this fact to the staff, who then asked me to wait." He waited for 10 to 15 minutes while the staff searched the embassy computer system and was then told that he was correct about the waiver policy and that he would be issued with a visa. "This enabled me travel to the meeting, albeit after the initial embarrassment."

"If the USA will not allow people living with HIV to enter its territory, then there will be no moral justification to take any global HIV and AIDS meeting to the USA, as the important constituency of the most affected will not be able to attend and contribute to such meetings," Pat says.

Rama

Evidence of family support, employment offer and no burden on State, but student visa denied due to HIV status

Summary of personal impact

Rama, a citizen of Mauritius, was denied a student visa even though his doctor was able to demonstrate that, although HIV positive, he was otherwise in good health and would not be a burden on Australia's health system. Solely due to his HIV status, Rama was prevented from studying in Australia.

Rama, 31, was doing technical jobs in Mauritius and wanted to go to Australia in 2007 for training and work experience. His sister, living in Australia as an Australian citizen, was willing to support Rama and give him food and accommodation during his studies. Rama gained entrance to an Australian college for a part-time course. He also found a part-time job, and the Australian employer confirmed this offer of employment in writing. Rama submitted his student visa application to the Australian Embassy, attaching a medical certificate as requested.

In a letter to Rama, having noted his HIV-positive status, the embassy requested him to submit additional information, including: a current assessment from a treating doctor or specialist regarding his CD4 count and viral load; results of liver function tests; and a report “addressing history, physical examination findings, diagnosis, management needs for the next five years and prognosis”. Rama submitted the information, apart from his viral load as these tests were not available in Mauritius. His doctor’s report stated that, based on all other available information, his CD4 count and the status of his immunity were likely very good, and that he had not presented any significant health problems. Despite this additional information, the embassy denied Jean’s student visa due to his HIV-positive status.

Ramesh

Same-day deportation... and HIV stigma upon return home

Summary of personal impact

Ramesh was deported from Oman after he tested HIV positive. Oman requires migrants to undergo annual HIV tests in order to renew their work permits; the policy has been that an HIV-positive result leads to deportation. Ramesh was not told he was being tested for HIV, counselled, or given his results. He lost his job and was exposed to stigma upon his return to India when the press revealed his HIV status. Forced to divorce by his in-laws, and feeling hopeless, Ramesh wasted a lot of money on fake cures and quack medicine in a desperate bid to become HIV negative.

Ramesh, from India, went to Oman as a car driver in 1992 and obtained a work permit and a sales job in a town called Salalah a year later. In 1997, he returned home for almost a year as he had saved enough money to build a house in his village and find a bride through the assistance of his family, as is the common practice. Back in Salalah to renew his work permit, he went to a clinic with his “sponsor”—“all migrants have sponsors”, he says—for the

required medical tests. As Ramesh did not understand Arabic, a form and the test results in Arabic were given to the sponsor. Ramesh was photographed and, with no explanation, his passport and documents were confiscated.

The sponsor proceeded to contact Ramesh's employer, who was saying, from what he could make out, that it was "the first time in the company's history that such an incident had occurred". Ramesh was told that he would be deported. He was aware only that he had "failed" a medical test. His results were known at 11 a.m. By 5 p.m. the company had settled his accounts, and by 7 p.m. he was on a flight to Muscat, watched by police, and then on to India.

He reached his region of India, where jobs were in very short supply, with hardly any money. Ramesh worried about how he would survive—and he was reeling: "How could a healthy, broad-chested man like me have some germs in my blood?" Then, a newspaper carried a provocative headline: "A Gulf Migrant Deported and Returned after Having Tested as HIV Positive". It named Ramesh's village, and as he was the only migrant to have returned from the Gulf, fingers immediately pointed at him. "Some people abused me," he says. "Some neighbours ostracized me. My wife asked what was wrong with me."

Many villagers did not have telephones, so migrants often gave a neighbour's phone number to Gulf employers. A manager from Ramesh's region, based in Oman, called Ramesh's neighbour and asked him to tell his family to take Ramesh to a hospital for tests. The request was announced to the village. His wife's family forced him to go to a hospital, where his wife tested HIV negative and he tested positive. They were still very fond of and committed to each other, but his in-laws forced them to divorce.

"I decided to find out as much as he could about this dreaded disease that had destroyed all happiness in my life," Ramesh says. He went to Mangalore, where doctors explained what HIV was and how it was caused and spread. He understood that HIV was "a disease that has no medicine in the world". He had no job, had lost his wife and lived with the feeling that his life was under threat. With his HIV status broadly known, Ramesh could not find work near his home. He travelled to a faraway city and worked as a salesman. His only goal was to somehow become HIV negative, and he spent a great deal of money on "quack" medicine and fake cures. He dreamed of an HIV-negative certificate, which Ramesh knew would mean he could go back to the Gulf, work and be happy again.

Ramesh turned to spiritual support, which he says was a source of strength. He became involved in a State AIDS Control Society project in his region. From this, he now earns a modest income, and through his work there, met his new wife.

Ronald

Deported Australian says he lost not only money and job, but also dignity

Summary of personal impact

"Ronald" had been living in China on a business visa for about a year when he applied for a resident's visa and in that process tested positive for HIV. He was summarily deported. He did not receive counselling and was not told of his status. He lost his job, his money and his dignity, and at the time of telling his story, was still unclear about what his rights are.

When Ronald, an Australian citizen who had been living in China for about a year, applied for a resident's visa, his required HIV test came back positive. "The hospital called me to come back to re-do the blood test, saying that they had lost the samples," he said. Two days later, immigration authorities called him for a "routine" interview. "They made me have photos taken, pay money, and then sit in a room for several hours. There were no questions and no 'interview'."

When Ronald asked to use the men's room, he was escorted there and back. He asked what was happening, and received a vague "routine" answer. "They then presented me with a letter, typed in Chinese, requiring me to sign it. I advised the officer that I could not read Chinese, but had the services of a translator that I could call to assist me with reading the letter. I was told that if I touched my mobile phone it would be taken from me permanently."

Ronald signed the letter, and police officers told him that he would be driven to the border with the Hong Kong Special Administrative Region and deported. His request to call his consulate was denied. An officer took Ronald home and gave him 10 minutes to pack. He gathered money, credit cards, an overnight bag and his computer. "All the time, the police officer remained at my side, advising me that I was not to contact anyone. I feigned needing the men's room, and while in there, wrote a note to my partner.

"I was driven to the border, made to pose for a series of photos with the police—for what purpose I am unsure, but there were about 10 photos with different officers—and then made to leave. I lost my job, several thousand dollars tied up in my apartment—I had to pay the remainder of the lease term—and my dignity."

Ronald says, "I still do not know what the letter that they forced me to sign said, and am unclear as to what my rights were... and if they were abused by Chinese legal standards."

Shaun

Work permit rejection and tourist visa hurdles spark advocacy campaign preceding the International AIDS Conference (2006)

Summary of personal impact

Shaun Mellors, an HIV-positive South African activist, was offered a job in Canada. His work permit was refused on the grounds of "medical inadmissibility," requiring a special "ministerial permit" to allow Shaun access to Canada. This initial refusal, and later hurdles encountered when applying for a tourist visa, sparked an advocacy effort to change the Canadian visa application form before the XVI International AIDS Conference (AIDS 2006) in Toronto, Canada.

Shaun had previously been classified as criminal for "fraudulently" obtaining a visa to enter the USA. In 2002, when the Toronto-based International Council of AIDS Service Organizations (ICASO) offered him a job, Shaun provided honest answers to all the questions on the Canadian visa application form. According to the information provided by Immigration Canada, a medical exam would be required to determine whether applicants or dependants had a serious communicable disease, or a condition that could place an excessive demand on Canada's public health care or social service systems.

In June 2002, Shaun and his partner consulted a pre-approved physician. The exam included HIV tests, and his partner tested HIV negative. According to Shaun, however, “the process left much to be desired.” “A person is sent from doctor to clinic to lab, without any form of counselling or explanation of what the tests are for, let alone post-test counselling,” Shaun said. The results went to the Canadian Medical Officer for Africa, who asked for viral load and CD4 count tests, as well as other exams to determine if there are “neuro-psychiatric problems which could be considered as a risk to public safety or health”. The results for viral load (less than 50 copies/ml) and CD4 count (540) were sent to the medical officer. Shaun and his partner sold their house and resigned from their jobs.

On 12 September, Shaun was told that he would not receive the permit as he was considered “medically inadmissible”. He requested further information on the basis of the decision. In response, he was reminded that he had been HIV positive since 1986 and on antiretroviral treatment since 1996. According to the medical report, “This condition is expected to progress, resulting in requirement for urgent assessment and recurrent treatment in a hospital setting, services that are also expensive... he would be eligible for these services, thus placing an excessive burden on the health care system.” The embassy did, however, request a special ministerial permit to allow him to work and live in Canada, and after interventions by partners within ICASO’s network, Shaun was given a temporary resident’s (ministerial) permit and a work permit. On 26 October 2002, Shaun and his partner flew to Canada.

Two years later, back in South Africa, Shaun applied for a tourist visa to attend a meeting in Toronto, Canada. The Canadian Embassy requested his CD4 count and viral load—a request that ultimately set in motion a major campaign to change the country’s visa requirements. “Our partners in Canada were alerted to this, and because preparations for AIDS 2006 [the International AIDS Conference] were well under way, a concerted advocacy effort to change the visa application form got under way. A number of international nongovernmental organizations, including the [International AIDS Society], and Canadian nongovernmental organizations worked tirelessly to change the law around visa applications in time for the conference.”

Conclusion

The above case studies illustrate some of the devastating impacts that HIV-related restrictions on entry, stay and residence have on the lives of people living with HIV. These stories show how such restrictions deny people living with HIV the right to family unification, undermine efforts to adopt HIV-positive children, provoke deep emotional distress, and rob bright and talented individuals of the opportunity to achieve their full potential through higher education.

The impact of HIV-related restrictions on entry, stay and residence: personal narratives was commissioned by the International Task Team on HIV-related Travel Restrictions. The Task Team was established by UNAIDS in January 2008 as an advisory/technical group whose role was to galvanize attention to such restrictions on national, regional and international agendas, calling for and supporting efforts towards their elimination. The principles of non-discrimination and the greater involvement of people living with HIV/AIDS Principle formed the core of the Task Team's work and provided the context in which its efforts were set.

The **Report** of the Task Team, presenting its **Findings** and **Recommendations**, can be found at www.unaids.org.

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