INTERNATIONAL NURSES DAY 2003

NURSES: FIGHTING AIDS STIGMA,
CARING FOR ALL

Information and Action Tool Kit
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Dear Colleagues,

Many of you confront the devastating reality of the HIV/AIDS pandemic each day. You routinely care for victims and struggle to maintain your strength in the face of great difficulty. We salute your courage, your expertise and your compassion.

The HIV epidemic has created a terrible burden for millions of individuals, families and communities worldwide. Relieving the suffering requires improved healthcare, better access to treatments, more vigorous prevention efforts, more effective social outreach, and support for those most vulnerable, particularly orphans.

But stigma and discrimination block the march forward against HIV/AIDS. They fuel the HIV/AIDS epidemic by creating a culture of secrecy, silence, ignorance, blame, shame and victimisation. Stigma prevents communities from addressing HIV/AIDS with the appropriate health care services or legal and educational strategies. What stops them is HIV prejudice. And all that will stop HIV prejudice is speaking openly about the facts.

Some people with AIDS are being denied basic rights such as food or shelter, and dismissed from jobs they are perfectly fit to perform. They may be shunned by their community, or most tragic of all, by their own family.

The fear of stigma leads to silence, and when it comes to fighting AIDS, silence is death. It suppresses public discussion about AIDS, and deters people from finding out whether they are infected. It can cause people -- whether a mother breastfeeding her child or a sexual partner reluctant to disclose their HIV status -- to risk transmitting HIV rather than attract suspicion that they might be infected.

But whatever laws and regulations are adopted, the most powerful weapons against stigma and silence are the voices of the world’s people speaking up about AIDS. By continuing to fight aids stigma and care for all, nurses will leading the way in breaking down the walls of stigma and silence. We hope the information, strategies and tools in this year’s IND kit will assist you in your fight against the cruelty of HIV/AIDS and the stigma imposed on its victims.

Sincerely,

Christine Hancock     Judith A. Oulton
President      Chief Executive Officer
AIDS attacks the body: Prejudice attacks the spirit. One is caused by a virus. One is caused by ignorance. Both can kill.

(New Zealand AIDS Foundation)

Introduction

More than twenty years after HIV/AIDS was first diagnosed, it continues to rouse negative reactions from individuals and communities, including fear, silence, denial, stigma, discrimination and even violence against people living with HIV/AIDS. That people already suffering from a serious illness should be subjected to rejection and hostility is cruel and deplorable. This same stigmatising attitude often means that effective prevention strategies will be blocked and access to treatment hindered, as societies and governments refuse to discuss HIV/AIDS openly or deal directly with its dreadful consequences.

The International Nurses Day (IND) kit 2003 takes on HIV/AIDS stigma, aiming to create a better understanding of its sources and presenting strategies to prevent or minimise its negative impact. ICN’s goal is to assist national nurses associations, nurses and others to raise awareness, mobilise public opinion, and organise events to fight AIDS-related stigma and discrimination. The IND activities are seen as an integral part of the overall campaign against HIV/AIDS-related stigma and discrimination in all its forms and in all settings.

- **Chapter One: Understanding Stigma**
  This chapter explains stigma and the social perceptions behind it.

- **Chapter Two: Sources of HIV/AIDS-related Stigma and Discrimination**
  Issues of sexuality, gender, race and ethnicity, socio-economic status, and fear of contagion are all addressed as sources of stigma and discrimination.

- **Chapter Three: Common Forms of Stigma and Discrimination and their Consequences**
  HIV/AIDS related stigma and discrimination are discussed within the contexts of: societies/communities, families, health care systems, workplaces and religious institutions. Marginalisation and poor treatment of individuals with HIV/AIDS can have devastating psychological, social, and economic consequences for individuals, their families and communities. Stigma can have negative effects on voluntary counselling and testing, willingness to disclose HIV status, health care-seeking behaviour, and quality of care received.
Chapter Four: Intervention Strategies to Fight Stigma and Discrimination
Ethical and human rights frameworks, evidence-based interventions, and other actions to reduce stigma and discrimination are discussed.

Annex 1 – Action! What Can You Do to Help?
Annex 2 – The PLHA-Friendly Achievement Checklist
Annex 3 – HIV Prejudice Test: Are You HIV Prejudiced?
Annex 4– Quotable Quotes: Speaking out against HIV/AIDS Stigma
Annex 5 – Sample Press Release
Annex 6 – Position Statement on Acquired Immunodeficiency Syndrome (AIDS)
“Many people suffering from AIDS and not killed by the disease itself are killed by the stigma surrounding everybody who has HIV/AIDS.” - Nelson Mandela, speech at closing ceremony, Barcelona Conference, 15 July 2002

As the HIV/AIDS epidemic continues its devastation, stigma towards those with the disease remains a pervasive problem. Stigma is an undesirable attitude that is deeply discrediting and reduces a person's status and worth in the eyes of society. Stigma can occur when four interrelated components combine in the context of social and economic power, namely:

- distinguishing and labelling differences;
- associating human differences with negative attributes;
- separating “us” from “them”;
- status loss and discrimination.

Stigma is not unique to HIV/AIDS. It has been associated with a variety of illnesses and conditions including tuberculosis, mental illness, epilepsy, physical anomalies, alcohol and drug abuse, physical and sexual abuse, race and gender. Stigma is mostly associated with disfiguring or incurable diseases and when infection is perceived to be a result of personal behaviour. It is also common in diseases that are seen to be caused by violation of social norms, such as socially sanctioned sexual activity. HIV/AIDS fits these perceptions.

The stigma associated with HIV/AIDS is based on public perceptions that people who are infected with the disease have violated a set of shared beliefs and values. Often these “violations” are linked to sex or to illegal and socially unacceptable behaviours, such as drug use. Men who are infected with HIV may be seen as homosexual, bisexual or as having sex with prostitutes. Women with HIV/AIDS may be seen as promiscuous. Society often perpetuates stigma and discrimination because of fear, ignorance or because it is convenient to blame the victim. By blaming specific individuals and groups, society attempts to justify denial of care and compassion to such groups.
Stigma – ‘felt’ and ‘enacted’

Stigma often leads to discrimination, which refers to any form of distinction, exclusion or restriction because of some personal characteristic. Discrimination against people living with HIV/AIDS (PLHA) represents a serious violation of their human rights. As a result of their negative experiences, individuals may internalise the stigma. It is, therefore, common to differentiate between the ‘felt’ stigma that refers to the shame and fear that the person perceives; and ‘enacted’ stigma, which refers to actual experiences of discrimination such as loss of a job, denial of health benefits or refusal of health insurance.

The public health community has demonstrated increasing awareness of the role of stigma in many diseases and disorders. Recent conferences have focused on the role of stigma in HIV/AIDS and the need to take action to address it. The International AIDS Conference in Durban, South Africa, in 2000 was themed *Break The Silence in HIV/AIDS*. The 2002 Conference in Barcelona, Spain was themed *Knowledge and Commitment for Action Against AIDS*. A recent discussion on stigma in health care through the Health and Development Network web site led to extensive debate on the issue.⁵

In summary, stigma and discrimination are produced by the attitudes and actions of families, communities and societies towards others perceived to have a “discrediting attribute” or an “undesirable difference”. Stigma and discrimination are social processes that are used to create social control and social inequality by creating “differences” in terms of illness or disability, class, gender, race, ethnicity, or sexuality. The following chapter will highlight the main sources of stigma and discrimination.

### Table 1: Total number of adults and children living with HIV/AIDS

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>5 million</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>New HIV infections in 2001</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults</td>
<td>4.2 million</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>2 million</td>
<td></td>
</tr>
<tr>
<td>Children &lt;15 years</td>
<td>800,000</td>
<td></td>
</tr>
<tr>
<td><strong>People living with HIV/AIDS</strong></td>
<td></td>
<td>40 million</td>
</tr>
<tr>
<td>Adults</td>
<td>37.1 million</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>18.5 million</td>
<td></td>
</tr>
<tr>
<td>Children &lt;15 years</td>
<td>3 million</td>
<td></td>
</tr>
<tr>
<td><strong>AIDS deaths in 2001</strong></td>
<td></td>
<td>3 million</td>
</tr>
<tr>
<td>Adults</td>
<td>2.4 million</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1.1 million</td>
<td></td>
</tr>
<tr>
<td>Children &lt;15 years</td>
<td>580,000</td>
<td></td>
</tr>
</tbody>
</table>

Total number of children orphaned by AIDS and living, end 2001: 14 million

AIDS-related stigma is complex and deeply ingrained (see Figure 1).

Five factors that contribute to HIV/AIDS-related stigma have been identified (*De Bruyn 1999*):

- The fear of contracting HIV.
- The association of HIV/AIDS with already stigmatised behaviours such as homosexuality, injection drug use, commercial sex work, etc.
- The fact that people living with HIV/AIDS are judged as having brought the disease on themselves.
- Religious or moral beliefs that equate HIV/AIDS with moral fault, such as promiscuity or ‘deviant sex’, that deserves punishment.

Analysis of the sources of HIV/AIDS-related stigma and discrimination shows that they are rooted in existing social and economic issues such as sexuality, gender, race and ethnicity, socio-economic status, and fear of contagion and disease.

**Sexuality**

In many societies, sexuality is defined by religious beliefs and regulated through legal, cultural, and ethical means. As a result, sexuality, particularly in women, young people, and those whose sexual orientation differs from the heterosexual norm, is often associated with promiscuity and sin. AIDS-related stigma is closely associated with sexual stigma. This is because HIV is mainly transmitted sexually and was first discovered in the homosexual community whose sexual practices are considered outside the “norm”. HIV/AIDS-related stigma and discrimination have therefore reinforced sexual stigma associated with sexually transmitted diseases, homosexuality, promiscuity, and prostitution.

**Gender**

Gender refers to the widely shared expectations and norms within a society about appropriate male and female behavior, characteristics, and roles. It is a social and cultural construct that differentiates women from men and defines the ways in which women and men interact with each other.
Gender is also used to stereotype and stigmatise people as “vectors” or transmitters of the disease. Recent UNAIDS studies in India and Uganda have shown that women may be doubly stigmatised as women and as people living with HIV/AIDS (PLHA)\(^\text{10}\). Women’s sexual behaviour is also commonly believed to be responsible for the heterosexual spread of HIV. In Brazil, for example, where surveillance data have shown high rates of HIV infection among monogamous married women, HIV-positive women are still widely perceived to be sexually promiscuous\(^\text{11}\). Equally, in many settings, men are blamed for heterosexual transmission, because of assumptions about male sexual behaviour, such as men’s preference or need for multiple sexual partners.

**Figure 1: Some determinants of HIV/AIDS – related stigma**

![Diagram showing determinants of HIV/AIDS-related stigma](image)

**Race and ethnicity**

Pre-existing racial and ethnic stigma and discrimination also interact with HIV/AIDS-related stigma. The HIV/AIDS epidemic has been characterised both by racist assumptions about “African sexuality” and by perceptions in the developing world of the West’s “immoral behaviour”. Stigma and discrimination of racial and ethnic minority groups contribute to their marginalisation, increase their vulnerability to HIV/AIDS, which in turn exacerbates stigmatisation and discrimination\(^\text{12}\). Such divisions and tensions waste resources and frustrate effective responses to prevent HIV infection.
**Socio-economic status**

The HIV/AIDS epidemic is occurring at a time of rapid globalisation and widening gaps between rich and poor. The exclusion associated with these global changes has added to social inequalities and stigmatisation of the poor, homeless, landless, and jobless. This leads to a vicious circle of poverty, which increases vulnerability to HIV/AIDS, which in turn increases poverty\(^{13}\). For example, in a study in India, hospital staff perceived the poor, slum-dwellers and the illiterate to be more likely “AIDS infected” than the rest of the population\(^{14}\). Because of such perceptions, socially and economically marginalized people are subjected to the double burden of HIV/AIDS-related stigma and discrimination.

**Fear of contagion and disease**

Fear of illness and fear of contagion are common sources of stigma and discrimination by health care providers and care givers as well as the general population. Attitudes and metaphors that equate AIDS with death, horror, punishment, shame, and “others” have added to these fears and reinforced stigma and discrimination.\(^{15}\)

Nurses and other health care providers can hold irrational or exaggerated perceptions of risk of HIV infection, as shown by the following statement from an agency nurse: “If I knew there were HIV patients in here I wouldn’t have come; and I can’t stay because I’ve got a young child at home”\(^{16}\). Fear of infection can lead health care providers to react with contempt, abuse or even refusal to care for PLHA.

As shown in the next section, stigma may be covert but discrimination manifests itself in many forms.
“Because my husband was sick, the world came to see and stare. When we used to pass in the streets, they came out to see, even made lines to stare. .... One time, my neighbour beat up their kid because he had come to my place ....”

(A woman with AIDS, Uganda)

HIV/AIDS-related stigma and discrimination are manifested in different ways at different levels: societies/communities, families, health care systems, workplaces and religious institutions.

Below are some settings where HIV/AIDS-related stigma and discrimination have been most frequently documented and where the right intervention can be effective in reducing the problem.

**Society and community**

Laws, policies, and administrative procedures often manifest stigma and discrimination under the guise public health measures necessary to protect the population. Examples of stigmatising and discriminatory laws and policies include:

- compulsory screening and testing for people seeking work permits
- compulsory notification of AIDS cases
- restrictions of the right to anonymity
- prohibition of people living with HIV/AIDS from certain occupations
- restrictions on international travel and migration
- detention or deportation of people with HIV/AIDS

Experience shows that such measures are ineffective in reducing the spread of HIV infection and only increase further stigma and discrimination, which in turn increase vulnerability and marginalisation. Such measures also create a sense of false security among populations who do not see themselves as belonging to these groups.

Other forms of societal stigma include refusal of housing, being ignored by friends and colleagues, and refusal of insurance coverage.
Family

“In my family I was the first to get AIDS. At one time during funeral rites for another person, an announcement was made that I got AIDS and that I had brought a curse to the family”

(Person living with AIDS, Uganda)

In most developing countries, the family is the primary caregiver and source of support for people living with HIV/AIDS (PLHA)\(^\text{19}\). However, negative family responses to HIV/AIDS are common and infected family members are often discriminated against within the home. There is evidence that women and non-heterosexuals are more likely to be badly treated than men or children\(^\text{20}\). Negative community and family responses to women with HIV/AIDS include blame, rejection, and loss of children and home.

Families may reject people not only because of their HIV status but also because HIV/AIDS is equated with “deviant” behaviours such as promiscuity, homosexuality, and drug use. In many cases, there is a “secondary stigmatisation” where stigma and discrimination are extended to families, friends and neighbours. Secondary stigmatisation and discrimination have played an important role in creating and reinforcing social isolation of those affected by the epidemic, such as the children and partners of people with HIV/AIDS\(^\text{21}\).

Health care systems

“That people already suffering (with HIV/AIDS), should be subjected to such indignity is intolerable and even more so when it occurs in health care institutions by health care professionals who should know better.”


“My blood was tested and from that day they refused giving me injections”

(Person living with AIDS, Bangalore, India)

Hospitals and health workers are often cited as part of the problem as the following statement from a Botswana non-governmental organisation shows: “They don’t want to look after you because they say it’s a waste of money, you are going to die after all. They don’t even call AIDS by name; they refer to it as ID [Immune Deficiency]\(^\text{22}\).

Some studies suggested that 40% to 60% of nurses and physicians would refuse care to people living with HIV/AIDS if they had the choice\(^\text{23}\). In an Indonesian study, more than 30% of respondents experienced rejection by health care workers and 15% reported their treatment was postponed because of their HIV status.\(^\text{24}\) Some examples of stigma and discrimination in health care systems include:\(^\text{25}\)
- HIV testing without consent
- rude comments
- ignoring patients’ concerns or requests
- failure to respect confidentiality by clearly identifying or labelling patients’ records, revealing sero-status to relatives without prior consent, or releasing information to the media or police
- denial of treatment and care or providing poor quality care
- early discharge and ‘dumping’ the patient on the family

A UNAIDS study in Uganda showed that health care workers tended to pay less attention to people with HIV/AIDS in the belief that it was pointless as they were going to die anyway. There was also evidence that private practitioners were charging people with HIV/AIDS more than other clients.\(^{26}\)

The stigma often extends to those who provide care or to the children orphaned by AIDS. It should be noted that stigma affects health care workers as well.

**Employment and the workplace**

“…, fellow workmates talk behind your back. …, the boss may sack you and your job is given to a healthier person…”

* (PLHA Voice, Uganda)

While HIV is not readily transmitted in workplace settings, people with HIV/AIDS have been terminated or refused employment because of a perceived risk of transmission. They are also likely to face stigmatisation and discrimination by their colleagues. For example there have been reports of employees refusing to work next to those with HIV or AIDS or those perceived to have the disease. Other discriminatory practices in the workplace include:

- pre-employment screening
- denial of employment to individuals who test positive
- termination of employment
- stigmatisation of PLHA who are open about their serostatus
- forced resignation

Few companies have developed strategies to combat stigma and discrimination or define their responsibilities toward employees with HIV.

**Religious institutions**

Religious leaders and organisations have often reinforced HIV/AIDS-related stigma and discrimination and they have done very little to challenge negative attitudes toward those living with the disease. The international symposium *Religious Health Organizations Break the Silence on HIV/AIDS*, was organised during the 13th International AIDS Conference in July 2000. There it was noted that religious doctrines, moral and ethical positions regarding sexual behaviour, sexism and homophobia, and denial of the realities of HIV/AIDS have helped
create the perception that those infected have sinned and deserve their ‘punishment’. The position of religious institutions seems to reinforce the status quo and the stigma associated with HIV/AIDS. Some religious leaders also oppose the use of condoms for safe sex. There are, however, some recent signs that the religious leadership is beginning to wake up to the realities of HIV/AIDS.

**What are the Consequences of Stigma?**

Stigma and discrimination fuel the HIV/AIDS epidemic by creating a culture of secrecy, silence, ignorance, blame, shame and victimisation. This causes increased pain and suffering and devastating social and economic consequences for the people living with HIV/AIDS (PLHA), their families and communities.

Stigma and discrimination felt by individuals are major barriers to utilising health services for prevention, diagnosis and treatment\(^{27}\). The shame associated with “felt stigma” discourages individuals from seeking voluntary counselling, testing and treatment. It also impairs their ability for self-care, to access care or to participate in research studies aimed at finding solutions. This means some people prefer not to know their HIV status for fear of loss of confidentiality and the associated risk of stigma, loss of job, break-up of relationships, social ostracism or even violence. It also means people may not take preventive measures to protect themselves and their partners from HIV infection.

“Enacted stigma” prevents societies from appropriately addressing HIV/AIDS-related issues at the community and national levels with the appropriate health care services and legal and educational strategies. Thus stigma and discrimination affect the quality of care received. (For more on “felt stigma” and “enacted stigma”, see Chapter 1.)

For some people testing for HIV is seen as futile, because they realise that they do not have access to treatment if they test HIV-positive. As a Zimbabwean participant in the Health and Development Network web discussions on stigma said, “Why should I go and get tested when I know for a fact I won’t be able to get the necessary treatment?”\(^{28}\). Even when individuals know they are HIV-positive, they may not seek counselling, testing or treatment in the clinic nearest to them for fear of stigma by the health personnel known to them – a good example of the *by-bass phenomenon*. Individuals may delay care, or seek care in distant health facilities where they can maintain their anonymity. This increases cost to the patient and to the health care system.

HIV/AIDS-related stigma and discrimination marginalize people living with HIV/AIDS and affect their ability to fulfil necessary, culturally expected and economically productive roles in society. The burden of their continued care may then fall upon families and communities with little or no resources or social support. For this reason, stigma and discrimination may greatly magnify the social, economic and personal consequences of HIV/AIDS.
Acknowledging stigma and prejudice is the first step to combating them. Fighting stigma and its effects could profoundly improve the lives of individuals with HIV/AIDS, their families and society. If treated with compassion and dignity, people living with this disease can lead fuller and more productive lives.

While it may be difficult to eliminate stigma and discrimination altogether, various interventions can reduce them.

**Ethical and human rights frameworks**

Ethical codes and human rights declarations provide broad frameworks for fighting stigma and discrimination. Professional ethical codes of conduct provide powerful guides for health care providers, based on respect for the right of people. Codes of ethics oblige health professionals to respect ethical principles, such as “doing no harm” and “doing good” to people in need of care. AIDS-related stigma and discrimination are clear violations of these codes. For example, the ICN Code of Ethics for Nurses (2000), affirms that “… *Inherent in nursing is respect for human rights, including the right to life, dignity and to be treated with respect*”. The ICN Code aims to ensure that nurses meet certain standards of professional ethical conduct.

Discrimination against people living with HIV/AIDS is a violation of their human rights. A framework based on human rights provides a means of monitoring and enforcing their rights, as well as addressing discriminatory practices. Similarly the UN Commission on Human Rights resolutions have confirmed, “*discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards*” 29.

Human rights actions to reduce effects of stigmatisation and discrimination can include:
- timely reporting of violations,
- access to hotlines,
- legal services and ombudsmen to monitor and report violations.

However, too often the human rights of people living with HIV/AIDS are violated with impunity and the measures to prevent violations are weak or non-existent.
Evidence-based interventions to reduce stigma and discrimination

This section reviews evidence-based interventions that can be used by national nurses associations, nurses and others to reduce stigma and discrimination. As summarised in Table 2, these interventions fall broadly into:

- Information based approaches
- Counselling approaches
- Coping skills acquisition
- Contact with infected and affected groups

Information based approaches

There is evidence that information and knowledge transmission about HIV/AIDS have positive effects on reducing stigma and discrimination. Information can be delivered in various forms including: advertisement, leaflets, information packs, videotape or presentation in a group or class. The information can include factual content on HIV/AIDS, its mode of transmission, and preventive measures such as condom use and safe sex. For example, a video presentation and a standardised presentation of AIDS facts given by a nurse educator to poor African American women showed that, compared to the control group, women exposed to educational intervention had a positive attitude toward PLHA soon after the interventions and after a two-month follow-up.

Similarly in Jamaica and Israel, significant increases in positive attitudes toward PLHA were achieved through information provided in peer education, lectures, pamphlets, or workshops.

Counselling approaches

Counselling can also decrease stigmatising behaviours. In counselling approaches, positive reinforcement in the form of praise and social support is provided for positive behaviours, behaviour change or maintaining safe behaviours. A combined information-based and counselling approach in Zimbabwe reduced HIV/AIDS related stigma. The same strategy increased family support and community acceptance in Uganda compared with baseline measurements.

Coping skills acquisition

A combination of information and coping skills acquisition has been shown to increase positive attitudes toward people living with HIV/AIDS. In a study of primary school children in Tanzania, teachers and health workers implemented a two-to-three-month programme consisting of AIDS-related information, small groups discussions about risk reduction and posters made by students on perceptions of HIV risk factors. Attitudes toward HIV positive people among school children at the 12-month follow-up showed significant improvement.

Another study involving physical therapy students used an information/coping
skills acquisition strategy that included a four-hour educational unit on factual information and resolving negative feelings. The strategy increased students’ knowledge, and increased positive attitudes toward those infected with HIV/AIDS and their willingness to treat them.\textsuperscript{37}

**Contact with infected or affected people**

Knowledge of or contact with affected or infected people used alone, or in combination with other approaches, seems to reduce stigma and discrimination by creating an opportunity to interact with a stigmatised group. Interactions through face-to-face conversations, hearing a testimonial from infected or affected people, or vicariously through the media help to demystify and dispel misinformation, and lead to empathy.

In a Canadian study, health professionals and people living with HIV/AIDS taught an HIV/AIDS elective class to nursing students to re-examine their attitudes, stigma and fears about the disease. The research showed that small group teaching that allows reflection and sharing of thoughts and feelings is effective in changing attitudes.\textsuperscript{38}

Another study looked at the effects of disclosure of HIV status of the well-known basketball player in the USA, Magic Johnson. The study showed that those with high stigmatising scores before had improved attitudes after the media exposure to Magic Johnson’s HIV status\textsuperscript{39}.

**Table 2: Types of Interventions**

<table>
<thead>
<tr>
<th>Type</th>
<th>Information-based Approaches</th>
<th>Coping skill acquisition</th>
<th>Counselling approaches</th>
<th>Contact with affected groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>Information or fact Based written an/or verbal communication</td>
<td>Learning a coping behaviour</td>
<td>Providing support for positive behaviour</td>
<td>Interaction with affected groups</td>
</tr>
<tr>
<td>Examples</td>
<td>- Information package - leaflet - classroom type - presentation of facts - media publicity - peer education - group discussions</td>
<td>- role play - imagery - relaxation - desensitising - scripting</td>
<td>- one-on-one counselling - support groups</td>
<td>- live testimonials - interaction with PLHA - visualisation of being a PLHA</td>
</tr>
</tbody>
</table>

Other actions to reduce stigma and discrimination

National nurses associations, nurses, policy makers and managers can initiate a number of interventions to fight stigma and discrimination wherever it happens, and to prevent it. A combination of interventions increases success. These include:

1. Creating supportive and safer workplaces

It is common to hear health workers say… “if the system does not care for me, why should I care?” A non-supportive and stressful work environment causes staff burnout and exhaustion. If health workers see that infected colleagues are stigmatised, not cared for or even terminated from employment, they will tend not to care for others, especially if it involves a risk of exposure. A caring and supportive environment will help reduce stigma and discrimination.  


National nurses associations, nurses and others have played key roles in creating “baby friendly” and “youth friendly” hospitals. Learning from these experiences, the concept of “HIV/AIDS patient-friendly” is an idea whose time has come. Preliminary work is underway in New Delhi, India, to establish hospitals that fit this category. The goal of such hospitals is to make services responsive to the needs of PLHA. Such measures include:

- ✓ policy development on matters such as pre-and post-test counselling
- ✓ confidentiality
- ✓ the importance of informed consent

Other measures to attune hospitals to the needs of HIV/AIDS patients include staff education and training, and strengthening universal precautions.


3. Training health care providers

At the beginning of the HIV/AIDS epidemic when stigma and fear and uncertainty were even more rampant, ICN and the World Health Organization (WHO) organised a two-year regional training-of-trainers project in eight African countries to mobilise nurses for AIDS prevention and care. As a result of their training in the project, nurses implemented changes in practice that improved contact with patients, increased use of universal precautions, and improved nursing outreach services in the community. Nurses felt increased confidence to work effectively in HIV/AIDS care and prevention.
Creative approaches such as role-playing, the use of puppets, drama and story telling are effective in dealing with taboo subjects such as sexuality, HIV/AIDS, stigma and other sensitive issues. Similarly, using people infected with or affected by HIV/AIDS as facilitators and teachers of health professionals can “humanise” the disease and communicate the reality of those living with AIDS.

4. Providing mentorship

Mentorship of students and junior staff where senior doctors and nurses serve as peer and role models should aim to foster stigma free health services and promote care with dignity and confidentiality.

5. Breaking the conspiracy of silence and secrecy

We need to demystify HIV/AIDS to the ranks of other chronic conditions and create an atmosphere of openness with confidentiality. Health care providers can normalise the health care environment through open discussions of HIV/AIDS with patients, in staff meetings, through health education and public meetings. We must promote disclosure of results to significant others while protecting confidentiality at the client, care provider and hospital management levels.

Another important strategy is to work with health professional associations and specialist groups in AIDS care.

6. Supporting general and specialist professional associations in AIDS care

The potential of health profession associations and their millions of members remains untapped. If properly mobilised, they can be a formidable force in fighting stigma and discrimination and in improving quality care. At present there are nursing/medical HIV/AIDS specialist groups in several countries and regions. These associations advance knowledge and understanding of HIV/AIDS nursing. A peer approach to disseminating validated knowledge and a forum for discussions are helpful in ensuring accountability, exploding myths and reducing stigma.

7. Providing adequate supplies and protective equipment

While the practice of universal or standard precautions should be the backbone of infection control, it is important that health care providers have sufficient supplies and equipment, especially when invasive procedures are involved or when risk of significant exposure to blood and other body fluids is likely. At the same time we must teach proper use of resources and supplies so that protective materials such as gloves and gowns are not used for routine and low risk procedures.
8. **Increasing access to post-exposure care and treatment**

It is noteworthy that health care providers are themselves stigmatised for their HIV/AIDS caring role, and if they are infected with HIV. The current global lobby for increased access to AntiretroViral Therapy (ARV) should equally apply to health care professionals, including access to post-exposure prophylaxis and treatment regardless of how these infections might have been acquired.

9. **Developing guidelines and policies**

Most health care systems lack clear guidelines and policies on various aspects of HIV/AIDS care. Where guidelines do exist, too often there is little effort to disseminate them to all levels of health workers. Development of a clear hospital policy on management of HIV-positive clients, reporting of adverse events such as needlestick injuries, and post exposure counselling and prophylaxis is required. A participatory approach to developing work plans and disseminating policies for implementation at the ward level would foster a team approach and accountability.

10. **Building on significant recent HIV/AIDS global events**

There is a growing focus on HIV/AIDS events such as the UN Security Council special session on AIDS, the UN Millennium Summit that affirmed AIDS as the most pressing problem worldwide, the African Summit on HIV/AIDS and TB, and the UN General Assembly Special Session on HIV/AIDS. Also, the Global Fund to Fight AIDS, TB and Malaria is a worldwide effort to mobilise resources for these diseases.

These events have highlighted the seriousness and importance of combating stigma. There is a groundswell of interest and good will, but we need commitment and action. We need to sustain the momentum with policy makers, health authorities, health professionals and the media. We must sensitise all levels of government, communities and health care workers to address issues of stigma and discrimination.
Conclusion

HIV/AIDS-related stigma and discrimination challenge us all. We cannot succeed unless our care and treatment involve dignity and compassion. Interventions to address stigma will only work if effective partnerships are built between governments, health care professionals and civil society, and with the active involvement of people infected and affected with HIV/AIDS. The international Council of Nurses (ICN) in its 2001 International Nurses' Day theme promoted the idea of "zero tolerance" for violence. We need to show the same level of intolerance to stigma and discrimination against people living with HIV/AIDS. As Dr. Peter Piot, Executive Director, UNAIDS, stated at the opening session of Barcelona AIDS Conference, “this is non-negotiable".
TOOL KIT FOR FIGHTING STIGMA
Annex 1

Action!
What Can You Do to Help?

Here are some concrete actions you can take in your own health care facility and community to raise awareness of HIV/AIDS stigma and discrimination.

In the health care facility

1. Use the PLHA-friendly hospital checklist in your own facility. Also distribute it among colleagues.
2. Take the “Are you HIV prejudiced?” questionnaire and distribute among colleagues.
3. Facilitate informal staff gatherings/discussions to share experiences in living and working with HIV/AIDS.
4. Use the ICN Position Statement on Acquired Immunodeficiency Syndrome included in this kit to inform discussions and initiatives.

In the community

1. Create a press release from the sample provided in this kit, and send to local media.
2. Send the “Are you HIV prejudiced?” questionnaire to media and local authorities with a cover letter explaining the initiative. For example, you may stress that we are all responsible for HIV/AIDS related stigma and discrimination. We as a community need to address our own stigmatising behaviours and fears. This small questionnaire can help each of us assess our own level of prejudice and raise our awareness of the problem.
3. Use the “Are you HIV prejudiced?” questionnaire and cover letter as a community handout.
4. Send the PLHA-friendly hospitals checklist to the local media with a cover letter.
5. Find success stories to share. For example, highlight people who are successfully living and working with HIV/AIDS.
6. Bring together groups in the community to discuss how serious stigma and discrimination are in their environment. Does anyone need help?
### Annex 2

#### Use this checklist to assess your facility

**THE PLHA-FRIENDLY ACHIEVEMENT CHECKLIST**

* A Self-Assessment Tool for Hospitals and Other Medical Institutions Caring for People Living With HIV/AIDS (PLHA).
* Jointly developed for the study “Improving Hospital Environment for HIV-Positive Clients in India” by: Population Council/Horizons (New Delhi and Washington, DC). SHARAN: Society for Service to Urban Poverty (New Delhi)

**Purpose of the Checklist:** The PLHA-Friendly Achievement Checklist is intended as a self-assessment tool for managers to use in assessing how well their institution (hospital, clinic, department) reaches, serves and treats HIV-positive patients.

**How to use the Checklist:** This current version of the checklist does not include a scoring system. It is simply a list of items that can be checked off as “true” or “not true.” The more items that are “true” for a given institution, the more “PLHA-friendly” it is. Division of Checklist items into domains and sub-domains, allows the user to pinpoint areas of strength and weaknesses. For example, one might find that their institution has excellent policies on counseling and testing, but that practices, training, and mechanisms to enforce these are lacking. Or one might find that their institution is providing excellent access to care for PLHA, but is not doing enough to protect their confidentiality.

**ACCESS TO CARE SERVICES**

**Practice**
- Care for PLHA (or patients awaiting results of an HIV test) is not denied, delayed or referred elsewhere for services available within the facility.
- Care for PLHA is of the same quality as the care provided to other patients. PLHA are not segregated or isolated.
- The hospital actively links PLHA to sources of ongoing palliative care and social support in their own communities.

**Training**
- All staff are trained in patients’ rights and the right of PLHA to equal care and confidentiality.
Quality Assurance
- An accessible patient grievance cell, which registers and addresses patient complaints, is in place and open daily.
- The existence of the grievance cell is posted in each ward and in all patient waiting areas.

Policy
- Hospital policy guarantees all of the above.
- Hospital policy on access and right to care is posted in all departments and patient waiting areas.

TESTING AND COUNSELING

Practice
- All HIV-tests are voluntary.
- All HIV-tests are accompanied by informed consent.
- All HIV-tests are accompanied by pre-test Counseling by a trained counselor.
- All test results are communicated to the patient during post-test counseling by a trained counselor.

Training
- All treating HCWs are trained in principles and procedures of voluntary testing and counseling.
- HIV-test counselors are trained and receive on-going refresher training.

Quality Assurance
- A committee is in place that ensures that the above procedures and training are in place.

Policy
- Hospital policy guarantees all of the above.
- Hospital policy on testing and counseling is posted in all departments and patient waiting areas.

CONFIDENTIALITY

Practice
- Information about HIV-status is communicated only to the patient and treating HCWs and is otherwise kept confidential.
- Information about HIV-status is never disclosed to the patient's family or friends, except with the explicit informed consent of the patient.
- PLHA beds, wards and files are not labeled in ways that would convey HIV status to other patients or staff.
Training
☐ All health care workers are trained in the principles of and patients’ rights to confidentiality.

Quality Assurance
☐ A committee is in place that monitors the management of information system to ensure that is adequately protects confidentiality.

Policy
☐ Hospital policy guarantees all of the above.
☐ Hospital policy on confidentiality is posted in all departments and patient waiting areas.

INFECTION CONTROL

Practice
☐ Universal precautions are practiced, in the same manner, with all patients at all times.
☐ Sound waste management is practiced at all times by all staff.
☐ All staff are informed about and provided with free Hepatitis vaccines and, if required, post-exposure prophylaxis (PEP).

Training
☐ All staff are trained in basics of HIV and Hepatitis transmission and prevention, infection control, including universal precautions, waste management and PEP.

Quality Assurance
☐ Essential supplies for universal precautions, infection control, and PEP are available at all times to all staff for universal precautions.
☐ An infection control team is in place and meets regularly (once a month or more) to monitor infection control practices and supplies.
☐ Information, education and communication (IEC) materials on infection control procedures are posted in all wards and staff areas.

Policy
☐ Hospital policy guarantees all of the above.
☐ Hospital policy guarantees a safe working environment for all HCWs.
☐ Hospital policy on infection control and staff safety is posted in all departments and patient waiting areas.
QUALITY OF CARE

Practice
- PLHA are provided the highest available standard of clinical management and care.
- Pregnant women are offered, though not compelled to accept, HIV testing, PMTCT (ARV treatment to reduce likelihood of mother-to-child transmission of HIV during delivery), and advice on infant feeding.
- Testing of pregnant women is voluntary, confidential and accompanied by pre- and post-test counseling.
- PLHA are offered or referred to advice about nutrition and health-promoting lifestyles.

Training
- Clinical staff are regularly trained and re-trained in case management of HIV/AIDS.

Quality Assurance
- ARVs and/or essential drugs for reducing mother-to-child transmission and treating opportunistic infections (O.I.s) are consistently stocked and administered.
- A team is in place to oversee care for PLHA and to track advances in clinical management of HIV/AIDS.
- Guidelines for HIV/AIDS case management are available in each department.

Policy
- A policy is in place that guarantees all of the above.
- The policy is posted in all departments and patient waiting areas.

For more information, please contact: Laelia Gilborn (lgilborn@pcdc.org) or Vaishali Sharma Mahendra (vmahendra@pcindia.org) of the Population Council, Horizons program.
**HIV Prejudice Test: Are You HIV Prejudiced?**

The acknowledgement of prejudice is the first step towards its eradication.

The following statements are helpful in assessing people’s attitude towards people living with HIV/AIDS.

I would feel comfortable living next door to somebody who is HIV positive or has AIDS.

Agree ☐ Disagree ☐

If I was introduced to someone at work who I knew was living with HIV or who has AIDS, I would feel comfortable to greet them with a handshake.

Agree ☐ Disagree ☐

People who are HIV positive only have themselves to blame.

Agree ☐ Disagree ☐

People who are living with HIV are treated like second-class citizens.

Agree ☐ Disagree ☐

Now answer these questions

1. Would your responses change if you knew you can not contract HIV by working, socialising, shaking hands or living next to someone with HIV?

2. Would you feel more comfortable if you knew that HIV can only be contracted during unprotected sex; by sharing HIV infected needles; in the womb, during birth or whilst breast feeding and from contaminated blood?

3. Would you be friendlier if you knew how much loneliness and isolation HIV prejudice can cause? And that fear of becoming stigmatised prevents people vulnerable to HIV infection from accessing testing and treatment services?

4. Would you be more understanding if you knew that thanks to new treatments, it is possible for people who are HIV positive to lead full and active lives?

All that stops them is HIV prejudice. And all that will stop HIV prejudice is the facts.

*(Adapted from a questionnaire disseminated by the National AIDS Trust, at Barcelona AIDS Conference, July 2002)*

For more information about this campaign, contact National AIDS Trust, New City Cloisters, 196 Old Street, London EC1V 9FR, UK. E-mail: info@nat.org.uk. Web site: www.nat.org.uk or http://www.areyouhivprejudiced.org.
Quotable Quotes:
Speaking out against HIV/AIDS Stigma

The following quotes can be useful for speeches, press releases, or other publicity materials.

1. Many people suffering from AIDS and not killed by the disease itself are killed by the stigma surrounding everybody who has HIV/AIDS.
   (Nelson Mandela, at closing ceremony of Barcelona Conference, 15 July 2002)

2. As people with HIV are living longer and healthier lives, it is vital that they live without the fear of discrimination.
   (Derek Bodell, AIDS Trust)

3. AIDS attacks the body: Prejudice attacks the spirit. One is caused by a virus. One is caused by ignorance. Both can kill.
   (New Zealand AIDS Foundation)

4. AIDS does not discriminate. Any one can get AIDS from sexual contact or sharing needles with a non-infected person.
   (New York State Department of Health)

5. Derek lost his entire family to AIDS. One year later they are still not talking to him.
   (London Lighthouse, UK)

6. Discrimination against people living with AIDS contradicts scripture.
   (AIDS-Hilfe Schweiz (AHS) Switzerland)

7. The stigma associated with HIV/AIDS is particularly damaging and often impacts upon the poorest and most vulnerable individuals and groups in society, many of whom are already disadvantaged and discriminated against on other grounds.
   (Professor Courtenay Batholomew, Trinidad Express, 23 September 2002. Stigma and Hypocrisy)

8. Since Father died, I have no clothing and food. Neighbours mistreat me. They chase me away at meal times. I go back home telling my Mother that they have sent me away so I can’t eat.
SAMPLE PRESS RELEASE
Stigma, Discrimination and the Conspiracy of Silence are Fuelling the AIDS Epidemic

ICN calls on governments, religious institutions and civil society leaders everywhere to replace silence, fear and blame with solidarity and hope

Geneva, 12 May 2003 — Stigma and discrimination fuel the HIV/AIDS epidemic by creating a culture of secrecy, silence, ignorance, blame, shame and victimisation, says the International Council of Nurses (ICN). “Stigma prevents societies from addressing HIV/AIDS with the appropriate health care services, legal and educational strategies,” declared ICN president Christine Hancock. “What stops them is HIV prejudice. And all that will stop HIV prejudice is speaking openly about the facts. It is past time for governments, civil society leaders and religious institutions to end the conspiracy of silence and shame surrounding HIV/AIDS.”

Stigma and discrimination are major barriers to utilising health services for prevention, diagnosis and treatment. The shame associated with HIV/AIDS discourages individuals from seeking voluntary counselling, testing and treatment and blocks prevention efforts. It also impairs their ability to access care, to manage appropriate self-care or to participate in research studies aimed at finding solutions. Many people prefer not to know their HIV status for fear of loss of confidentiality and the associated risk of stigma, loss of job, break-up of relationships, social ostracism or even violence. It also means people may not take preventive measures to protect themselves and their partners from HIV infection. Fear of becoming stigmatised prevents people vulnerable to HIV infection from accessing testing and treatment services.

All sectors of society

Stigma directly affects the capacity of governments to respond effectively to the devastation of the HIV/AIDS epidemic. The fears and taboos surrounding the disease translate into silence and inaction, despite the catastrophic consequences for individuals and societies. Opportunities for prevention are missed, care and treatment remain inaccessible and the toll of death and misery climbs.

1 www.unaids.org
Though health care providers worldwide show great compassion and courage daily in caring for people living with HIV/AIDS, unfortunately they too can be perpetrators of stigma and discrimination. A non-supportive and stressful work environment causes staff burnout and exhaustion. If health workers see that infected colleagues are stigmatised, not cared for or even terminated from employment, they will tend not to care for others, especially if it involves a risk of exposure. A caring and supportive environment attentive to universal precautions will help reduce stigma and discrimination.

Religious organisations have done very little to challenge negative attitudes toward those living with the disease. The international symposium Religious Health Organizations Break the Silence on HIV/AIDS, was organised during the 13th International AIDS Conference in July 2000. There it was noted that religious doctrines, moral and ethical positions regarding sexual behaviour, sexism and homophobia, and denial of the realities of HIV/AIDS have helped create the perception that those infected have sinned and deserve their ‘punishment’.

Countering Stigma

The battle against stigma has many fronts, but begins with acknowledging the terrible power and pervasiveness of HIV/AIDS stigma and prejudice.

Efforts must be put into education to encourage better understanding of AIDS and the HIV virus. Understanding and support for people living with HIV/AIDS must be promoted and their contribution to policy and programmes be encouraged. Supportive policies and legal constraints must be fought for. Discrimination against people living with HIV/AIDS is a violation of their human rights. A framework based on human rights provides a means of monitoring and enforcing their rights, as well as addressing discriminatory practices.

HIV/AIDS-related stigma and discrimination challenge everyone. Interventions to address stigma will only work if effective partnerships are built between governments, health care professionals and civil society, and with the active involvement of people infected and affected with HIV/AIDS.

The International Council of Nurses is a federation of more than national nurses’ associations representing the millions of nurses worldwide. Operated by nurses for nurses, ICN is the international voice of nursing and works to ensure quality care for all and sound health policies globally.

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Annex 6

Acquired Immunodeficiency Syndrome (AIDS)

ICN Position:

ICN deplores the stigma and marginalisation of people living with HIV/AIDS and the disastrous social and health consequences of this stigma, and calls for competent, compassionate care.

National nurses associations, employers and nurses have a responsibility to:
- Ensure all health care providers have access to up-to-date information about HIV/AIDS, its mode of transmission, prevention, counselling and guidelines for safe practice.
- Ensure that nurses are competent to provide care and counselling to patients and health care providers. This includes knowledge of universal precautions and acceptance of their ethical and moral duty to care for people living with HIV/AIDS.
- Secure a safe environment, including protective equipment and materials, that permits adequate care to people living with HIV/AIDS and ensures protection of nursing personnel from exposure to HIV as well as other blood borne diseases such as hepatitis B and C.
- Lobby governments and others, including drug manufacturers, to make antiretroviral therapy (ART) accessible to people living with HIV/AIDS.

Background

Acquired Immunodeficiency Syndrome (AIDS) is a global public health threat that continues to increase the burden of disease. World-wide there are over 36 million people living with HIV/AIDS and this number continues to increase. ICN is particularly concerned about the growing prevalence of HIV infection in women, young people and other vulnerable populations. Lack of access to services, low socio-economic status and societal values that tolerate violence, sexual abuse and other violations of women’s rights continue to fuel the epidemic in women.

Irrational and discriminatory treatment of people living with HIV/AIDS continues to be reported in many countries, with violations of their rights to employment, housing, education and even health and nursing care.

Maintaining the quality of life of people with HIV/AIDS is possible mainly through extensive, competent and compassionate nursing care. Yet, the
provision of care for persons living with HIV/AIDS is raising health and occupational concerns for nurses and other health care workers. Furthermore, nurses need to examine their own personal attitudes and stereotypes toward people living with HIV/AIDS as these can compromise compassionate care.

Due to economic difficulties, countries may be unable to allocate appropriate resources for care of people living with HIV/AIDS. Thus, health services in these countries lack the proper facilities, personal protective equipment, and other materials to care for people living with HIV/AIDS. The use of antiretroviral therapy (ART) has greatly improved the health and quality of life of people living with HIV/AIDS. However their high cost has made them inaccessible to many, especially in developing countries.

HIV/AIDS has been declared a serious threat to national security and to economic development.

ICN urges member national nurses' associations to:

- Actively participate in sensitising and educating the public about HIV/AIDS.
- Take measures to combat violence against women including rape, sexual abuse, child prostitution and trafficking.
- Work to protect the basic human rights of people living with HIV/AIDS, their families, the public and nurses who care for those living with HIV/AIDS.

Adopted in 1989
Revised in 2001

Related ICN Positions:
- Reducing environmental and lifestyle-related health hazards
- Nurses and Human Rights
- Reducing travel related communicable disease transmission
- Occupational health and safety for nurses
- Impact of HIV/AIDS on nursing/ midwifery personnel
- Socio-economic welfare of nurses

The International Council of Nurses is a federation of more than 120 national nurses’ associations representing the millions of nurses worldwide. Operated by nurses for nurses, ICN is the international voice of nursing and works to ensure quality care for all and sound health policies globally.
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