A Profile of the Stigma and Discrimination faced by People Living with HIV/AIDS

Study conducted by
The Centre for Policy Alternatives (CPA)
for
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HIV/AIDS BASIC FACTS

Acquired Immune Deficiency Syndrome (AIDS) is a pattern of severe infections caused by the Human Immunodeficiency Virus (HIV). HIV destroys white blood cells essential to the healthy functioning of the body's immune system.

A person can live with HIV for many years without any symptoms. The only way to diagnose infection is through a blood test – you cannot tell if someone is living with HIV by looking at the person.

Prevention of HIV infection is the top priority, as HIV/AIDS cannot be cured, and there is no vaccine.

However, drugs are now available in Sri Lanka to reduce the amount of virus in the body. This means that people with HIV/AIDS can live longer and healthier lives and continue to contribute to their communities and support their families while living with the virus. With proper treatment, AIDS is no longer a fatal disease.

There are three major routes of HIV transmission:

- Through all unprotected (i.e., without a condom) sexual acts (vaginal, anal, oral)
- Through contaminated blood and blood products, which can be transmitted by transfusion or through injecting equipment or blades
- From an infected woman to her child during pregnancy, delivery, and breastfeeding

HIV is *not* transmitted by:

- Casual contact, such as shaking hands, hugging, kissing, coughing or sneezing
- Sharing food, utensils, cups, glasses, toilets, showers, telephones or swimming pools
- Looking after, living, working or studying with someone living with HIV/AIDS
- Insect bites (mosquitoes, fleas, lice, bedbugs, flies, or other household pests)

HIV/AIDS in Sri Lanka:

- Since the beginning of the epidemic in 1986, 712 people are known to have tested positive for HIV as of end-September 2005
- However, it is estimated that 3,500 are currently infected with HIV
- To date, 144 people have died of AIDS-related illnesses, and it is believed that 56 people are currently living with AIDS
- The vast majority (85%) of known infections have been transmitted through unprotected heterosexual sex

1. Introduction

According to recent statistics from the Sexually Transmitted Diseases (STD) Clinic in Sri Lanka, there are currently 712 people in Sri Lanka living with HIV/AIDS. However, as a result of the stigma, discrimination and fear associated with HIV/AIDS, many people have been reluctant to reveal their HIV/AIDS status. Furthermore, there are probably countless others who are simply unaware that they are infected. As a result, the actual number of people living with HIV/AIDS is unknown, although it is estimated by UNAIDS to be 3,500.

Today, people living with HIV/AIDS have to deal with more than just the trauma of being infected by an immune-system destroying virus. They must also face the humiliation of social ostracism. HIV continues to be considered extremely contagious, and myths regarding how it can be contracted abound. For example, many Sri Lankans, regardless of educational attainment, believe that HIV/AIDS can be contracted by merely touching a person infected by the HIV virus. The fact is that HIV/AIDS cannot be transmitted by casual behavior, and there is no risk to living, working or studying with someone living with HIV/AIDS.

HIV/AIDS leaves people both physically and emotionally vulnerable: physically, because their immune systems are fighting a difficult battle, and emotionally because of the threat of death, and the stigma and discrimination attached to a condition that is associated with sex, sex work, and injection drugs. As a result, people living with HIV/AIDS are sometimes forced out of their homes and jobs. They can be rejected by families and friends. Often, they are accused of being personally responsible for their situation. As a consequence of the notion that particular social groups and sectors are more vulnerable to HIV than others (e.g., those who sell sex, men who have sex with other men, and those who inject drugs), people already on the margins of society encounter greater hostility and face further stigma and discrimination. These people are viewed as the carriers of HIV. Society's negative response has sent infected persons underground, further accelerating the spread of the virus in Sri Lanka. The fear of humiliation and hostility has led many persons to not seek medical assistance or advice and remain in the shadows, passing the infection on to others. It has also kept people from undergoing a blood test for HIV, out of fear of the stigma and discrimination that could follow from a positive test result. Therefore, it is extremely important to create awareness regarding HIV/AIDS, educating the public on the facts and dispelling the myths surrounding it.

In view of this need to raise awareness on the issue, the Asia Pacific Leadership Forum (APLF) commissioned the Centre for Policy Alternatives (CPA) to conduct a study on the stigma and discrimination faced by people living with HIV/AIDS and their families, in the areas of education, employment, family life, health care, housing and social life. The study looks at the experiences and needs of people living with HIV/AIDS and their families in the aforementioned areas and formulates recommendations to help reduce levels of stigma and discrimination with regards to HIV/AIDS.

2. Methodology

The study was conducted in two phases. The first part consists of information received through direct interviews with people living with HIV/AIDS, their families and health care staff. These interviews aimed to find out the nature of their experiences, whether their rights

have been violated and if they have been subjected to stigma and discrimination in the areas of education, employment, family life, health care, housing and social life.

Target groups were identified with the assistance of organizations working with people living with HIV/AIDS and hospitals. Interviews were conducted in Sinhala, Tamil and English, depending on which language the interviewee felt most comfortable conversing in. The questionnaire was drafted after consultations with a steering committee comprised of Mr. Nigel De Silva (Lanka +), Mr. Sherman de Rose (Companions on a Journey), Ms. Janet Leno (UNAIDS), Ms. Nynke Kuperus (UNDP), Dr. Paikiasothy Saravanamuttu (CPA) and members from the Social Indicator of CPA. The interviews were conducted over a period of three months. The research team conducted 24 interviews – 18 people living with HIV/AIDS and 6 family members, in addition to several interviews with health staff treating people living with HIV/AIDS. Due to concerns over confidentiality, the names of the interviewees have been withheld.

The initial findings were presented at a discussion in June 2005. At the discussion it was suggested that a separate component be included to look into the experiences known to caregivers. As a result, CPA contacted several caregivers and individuals working on HIV/AIDS. CPA received feedback from Salvation Army (SA), Companions on a Journey, Lanka+, and Alliance Lanka. Feedback from these organizations is included in this document in boxes for easy reference.

3. Limitations

The research team encountered several difficulties in obtaining access to people living with HIV/AIDS and their families. Many people living with HIV/AIDS, having faced stigma and discrimination as a result of their status, were unwilling to share information for fear of further repercussions. They also voiced concerns regarding the protection of their identities and respect for confidentiality. These concerns arose from previous experiences in which their confidentiality had been breached, and details from their interviews leaked. Furthermore, interviewees may have also faced more subtle forms of discrimination and insensitivity and this may not have been conveyed to the research team.

4. Health Care

The findings indicate that many cases of discrimination have occurred in the health sector. However, despite this, many interviewees still had faith in the public health care system. They believed that the services in the Infectious Diseases Hospital (IDH) and Ward 33 of the General Hospital were good, and that they were treated well. A few agreed that free health care provided by Government hospitals gave people who could not afford private health care access to treatment they would otherwise be denied. However, there was much consensus that awareness among health staff, in public and private hospitals, must be addressed. They brought up several instances where health staff – including doctors, nurses, attendants and minor staff – had discriminated against people living with HIV/AIDS and their families.

a) Breach of Confidentiality

According to the interviewees, there were several cases in which confidentiality regarding a patient's HIV status was not respected. A few interviewees mentioned that they had lost their jobs as a result of their status being made public. In one case, the lab technician had been shocked by the results, for it had been the first time he had seen a test come back positive for HIV. He had shared the information with his colleagues at the lab and the rest of the hospital. In the case of a patient who has since passed away due to complications resulting from AIDS, the interviewee was diagnosed with HIV at the General Hospital. A person working in the hospital had found out his HIV status and spread this information around their village. This resulted in the stigmatization of both the patient and the family by members of the community.

Another case which implicates the confidentiality issue occurred at a private hospital. The patient had been tested there since his brother-in-law was employed by the hospital. When the test result returned positive, prior to informing the patient, the doctor had passed the result on to the patient's brother-in-law. Furthermore, the test results had been leaked by the hospital lab, and as a result, the entire hospital staff learnt about it. The patient stated that the immediate family was only notified after everyone in the hospital had already found out. People outside the hospital, such as van drivers parked near the hospital, were told of the case. One such van driver was from the same village as the patient and spread the news of the patient's HIV+ status throughout the village. This led to various acts of discrimination – people wanted them to leave the village, making derogatory comments and informing the child's school, which in turn led to complications at school.

"*The doctors at the General Hospital told everyone who came to see him that he has HIV. The thing is, he was moved from the bed to the ground, so people in our family asked them why, and then the doctors told them that he has HIV, we don't generally keep AIDS patients. They had said a lot of things to my younger sister's husband. So everyone in our family knows about his status.*"

"Attendants bring visitors from other wards and show them the HIV+ people pointing them out as if they are exhibits; hence it is clear that they discuss these cases in other wards in order to appear important. In one instance the father of one SF[1] was so upset when this happened that he said his son was admitted for TB but the attendant loudly argued with him in front of the visitors and said it was HIV."

"A male SF suffering from one of the opportunistic ailments was admitted to a government hospital and, in all fairness to the doctor that had ordered blood tests, he in confidence told the doctor that he was HIV+. This doctor promptly informed the entire staff and they in turn told all the other patients in the ward. Our SF was shunned and treated like a leper, the staff not even approaching his bed to give him a meal. This was thrown on to his bedside table from a distance. At visiting time visitors for the other patients treated him like an exhibit at the zoo. He finally ran away from the hospital and we could not trace him for months."

"In 2004 a male aged 28 was admitted to the General Hospital. While waiting for an operation to be conducted the patient had undergone immense stigmatisation and ridicule by

[1] "Special Friend" is a term used by the Salvation Army.

the staff. The staff had passed the word around about his status. He was made to stay seated on a bench for 1 and ½ days without any care and finally was not operated on as the hospital said that they were not ready for him."

"In 2005 a female was admitted to the General Hospital. As she was to undergo an operation she was placed on a gurney, and placed by the public toilets until her turn to go into the theatre. While she was outside the toilet, she was ridiculed and shamed by the staff. The other patients were told of her status. As a result of the turmoil she got a headache. When she asked for two Panadols, the attendant cut an empty saline bottle and gave her to drink water from that. When she was taken into the theatre she was still ridiculed by those attending on her who said that she had got this disease due to her own fault and that she deserves what she gets."

"A male aged 52 was admitted to a government hospital. A staff member of the hospital had gone to his village and told everyone about his status. This person even took the trouble of calling the patient's students at their residence to inform them about his status. (He was a tuition master and had classes at his home). He lost all his students and found it hard to live in the neighbourhood. He grew very weak and was admitted to the IDH and was looked after well by the staff."

b) Unprofessional/Unkind Treatment by Health Staff

Health staff should be educated on and sensitized towards HIV/AIDS, so that they will be able to take proper precautions and treat the patients in a non-discriminatory manner. It is also important that health staff are knowledgeable about the disease, so that they can educate the public and give them accurate information, thereby dispelling fear and misconceptions.

At a government hospital, a patient was operated on by hospital staff without any testing or consultation with the patient's family. After the operation, the patient's mother had informed the doctor that the patient was HIV+. Though the doctor had behaved respectfully towards the patient and family, the attendants and minor staff had treated both the patient and family badly. The mother of the HIV+ person, when interviewed, stated that the health staff were ignorant of HIV/AIDS and this resulted in stigmatization and discrimination. She went on the mention that the hospital staff had even refused to touch the sheets on the patient's bed.

"*The doctor there told me that there is nothing we can do, death is the only thing. So I asked him when will my husband die. Then the doctor said that he couldn't say. It could be tomorrow or day after or a year or two but that he can't say. Then I asked if there was any medicine for this and he said no, there is medicine but you won't be able to afford it. You have to go abroad and get treatment. Death is the only thing.*"

The majority of the interviewees stated that they sought counseling after finding out that they were HIV+. This generally had a positive impact in helping people cope with their HIV/AIDS status and provided support for their families. However, in one case, a doctor advised the spouse of an HIV+ person to leave him. In this case, the HIV+ person had hoped the doctor could explain to his spouse the nature of HIV/AIDS to raise her awareness of HIV/AIDS thereby preserving the relationship. Instead, the doctor's advice

resulted in the spouse leaving him as well as having a negative impact on the relationship he had with his child.

An interviewee related her experiences in a government hospital, where staff, including doctors, had made derogatory comments and scolded her for being HIV+. On one occasion, her hand had passed over the doctor's tea cup; she had been scolded by the doctor for infecting the cup. On another occasion, her husband, who is also HIV+, was admitted to hospital for treatment. When he was discharged, his mattress was burned in his and his family's presence.

A similar case of discrimination occurred at a government hospital, where the patient had given birth. The nurses on duty had refused to touch her sheets and had insisted that the patient change them herself. This was soon after she had given birth and was unable to move from her bed. After the birth, a nurse had put a sign up saying that the patient had an infectious disease. When the people from the village saw it, people made derogatory remarks about her and her family, and her mother had been sent offensive letters. The same patient experienced discrimination at the Lady Ridgeway Children's Hospital in Colombo, where her child was warded. The nurses had not allowed the child to play with other children, claiming that it put the other children at risk for HIV. They had not permitted the patient to use the common bathroom, giving her a separate bathroom and space to wash her clothes.

"It is obvious this monumental indifference on the part of the staff is due to the patients being HIV+. For example, when we asked the nurse to please look after the Immersion Heater and Walker that belonged to the Salvation Army, her reply stunned us: 'We value our lives too much to touch anything they use'."

"Another male SF at the IDH was totally alone night after night, not a single attendant or nurse bothered to check on him. Depression is bad enough but isolation and fear in such lonely surroundings one night drove him to attempt suicide with a cord round his neck. In the morning he was found fortunately still alive and it was proof that no one had bothered to check on him in the night."

"In September 2004 a female SF got very serious and due to the IDH being on strike we were forced to admit her to the General Hospital in Colombo. The staff first isolated her in a room at the end of the ward, did not even approach her, not changing her linen or clothing, leaving her to lie in faeces and urine. We provided pampers but even these were not used. None of the nurses would even give her a sip of water from the cup (she was too weak to sit up and take from her bedside table). At one stage they tied her legs to the bed as she was rolling about in anguish. The sister in charge of the ward said her staff did not have the time to look after her and were not trained in HIV care."

"A sister in charge of the reception desk at the STD Clinic in Colombo, flatly refused to let a member of the SA[2] staff accompany the SF into the doctor's room. After weeks of counselling we managed to bring a new SF to the clinic for testing assuring him that one of us would be with him all the time (since we are always allowed to do so) and when we were

[2] Salvation Army

prevented, the SF ran away and all our efforts were in vain. A complaint to Dr. Sujatha Samarakoon brought prompt results as she was equally shocked at the attitude of the nursing staff there and took immediate remedial measures on our behalf."

"One young Doctor checking on one of our SF in our presence warned the nurses (in front of the SF) that they should not touch them without gloves for otherwise all of them, the nurses and he the doctor himself would end up with HIV and then would have to go begging to the Salvation Army! He and the nurses were highly amused at his humour."

"It has been stated that the nurses, attendants and doctors of Ward 33 of the General Hospital treat all of our members with respect and good care, but there are a few complaints against a handful of doctors who have taken over from the doctors that were practicing at the General Hospital. The remarks are that they are not as friendly, they are cold, not hospitable, to the extent of not coming close to the patient. One of the comments was that when one of our members placed their hand on the doctor's table, he was scolded for doing that."

"In 2004 a male aged 31 had to take a phlegm test at the Medical Research Institute (MRI) in Borella. The test required three samples of saliva, to be given in three days in a row. The first day when going with the field officer of Lanka+, he was chased out of the room and told that he should not come inside the room. So the field officer brought in the sample and handed it over. On the second day he did not come inside knowing that he would get scolded again. He had merely stepped in to hand the sample to the field officer and he was scolded again. On the third day the field officer was drilled as to what her connection was to this man: whether he was her husband, how did he get it, was she tested and so on. Then he was scolded again and told that the next time he should take the sample at home and not come there and cough up spit."

"In 2004 a male aged 42 was signed up for a hernia operation at the General Hospital, but was refused treatment in three other hospitals due to his status. Finally the date was set and the operation was scheduled. After coming from a distance and getting admitted, he was told that they could not do it on the stipulated date and to come back on the 18th of the following month. In pain he had returned. He was admitted for two days and then was told that the operation could not be done and that another day would be scheduled for him. This broke his spirit and without informing anyone he had left the hospital."

"In 2001, a female aged 27 and her husband and children being HIV+, were admitted to Lady Ridgeway due to an illness of her child. While undergoing treatment, she was not even allowed to sit on other benches, or even touch the taps to take water. She was told to use the tap that was outside. The attendants didn't allow her to wash her child's and her clothes. She was told to send them home and get them washed there. The other patients in the wards were informed of her status and they came to look at her and the child. The nurses would stand at a distance and speak to her."

"In 2001 a female aged 45, was informed of her status at the General Hospital in a very cruel manner. She was told that she had 'AIDS' and that she would be sent to a distant place where there is a hospital in the jungle where there were over a thousand 'AIDS' persons.

'You have been going out with prostitutes and getting these diseases and trying to spread it to us. Don't know how many you have infected by now. And now you are coming here and bothering us' was what she was told. Due to the stigma and the ridicule that this family was going through, her husband drank poison and died at a place of worship, shouting "It is you who have done this to me" at the people, before he died. After a staff member of the hospital revealed her status to her village, the villagers in turn set fire to her home while she and her two daughters were sleeping, and they had to escape with only what clothes they had on at that time."

"In 2004 a male aged 34 was at the STD Clinic waiting for blood to be taken for the CD4 count and there was another HIV+ person in the bleeding room. In front of this patient the other person was questioned about his private life. The nurse who was taking the blood was preoccupied and was not taking the blood properly. Even after the blood was taken of the previous person, he was told to wait for a while. He stated that he was feeling dizzy. They told him to lie down for a while. The second person was then bled for the test. During this time there were a lot of attendants and nurses coming in and out of the bleeding room. Then they asked the first person to get up and leave. He got up and as soon as he was leaving he started bleeding and there was blood all over the floor. There was panic amongst the staff and they scolded this person."

"In 2005, a male aged 34 went to the STD Clinic for a full check-up in order to get ARV treatment. The doctor seeing him was not aware as to what was supposed to be done and the HIV+ person had to enlighten her as to what needed to be done. There was an observer who had got permission from the client and was supervised by the doctor. There was a conversation going on as to who was going to do the check-up. (It seemed like they were both nervous to touch the client). Then finally once the doctor decided to do the check-up, she apologized to the client that she had to use gloves because she did a lot of cooking at home and had a few cuts on her hand. The client in turn replied that there was no need to apologize as it was 'universal precaution' methods that she had to practice and that it didn't bother him. The doctor did the check-up but with an aura of extreme nervousness. Once the check-up was done, and they were waiting for another doctor, the medical officer started asking personal questions from the client, such as – where, when and how he got infected. But the client refused to answer as he felt that he did not want to answer such intimate questions to someone he did not know."

c) Lack of Informed Consent/Counseling

The majority of the people interviewed stated that they had consented to being tested**.** At the same time, nobody had informed them about HIV/AIDS . Many had very little knowledge on what HIV/AIDS is, and some had misconceptions on how it could be transmitted. The majority of interviewees claimed that the doctor present had explained what HIV/AIDS was only after the results had come back positive. The doctors had then directed the people to places such as Salvation Army and Lanka+ to get assistance and support. There were no cases where pre-test counseling was conducted.

d) Refusal of Treatment

There was one case in which a person was refused treatment at a private hospital as a result of being HIV+. The interviewee had been admitted to the Asiri Hospital and his blood was tested. He had notified the health staff of his positive status so that they could wear gloves. This had resulted in his being refused treatment, and the doctor-in-charge had stated that it was hospital policy not to treat HIV+ patients.

e) Lack of Basic Services

"On admission we found that the patients are left alone in the rooms without even the beds being prepared for him\her, also without any assistance to arrange their belongings in the bedside cupboards. These cupboards are very dirty and inside are discarded empty plastic bottles, bags and a conglomeration of rubbish. We set about cleaning these out, arranging the beds, then discovered that no pillows are provided as they burn these after the departure of each patient and expect the families to provide this as well as the covering sheet. Also, no plates, cups and cutlery are given and we were very helpfully advised to buy everything in plastic to avoid breakage!"

"Since we were admitting the SF at noon we took along the lunches but were amazed to discover on inquiry that they were not entitled to any meals till the next day at noon. The reason being that the person who enters the meals book does so only in the morning so any admissions after that are left to starve! We had to purchase a flask and all the requirements for a cup of tea to be prepared (by the patient) as well as food for dinner and breakfast the next day. We were then informed that we should buy an Immersion Heater as well as they were not prepared to even provide hot water to make tea or mix a cup of Marmite."

"Though we were told that they should call for help, there are no call bells, so how do these people who are quite weak shout till they are heard? The youth was very weak and he said that unless his mother is there no one bothers about him. This was confirmed when one day we visited him at noon and though he was hungry no lunch was provided; and the nurse said that because his mother normally brings lunch for him at about 2 p.m. they did not give him anything to eat. This meant that he was left hungry for about two hours till his mother arrived with the meal. Supposing she got delayed or did not turn up he would have been left without food. This is the reason we visit them daily and provide nourishing milk foods, cheese, fresh fruit, including biscuits and snacks and very often find that all this has been pilfered."

"The toilets are in a filthy condition so much so that the wife said she holds up as long as she can. She also said she was reluctant to even have a bath. The conditions were so bad."

f) Screening of Blood

The National Blood Transfusion Centre in Colombo and its branches in the rest of Sri Lanka screen blood before making it available to all government hospitals. Most private hospitals have their own facilities to test blood but there does not seem to be a uniform method in practice. This could lead to loopholes in the system where contaminated blood is made available. Blood should be tested by all medical facilities before being made available for transfusions as this would reduce the risk of contaminated blood being used.

The giving of contaminated blood to a patient by health staff or an institution is an act of negligence. An interviewee narrated the details of his wife's operation in May 2002, at Sulaiman Hospital. The hospital gave her blood obtained from Durdens Hospital. She later tested HIV+, and after questioning the hospital authorities, the family found out that she had contracted the virus from contaminated blood used during the transfusion. When the family raised this issue with the authorities at Sulaiman Hospital, they placed the blame on the patient and refused to take any responsibility.

g) Other Issues

Issues pertaining to access to health care and medication needs to be addressed. A few interviewees cited financial difficulty in receiving such access. Assistance was provided by various organizations, such as the Salvation Army and Lanka+, but this was limited and did not cover all procedures.

In the interviews conducted, there was no evidence of forced medical procedures such as sterilizations and abortions. The majority stated that the results had been conveyed to them before any family members or others.

A few interviewees who had tested positive had got their spouse or partner tested. Except for one case, the test was done with the consent and knowledge of the spouse or partner. In one particular case, the husband had got his wife's and child's blood tested without their knowledge; his rationale was that his wife would never have consented to the test.

5. Education

In the interviews conducted, there were very few cases where discrimination took place in the area of education. In two situations where such discrimination had taken place, it was by parents of other students, and not by the institution itself. In one case**,** parents of other students had found out that the mother of a student was HIV+. They had requested that that child be removed from the school. In another case, a few parents had removed their children from a pre-school on account of the presence of a child whose father had died of AIDS and whose mother was HIV+. The teacher had stood by the child and refused to discriminate against him.

In another case, an interviewee recounted that her two daughters had stopped going to school as parents of other students had made derogatory comments towards them regarding their parents' HIV+ status. The priest in the temple had intervened, giving a letter stating that the children were good children and well brought up. The school had then allowed the children to return to school.

"From the time children are small – from Grade 6 or I think it's not enough from Grade 6 because when we were in Grade 6 we were quite small. But now from Grade 5 at least the schools should do awareness raising …They should teach them in depth that there is such an illness and this is a way of getting it. They should tell them there is an illness like this called HIV… Small children should definitely be educated – but both girls and boys. Not only girls. They should be put together and taught these things. Having a separate programme for girls and a separate programme for boys won't work either. They must be put together".

6. Employment

The majority of the people interviewed during the study were unemployed, and a few were self-employed. Several cases involving discrimination in the workplace were highlighted. In these cases, the people living with HIV/AIDS had to leave their employment.

a) Loss of Employment

One interviewee narrated several instances where he had been asked to leave his job as a result of his HIV status. He had started working in a restaurant with his cousin, when someone leaked his status to his cousin; his cousin had then requested he quit. The cousin's concern was that no one would come to the restaurant if they knew that there was a HIV+ person working there. The interviewee's second job was at a flower shop, but after six months, the owner had heard about his status and forced him to leave. In this situation, the owner had not even allowed the interviewee to come by the shop to collect his pay cheque, but had insisted on posting it.

In another case, a husband was employed to deliver bread. He lost his job when his employers found out he was HIV+. In yet another case, the interviewee was employed by MAS Holdings and had taken some days off as a result of his deteriorating health. When questioned by his boss, he had revealed his HIV status. The boss had told him that others in the company might not feel comfortable working with a HIV+ person and might decide to leave. As a result, the interviewee felt pressured to resign from his employment.

"A qualified computer operator (SF) who was found to be HIV+ was sacked from his post overnight and the reason given was that they just could not employ an infected person in their establishment. He then applied to other organisations and found that every interview he went for he was rejected because his previous employer somehow was keeping track of him and informing every interview panel of his ailment."

"Villagers drove out an entire family when the husband was found out to be HIV+ so he automatically lost his job. After his death his wife was finally permitted to return to her house with her four children only because they believe up to this day that she is negative though in fact she too is HIV+. She does not dare apply for a job in the vicinity as she is fearful that one day she will be thrown out of it (if her secret leaks out). We have helped her in a home micro project so that she can support her four children. The example here is that the HIV+ person is fully aware that there is no chance whatsoever of holding down a job once found out."

"In 2004 a male aged 45 was working at a bakery. After the bakery found out about his wife's status they stopped him from coming to work and told him to stay away and not to even go to the boutiques that he used to supply bread to. Even the boutique owners have got to know the news and are keeping their distance."

b) Mandatory Testing

Several interviewees claimed that they had learned of their HIV status as a result of tests that are mandatory for those going to the Middle East for employment. There was no pre-test or

post-test counseling available. They stated that even when tests are done in Sri Lanka, further tests are performed when people reach the Middle East.

c) Breach of Confidentiality

Another issue that needs to be considered by employers is the protection of an HIV+ person's confidentiality. An interviewee stated that he had not divulged his status to anyone as he did not want to be stigmatised or discriminated against. News of his positive status was leaked to third parties by his employer which led to problems from people in his area and workplace.

"The agency that sent me to Dubai has not protected my confidentiality. The fact that I'm positive has leaked from there."

"In 2000 a female aged 38 was working abroad as a housemaid. While waiting for her passport details to be processed for her next contract, the agency had found out about her status and had accused her of bringing AIDS into the country."

d) Initiatives to Raise Awareness/Educate-

An interviewee stated that there are initiatives to raise awareness and educate people in the workplace about HIV/AIDS. Presently, the *ILO Code of Practice on HIV/AIDS and the World of Work* is being implemented by some workplaces. This ensures that people who are HIV+ cannot be fired due to their status. Furthermore, the Ceylon Chamber of Commerce has initiated a programme to address issues raised related to HIV/AIDS.

A few officers have started awareness-raising campaigns in their workplaces. An interviewee informed the CPA team that various initiatives are underway to educate and sensitise employees. For example, the Nurses Association of Sri Lanka has conducted workshops in this regard, aimed at nurses from across the island. There have also been workshops conducted in factories and in the military, where various organizations have spoken on HIV/AIDS.

7. Family Life

Many of those interviewed felt shock at first finding out that they were HIV+. They questioned why and how they had contracted the disease, many times asking 'why me?', 'what did I do to deserve this?' and 'why am I getting it at this time when I have a good job and loving family?' They also wondered how they would be able to face their families, friends, colleagues and society in general.

"I was shocked and it affected the spirit of my existence. Why me was the question. It kicked me. I had a stable life, a caring and loving wife who had just got pregnant and at work I was steadily climbing the corporate ladder. All went into a doom because of this. I wanted to lock myself in my room because I thought even my presence in public would affect others."

a) Positive Aspects

The majority of interviewees have only shared knowledge of their HIV+ status with their close family: spouses, children, parents or siblings. It is only in a few cases that they have revealed it to others.

"*It was not easy in the beginning. It was not something that you can tell your parents, family or your friends. But now I have built a stable environment around me which makes my existence much easier."*

According to the majority of the interviewees, their close family and friends were supportive and understanding, and looked after their needs. All the interviewees admitted that family members and friends who were informed of their status had initially been shocked; people who were unaware or had little knowledge regarding HIV/AIDS were fearful. A few interviewees admitted that family and friends had treated them differently after finding out their status. However, after learning more about HIV/AIDS, they often became more accommodating and understanding. There were a few cases in which family members had been unconditionally supportive. One interviewee stated that he had even married after finding out his HIV+ status, for when he had notified his fiancée of his HIV status, she had still wanted to marry him.

The majority of interviewees stated that they received emotional and psychological support from their families and friends; some even received financial support.

b) Negative Aspects

There were situations where things turned out more negatively. In one such case, an HIV+ person was deserted by his spouse. His parents too had refused to see him when he first informed them, but over time the situation improved. His siblings, however, had been supportive from the outset.

"*I had a lot of problems from my family because what they tried to do was to somehow separate the two of us. They told me to think of my children and that my children won't have a future and what sort of future will they have, how will they go to school if people find out etc. They ostracised him a lot and they didn't even let us eat from the plate he used to eat on….We live with my mother and after his ticket was cut and he was allowed to go back home, my mother said that she can't keep him. As soon as we came home my mother asked him to leave home and not to come back… During that time my mother ostracised him and discriminated against him a lot. She wouldn't talk to him, didn't let him come to the veranda, wouldn't let him sit on the chairs, wouldn't let him watch TV. So the whole time he was in the room, on the bed. So mentally he fell down a lot. More than because of the HIV, because of this discrimination he mentally fell down a lot…. Now that my husband is abroad and earning, my family's attitude has changed. When he was here without a job, they even discriminated against our children. The thing is when we lost everything – we lost it all. Financially we were at zero. So everything we used was my mother's. So when the children put on the TV or radio she used to scold them."*

"A male school teacher, who was married with two children was detected HIV+ at a government hospital following a lengthy period of various sicknesses. Due to his ill health he couldn't continue teaching and resigned prematurely on heath grounds. His family deserted him upon the HIV+ diagnosis. His wife left him taking his children along with her. The little support he got was from his elder brother who kept him in a cow shed away from home

fearing that they might contract HIV. He starved as he didn't have any income to buy food and attempts to get away from that place resulted in that he was chained to the shed. The AIDS Coalition when informed of his plight offered to bring him down to Colombo and admit him to the IDH. His relatives and he himself refused saying it will be difficult for them to visit Colombo on a regular basis. He was provided with financial assistance to purchase food items and clothing. In 2004 he died exposed to the monsoon rains in his cowshed, ravaged by opportunistic infections."

Many of the interviewees could not recall incidents in which they or their families were threatened, assaulted, harassed or ridiculed as a result of HIV/AIDS. There was one situation, however, in which a woman was threatened and assaulted by her brother-in-law. Her husband's HIV+ status was known to most in the village, having been leaked by a health worker in the hospital. Her husband's brother had wanted her and her family to leave the village, as they were scared that people in the village would be affected by the illness.

A few interviewees stated that they used separate utensils, but this was mostly out of choice. Only in one case was an HIV+ person forced to use separate utensils.

There has been discrimination against the family members of HIV+ persons. They have lost employment, been insulted, assaulted and treated differently by health staff. A mother of an HIV+ person stated how the patient and the rest of the family were treated differently in hospitals, and that the hospital staff did not even want to touch the bed sheets they used. She recounted that the IDH was different as the staff were knowledgeable about HIV/AIDS. The family had supported the patient during her illness, but the patient's husband had deserted her and remarried. According to the mother, she feels that society is still afraid and therefore, issues related to HIV/AIDS are not frequently discussed.

A few people did not disclose their status to people outside of their close family and friends out of fear for the safety and well-being of their family members. They felt that people were not aware or had little knowledge of HIV/AIDS, and that disclosure would result in stigmatisation and discrimination. Until society becomes more aware and accepting of people living with HIV/AIDS, they are unwilling to disclose their status to outsiders.

"*I have to think of my children – they are three girls – there will be problems if people find out. We will die but they have to live".*

8. Housing

Many of the people interviewed lived in their own homes and thus had not experienced any discrimination as far as housing was concerned. There were a few cases of people living with HIV/AIDS who rented housing and experienced discrimination. In one instance, a couple, both HIV+, had to change residences as people in their village made it difficult for them to remain there. One day the house they were living in was set on fire; this prompted the family to move. In a few cases, the family had wanted the person who is HIV+ to leave home. With an increase in awareness and education, many have been able to return to their family homes and receive their families' support.

9. Social Life

Due to ignorance and fear, people living with HIV/AIDS and their families are often treated with insensitivity and cruelty. Lack of awareness on what HIV/AIDS is and how it can be transmitted has left many people with misconceptions about the disease. Fear and ignorance can lead to various discriminatory practices, which sometimes turn violent.

During its research, the CPA team came across several organizations conducting programmes to raise awareness and educate people about HIV/AIDS. While it is encouraging that these programmes are taking place, they often lack any follow up. Projects and programmes are implemented for a short duration, which is often insufficient to adequately promote awareness. Therefore, it is unlikely that levels of stigma and discrimination will decrease, as effective programmes have yet to reach the people. There needs to be more long term planning, with target groups identified, and awareness-raising and education programmes conducted in a systematic, consistent manner. It is also suggested that there be more work done at the grassroots level.

"S*ociety is still weak. They think this is an infectious disease. Now infection through blood is rare so people think – ah these people have gone astray and engaged in wrong practices that's why they have got it. That kind of wrong impression people have…*"

"A female whose younger sister died of HIV leaving her little daughter in her care is now suffering from another form of stigma in spite of the fact that she and her entire family are negative. She cannot give her grown up daughters in marriage because the neighbours are warning every young man that visits the house that the daughters are infected with HIV. She is so terrified of this situation that she will not hear of an awareness programme being conducted in the neighbourhood as she is convinced it will only make matters worse."

"A male, married with two kids, had no proper employment, but was working as a tour guide at the surrounding beaches. He was admitted to a government hospital with a persisting fever. He was detected as HIV+ and was transferred to the General Hospital, Colombo for a confirmatory test. Upon his admission to the General Hospital, a minor staff member of the hospital who was from the same area as the patient spread the news about his HIV status in his neighbourhood. Upon his return from the hospital he found the whole neigbourhood hostile towards him and his family. They were avoiding him and were taunting him with various allegations that he will spread the disease in the neighbourhood too. This rejection from his neighbours resulted in problems within his immediate family as well. There were several instances where his wife fought with him over the matter, as she was also HIV+. Pressure was also brought on him about his two young daughters as the family was concerned that they will never be able to get married to decent men because of their father's HIV status. The unfriendly and hostile attitude of the neighbors was at its highest when they burnt a portion of his house. He committed suicide. His widow left the village with the two young girls to live in an unknown area."

"In 2001, after the village found out the HIV status of the husband, the wife and the children were ridiculed and tormented to an extent that they (school going teenagers) had to stop their schooling. The wife was given poison into her hand in order to give it to her

husband and put an end to his life. After this whole ordeal, the husband could not deal with the suffering that the family was going through and committed suicide. After the husband's death, while the wife and the two children were sleeping, the villagers set fire to the house. But the family managed to run to safety. Since then they have not visited their home."

"In 2004 there was a case where the wife was positive. Husband and children were negative. The village found out the wife's status and had prevented them from using the village well. There have been notices dropped frequently at their doorstep asking them to leave the village and their ancestral home."

"In 2004, a male tuition teacher who was respected by the villagers and the children of the village was forced to stop his practice. After he got very ill and close to death, his daughter had come and met him only three times in the course of three months. She had come to see him to get him to write his will and to get hold of his property. While he was in bed he had stated that if he got better he could not go back home as the daughter and the family did not want him there. He finally died in Colombo without any family and friends, only his new found family from Lanka+."

"In the year 2000 a housemaid returned to Sri Lanka because there was a problem with her blood. The story that went around her village was that she was HIV+. As a result her husband threw her out. The villagers threw stones at her. Finally a local NGO spoke to the villagers and to the Grama Sevaka and managed to convince them that she did not have HIV. Her husband took her back and they went to a clinic and proved that she was not HIV+."

The majority of the interviewees were unaware of any programmes to raise awareness on HIV/AIDS conducted by local authorities such as the Municipal Councils, Urban Councils and Pradeshiya Sabhas. One interviewee mentioned a programme conducted by one Municipal Council. No such programs conducted by the Grama Sevaka, the Judiciary or Police seem to exist.

The interviewees claimed that the involvement of religious leaders in addressing HIV/AIDS related issues was very limited. A few individuals closely associated with religious institutions had assisted in awareness-raising and education, but this was done more in their personal capacities than with institutional involvement. Many felt that religious leaders should play a larger role in reducing stigma and discrimination by speaking to their constituents.

An interviewee informed the CPA team that there are a few religious groups that use the promise of curing HIV/AIDS to convert people.

"*I was converted to a sect of Christianity (Evangelists – 'Ekkalath Thoni') promising that my HIV positive status would be cured. I attended their religious sermons regularly for three months and then later realised that it was a fake campaign technique being used to convert people. I stopped attending the Sunday sermons thereafter and started going to Hindu temples once again."*

Many interviewees felt that media has played a positive role in educating and raising awareness among the public about HIV/AIDS. There have also been situations where the media have provided incorrect information on HIV/AIDS-related issues. For example, an article in a newspaper stated that a doctor in India had found the cure for HIV. This article had prompted parents of an interviewee to plan on sending him to India to be 'cured'. Fortunately, the interviewee had convinced his parents that it was a hoax.

There was general agreement by the interviewees that more needs to be done by the media in raising awareness and reducing the stigma attached to HIV/AIDS.

"*The media has informed and educated society only up to a certain extent. But this is not enough. They don't educate people properly on TV. They never say on TV that although HIV/AIDS is incurable, it can be controlled. They say that when you take medicine the risk level (effect) is reduced but people don't know whether this means it is curable or that it can be controlled. They convey the wrong idea. They don't say that by controlling HIV you can continue a normal life.".*

There have also been cases where the media have presented HIV/AIDS in advertisements and pictures in such a way that they have created fear and even traumatized people living with HIV/AIDS and their families. This was especially true of an advertisement for AIDS Day – it was a half page print advertisement depicting a body being prepared after death. This had traumatized one person living with HIV/AIDS and his family who feared an outcome similar to what had been portrayed. Other advertisements that created a negative impression used fear-generating phrases such as 'AIDS Kills'. Some felt that a more human element should be used, with people living with HIV/AIDS portrayed as human and possessing feelings.

Confidentiality has also been an issue in media coverage. An organization working on HIV issues informed the CPA team of a newspaper article on the death of a child as a result of AIDS. The article had given details regarding the occupation of both parents, the part of the country they resided, the previous death of their first child, and the subsequent death of the second child. From the information provided, people in the area where the family resided had managed to identify them. When raising awareness, it is important that articles and clippings in the media are sensitive to issues of anonymity concerning people living with HIV and their families.

"*My husband's death succumbing to his HIV positive status was carried as front page news in the widely circulated local newspaper published in Jaffna. They had not mentioned his name but had given the name of the village and other relevant details which were well enough for people in my community to identify the person as my husband. This was how people came to know of my HIV positive status and the negative outcomes of it."*

Interviewees stated that they had not seen any programmes on HIV/AIDS carried by Sri Lankan TV channels, but had watched programmes on Indian TV channels, which many in Jaffna can access.

The majority of the interviewees received some assistance. Organizations such as the Salvation Army, Lanka+, Nest, as well as individuals, have helped people living with HIV/AIDS and their families. Assistance ranged from financial support to counseling and other forms of emotional support. Some were part of support groups that met on a regular basis. Many who were interviewed received continuous assistance.

10. Recommendations

The feedback received through interviews and focus group discussions has assisted in drawing a profile of the problems faced by people living with HIV/AIDS in the areas of health care, education, employment, family life, housing and social life. Though only a limited number of interviews were conducted, they highlighted important issues that must be considered by stakeholders when attempting to reduce levels of stigma and discrimination. Further, it is vital that future initiatives keep in mind people living with HIV/AIDS and involve them as much as possible in the process.

The following recommendations have been made taking into consideration the research findings and the feedback received at the discussion. The recommendations are targeted at various actors including government institutions and officials, employers, educational and health institutions, the media, religious leaders, professional bodies, the donor community and civil society.

Ministry of Health (MOH):

- MOH needs to deliver a strong message to all health care workers that people living with HIV/AIDS and their families are to be treated with respect and professionalism. This message should be backed up with training programmes for health care staff, new recruits and health administrators, at the national and regional levels.

- MOH should formulate and implement a policy that ensures all HIV tests are performed by adhering to standards such as voluntary testing, informed consent, pre and post test counseling and confidentiality.

- MOH should provide training and resources for universal precautions which will ensure that health care staff are protected when dealing with HIV/AIDS. This should include the provision of plastic gloves, masks, sharps boxes for safe disposal of needles and adherence to safe laboratory practices.

- MOH should formulate and implement a comprehensive and multisectoral HIV/AIDS policy and regulations related to HIV/AIDS.

- MOH should introduce guidelines and strengthen existing structures to ensure that blood is tested by all medical facilities, which follow a uniform method, thereby reducing the risk of using contaminated blood.

Central Government, Provincial Governments and Local Authorities:

- The Central Government, Provincial Governments and Local Authorities should take a greater role in raising awareness. There should be a code of best practices that provide guidance to local and national policymaking bodies on means of actively involving people living with HIV/AIDS at various levels.

Ministry of Labour and Employers:

- In line with the draft policy of the National AIDS Committee, it is strongly recommended that the Ministry of Labour expand support to employers to provide workplace education and non-discriminatory policies regarding HIV/AIDS.

- In line with the policy to ensure consent, confidentiality and counseling with all HIV tests, mandatory HIV testing as a pre-condition to accessing and retaining employment, educational opportunities or life insurance policies should not be allowed.

Educational Institutions:

- Educational Institutions should ensure that there are no discriminatory procedures or practices that may hamper or bar a student's education.

- Programmes should be carried out to raise awareness and educate the teachers and students on HIV/AIDS and related issues.

Media:

- Greater media coverage on HIV/AIDS is essential in raising awareness levels. These programmes should be conducted in all three languages – Sinhala, Tamil and English – and be transmitted across Sri Lanka.

- It is important that media personnel, including editors, journalists and cameramen are made aware of the sensitive nature of the topic, and given training on sensitive and accurate reporting which will result in respecting the rights of people living with HIV/AIDS and protecting their privacy. Further, it will assist in portraying the true nature of HIV/AIDS and dispel any myths and fears associated with it.

Advertising Agencies:

- Advertising agencies should raise awareness among professional involved in advertising on HIV/AIDS and provide training on modalities of sensitive advertising. This would ensure sensitized advertising which respects the privacy of people living with HIV/AIDS.

Religious Leaders:

- Religious leaders should take an active role in promoting awareness about and working to reduce stigma and discrimination related to HIV/AIDS. Programmes should be initiated at the national, regional and local levels.

Professional Bodies:

- The Judiciary, Police, Bar Association, Accredited Advertising Agencies' Association and others should implement programmes to sensitize their members on HIV/AIDS issues.

Civil Society and the Donor Community:

- More programmes aimed at raising awareness and educating the public on HIV/AIDS must be conducted. These should be more long term and should involve follow up work.

- Providing medical, legal and other assistance to people living with HIV/AIDS and their families.

ANNEX I

Respondents-

Sex

		Frequency	Percent
Valid	Male	7	41.2
	Female	10	58.8
	Total	17	100.0

Religion

		Frequency	Percent
Valid	Buddhism	10	58.8
	Hinduism	2	11.8
	Islam	1	5.9
	Roman Catholicism	3	17.6
	Christianity	1	5.9
	Total	17	100.0

Age

		Frequency	Percent	Cumulative Percent
Valid	15 - 25 Yrs	1	5.9	5.9
	26 - 35 Yrs	6	35.3	41.2
	36 - 45 Yrs	9	52.9	94.1
	46 - 55 Yrs	1	5.9	100.0
	Total	17	100.0	

Marital Status

		Frequency	Percent
Valid	Single	3	17.6
	Married	7	41.2
	Widowed	7	41.2
	Total	17	100.0

Ethnicity

		Frequency	Percent
Valid	Sinhala	13	76.5
	Tamil	3	17.6
	Muslim	1	5.9
	Total	17	100.0

First Language

		Frequency	Percent	Cumulative Percent
Valid	Sinhala	13	76.5	76.5
	Tamil	3	17.6	94.1
	English	1	5.9	100.0
	Total	17	100.0	

Occupation

		Frequency	Percent
Valid	Housewife	1	5.9
	Self employed	3	17.6
	Elementary Occupations	2	11.8
	Unemployed	7	41.2
	Other	4	23.5
	Total	17	100.0

Education

		Frequency	Percent	Cumulative Percent
Valid	Cannot read and Write	1	5.9	5.9
	Up to grade 5	1	5.9	11.8
	Grade 6-9	4	23.5	35.3
	Up to O'Level	7	41.2	76.5
	O'Level	2	11.8	88.2
	Advanced Level	1	5.9	94.1
	Professional	1	5.9	100.0
	Total	17	100.0	

Income

		Frequency	Percent	Cumulative Percent
Valid	Rs. 5,000 or less	6	35.3	35.3
	Rs. 5,001 - 10,000	5	29.4	64.7
	Rs. 10,001 - 20,000	2	11.8	76.5
	No Income	4	23.5	100.0
	Total	17	100.0	

Rural/Urban

		Frequency	Percent
Valid	Rural	6	35.3
	Urban	8	47.1
	Not Given	3	17.6
	Total	17	100.0

Family Members-

Sex

		Frequency	Percent
Valid	Male	1	16.7
	Female	5	83.3
	Total	6	100.0

Religion

		Frequency	Percent
Valid	Buddhism	4	66.7
	Christianity	1	16.7
	Pentecoste	1	16.7
	Total	6	100.0

Age

		Frequency	Percent	Cumulative Percent
Valid	15 - 25 Yrs	1	16.7	16.7
	46 - 55 Yrs	5	83.3	100.0
	Total	6	100.0	

Marital Status

		Frequency	Percent
Valid	Single	1	16.7
	Married	2	33.3
	Widowed	3	50.0
	Total	6	100.0

Ethnicity

		Frequency	Percent
Valid	Sinhala	6	100.0

First Language

		Frequency	Percent	Cumulative Percent
Valid	Sinhala	6	100.0	100.0

Occupation

		Frequency	Percent
Valid	Housewife	1	16.7
	Self employed	1	16.7
	Elementary Occupations	1	16.7
	Unemployed	2	33.3
	Other	1	16.7
	Total	6	100.0

Education

		Frequency	Percent	Cumulative Percent
Valid	Up to grade 5	2	33.3	33.3
	Grade 6-9	2	33.3	66.7
	Up to Advanced Level	1	16.7	83.3
	Advanced Level	1	16.7	100.0
	Total	6	100.0	

Income

		Frequency	Percent	Cumulative Percent
Valid	Rs. 5,000 or less	3	50.0	50.0
	Rs. 5,001 - 10,000	2	33.3	83.3
	No Income	1	16.7	100.0
	Total	6	100.0	

Rural/Urban

		Frequency	Percent	Cumulative Percent
Valid	Rural	5	83.3	83.3
	Urban	1	16.7	100.0
	Total	6	100.0	

ANNEX II

Questionnaire: People Living with HIV/AIDS

Date……..
Place…….

Interviewed by ……... ……
Interview no ……

(I) Personal Data

1.) Sex:
1. Male 2. Female

2.) Religion:
1. Buddhism 2. Hinduism 3. Islam
4. Roman Catholicism 5. Christianity (Non-RC)
6. Other _____

3.) Age:
1. 15 – 25 yrs 4. 46 – 55 yrs
2. 26 – 35 yrs 5. 56 – 65 yrs
3. 36 – 45 yrs 6. 66 yrs and above

4.) Marital Status
1. Single 2. Married 3. Divorced
4. Widowed 5. Other_____

5.) Ethnicity:
1. Sinhala 2. Tamil 3. Muslim 4. Burgher
5. Other _____

6.) First language:
1. Sinhala 2. Tamil 3. English 4. Other _____

7.) Occupation of the respondent **(SINGLE CODE ONLY)**

1. Executives, Managerial and Administrative Professionals	8. Housewife
2. Professionals	9. Retired
3. Technicians and Associate Professionals	10. Business
4. Clerk	11. Self employed
5. Travel, Restaurant, Protective Service Workers and Sales Workers	12. Elementary Occupations
6. Agricultural and fisheries workers	13. Unemployed
7. Students	14. Other

(II) Level of Education

8.) Could you please tell me your educational qualifications? **(SINGLE CODE ONLY)**

1. Cannot read and write	8. Advanced Level
2. Literate but no formal education	9. Vocationally trained
3. Up to grade 5	10. Technically trained
4. Grade 6-9	11. Professional
5. Up to O' Level	12. Undergraduate
6. O' Level	13. Graduate and above
7. Up to Advanced Level	

9.) What is your personal income?
Per month

1. 5,000 or less	2. 10,000- 5,000	3. 20,000-10,000
4. 30,000-20,000	5. 40,000-30,000	6. 50,000-40,000
7. Over 50,000		

(III) Privacy

10.) When and how did you find out your status?
…….

11.) Where was the test taken?
……..

12.) Did you give your consent for the test?
…… …….

13.) If Yes, what advice/ counselling was given prior and after the test?
……..

14.) If No, how did you find out that the test was taken?
……

15.) What was your reaction?
..……..

16.) What steps did you take?
……

17.) Who informed you of the result?
…….

18.) How were you informed?
……

19.) Was anyone told of your results before you were informed? ……

20.) If Yes, who?
……

21.) Did they tell others of your HIV status? ……

22.) Was this done with your consent? …….

23.) How do you feel about others knowing of your status?
……

24.) Why? ……

	YES	NO
25.) Were you forced to tell anyone of your HIV status?		
Who: Family		
Friends		
Employer		
Other (Specify)		

26.) Did these people tell anyone else about your status? ……

27.) How many people know about your status? ……..

28.) Does your family know about your status? If No, why? ……
……

29.) Were you forced to tell of your status to others?

……

30.) If yes,

What were the reasons that lead to it? ……..

How did people react? ……...

What were the affects? (Positive? Negative?) ……..

Were you surprised by the reactions? Affects? Give reasons. ……..

What do you think of the levels of stigma and discrimination due to HIV and AIDS? Give reasons.……

If No,

- What were the reasons for not revealing your status?

……..

- How did people find out?

……..

- How did people react?

……..

- What were the affects? (Positive? Negative?)

……..

- Were you surprised by the reactions? Affects? Give reasons.

……..

- What do you think of the levels of stigma and discrimination due to HIV and AIDS? Give reasons.

…….

31.) Have you faced discrimination due to your status?

…….

32.) Have your family or people associated with you experienced discrimination as a result of your status? If yes, in what ways?

……..

33.) Did you or anyone associated with you get support without having to ask for it? …….

34.) What kind of support? Who gave it? ……

(IV) Health Care

	V. GOOD	GOOD	UNHELPFUL	NO COMMENT
35.) How is the status of the Healthcare System?				

36.) Has a hospital refused to treat you as a result of your HIV status?
……..

37.) Have there been delays in treatment/providing medicine as a result of your HIV status? ……..

38.) Have you had to pay extra for health care services as a result of your HIV status? ……..

39.) Has your family or people associated with you ever been refused treatment by a health care worker or hospital as a result of your HIV status?
…….

40.) Has your family or people associated with you ever experienced delays in treatment/care as a result of your HIV status? …….

41.) Has your family or people associated with you ever had to pay extra as a result of your HIV status? ……

42.) Has anyone advised you not to seek health care services? Give details.
……..

43.) Have you ever been denied or lost insurance or benefits as a result of HIV your status or for taking a HIV test? ……..……

44.) Has your family or people associated with ever been denied insurance or benefits as a result of your HIV status? …….……..

(V) Social Life

45.) Have you/family member ever been, as a result of your/family member's HIV status,	YOU		FAMILY MEMBER	
	YES	NO	YES	NO
Threatened				
Assaulted				
Ridiculed				
Insulted				
Harassed				
Others (Specify)				

46.) Have you ever undergone any medical or health procedures without your consent?	YES	NO
Abortion		
Sterilisation		
Other (specify)		

47.) Have you ever had to disclose your HIV status when applying for a visa, leaving or entering a country? ……

48.) Have you/family member ever been, as a result of your/family member's HIV status,	YOU		FAMILY MEMBER	
	YES	NO	YES	NO
Detained				
Quarantined				
Isolated				
Segregated				

49.) Have you ever been charged or brought to court on an offence or act related to your status? …….

50.) Have you/family member ever been, as a result of your/family member's HIV status, excluded from joining any	YOU		FAMILY MEMBER / FRIENDS	
	YES	NO	YES	NO
Organisation				
Club				
Society				
Meeting				
Gathering				

51.) Has your family or people associated with you restricted you or stopped you from joining any organisation, club, society or meeting?
……..
52.) How helpful have religious leaders in your area been in HIV/AIDS work? (education, awareness raising, advocacy vs. increasing stigma and discrimination etc.)
……..

53.) Have they been effective? Give details.
……..

54.) Have actions (related to HIV/AIDS) by religious institutions and religious leaders directly affected you, your family or anyone closely associated with you?
……...

55.) Has any group/body such as the	Acted in a way to Increase Stigma & Discrimination		Introduced programs to educate & raise awareness on HIV/AIDS	
	YES	NO	YES	NO
Urban Council				
Municipal Council				
Pradeshiya Sabha				
Grama Sevaka				
Police				
Judiciary				
Other (Specify)				

56.) Have the programs introduced on HIV/AIDS been effective? Give Details.
……..

57.) What other bodies/agencies should be involved in this process?
…….

58.) Do you feel that the media has given adequate information on HIV and AIDS? ……..

59.) Do you feel that the media has informed and educated society on HIV and AIDS? ……...

60.) Have you come across any articles, clippings, documentaries or any other media related items which are discriminatory towards people living with HIV or people associated with HIV? …….

61.) Do you think media coverage on HIV and AIDS has influenced people's thinking and behaviour towards PLWHA? ……..……..

62.) Has the media coverage had an impact on your life? If so, How? ……..

63.) How can it be improved? ……

(VI) Education

64.) With regard to Education, have you/family member ever been, as a result of your/family member's HIV status,	YOU		FAMILY MEMBER / FRIENDS	
	YES	NO	YES	NO
Harassed				
Dismissed				
Suspended				
Prevented				
Other (Specify)				

65.) If Yes, Could you please explain?

……

66.) How did the school/university learn about your HIV status? ……..……

67.) Have you/family member ever been, as a result of your/family member's HIV status, denied admission to an educational institution?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

68.) Have you ever travelled abroad for education? ……..

69.) Were you tested whilst you were studying abroad? …….

(VII) Employment

70.) Does anyone at your workplace know of your status? ……..

71.) If Yes, who? ……..

72.) How? …….

73.) Has their relationship with you changed since finding out your status?……..……

74.) Have you/family member ever experienced any discrimination at work as a result of your/family member's HIV status?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

75.) Have you/family member ever been terminated from work as a result of your/family member's HIV status?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO
76.) Have you/family member ever been harassed at work as a result of your/family member's HIV status?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

77.) Has your work changed as a result of your HIV status?
……..

78.) Have you/family member ever been offered early retirement as a result of your/family member's HIV status?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

79.) Have you/family member ever been denied a promotion as a result of your/family member's HIV status?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

80.) Have you/family member brought to the attention of the management any forms of inequality that you/they experienced?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

81.) What was the outcome? ……..

82.) Were you, your family or people associated with you satisfied with the outcome? ……...

83.) Did you/family member ever go to anyone outside the workplace for assistance?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

84.) What was the outcome?
……

85.) Has anyone outside the workplace offered to help as a result of any inequalities?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

86.) What was the outcome? ……..

(VIII) Housing

87.) Have you ever been refused housing as a result of your HIV status?
……..

88.) Have you/family member ever been forced to change residence as a result of your/family member's HIV status?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

89.) Have you/family member been refused a housing loan as a result of your/family member's HIV status?	YOU		FAMILY MEMBER	
	YES	NO	YES	NO

90.) With regard to housing have you ever been asked to leave as a result of your HIV status by	YOU		FAMILY MEMBER / FRIENDS	
	YES	NO	YES	NO
Family Members				
Landlords				
Others (Specify)				

(IX) Family Life

91.) Have you ever been tested for HIV/AIDS during pregnancy?
……..

92.) Did you consent to the test?
…….

93.) If Yes, what advice/ counselling was given prior to and after the test?
…….

If No,

- How did you find out about the test having being taken?
  ……..
- What was your reaction? …….
- What steps did you take? …….

94.) Have you ever been tested because of an illness of your spouse, children, parents or partner?
……

95.) Did you consent to the test? ……

96.) If Yes, what advice/ counselling was given prior and after the test?
……..

If No,

- How did you find out about the test having being taken?
  ……
- What was your reaction?
  ……
- What steps did you take?
  ……

97.) How did your family find out about your HIV status?
…….

98.) How did they react? ……
…….

99.) Reasons behind their reaction (society norms, religion, culture, ethnicity, economic background etc.)
…….

100.) What was the reaction to your HIV status from your	Kind / Supportive	Unkind	Deserted
Spouse			
Partner			
Child			
Parent			
Other family member (Specify)			

101.) Have you lost any financial support from your family as a result of your HIV status? …….

102.) Have there been any forms of discrimination within the family as a result of your HIV status, such as	YES	NO
Using Separate Utensils		
Using separate toilet facilities		
Isolation of person outside the house		
Other (specify)		

103.) At present, what are your needs? …….

104.) What are the needs of your family and people closely associated with you? …….

105.) Do you have any suggestions to make to reduce levels of stigma and discrimination associated with HIV/AIDS? What recommendations can you make?
……
106.) Any other comments that would assist in the study
…….

107.) Have you or anyone associated with you sought counselling?
……..

108.) If yes, give details.
……..

109.) If no, why?
……..

110.) Have you or anyone associated with you sought support? (emotional, monetary, etc.)
……

111.) If yes, what kind of support? …….

112.) Who? …….

If No, Give reasons.
……..

113.) Did anyone refuse to help? …….

114.) If Yes, give details.
……

If No, give details.
……

115.) Did the support you receive adequately address your needs? ……

116.) Was it a single instance or continuous?
……..

117.) If it was more than once, how often did it happen?
……..

118.) Any problems/obstacles that should be overcome?
……

119.) In your opinion, what programs should be conducted/introduced to eradicate stigma and discrimination? …….

120.) From what areas would you like to get support?
……

1. NAME:		
2. PROVINCE	**3. DISTRICT:**	
4. 1. Rural **2. Urban**		
5. DIVISIONAL SECRETARIAT (DS):		
6. GRAMA NILADHARI DIVISION (GND)		
7. DATE:	**8. START TIME:**	**9. END TIME:**

THANK YOU!

Researcher's comments/analysis-

Questionnaire: Family Members of PLWHA

Date ……..
Place ……..

Interviewed by ……
Interview no ……

Relationship to PLWHA …….

(I) Personal Data

1.) Sex:
2. Male
2. Female

2.) Religion:
1. Buddhism 2. Hinduism 3. Islam 4. Roman Catholicism
5. Christianity (Non-RC) 6. Other _____

3.) Age:
3. 15 – 25 yrs
4. 26 – 35 yrs
3. 36 – 45 yrs
4. 46 – 55 yrs
5. 56 – 65 yrs
6. 66 yrs and above

4.) Marital Status
1. Single 2. Married 3. Divorced
4. Widowed 5. Other_____

6.) Ethnicity:
1. Sinhala 2. Tamil 3. Muslim 4. Burgher
5. Other _____

6.) First language:
1. Sinhala 2. Tamil 3. English 4. Other _____

7.) Occupation of the respondent **(SINGLE CODE ONLY)**

1. Executives, Managerial and Administrative Professionals	8. Housewife
2. Professionals	9. Retired
3. Technicians and Associate Professionals	10. Business
4. Clerk	11. Self employed
5. Travel, Restaurant, Protective Service Workers and Sales Workers	12. Elementary Occupations
6. Agricultural and fisheries workers	13. Unemployed
7. Students	14. Other

8.) Could you please tell me your educational qualifications? **(SINGLE CODE ONLY)**

8. Cannot read and write	14. Advanced Level
9. Literate but no formal education	15. Vocationally trained
10. Up to grade 5	16. Technically trained
11. Grade 6-9	17. Professional
12. Up to O' Level	18. Undergraduate
13. O' Level	19. Graduate and above
14. Up to Advanced Level	

9.) What is your personal income?

Per month

1. 5,000 or less
2. 10,000- 5,000
3. 20,000-10,000
4. 30,000-20,000
5. 40,000-30,000
6. 50,000-40,000
7. Over 50,000

10.) How did you find out about the HIV status of your family member?

……

11.) What was your reaction? Give Reasons.

……

12.) Have you, on your own initiative, revealed the HIV status of your family member to others?

……

13.) If yes,

What were the reasons that lead to it? ……..

How did people react? ……...

What were the affects? (Positive? Negative?) ……..

Were you surprised by the reactions? Affects? Give reasons. ……..

……

What do you think of the levels of stigma and discrimination due to HIV and AIDS? Give reasons.

……

If No,

- What were the reasons for not revealing the status of your family member?

……..

- How did people find out?

……..

- How did people react?

……..

- What were the affects? (Positive? Negative?)

……..……

- Were you surprised by the reactions? Affects? Give reasons.

……..

- What do you think of the levels of stigma and discrimination due to HIV and AIDS? Give reasons.

……

14.) Have you faced discrimination due to the status of your family member?

……

15.) Have you as a family member of a PLWHA experienced discrimination as a result of their status? If yes, in what ways?

……..

16.) Have you sought counselling?

……

17.) If Yes, give details.

……..

18.) If No, why? ……...

19.) Have you sought support?	YES	NO
Emotional		
Monetary		
Other (Specify)		

20.) If Yes, what kind of support? …….

21.) Who? …….

If No, Give reasons.

……..

22.) Did anyone refuse to help? …….

23.) If Yes, give details.

……

If No, give details.

……

24.) Did the support you receive adequately address your needs? ……

25.) Was the support you received,	YES	NO
A single instance		
continuous		
sporadic		

26.) If it was more than once, how often did it happen? …….

27.) Did you get support without having to ask for it?
……..

28.) What kind of support? Who gave it? ……

(II) Health Care

29.) Have you ever been refused treatment by a health care worker or hospital as a result of your family member's HIV status?
……

30.) Have you ever experienced delays in treatment/care as a result of your family member's HIV status? ……

31.) Have you ever had to pay extra as a result of your family member's HIV status? ……

32.) Have you ever been denied insurance or benefits as a result of your family member's HIV status? ……..

33.) Have you ever been treated differently as a result of your family member's HIV status, by a	YES	NO
Street Vendor		
Trishaw Driver		
Other such person (Specify)		

(III) Social Life

34.) Have you ever been, as a result of your family member's HIV status	YES	NO
Threatened		
Assaulted		
Ridiculed		
Insulted		
Harassed		
Other (Specify)		

35.) Have you ever been, as a result of your family member's HIV status,	YES	NO
Detained		
Quarantined		
Isolated		
Segregated		
Other (Specify)		

36.) Have you been excluded from any organisation, club, society, meeting or any other gathering as a result of your family member's HIV status?

……

37.) Have you ever restricted or stopped your family member living with HIV, from joining any	YES	NO
Organisation		
Club		
Society		
Meeting		
Other (Specify)		

38.) Have you been refused entry to any support group?

……

39.) How effective have religious leaders in your area been with regard to HIV/AIDS work such as	YES	NO
Education		
Awareness Raising		
Advocacy vs. increasing Stigma & Discrimination		
Other (Specify)		

40.) Have actions (related to HIV/AIDS) by religious institutions and religious leaders directly affected you, your family or anyone closely associated with you?

……..…….

41.) Has any group/body such as the	Acted in a way to Increase Stigma & Discrimination		Introduced programs to educate & raise awareness on HIV/AIDS	
	YES	NO	YES	NO
Urban Council				
Municipal Council				
Pradeshiya Sabha				
Grama Sevaka				
Police				
Judiciary				
Other (Specify)				

42.) In your opinion, what programs should be conducted/introduced to eradicate stigma and discrimination? …….

43.) What other bodies/agencies should be involved in this process?
…….

44.) Do you feel that the media has given adequate information on HIV and AIDS? ……..

45.) Do you feel that the media has informed and educated society on HIV and AIDS? ……...

46.) Have you come across items discriminatory to PLWHA, such as	YES	NO
Articles		
Clippings		
Documentaries		
Other media related items (Specify)		

47.) Do you think media coverage on HIV and AIDS has influenced people's thinking and behaviour towards PLWHA? ……

48.) Has this had a negative impact? If so, How? …….

49.) How can it be improved? ……

(IV) Education

50.) Have you been harassed, dismissed, suspended or prevented from receiving education as a result of your family member's HIV status?
……

51.) If Yes, what did they do? ……..

52.) How did the school/university learn about your family member's HIV status? ……

53.) Have you ever been denied admission to an educational institution as a result of your family member's HIV status?
……

(V) Employment

54.) Have you ever experienced any discrimination at work as a result of your family member's HIV status?	YES	NO

55.) Have you ever been terminated from work as a result of your family member's HIV status?	YES	NO

56.) Have you ever been harassed at work as a result of your family member's HIV status?	YES	NO

57.) Have you ever been offered early retirement as a result of your family member's HIV status?	YES	NO

58.) Have you ever been denied a promotion as a result of your family member's HIV status?	YES	NO

59.) Have you brought to the attention of the management any forms of inequality that you experienced?	YES	NO

60.) What was the outcome? ……

61.) Were you satisfied with the outcome?
……..……..

62.) Did you ever go to anyone outside the workplace for assistance?
……

63.) What was the outcome? ……

64.) Has anyone offered to help as a result of any inequalities? ……

65.) What was the outcome? ……..

(VI) Housing

66.) Have you had to change residence as a result of your family member's HIV status? Give details.
…….

67.) Have you been refused a house loan as a result of your family member's HIV status?
……

68.) With regard to housing have you ever been asked to leave as a result of your family member's HIV status by	YES	NO
Other Family Members		
Landlords		
Others (Specify)		

(VII) Family Life

69.) Have you ever been tested because of an illness of your spouse, children, parents or partner?
……

70.) Did you consent to the test? ……

71.) If Yes, what advice/ counselling was given prior and after the test?
……..

If No,

- How did you find out about the test having being taken?

……

- What was your reaction?

……

- What steps did you take?

……

72.) Have you ever, because of their HIV status, deserted your	YES	NO
Spouse		
Partner		
Children		
Parents		
Siblings		
Other family member (Specify)		

73.) Have you stopped any financial support to your family member as a result of his/her HIV status?
……

74.) Have there been any forms of discrimination within the family as a result of your family member's HIV status, such as	YES	NO
Using Separate Utensils		
Using separate toilet facilities		
Isolation of person outside the house		
Other (Specify)		

75.) Are you treating your family member any differently after finding out about their HIV status?
……

76.) What are the needs of your family and people closely associated with you?
……..

77.) Do you have any suggestions to make to reduce levels of stigma and discrimination associated with HIV/AIDS? What recommendations can you make?
……...

78.) Any other comments that would assist in the study
…….

10. RESPONDENT'S NAME:		
11. PROVINCE	**12. DISTRICT:**	
13. 1. Rural **2. Urban**		
14. DIVISIONAL SECRETARIAT (DS):		
15. GRAMA NILADHARI DIVISION (GND)		
16. DATE:	**17. START TIME:**	**18. END TIME:**

THANK YOU!

Researcher's comments/analysis-

