Challenging stigma and discrimination

Sulaiman (centre) in Uganda, found that being open about his HIV status reduced stigma and discrimination.

Stigma and discrimination are daily issues for people infected and affected by HIV. Fear of stigma and associated discrimination affects, for example, whether people go for testing, whether they share their fears with family, friends or colleagues, or, if they know that they are HIV positive, if they disclose this. The stigma attached to HIV/AIDS also affects access to health services, employment, and how people thought to have HIV are treated by their community and social groups such as their church, temple or mosque.

Challenging stigma and discrimination can lead to immediate improvements in how people living with HIV/AIDS look after themselves, and the support available to them, and their access to health and other services. It also improves the lives of people who care for people with HIV, and there is some evidence to suggest that where HIV/AIDS can be talked about openly, without stigma, prevention programmes are more effective.

This issue of AIDS Action looks at what is meant by stigma and discrimination and some of the causes of the high levels of stigma and discrimination associated with HIV/AIDS. It includes examples of programmes and activities that have successfully helped challenge and overcome stigma and discrimination at an institutional level (in the workplace and health institutions) and at a social and community level.

Supporting efforts to protect human rights is another important way of reducing stigma, which also means changing discriminatory policies and legislation. This issue looks at advocacy as an important tool to bring about such change.

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Standing up to stigma

Understanding and challenging stigma and discrimination are key to HIV prevention and care efforts.

What is stigma?

Stigma means literally a mark on someone or a group of people. People who are stigmatised are looked at negatively by other people and they are often discriminated against. For instance, they may be denied the right to work, education, housing or health services. People who are associated with HIV-positive people, such as carers, family or friends may also be stigmatised. People who belong to groups that are associated with HIV, such as resource-poor migrants, sex workers, and men who have sex with men, may face stigma and discrimination because they belong to these groups. People may also internalise stigma and believe that they deserve to be discriminated against or treated badly.

Why is there so much stigma around HIV?

HIV is a chronic illness like cancer. Why should people infected or affected by HIV be stigmatised and discriminated against, while people with cancer are not? One reason may be that, early prevention programmes associated HIV with so-called ‘bad’ behaviours, including sex outside marriage and intravenous drug use, as well as with death and dying.

Effects of stigma

Stigma is a barrier to people with HIV disclosing their status and getting access to available support and care services, and to HIV prevention that encourages people to adopt safer behaviour. Associating HIV with ‘bad’ behaviour and death discourages people from finding out if they are HIV positive or, from disclosing their status if they know that they are. Stigma constantly reminds members of discriminated groups that they are social outcasts or even deserve to be punished. If people are mocked or treated with hostility, they may feel uncared for and are therefore less likely to take steps to protect themselves.

For an HIV-positive woman facing isolation, secrecy, discrimination, poverty and failing health, a support group can mean the difference between fear and shame and a positive and forward-looking approach to life. From Hope to Power, International Community of Women Living with HIV/AIDS.

Providing quality counselling involving both partners wherever possible in pre- and post-test counselling. If only one partner is tested and counselled they may be blamed for bringing HIV into the relationship.

With thanks to Tim Frasca, Corporación Chilena de Prevención del SIDA, General Jofré 179, Santiago, Chile.
E-mail: chilaids@chhps.mic.cl
Exploring attitudes and feelings

Practical activities can help people talk more openly about HIV

HIV/AIDS education often focuses on ‘giving’ people facts. But having more information about HIV is not enough to bring about changes in attitudes and behaviour. Trainers and educators are now recognising the advantages of involving people in discussions about HIV. Here are some examples of practical activities that encourage people to talk about HIV.

ACTIVITY

Digging Deeper

HIV is still rarely talked about openly. The problem of stigma is growing in communities where more people have HIV and are becoming ill with AIDS. Families, who may be already burdened by poverty, often feel despair and sadness at watching their loved ones die. They need support, but are being shunned by their community.

Aim to help community members talk about the personal impact of HIV/AIDS and to encourage them to think about their feelings towards people with HIV. Helping them to ‘dig deeper’ into their response to this issue, helps overcome people’s prejudices and fears.

Time about 30 minutes

1. Start by asking: ‘What does a person with HIV mean to you?’
2. Whatever the response to this question, the trainer must ask the question ‘Why?’ and invite different people to respond. The question ‘Why?’ is repeated after every answer, and in this way people will explore their real feelings and the problem.
3. Finally the trainer asks: ‘Is this a real problem?’ and ‘How can this problem be solved?’

Source: Starting the discussion: steps to making sex safer, Healthlink Worldwide

Understanding Feelings

Aim to explore the ways in which prejudice and discrimination affect people’s options in everyday life.

Time about one hour

1. Write down some ‘roles’ that people in your community play on separate pieces of card, for example: married woman; migrant worker; 18-year-old heterosexual man; gay man with HIV; 35-year-old drug user; sex worker; 17-year-old girl with HIV; pregnant woman; 50-year-old blind woman; middle-aged business man.
2. On a sheet of paper, write a list of activities such as: go for a job interview; travel to work; buy a plot of land; ask your sexual partner to use a condom; go to the health clinic; take your partner to meet your family; make long-term plans for you and your family; have children.
3. Ask everyone to imagine that they are the person described on their cards, and to think for a minute about what their life is like as this person.
4. Ask everyone to look at the role cards, and ask them to look at the role but not to tell anyone else what their card says.
5. Then explain that you are going to read out a list of activities, asking ‘Can you do this?’ for each. Ask everyone to take one step forward if they (in their role) can answer yes. If the answer is no, the person stays where they are.
6. Read out each statement in turn. When all the statements have been read out, everyone is likely to be standing at different distances from the starting point.
7. Starting with the person who has moved farthest, ask each group member to reveal their role and make one statement about their experience of the exercise.
8. Sit down again and discuss:
   - What were the restrictions imposed on people by their roles?
   - What factors influenced whether they stepped forward or not?
   - Did assumptions or lack of knowledge of the role, influence the decisions they made?
   - What have they learned about the effect of prejudice and discrimination?

Source: Positive Development, Healthlink Worldwide
People living with HIV or AIDS are often presented in the media as weak, hopeless victims, which exacerbates the stigma associated with HIV. However, many people with HIV live ‘positively’ with the diagnosis, by accepting it and taking control of their lives.

Christian Aid is a non-governmental organisation which supports many HIV/AIDS organisations that are empowering people with HIV to live positively. To reflect this aspect of their work, Christian Aid decided to hand over the cameras to a group of HIV-positive people so that they could speak for themselves.

Fondation Femme Plus (FFP), a women’s HIV/AIDS organisation based in Kinshasa, the Democratic Republic of Congo, was chosen as the partner organisation for this activity.

Women take control
FFP was founded in 1994 by a group of women who were HIV positive or who had close family members who were HIV positive. Confronted with the misery and the suffering of widows affected by HIV/AIDS and abandoned by their families, they decided to fight against the disease by denouncing the discrimination and marginalisation that these women faced. FFP encourages families to accept HIV-positive family members and HIV-negative people to be in solidarity with people living with HIV.

The organisation promotes understanding of HIV/AIDS through educational seminars and the media and helps people to live positively through income-generating activities, counselling and psychological support.

The project
Fifteen HIV-positive women took part in the project facilitated by PhotoVoice, a UK-based organisation. They received training in basic photography and documented their day-to-day lives over the course of a month.

The women gave many different reasons for wanting to take part in the project. These included: ‘It will reassure me that I am a useful member of society’; ‘I will be able to educate people about HIV/AIDS and teach people how AIDS can be prevented; I want to educate people with HIV how to live positively, I want to learn a new skill so that I can earn money to be able to feed my family.’

Gaining strength
The training course inspired and encouraged the women. Women who were often coming for medical help, came to life and stayed the whole three weeks without being ill. Women who had given up on their appearance started to pay attention to the way they looked again.

At the end of the course an exhibition was held at the restaurant owned by FFP. The women chose to include pictures of people caring for people with HIV, a woman’s legs covered in sores, HIV-positive women relaxing together and enjoying themselves, an HIV-positive woman selling chikwangue (a Congolese traditional meal) to make a living.

The exhibition was very well-attended including people from the print press and television, non-government organisations, the Director of Health and the general public.

The next step
The women will receive further photography training and will continue to document their experience of HIV/AIDS. Photographs will be exhibited in London and the Democratic Republic of Congo. It is hoped that the exhibition in Congo will travel so that as many people as possible will be able to see the photos. It will also include information about HIV/AIDS to reinforce the messages of the photos, imploring people to care about people with HIV and to think about their behaviour.

Thanks to Louise Orton, Christian Aid, 35-41 Lower Marsh, London SE1 7RT, UK.
E-mail: loorton@christian-aid.org

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Action in institutions

Tackling discrimination in the workplace and in health facilities helps reduce stigma and discrimination and create supportive environments for HIV-positive people.

Discrimination in the workplace and in health facilities is a daily experience for many people affected by HIV. In the workplace it can mean that people avoid promotion or changing jobs, for fear of testing. Or, they may leave work before they need to, because of discriminatory practices. Discrimination in health services can discourage people going for treatment or regular check-ups. It can also discourage health workers who think they maybe HIV positive from going for an HIV test or health workers who know they have HIV from disclosing their status.

Below are two examples of projects seeking to tackle institutional discrimination.

Working with businesses

In South Africa, recognising the need for greater involvement of people living with HIV/AIDS in managing the HIV/AIDS epidemic, has led to the development of an innovative work-based programme. GIPA is a partnership between business, labour, civil society, Government and the United Nations and people with HIV. It uses the unique expertise and experience of people living with HIV to:

- develop and implement non-discriminatory work-based policies and programmes.
- increase the understanding of the HIV/AIDS epidemic within partner organisations in order to reduce stigma and discrimination.
- establish networks and support structures for people living with HIV within partner organisations.

Organisations report that personal contact with someone living with HIV/AIDS is one of the most effective interventions, that its impact is unequalled and that support programmes substantially reduce the number of sick and absent workers.

For more information contact kmagome@un.org.za or jhill@un.org.za

After my boss heard that I had HIV my life started to fall apart. Somehow my colleagues found out. There was talk, talk and more talk. People began to call me names. Graffiti went up on the toilet walls. Eventually it was too much. I quit the job.

From The AIDS Law Project CALS, South Africa.

Health workers take a lead in the community

In 1991 in Iganga, eastern Uganda, many people with AIDS were dying miserably, without support from hospital staff, community members or even their own families. To counter this, a small group of health workers at the District Hospital set up Iganga District AIDS Care (IDAC), to make health services and social support available to people with HIV and to raise community awareness and understanding of AIDS.

Volunteers from the hospital and community were trained as HIV/AIDS counsellors. The hospital provided a room where IDAC could offer counselling and a weekly clinic for people with HIV/AIDS. The District Health Service provided transport for IDAC’s outreach work and later supported IDAC to train community AIDS workers. Each worker visited 10-15 families a month to give information and emotional support, and to help resolve problems such as stigmatisation of HIV-positive people within families.

In 1998 IDAC changed its name to ‘Integrated Development Activities and AIDS Concern (IDAAC), reflecting its expanding focus. IDAAC has raised the profile of HIV/AIDS in Iganga and Bugiri Districts and helped to reduce the stigma, fear and secrecy that previously surrounded the epidemic.

Source: Open Secret (see resources, page 8).

‘I told the hospital administration, who are my employers, about my HIV-positive status. They responded with a lot of understanding. I was put on light duties. For example, I don’t do night shifts or work that would bring me into contact with a lot of blood.’ Nurse Apofia Naikoba

Nurse Apofia Naikotu Naikoba (left) runs the family planning unit at Iganga District Hospital in Uganda. She is also HIV positive and a trained HIV/AIDS counsellor.
Positive involvement

Understanding the issues that affect the involvement of HIV-positive people in community-based organisations, leads to improved provision and participation.

People with HIV can play an important role in strengthening community-based prevention, support and care services. However in many countries such as Burkino Faso and Ecuador, few people with HIV are involved in these services. The Horizons Project (a research initiative implemented by the Population Council and its five organisations, including the International HIV/AIDS Alliance) is looking at the reasons for this, and at ways to improve the effectiveness of community-based organisations.

Background

Five community-based organisations in both Burkino Faso and Ecuador, were chosen to take part in the Horizons study. Other participants included health and social workers, people infected or affected by HIV who receive services from these organisations, relatives of members living with HIV/AIDS, health policy makers, and community leaders.

Research findings

The research found that the involvement of HIV-positive people in the design and delivery of services varies widely depending on:

whether or not the community-based organisation is a self-help organisation founded and managed by HIV-positive people themselves or a more general service provider that may or may not include HIV-positive people among its leadership.

If HIV-positive people are involved in leadership roles, organisations are more likely to identify and respond to the real needs of HIV-positive people and their families. However HIV-positive people in self-help organisations must be prepared to be 'visible' outside the organisation, which is not always easy due to high levels of stigma and discrimination.

Benefits of involvement

The study identified many potential benefits of becoming involved with community-based organisations. Most HIV-positive people report feeling less isolated and more empowered. Also when HIV-positive people are involved, community-based organisations are often better able to identify the needs of the population and to make the services they provide more effective, appropriate and meaningful. HIV-negative members may also gain a broader understanding of HIV-positive people as comrades in a common cause rather than simply service recipients.

Obstacles to involvement

In Burkino Faso and Ecuador, fear of stigma and discrimination prevents many HIV-positive people from becoming involved with community-based activities (see box). Members of several community-based organisations suggested ways to overcome this including:

- provide psychological support and education to HIV-positive people about how to respond if confronted by stigma and discrimination
- raise awareness among testing and care workers and train them so they can help HIV-positive people deal with these issues
- guarantee confidentiality to HIV-positive volunteers so they can each decide whether to disclose their sero-status
- create support groups solely for HIV-positive people to boost their confidence and protect confidentiality within community-based organisations
- sensitise HIV-negative members about their own attitudes towards people with HIV (see exercises on page 3).

Thanks to Christophe Cornu, International HIV/AIDS Alliance and Doris Herrera, Alfred Ouedraogo and Norma Velasco of the research teams in Burkina Faso and Ecuador. For more information contact the Horizons Project (see page 8 for contact details).

Barriers to involvement

- Most HIV-positive people do not even know they are infected.
- People living with HIV/AIDS fear stigmatisation and discrimination if they are seen to be involved with an HIV/AIDS-related community-based organisation.
- Many community-based organisations and non-governmental organisations do not sufficiently publicise their services or provide opportunities for HIV-positive people.
- There are few formal referral systems to link up HIV-positive people with community-based organisations.
- Voluntary work can be exhausting for HIV-positive people.
- Many community-based organisations lack training opportunities for HIV-positive people.
Bringing about change

Advocacy takes many forms, depending on the target audience and situation, but there are some basic things to think about if advocacy is to be effective.

Exploring useful local partnerships, as in this example from Latin America, can improve the effectiveness of advocacy programmes.

One way to describe advocacy is ‘pleading for or supporting’ a cause. It is about social change – about creating an environment where specific goals can be achieved. These goals can be as diverse as improving services for people living with HIV, increasing their involvement in decision-making, challenging discrimination towards people infected or affected by HIV, or promoting safer sexual behaviour.

Advocacy can take many forms, depending on the target audience and situation. Activists may use confrontation to publicise their cause and to influence others through the media. Advocacy can be a formal process such as targeted action to change laws (see box). It can also be an informal process of ‘quiet persuasion’ – the everyday business of promoting, urging, encouraging, persuading, and showing by example. For example in southern Africa, HIV-positive people are urging their communities to be more open about HIV, and women’s groups are trying to raise awareness about gender rights and equal treatment.

Planning activities
A simple framework can help identify key issues and structure formal action making it more effective.

1. Select the issue or problem you wish to address.
2. Analyze and research the issue or problem.
3. Develop specific objectives – know what you would like to achieve. Make goals as clear and as concrete as possible.
4. Identify who you want to hear your message and persuade to make changes, for example policy makers or particular individuals.
5. Identify your resources.
6. Identify your allies – people who support your cause and people who can influence change.
7. Create an action plan – outline the steps needed to achieve these goals and develop a realistic timeline.
8. Implement your action plan – assign tasks to specific people so that it is clear to everyone who is responsible for what.
9. Monitor, evaluate and adapt your plan.

Advocacy is more likely to succeed when it actively involves people living with HIV. Also, involve people affected by HIV and vulnerable groups such as sex workers or migrants when appropriate.

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E-mail: infor@icaso.org
Helping children cope

It isn’t always easy being open about HIV. I once received a letter from my daughter who was at boarding school. She was only eight at the time. Some other people had been taunting her; saying ‘Your father has AIDS’ and so on. I went to the school to talk to her about it. I said this is a problem, but how sure are you that the fathers of these children don’t have AIDS? So next time they say your Dad has AIDS, you just ask them ‘Are you sure your Dad is safe?’ So she did that and it worked. Since that time, she says, everybody is minding their own business.

Rev. Gideon Byamugisha, PO Box 14297, Kampala, Uganda

Health worker training

As part of their training, young physicians need to receive information on legal aspects of HIV. They also need to have support to look at their own attitudes to HIV, including possible stigma and discrimination they feel towards people with HIV. This will help them to provide a better quality of care for HIV-positive people.

Dr S. Kh. Sarmaneae, PO Box 143, 450071, Ufa, Russia

Industry must lead the fight

The fight against the HIV epidemic cannot be left to governments and non-governmental organisations alone. With access to marketing, organisational resources and communication technologies, and the ability to mobilise employees and in turn local communities, businesses are in the unique position to implement effective HIV/AIDS prevention programmes.

Asian Business Corporations that are partners of the Thailand Business Coalition on AIDS, recognise their responsibility to all their employees, including those with HIV/AIDS. They seek to provide equal access to accurate information, prevention methods and research on HIV/AIDS to help employees make good decisions about their health. Members are also promoting comprehensive and sustainable program development that assures all peoples and groups are treated fairly in order to foster better social responsibility.

Anthony Pramualratana, 270 Raintree Office Garden, 2nd Floor, D2 Building, Japanese School, Rama 9 Road, Bangkok 10310
E-mail: tbca@ksc.net.th

AIDS Law Project, South Africa

is an advocacy and education project that seeks to prevent discrimination against people living with HIV/AIDS and promote a culture of human rights and equity for all. Carries out litigation, offers free legal advice, undertakes research for policy formulation and produces awareness materials for lobbying and advocacy.

Contact: Mark Heywood, E-mail: heywood@low.wits.ac.za. Or visit the following website where a number of useful publications can be downloaded free: http://www.thri.ca/partners/alp

Internet resources

The worldwide directory of AIDS information and documentation centres is now available in English and French on the following website: http://www.hivnet.ch

Printed resources

E-mail: horizons@pcdc.org
Website: http://www.popcouncil.org

Open secret: People facing up to HIV and AIDS in Uganda (No. 15 in the Strategies for Hope Series) describes how in Uganda, openness about HIV and AIDS and action at all levels, has breached the wall of silence around the HIV epidemic and reduced HIV-related stigma and denial. Available for £4.50 from Teaching aids At Low Cost (TALC), PO Box 49, St Albans, Herts AL1 5TX.
Fax: +44 1727 846852
E-mail: talcuk@binternet.com
Website: www.stratshope.org

Positive development: setting up self-help groups and advocating for change is a practical manual for people living with HIV. It includes practical activities for developing advocacy skills. Single copies available to readers in developing countries (£15/US$30 elsewhere) from Healthlink Worldwide.

Protocol for the identification of discrimination against people living with HIV (UNAIDS/00.05E). Available free from UNAIDS, 20 Avenue Appia, CH-1211, Geneva 27, Switzerland. Fax: +41 22 791 4165.
E-mail: unaid@unaid.org.
Website: http://www.unaid.org

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