



Indira Gandhi National Open University
School of Social Work

MSWE-001
HIV/AIDS: STIGMA,
DISCRIMINATION AND
PREVENTION

**Understanding and Responding to
Stigma and Discrimination**

4



MSWE-001
HIV/AIDS: Stigma,
Discrimination and
Prevention

Block

4

UNDERSTANDING AND RESPONDING TO STIGMA AND DISCRIMINATION

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August, 2009

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ISBN: ISBN: 978-81-266-4195-6

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Printed and published on behalf of the Indira Gandhi National Open University, New Delhi, by Director, School of Social Work.

Laser typeset by Nath Graphics, 1/21, Sarvapriya Vihar, New Delhi-110 016.

Printed at :

BLOCK INTRODUCTION

The worldwide HIV/AIDS pandemic represents an intersection of medical and social problems virtually unique in modern history. The resulting convergence of challenges begins with the impact of the virus on the human body, best addressed by the objectivity of biological and medical science. Towards that end, medical providers have been assisted by researchers, epidemiologists, and public health educators in a host of governmental and non-governmental capacities.

Striving to understand how, where, and among whom the virus spreads, they have turned their attention to raising public awareness of risks associated with HIV, educating on methods of preventing viral transmission, encouraging testing, and maintaining systems needed for post-test counseling and partner notification. Virtual armies of professionals and volunteers have focused attention on improving access to barriers, educating those at risk regarding abstinence, safer sex, and harm reduction associated with injection drug use. They have facilitated women's increased control over sexual exposure through development of microbicides, and tirelessly pursued the development of effective vaccines. Working together with pharmaceutical industries and government, they have greatly increased medical options for treating HIV-related disease, and advanced the distribution and availability of medications worldwide.

Still, we are faced with a seemingly relentless global health crisis. How, in the context of all this effort and remarkable progress, do we explain the alarming durability of the virus, and our inability to conquer it once and for all? In Block 4, we will consider the frightening implications of stigma and discrimination as all-too-human obstacles to ultimate success. Ironically, we will see that the personal and social attitudes shaping the response to HIV/AIDS have roots nearly as deep, though fortunately not quite as mysterious, as the virus itself. And in this context, AIDS will emerge, as some have labeled it, as the "great teacher" (Archibald, 1997, p. 12), weaving medical, behavioral, economic, moral, ethical and spiritual threads into a common cloth with the potential to help us better understand the complexities of human existence.

In the units that follow, we will establish a common language for describing the personal and social responses to HIV/AIDS that have so powerfully shaped global efforts to date. Grounding them in theory, we will consider how they manifest through religious, communal, and political practices, and are reinforced, intentionally and unintentionally by individuals and institutions which otherwise would have seemingly little in common. In the process, we will see how certain of these attitudes cut across cultural differences, though the particulars of their expressions may vary. And, we will see that much good work has been done, and much more can be done, to deepen our understanding of the human side of a persistent viral pandemic.

Social workers have many important roles to play in responding to HIV/AIDS. None may be greater than rising to the responsibility of becoming more aware of our own contribution to the problem, then dedicating ourselves to removing yet another obstacle in the fight against this dreadful disease.

UNIT 1 THEORIES AND MODELS OF STIGMA AND DISCRIMINATION

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Prof. Neil Abell*

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1.0 OBJECTIVES

Although stigma and discrimination did not originate in the context of HIV/AIDS, their influences on our understanding of and response to the virus are extensive. In this unit, the learner will:

- learn how stigma and discrimination have been defined in the social science literature in the West,
- understand how they arise and are sustained in social and psychological contexts,
- appreciate the implications of stigma for health care and social service delivery, and
- learn how they have been prioritized in the international responses to the HIV/AIDS pandemic.

1.1 INTRODUCTION

Stigma and discrimination are multi-layered responses concerning differences among people. In the context of mental and physical illness, they shape the understanding of such conditions by those who are diagnosed, their family members and communities, and the professionals attempting to meet their needs. Many influences impact the experience and expression of stigma, ranging from the nature of the illness itself to the characteristics of those who bear it and the social and cultural contexts in which they find themselves. Political, economic, social, and religious factors add to the complexity of assigning meaning to mental and physical illness, and nowhere are these more potent than among those dealing with HIV/AIDS.

In this unit, we will overview core constructs and definitions, identify primary theories and variables influencing our understanding. We shall also consider the moral and ethical implications of interpreting illness not simply as a physical condition, but as a broad statement about the deservingness and character of the afflicted. As we will see, the roots of these reactions to conditions we fear and are tempted to judge run deep. Seeing this clearly is the essential first step in moving from reactivity to intentional action, as we serve those infected with and affected by HIV/AIDS.

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1.2 CORE CONSTRUCTS AND DEFINITIONS

In modern social science, stigma was first described by Erving Goffman in the context of mental illness, physical deformities, and other socially deviant behaviors (Goffman, 1963). He defines *stigma* as “an attribute that is deeply discrediting” resulting in reducing the targeted person “from a whole and usual person to a tainted, discounted one” (USAID, 2005). Phrased in this way, the attribute triggering this association may be a diagnosis of mental illness (i.e. schizophrenia), or behaviours viewed as unacceptable based on the conventional social norms (i.e. commercial sex work or injection drug use). The process of devaluing persons carrying these characteristics is known as *stigmatizing*.

Taken a step further, *discrimination* is “unfair or unjust treatment of an individual based on his or her real or perceived status” (UNAIDS, 2003). This underscores the fact that the individual may not actually have the characteristic in question, but merely be *assumed* by others, to have it. Consequently, beliefs about another, *whether they are true or not*, may be enough to trigger treatment, putting their fundamental human rights at risk, and compromising them politically, economically, socially, or psychologically. Discrimination can manifest as *shaming* others for their condition (whether or not they can control it), or *blaming* them for having the condition in the first place (assuming they could have behaved in ways that would have prevented it).

Gregory Herek summarized how this process might be applied to persons infected with or affected by HIV, defining AIDS-related stigma as “prejudice, discounting, discrediting, or discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated” (Herek, 1999). Noting that such discrimination could manifest as personal rejection or even violence, he identified four characteristics associated with HIV/AIDS that were likely to evoke stigma. These included:

The assumption that those infected with HIV, bore the sole responsibility for their illness (i.e., they could have avoided it).

HIV/AIDS is an illness that is unalterable, and generally degenerative. Although the quality of life continues to improve with advances in medical treatment and distribution of antiretroviral medications, HIV-related illness remains incurable, and is viewed by the general public to be fatal.

HIV is a condition that is contagious, and with the potential to cause harm to others in ways that are not clearly understood by them. Decades of prevention education and HIV/AIDS awareness campaigns have not eliminated widespread belief in myths or misunderstandings regarding how HIV is transmitted, or skepticism about the effectiveness of barrier methods or various universal precautions as tools for prevention.

Finally, HIV/AIDS can disrupt social relations and may be viewed by others as “repellant, ugly, or upsetting” (Herek, 1999). While HIV-related disease may remain hidden from view for many years, in its advanced stages, it causes PLHA to appear notably ill, weak, losing their stamina, and triggering distress in others.

Varying Presentations

Stigma and discrimination appear in varying forms, and are associated with a range of motivations representing differing aspects of fear. Shaming and blaming are very

common. While these and other motivations are not unique to HIV/AIDS, they will be illustrated throughout this Block largely in that context.

Ann Jacoby distinguished experienced stigma versus expressed stigma, associated with the “undesired differentness” (Goffman, 1963, in Jacoby, 1994, p. 269) of people with epilepsy. Adapted to the context of HIV/AIDS, this guide us in differentiating processes that are *felt* versus *enacted*. *Felt* stigma is (or at least, by the perpetrator, is thought to be) held within; experienced as an emotional reaction to or cognitive judgment about the person thought to be HIV+, but not revealed directly through words or actions. *Enacted* stigma, on the other hand, is directly expressed. Perpetrators may or may not be aware of it, but someone observing their actions or “body language”, or listening to their words, would see or hear discrimination being expressed towards another.

The relation between the felt and enacted stigma and discrimination, and the potential disconnect between what we think we are saying or doing, and what others perceive in the context of HIV/AIDS, is crucial. Just as stigma may be attributed to others based on perceptions (rather than realities) of how they actually are, social workers may be viewed as stigmatizing others whether or not they are aware of it or see themselves as doing so. People with good reason to believe they are “marked” for unfair or unjust treatment (as if PLHAs), are likely to be very sensitive to the least suggestion that they are being thought of or treated differently, and react accordingly. While we need not “take the blame” for things we have not done, being aware of the high likelihood of PLHAs being mistreated by others, can heighten our resolve to make sure we are not adding to the problem, on purpose or otherwise.

The notion of *internalized* stigma (sometimes called *self-stigma*), is an additional twist on these dynamics. In such cases, “stigmatized individuals or groups may accept that they ‘deserve’ to be treated poorly and unequally” (USAID, 2005). Unfortunately, this is partly the result of “successful” shaming and blaming, wherein PLHAs conclude, based on accumulated social and institutional pressures, and value judgments, that they are in fact responsible for their condition, and could or should have done something to prevent it. We shall return to this notion as an issue for public health ethics later below. For now, it is important to note that while internalized shame and blame can sometimes motivate positive change, it can just as likely inhibit PLHA from believing they deserve to be treated well, and restrict them from seeking services or meeting their needs.

Finally, Herek (1999) specifies two components of HIV/AIDS stigma that may worry those who interact with PLHA. The first of these is *instrumental* stigma - the fear that we might contract the virus from someone who is HIV+. Social workers, family members, and friends, or members of the wider community may be concerned about the risk of becoming HIV+, simply through casual contact with PLHA. Sexual partners, injection drug users and their partners may have objective concerns that interacting with the PLHAs would increase their risk of becoming HIV+. In contrast, *symbolic* stigma arises from the social meanings attached to HIV/AIDS, and has the fear that if others know that the individual had contact with PLHA (in professional or informal ways), they will be treated with the same judgments and discrimination directed towards PLHA. Whether we are concerned about “catching” the virus, or being treated as if HIV+, or both, these two forms of stigma would shape our interactions with PLHAs, in powerful ways.

Check Your Progress I

Note: a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

- 1) Stigma and discrimination are sometimes experienced privately, and other times communicated openly. Name the two types of stigma associated with these differences, and briefly illustrate how they might appear in a PLHA experiencing internalized stigma.

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- 2) Considering Herek’s observations on the aspects of HIV/AIDS that may trigger stigma and discrimination, why might social workers serving PLHAs experience instrumental- or symbolic stigma, even though they have been educated correctly about “the facts”?

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1.3 THEORETICAL FOUNDATIONS: SOCIAL PSYCHOLOGY AND EXPANDED SOCIOLOGICAL VIEWS

Various other notions regarding stigma can be usefully framed in social psychological terms, in order to help deconstruct the process, and hopefully make it easier in understanding and addressing the same. Link and Phelan’s (2001) original work, later adapted with associates (Link, Yang, Phelan, & Collins, 2004; Yang, Kleinman, Link, Phelan, Lee, & Good, 2007), provides us a strong, primary, theoretical framework.

In the most basic formulation, Link and Phelan (2001) describe social psychological processes illustrating a sequence of steps in stigmatising and discriminating. Each of these steps, require a *perpetrator* (the person engaged in judging or acting), and a *target* (the person being so judged or treated). In the instance of *internalized* stigma, these two roles are both enacted by the targets, who takes on external views held in the larger society, and carries them as negative self-judgments within.

People can only be successfully stigmatised if they lack power - social, economic, or political - in comparison to the perpetrator (Link & Phelan, 2001). Jonathan Mann, the founding director of the World Health Organization’s Global Programme on AIDS, insisted that “in each society, those people who before HIV/AIDS arrived were marginalized, stigmatized, and discriminated against, become those at highest risk of HIV infection....” (Shoofs, 1998). In other words, those who are already looked down upon by society, are at greatest risk of infection. And, once infected, they are at even further risk of being cast out.

The first step in the stigma process is *labeling*. This includes using names for others, that are deeply discrediting and reduce them from a human whole, to a tainted or discounted one. Calling someone who uses injection drugs a “junkie”, or someone who is sexually attracted to others of the same gender a “pervert,” strips them of their other roles and functions (i.e. father, mother, employee), and strongly identifies them with something considered outside the social norm.

The second step in the process is *stereotyping*. It implies overlaying co-existing judgments about others, assuming that the labels assigned to them carry associations with other personal attributes (i.e. immorality or promiscuity), which further discount or discredit them. Stereotypes sometimes originate in observations (i.e., noticing that someone is unfaithful to a spouse or partner), but ultimately aim to create a broadly negative impression of the person being targeted. If someone was already marginalised because of sexual orientation, poverty, or social class, becoming HIV positive only exaggerates the negatives, in the eyes of the others. As the list of negative impressions regarding the other grows, it becomes much easier, to justify thinking harshly about them. Thus, they become increasingly more likely to be mistakenly associated with them.

These two processes lead to the third step, that is the creation of outgroups, thereby *separating* “us” from “them”. In this process, perpetrators attempt to reinforce the distinctions between themselves (“us” - people, who are not negatively labelled or stereotyped) and others (“them” - people, who are labelled or stereotyped), in order to create a sense of distance and safety. During this stage, perpetrators may attempt to convince people, whose opinions they value (i.e. co-workers, family members, fellowships or fellow-worshippers), that they are not like the threatening “others” by exaggerating their moral superiority, making harsh statements about the “others”, or choosing to keep quiet when PLHAs are being targeted.

The fourth step is to broadly *discriminate*, treating others in an unjustifiably different manner (i.e. distinguishing, excluding, restricting, shaming, or blaming) based on suspecting or knowing they have HIV/AIDS. In effect, having labelled someone as unacceptably different, exaggerating their characteristics, by piling on real or imagined stereotypes, and making sure that others know “we” are not like “them”, a circle is drawn around the “other”, making it easier to justify targeting them for unfair treatment or abuse.

For the most part, these processes are driven by fear. Such fears emerge from concerns, that we will get HIV from someone who has it, or risk being treated like they are treated in society, unless we clearly distance ourselves from them and their perceived characteristics. Emotions play a large role during each step, clouding our thinking, and heightening the anxiety of being infected or of being associated with others, who are cast out. It is easy to see this as a trap, difficult to escape, as breaking the cycle requires the ability to see circumstances objectively, the confidence to understand where we truly are and are not at risk, as well as the willingness to effectively confront the social, political, and communal circumstances that reinforce such hurtful treatment of others.

The stigma process is further complicated by very fear of losing control over the core values, held by ourselves or our societies. This additional moral dimension to understanding stigma and discrimination, helps us recognise that, while many of the outcomes are hurtful and damaging, the roots of these processes are not exclusively “bad” (Yang, et al., 2007). In fact, they can be motivated to a certain degree, by desires to retain traditions viewed as essential to the well-being of society. And this

brings us back to the notion of HIV/AIDS as “the great teacher”. The overwhelming impact of the virus, and the threats posed to public health by our inability to restrain it, force us to reconsider which parts of our upbringing and cultural values truly are essential to well-being, and which, on reflection, may actually stand in the way of effectively protecting us from harm.

Writing on the similarities between stigma and prejudice, Phelan, Link, & Dovidio (2008) note that stigma and discrimination serve three functions:

- “exploitation and domination (keeping people down)
- norm enforcement (keeping people in), and
- disease avoidance (keeping people away)” (2008, p. 358).

Clearly, each of these play a significant part in protecting “us” (the uninfected) from “them” (the infected or identified “at risk”). The challenge is to introspect clearly, when these processes do more damage than good; to recognize when the resulting discrimination itself becomes a violation of acceptable social norms; and to act intentionally to promote equal access to social resources while protecting public health. Social work values require us to look deeply into our own biases and judgments, and to initiate steps to recognize and protect the rights and dignity of our clients.

Check Your Progress II

Note: a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

- 1) Social psychology identifies four primary steps in the stigma and discrimination process. Briefly illustrate each of the steps, as they might apply to a PLHA, who was also a commercial sex worker.

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- 2) The moral dimension of stigma and discrimination recognizes that not all motivations to think of or treat others differently are unreasonable, even though their ultimate effect may be hurtful. Briefly discuss some views that would make judging or condemning others defensible from the moral point of view.

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1.4 IMPLICATIONS FOR HEALTH CARE AND SOCIAL SERVICE DELIVERY

Stigma and discrimination, as defined above, are both background and context for the delivery of health care and social services. PLHAs, their family members and friends, and those at risk or simply assumed to be at risk for acquiring the virus, are

all potential targets. They may be shamed for who they are or who they are thought to be, and blamed for being HIV+, or for having characteristics associated with greater risk. Others may fear becoming ill, or being outcast, or both, as a result of interacting with those, targeted based on their HIV status or associations.

Health care and social service workers are no exception to these attitudes and behaviours. On the one hand, they are at risk for “secondary” stigma; being judged or discriminated against not because of their own status, but, because of the status of those whom they work with. Not everyone who choose such occupations, do so because they understand HIV/AIDS, or have consciously decided to work with those suffering from its effects. Sometimes, they unexpectedly find themselves working with PLHAs (i.e., they didn’t imagine PLHA would be part of their caseload), and are largely unprepared to manage their own lack of knowledge or emotional reactions to such a reality. Such workers are not immune to the “human factor”, or the tendency to judge or discriminate against that which we misunderstand or fear. For this reason (as will be see in greater detail in later units in this Block), social service and health care providers must be exceptionally dedicated to noticing and understanding their own reactions, and initiating the necessary steps to minimise the unanticipated, negative impacts on their services.

Parker and Aggleton (2003) emphasized the importance of reframing stigma and discrimination in the broader contexts of power and domination, encouraging recognition that social inequality is a driving influence in creating and sustaining the maltreatment of some members of society. Viewed in this way, we can see that the very structure of health care and social services flows from underlying notions of threats to the social order, and responses necessary to protect it. Such dynamics determine decisions - political and social - about who deserves the service, what they should be offered, and how. Thus, services made available to or withheld from PLHAs, are shaped “by concrete and identifiable social actors seeking to legitimize their own dominant status within existing structures of social inequality” (Parker et al, 2003).

Those persons in charge of designing and directing health care and social services, are no less at risk of being “caught up” in such processes, than those who deliver these services on a daily basis. In the most innocuous sense, they are merely reinforcing what is good and necessary for the well-being of their families, communities, and society. More dangerously, they are unconsciously contributing to reinforcing such systems meant to punish those who have strayed from socially constructed understandings of “right and wrong”, and have only themselves to blame for their misfortune.

Somewhere in the middle, Bayer (2008) has called for an improved understanding of the ethics of stigmatising. Summarising from a complex position, he proposes that in some circumstances, shaming or blaming others for perceived misbehaviour may protect important aspects of the social order, without unduly violating the rights and dignity of others. It may even be possible to use these influences for promoting desirable change in social norms over time. He observes, “shaming and blaming those whose sexual behaviours involve violence or abuse, may ultimately lead to positive change and therefore be ethically acceptable, while doing the same to those whose behaviour “merely fails to conform to conventional standards of morality” (Bayer, 2008) may not pay off.

Obviously, issues raised in this manner are intensely personal, and depend heavily on the cultural contexts and values in which we live. This is all the more reason to remember that service providers are not immune from shaming or blaming their

clients, or for limiting access to services to those they view as objectionable. As we will see in later units, those who fear being stigmatised are less likely to seek HIV/AIDS education or testing, to return for test results once tests are undertaken, to ask for medical care and adhere to antiretroviral therapy, or even disclose their HIV status to others.

All of these are threats to public health, since people who do not know their status or seek treatment when they do know, are more likely to increase the spread of the virus to others. And ultimately, the family members and loved ones of social workers, nurses, and doctors, who stigmatise and discriminate in the course of service provision, are like everyone else in society, at greater risk as a result.

Guidelines for Media Coverage in India

Recognizing the risks to public welfare associated with negative labelling and stigmatising of PLHAs, the Press Council of India recently formally acknowledged that biased reporting resulting in stigma and discrimination, was a particular concern in stories involving HIV/AIDS (UNAIDS, 2008). Following a court case where such reporting led to discrimination against a child, the Council revised its “Guidelines on HIV and Media” (October 2008) to include the following recommendations for journalists, sub-editors, and newsroom staff in all media:

1. be objective, factual and sensitive
2. ensure accurate language and terminology
3. demystifying myths related to prevention of HIV and miracle cures
4. uphold confidentiality and obtain informed consent
5. avoid discrimination
6. ensure gender sensitive reporting
7. ensure sensitivity on child-related stories
8. ensure balanced and responsible coverage
9. ensure regular training on HIV for media
10. adopting the existing stylebook or guidelines on HIV reportage

The overall aim of these guidelines was to remind media professionals, that their story is “objective, factual and sensitive”, even more so when they are reporting on HIV. This includes highlighting positive stories where appropriate, without underplaying the fact that HIV is a serious issue. Telling the whole story means giving it a human face, and allowing the voices of people living with HIV/AIDS (PLHAs) to be heard” (UNAIDS, 2008). These guidelines represent an important integration of the ethics of stigma and discrimination, recognising that not all behaviours are socially acceptable, and also that exaggerated or distorted reporting can do more harm than good.

1.5 PRIORITIZING STIGMA INTERVENTIONS IN INTERNATIONAL RESPONSES TO HIV/AIDS

The UNAIDS (2007) observes that although they are pervasive challenges to public health and human rights worldwide, HIV/AIDS related stigma and discrimination “remain seriously neglected issues in most national responses to HIV”. Peter Piot, the executive director of UNAIDS states “since the beginning of the epidemic, stigma, discrimination, and gender inequality have been identified as major obstacles to effective responses to HIV. Yet, there has never been serious political and

programmatic commitment to doing anything about them” (UNAIDS, 2007). This is despite major campaigns by numerous regional and national non-governmental organizations (NGOs) designed to raise awareness regarding the issues and to promote interventions addressing them. In its executive summary, the report identifies seven specific recommendations for national AIDS authorities, international NGOs, and other partners, directed at addressing these challenges. They are:

building an understanding commitment to stigma and discrimination reduction by using existing tools to measure them and their impact on programmatic responses to HIV

inspiring leadership, understanding, and high level commitment, on the necessity of reducing stigma and discrimination in national AIDS responses

facilitating inclusion of stigma reduction strategies in national HIV strategic planning, funding, and programming

using or promoting approaches that address the root causes of stigma and discrimination

advocating multi-faceted national approaches, including initiatives such as “know your rights” campaigns, social change communications, social mobilization, participatory education, interaction between PLHA and key audiences, celebrity champions and media campaigns, and legal support to those affected by stigma and discrimination.

promoting and facilitating systematic approaches such as programme evaluation and operational research

The broad span of these proposals reflect the wide-ranging impact of stigma and discrimination in the long-term fight against HIV/AIDS, and the gathering momentum for effectively addressing them. As we will see, many of these recommendations have implications for social workers on all levels, from better understanding of our own responses to PLHAs, especially in shaping the programmes and policies of the organizations where we work, and also in order to advocate for meaningful change in the acceptance and management of illness in our families, communities, and societies. Thus, with our help, those facing this life-threatening disease will be more confident, asking for and receiving what they need to be well, in environment that help, rather than hinder.

Check Your Progress III

Note: a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

- 1) Social workers are people, just like everyone else. Identify some of the reasons why they may also have tendencies to stigmatise and discriminate, and briefly discuss the difficulties they may face when considering whether or not such tendencies are unethical.

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2) The Guidelines on HIV and Media promoted by the Press Council of India, are good examples of some of the principles advocated by UNAIDS, in promoting positive social change. Which of the recommendations do they most clearly address, and how?

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1.6 LET US SUM UP

HIV/AIDS related stigma and discrimination, represents the “second pandemic” associated with this global health crisis. While there has been much progress in medical care and in the distribution of antiretroviral medications, the social aspects of HIV-related disease are persistent and severe. Many people shame or blame PLHAs, and reject or distance themselves from those they imagine *might* have the virus. Through labelling, stereotyping, separating, and discriminating, they show their fear of acquiring the disease and/or being treated by others as if they have it, or both. While many of these processes are intensely personal, they also operate on broad social levels, and reflect impulses to hold power over others, and dominate those who are already marginalized or otherwise live outside the established social norms. Social service and health care providers are also likely to reflect some of the same tendencies when interacting with their clients or patients.

Considerable attention is being brought to bear on these problems and increasingly, national and international organizations are joining campaigns to raise public awareness and reduce the negative impacts of stigma and discrimination. Recognizing that public health is threatened when ill people fear learning their status, disclosing it to others, or seeking testing and treatment for their disease, programmes are now being developed to recognize stigma and discrimination, and promote programmes to reduce it. In subsequent units, we will learn more about how these issues manifest within and across differing levels of society and culture, how they are expressed in social service and health care settings, and what social workers can do to improve circumstances and outcomes for their clients at risk for or living with HIV/AIDS.

1.7 FURTHER READINGS AND REFERENCES

Bayer, R. (2008). Stigma and the ethics of public health: Not can we but should we. *Social Science & Medicine*, 67, 463-472.

Goffman, E. (1963). *Notes on the management of spoiled identity*. Englewood Cliffs, N.J. Prentice Hall.

Herek, G. M. (1999). AIDS and Stigma. *The American Behavioral Scientist*, 42(7), 1102-1112.

Link, B.G., & Phelan, C.G. (2001). ‘Conceptualizing stigma’. *Annual Review of Sociology*, 27, pp. 363-385.

Link, B.G., Yang, L.H., Phelan, J.C., & Collins, P.Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, 30(3), 511-541

Joint United Nations Programme on HIV/AIDS (UNAIDS) (December, 2003). *Stigma and discrimination fact sheet*. Retrieved November 9, 2008 from <http://www.unaids.org>

Parker, R., and Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*, 57, 13-24.

Shoofs, M. (1998). *Remembering HIV/AIDS pioneer Jonathan Mann*. Retrieved December 11, 2008 from <http://www.thebody.com/content/art2779.html>

UNAIDS (November 19, 2008). *New guidelines for media reporting on HIV in India*. Retrieved November, 20, 2008 from:

<http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/2008111>

[new_guidelines_media_India.asp](http://www.unaids.org/en/KnowledgeCentre/Resources/FeatureStories/archive/2008/2008111)

UNAIDS (2007). *Reducing HIV stigma and discrimination: A critical part of national AIDS programmes*.

Geneva: Joint United Nations Programme on HIV/AIDS. Retrieved on October 2, 2008, from: <http://www.unaids.org>.

United States Agency for International Development (USAID) (June, 2005) *Working report measuring HIV stigma: Results of a field test in Tanzania*. Retrieved November 6, 2008 from

<http://www.popcouncil.org/horizons/ORToolkit/AIDSQuest/instruments/stigindicators.pdf>

Yang, L.H., Kleinman, A., Link, B.G., Phelan, J.C., Lee, S., & Good, B. (2006). Culture and stigma: Adding moral experience to stigma theory. *Social Science & Medicine*, 64, 1524-1535.

1.8 ANSWERS TO CHECK YOUR PROGRESS

Check Your Progress I

- 1) Felt stigma refers to judgments or biases held toward PLHA that are thought to be kept within, rather than outwardly expressed. PLHAs managing internalized stigma might think of themselves as “sinners” or otherwise undeserving of others’ compassion because they brought the virus on themselves through immoral or careless behaviour. Even though they do not tell others about this low self-image, they may still suffer from it emotionally and become depressed or resentful. Enacted stigma is outwardly expressed as discrimination. PLHAs experiencing this may do themselves harm by delaying getting a test to confirm their HIV status, failing to seek medical treatment or care, or withdrawing from others for fear they will be hostile or rejecting.
- 2) As Herek points out, several aspects of HIV/AIDS (i.e. the degenerative nature of the disease, its contagious qualities, or the “repellant, ugly” images it triggers) can stimulate fear. Concerned about avoiding becoming infected, or being treated by others as if we might be, social workers may forget what they have learned about viral transmission, and wonder whether casual transmission is more likely than they’ve been taught. Similarly, if others in their personal lives are less educated and aware, social workers risk rejection by or isolation

from people who are important parts of their lives. It is “only human” to worry about these consequences. All the more reason to think clearly and act responsibly when working with HIV/AIDS.

Check Your Progress II

- 1) A PLHA who was also a commercial sex worker might be labeled as a prostitute or whore. Based on that, he or she might then be stereotyped by assuming other characteristics such as being filthy, immoral, or uneducated. This could lead to attempts to separate “us” from “them” by publically stating to others how much we hate the sight of a sex worker on the streets, or by remaining silent when someone says the PLHA is “belongs in the gutter” for being immoral. Finally, we may discriminate by attempting to make the PLHA feel ashamed at the beginning of a professional interview, or by agreeing with co-workers to offer fewer or less desirable services to such persons.
- 2) Social values and norms are reinforced by others living by them, and encouraging others to do the same. Disapproving of sexual exploitation of children, or discrimination against the poor are examples of putting this into action. If we labeled perpetrators of such acts as “child abusers” or “tyrants”, or stereotyped them as “dangerous” or “mean”, we would be helping others to see that their actions were unacceptable, and that they deserved to be treated differently until they could get their behaviors under control. The question should be whether the behaviors can be objectively determined (rather than “assumed” or “guessed” by others) and whether the other characteristics accurately describe related tendencies that go along with the qualities considered unacceptable in a well-functioning society.

Check Your Progress III

- 1) Social workers, like everyone else, are raised with specific guidance about what is right and what is wrong. Such moral and ethical education serves an important function in helping them make difficult decisions (as when their personal desires conflict with the well-being of others or the greater good). Bayer writes that sometimes holding others responsible for unacceptable actions is important, and that within reason, shaming and blaming are among the tools for doing so. Determining when such actions are unethical becomes more difficult when the behaviour we’re responding to does not clearly bring harm to another, but does violate moral or other teachings about what is “normal” and appropriate.
- 2) The guidelines could appropriately address many of the UNAIDS recommendations. For example, they “promote approaches addressing the root causes” of stigma and discrimination by requiring journalists to think carefully about the accuracy of their stories, especially regarding most vulnerable people such as children, and to avoid spreading inaccuracies and myths that might, for instance, stem from unreasonable stereotypes. They also advocate social change and media campaigns by encouraging accuracy in reporting, and recommending ongoing HIV education for members of the media.

UNIT 2 SOCIAL STIGMA: UNIVERSAL AND CULTURALLY SPECIFIC

Prof. Neil Abell*

Contents

- 2.0 Objectives
- 2.1 Introduction
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- 2.3 International and National Scenarios
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- 2.6 Answers to Check Your Progress

2.0 OBJECTIVES

Stigmatising and discriminating against people infected with or affected by HIV/AIDS, greatly impedes the efforts of those engaged in prevention and care. In this unit, the learners will:

examine the various domains (family, community, and society) in which these processes are experienced and expressed

consider differences and similarities in understanding and responding to them from national and international perspectives

learn how they have come to be seen as “common at the core”, identifying themes that apply across cultural and national boundaries, and

appreciate the magnitude of the problem and the work that lies ahead

2.1 INTRODUCTION

HIV/AIDS stigma and discrimination appear in multiple forms within and across cultures and societies. Whether felt or enacted, tendencies to think or behave in ways that label, stigmatise, alienate, or discriminate against others are seemingly universal human traits. These have profound influence on both the experience of HIV-related disease and on personal and professional responses to it. The effects are so wide ranging that PLHAs may experience self-stigma, shaming and blaming themselves for their condition, thereby limiting their willingness to tell others of their HIV status or ask for needed services and support.

In this Unit, we will examine how stigma and discrimination manifest on multiple levels within the family, community, and society. Considering that each of these areas is appropriate for social work intervention, an understanding of what PLHA and those at risk for HIV may experience is crucial. Hence major considerations would include: How is it that traditional sources of support may “break down”, adding distress to circumstances that are already challenging? What can be done to increase awareness of unhelpful thoughts and behaviours, and enhance the likelihood that PLHAs can find the care and support they need much?

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While some have argued that responses to stigma and discrimination have been lacking, much good work has been done on national and international levels to recognise the nature of the problem and build an understanding of what is needed to help. Some international researchers have concluded that enough is now known about the nature and expression of stigma across cultures to enable us to move ahead with constructive, practical responses. If, as they propose, stigma is “common at its core”, what are the elements we should all be aware of, and how should we begin the task of educating others? The present Unit will review some of those common principles, and gain an understanding of the important work that lies ahead.

2.2 STIGMA WITHIN THE FAMILY, COMMUNITY, AND SOCIETY

The Academy for Educational Development (AED), International AIDS Alliance (Alliance), and the International Center for Research on Women (ICRW) have supported numerous studies on the nature and impact of HIV/AIDS stigma, resulting in the publication of a *Toolkit for Action* (AED, Alliance, & ICRW, 2007). Several important observations and illustrations from the *Toolkit* are included throughout this Block, beginning here with observations on the causes, forms and effects of stigma across family, communal, and social systems. The Toolkit, available as a free downloadable document (refer Suggested Reading), consists of text briefly covering each topic, accompanied by group exercises to be used in workshops on HIV stigma and discrimination. As indicated in Figure 2.1, one such workshop encouraged reflection and discussion on the roots of stigma, how it is expressed and experienced, and some of the consequences that flow from blaming and shaming others.

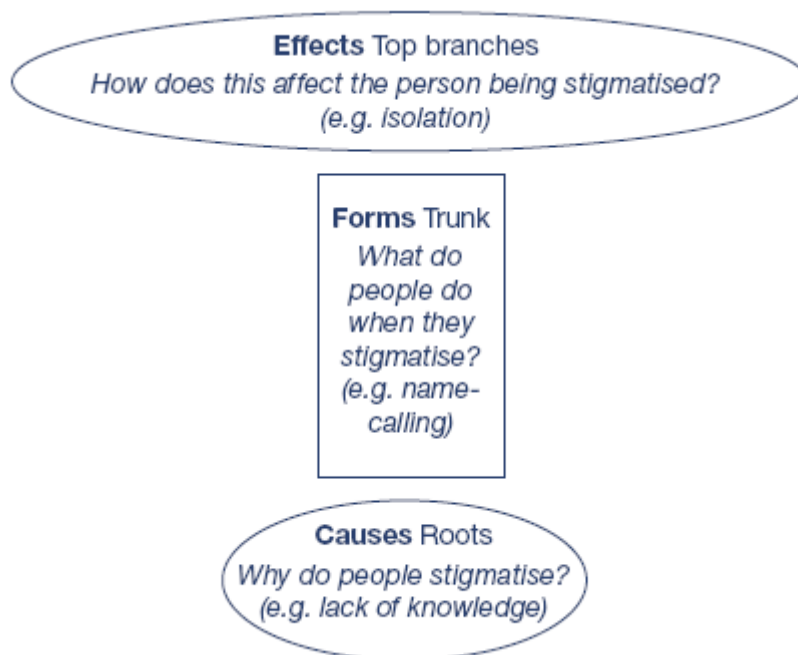


Figure 2.1: *Causes, forms, and effects of stigma*

Source: International HIV/AIDS Alliance (2007a). *Understanding and Challenging HIV Stigma: Introduction and Module A*, p. 29.

The workshop participants hailing from an African nation were encouraged to think of a “stigma and discrimination tree” consisting of roots, trunk, and top branches. Prompted by some introductory questions, they applied these concepts and, through reflection and discussion, identified the following points as the causes, forms and effects of stigma:

Causes (Roots)

The workshop participants were made to discuss why people stigmatized. The discussion revealed that people invariably held a moralistic view that PLHAs were “sinners”, “promiscuous”, “unfaithful”, “sleeping around”. People’s also held strong beliefs about “pollution”, “contagion”, “impurity”, etc. Ignorance and misconceptions made people fear physical contact with PLHIV as reflected in the words “fear of infection”, “fear of the unknown”, “fear of death”. Subtle issues such as gender and poverty figured out considering the fact that women and poor people more stigmatised than men and the “rich”. Prejudice too manifested as with the tendency to judge others.

Indepth analysis on causes

An in depth analysis of the cause of stigma revealed the following points:

Poverty

Poverty can lead people to stigmatise; being perceived as poor is indeed a stigma

Poor women are forced into transactional or commercial sex

Poor people who appear malnourished or emaciated and hence are most likely to be stigmatized. They cannot hide their HIV condition in the manner that a rich person can since there are no walls to hide them causing them to be easily seen by neighbours

Ignorance

Lack of knowledge on the modes of HIV transmission, can increase the possibility of the person contracting HIV, through casual contact

There are others who believe that casual contact with PLHAs can cause infection

Some others have the knowledge, yet don’t believe it. They think that they can still get HIV through casual contact.

Forms of stigma (Trunk)

Stigma acted out finds expression in the following forms of discriminatory practices: name-calling, scape-goating, finger-pointing, teasing, ridiculing, labeling, blaming, shaming, judging, backbiting, rumour-mongering, gossiping, making assumptions, neglecting, rejecting, ignoring, isolating, refusal to share utensils, avoiding or staying at a distance, harassing, inflicting violence (physically), abuse, etc.

There are other forms of stigma:

self-stigma - blaming and isolating oneself

stigma by looks or appearance

associated stigma - stigmatizing family and friends for simple reason of being associated with the HIV positive

Effects or consequences (Top Branches)

The following are the consequence of stigma: shame, denial, self-isolation, loneliness, neglect, loss of hope, resignation, depression, suicide, alcoholism, isolation.

Self-rejection implying giving up on oneself, may manifest in the form of self-blame, self-pity, self-hatred, anger, violence, withdrawal from public activities (e.g. church membership), stonewalling (stop communicating). Others sense a feeling of worthlessness, manifested as feeling unproductive, impotent, useless or not being able to contribute. Still worse others are alienated, being forced to leave community or experiencing family disruption in the form of divorce, separation, or being abandoned or kicked out of family. Quarrels ensue within the family, with its members arguing over who is responsible for this situation and who will take care of the PLHA. Being at the receiving end their property is grabbed by relatives or even the society. Yet others, get alienated at the workplace, by being terminated or fired from work, loss of promotion. Some also get evicted from rented accommodation. Children lose scholarships, experience scholastic backwardness, or even eventually, dropout from school. In the wake of AIDS death children are also orphaned and are often forced to take to the streets. Abuse or ill-treatment by relatives is not uncommon.

The HIV+, are often deprived of medical care too. The health care staff perceive any service done this way as a “waste of resources”. In the wake of discrimination, they eventually stop making use of clinics, give up on medical compliance, refuse to attend voluntary counselling and testing programmes, and for that matter, even home-based care programme. Others in denial are reluctant to take medication, suspend treatment and eventually turn out their vengeance by spreading the infection (Alliance, 2007).

As we can see, many of the causes, forms, and effects reflect painful circumstances with implications for the PLHA, as well as the family, their loved ones, and community. Reflecting on these statements, it is possible to conclude that the social aspects of HIV/AIDS can be just as devastating as the physical illness itself. For people struggling with such realities, there are seemingly numerous motivations to (self)-isolate or withdraw, leading to increased suffering and further complications related to the disease. When non-infected people witness or participate in such treatment, even if they do so silently, they may also decide that if they ever fear being exposed to HIV, they will not get tested. And if they do for real, test HIV+, they will keep it to themselves, and not ask for treatment or support. These are the general circumstances, social workers must first learn to recognize, and then determine to address in themselves, their families, and communities on both personal and professional levels.

The *Toolkit* is divided into various modules addressing different aspects of stigma and discrimination. In Module D, emphasizing the family, a report from a church volunteer participating in a workshop for community developers, described her experience with a PLHA in a rural community:

“(on finding him to be HIV positive and empathetic to his plight)... they built him a small hut, where he lay day and night, waiting to die. Hardly anyone visited him to socialise. They would only to put food on the floor and leave.”

Initially, when the social worker visited him, no one allowed him to enter his room. But when the worker insisted, they obliged. The worker describes that when she opened the door to get in, the stench was horrible! She went outside, fetched some water and warmed it, and later bathed him with the help of two young men in the family. They sat him in the sun - something he had not done for months together.

They cleaned his room and washed his clothes, which were caked with filth. While they were cleaning the room, porridge was cooking on the fire. After the cleaning, the worker sat there, feeding him porridge and talking to him.

The social worker kept on seeing, bathing and feeding him almost every day. Seeing this, the relatives too started doing the same. He died three weeks later, not an outcaste, but one loved and created in God's image. The worker reminisced how, when she told him God loved him, he held her hand tight" (Alliance, 2007b, p. 3).

This story helps to demonstrate how the academic and professional understanding of stigma and discrimination could be translated into something more deeply personal, profound and dynamic. No doubt, the family of this PLHA was very distressed and conflicted, feeling in some ways that their loved one had brought shame and suffering on himself and them. When the church volunteer recognized his need, and demonstrated that it was possible to care for him without also contracting the virus, the family members taking her example, joined in supporting the client, realising that he was indeed in need of their support. In Unit 4, we will return to these themes as a basis for cultivating personal and professional compassion.

Taking this illustration a step further, we can see that the family may also have had realistic fears regarding caring for their loved one. As the *Toolkit* illustrates, stigma expressed *towards* the family is also a serious concern. When workshop participants in Zambia, Ethiopia and Tanzania were asked to reflect on how neighbours, and other community members responded to families of PLHAs, they identified a broad range of issues and examples as cite below:

Forms of stigma towards families living with HIV

Stigma may manifest in the form of isolation and rejection of families suspected to have HIV and AIDS. They are subjected to name-calling, finger-pointing, gossip, rumour-mongering, backbiting, etc. Rumours about HIV and AIDS, were used as a weapon to denounce families. Speculations were made about other people, based on observed symptoms. Stigma was also said to have been triggered by visits or food relief provided by HBC workers. Others experienced severe shame, suffering loss of family honour, as voiced in the comment, "You have discredited/shamed our family". Yet others snoopied; people visited out of mere curiosity, to witness the condition of the PLHAs as if asking whether s/he was finished. Many did not allow children to play with (PLHA) neighbour's children, while others refused to share things with the family (pots, stools, containers, etc.).

How do neighbours treat households they think have HIV?

The neighbours insist with the landlord, to evict the family out of rented accommodation. They stop the family or family member living with HIV (PLHA) from using the community toilet, and gossip about anyone who frequently used the communal toilet. Paradoxically, others stop visiting the affected family, but worry about being blamed for not visiting. Many neighbours stop exchanging foodstuffs with the family. In Africa, it was not unusual to remark and joke about the patient dying, hinting that he won't live until Christmas!

Why do neighbours behave this way?: Rationale

Neighbours often behave irrationally, due to misplaced fear of infection about sharing the same toilet, and of children being infected through contact with families taking care of PLHAs. This may be rationalized due to the ignorance, or a lack of sympathy about the heavy burden on the family caring for the PLHA.

Neighbours

The following are the comments commonly raised by the neighbours. “we fear our children will get infected, so we stop children of the affected family from playing with ours”; “if the family is a member of a community group, we kick them out”; “this family brings disgrace to community/village.” More candid was the remark, “We visit for a while, then at intervals and finally we stop altogether.” Others were honest and commented, “We are sympathetic that they are spending all their money on medicine.” Others are judgmental and remark cruelly, ‘She was unfaithful so she is reaping what she sowed’.

Family

The family affected rationalised their distancing on grounds of fear of isolation, fear of losing contact with the (other) neighbours, or being called names behind our backs. They perceived that the others pretended to be nice, but behind our backs they are judging us. The affected families witnessed that If they were ask about the PLHAs, they would say that PLHA was fine; this is said only to stop them judging the family. Further, they discouraged people from visiting; and if they came, they would keep them in the sitting room, and the PLHA in the bedroom in the back. They even discourage visits to the hospital; if someone comes to visit, they would say, “Sorry, she is sleeping” (Alliance, 2007).

From the above illustrations, we can appreciate the very real fears families experience, risking being misunderstood, or even shunned by people who would otherwise be their friends. This is a big price to pay, especially when family members may regard the harsh treatment by the community was brought on to them, by a family member’s misbehaviour or immorality. Much understanding and support is needed for families, neighbours and communities to absorb the distress accompanying HIV/AIDS. Dealing with the unavoidable physical and health consequences is hard enough; suffering rejection and shame, even risking loss of work or exclusion from social networks may be too much for some to bear. For social workers, these become opportunities for education, providing examples of safe and supportive care, and advocating for social justice and access to necessities of living.

Check Your Progress I

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

- 1) Imagine a PLHA in a community you serve. Create a brief scenario in your mind, guided by the examples provided by the *Toolkit*. Reflecting on the “root, trunk, and top branches” of the stigma experience, briefly discuss why people in your community might stigmatize, how they think or behave when they do, and what effect this might have on the PLHA you imagined.
- 2) Stigma and discrimination are not limited to PLHA. Again considering a community you serve, reflect on how family members or loved ones of a PLHA might also be thought of or treated by neighbours or the community. What are the issues they might face in daily life, and how would the response of your community encourage or discourage them from openly caring for the family member, who happened to be a PLHA?

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2.3 INTERNATIONAL AND NATIONAL SCENARIOS

Edwin Cameron, a South African judge, who happened to be HIV+, has written that “stigma is perhaps the greatest dread of those who live with AIDS and HIV... stigma’s irrational force springs not only from the prejudiced, bigoted, fearful reactions others have to AIDS... it lies in the fears and self-loathing, the self-undermining and ultimately self-destroying inner sense of self-blame that all too many people with AIDS or HIV experience themselves” (Knight, 2008). As one consequence, PLHAs worldwide have found themselves isolated and struggling to gain access to services and basic human rights, as many countries have no legal or policy frameworks supporting the establishment of networks of PLHAs. This is especially true for traditionally marginalized people, as evidenced by the fact that nearly half of the countries included in the United Nations’ Secretary General’s 2007 report on human rights noted, “existing policies *prevent* stigmatised groups such as sex workers and injecting drug users, from accessing prevention programmes” (Knight, 2008).

We have already seen illustrations of stigma and discrimination drawn from sub-Saharan Africa. Similar stories could just as easily be drawn from central Europe (Kelly, et al., 2004), the islands of the Eastern Caribbean (Abell, et al., 2007), or North America (Florida Department of Health, 2007). In each society, differences in culture, ethnicity, gender, and social class shape, but do not substantially change the risk that PLHA, their family members and loved ones will be subjected to, as a consequence of HIV status. Knight observes that the cultural taboos associated with common routes of viral transmission (same sex relationships, sex work, and injection drug use) have played a critical role around the globe. Knight (2008) writes, “If HIV were transmitted in some other way, through some ‘innocuous means’, the world might well not be experiencing today’s pandemic. But prejudice leading to stigma has silenced politicians and other leaders for too long, and everywhere action has come too late”.

Addressing the national scenario, Mawar, Sahay, Pandit and Mahajan (2005), citing multiple sources, write that:

“In India, public health officials until recently, held that only women in prostitution, homosexuals, or intravenous drug users (IDUs), could contract AIDS, largely ignoring a dramatic rise in new AIDS cases among monogamous, married women. Even diseases like tuberculosis (TB) carry stigma, as children with TB were not permitted to return to classes, even after successful treatment due to misconceived notions that they would still spread the disease to others. The HIV/AIDS scenario appears to be even worse as this still remains an incurable disease. The persons suffering from stigmatized diseases are assumed to have violated certain social norms and taboos and thus (be) responsible for it... lessons learnt from the successful experiences dealing with stigma associated with other diseases, must be borne in mind, when HIV/AIDS related programmes are developed, as it amounts to denying the rights of the infected individuals”.

The authors note that the National AIDS Control Organization (NACO) has recognized the importance of this issue, and promotes provision of community and family based care in an enabling environment free from stigma and discrimination. At the same time, they express concern that specific strategies and programs addressing these concerns are lacking, particularly regarding vulnerable populations

including youth, people with sexually transmitted infections, men who have sex with men (MSM), and those who use injection drugs (IDUs).

Mawar et al. (2005) observes that social norms such as subservience in marriage (often reinforced by violence), can impair women's abilities to protect themselves. Women are often blamed for bringing HIV into the family, and sometimes accused of being prostitutes or drug users. They carry the double burden of caring for themselves in addition to their families. IDUs, especially prevalent, for example, in Manipur, risk being quarantined if HIV+, and may be required to undergo mandatory testing, and subsequently tattooed for identification. PLHA deciding to disclose their HIV status to others risk "disgrace, disharmony, concern about insurance and employment, (and share) a desire to protect oneself and others emotionally and from violence" (Mawar, 2005). The authors conclude that "a human rights approach lies at the heart of any HIV/AIDS programme that seeks to prevent HIV transmission and supports those already infected" (Mawar, 2005).

Common at its Core

Scholars writing with support from the International Center for Research on Women shared concerns about the nature and expression of HIV/AIDS stigma, particularly the question as to whether, and to what extent experiences differed across cultures. Clearly, each society and community expresses uniquely identifying characteristics and cultural practices, but how much do these shape the forms of stigma encountered in various settings, is to be considered? Following an extensive review of the literature and hands-on empirical research in four countries (Ethiopia, Tanzania, Vietnam, and Zambia), researchers found that "HIV and AIDS-related stigma is far less varied and context-specific than may have been imagined" (Ogden & Nyblade, 2005), concluding that "differences are largely superficial and need not stand in the way of developing programs and interventions."

The good news, then, is that social workers can get to work, confident that the major issues have been identified. Strategies for addressing stigma can be focused on both individual and structural change, with emphasis on two key underlying causes (Ogden and Nyblade, 2005):

- 1) knowledge and fear, and
- 2) values, norms, and moral judgments

Ogden and Nyblade emphasize that. "it is not sufficient to intervene *only* at the structural levels. While power relations that foster inequality are structural, they are perpetuated by *individuals*, individuals who are well placed to institute change if motivated to do so and given a supportive environment. We thus call for an intervention that starts with the conviction that individual attitudes can and do make a difference, and that long-term and far reaching stigma reduction can start with individuals. Depending on the context, it may be necessary to intervene with people in positions of power and influence; people who determine to a large extent what messages are delivered and how; people who have the power to institute anti-discrimination laws and policies; and, people who are in charge of carrying out these laws and policies. In *all* contexts, it will be appropriate and necessary to intervene at the community level with community members, including health care workers, people working with faith-based and community-based organizations, and people living with HIV and AIDS and their families" (Ogden and Nyblade, 2005).

As the learner will see in Units 3 and 4, social workers can draw much good guidance from existing research, adopting and adapting current strategies to best suit the

particulars of their own environments. While the challenges are great, and the problems persistent and deeply rooted, we have good reason to be encouraged that a map has been drawn showing us both a starting place and a destination as we work to reduce the impact of stigma on HIV/AIDS services.

Check Your Progress II

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) What are some of the “cultural taboos” you are most likely to encounter when working with HIV/AIDS in the communities you serve? Where do they come from? How are they reinforced, and what are the consequences of breaking them?

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2) One common theme in stigma intervention is the importance of supporting human rights through encouraging both individual and structural change. Who are the powerful and influential people in your community? What organizations do they lead or represent? Name some topics or information you might include if you wanted to help them better understand how stigma is harmful to PLHAs.

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Recognizing the magnitude of the problem

As we have seen, HIV/AIDS is a tremendously complex problem posing challenges for families, communities, and society. As indicated in Figure 2.2, a broad range of factors influence the prevalence of the disease.

Figure 2.2: Factors that reinforce or help reduce HIV/AIDS prevalence

Factors that reinforce HIV/AIDS	Factors that reduce HIV/AIDS
Gender inequity & male domination	Gender awareness, sensitivity & sexual equality
Poverty & continuing impoverishment	Mobilization of resources
Increasing urbanization & migration	Integrated & supportive communities
Lack of information & epidemiological data	Strategic Information
Inadequate & isolated institutions	Multi-sectoral approach & sharing of information
Isolated & marginal civil society	Civil society engagement
Oppressed & disadvantaged communities	Empowered communities
Disconnected or authoritarian government often in conflict with voluntary organizations	Committed government & voluntary sector involvement
Lack of political commitment	Political leadership & advocacy
Reactive & fragmented approach	Proactive & holistic approach

Source: Hall, 2007

From gender inequities to pervasive poverty, oppression, and incomplete social and governmental responses, all must be considered respectfully in light of prevailing cultural values and realities. Hall (2007) argues that social workers are uniquely

positioned to address such concerns. In their training and work experience, social workers develop the necessary knowledge, skills and values, needed to support people as they cope with stresses, changes and crises, including those triggered by illness, marginalization and discrimination. Many other professions and individuals are involved with psychosocial care and emotional support, including nurses, psychologists, doctors, community activists, volunteers and family members. However, the social work profession, by virtue of its holistic perspective, is capable of responding to the needs of vulnerable populations, helping people gain more control over their lives-in partnership with them-and addressing major political, social and economic issues (Hall, 2007).

Particularly in impoverished settings, social workers are challenged to address basic elements of human rights and dignity. Citing an early International Federation of Social Workers (IFSW) policy statement on HIV/AIDS, Hall (2007) concluded that, “there is need to ensure through proactive advocacy that all people affected by HIV/AIDS have proper food, housing, education and health care, and be able to exercise their rights in this regard without hindrance.” The task will not be easy, warranting recognition of stigma and discrimination as the “third phase of (the) HIV pandemic” (Mawar, et al., 2005). Indeed, Knight has identified the need for an “exceptional” response, quoting Peter Piot, former UNAIDS Executive Director: “The impact of AIDS is exceptional because of its impact now and the future threats it poses. It primarily kills adults in their prime, those who drive economic growth of a nation, and provide care for the very young and the elderly. Too many countries, especially in sub-Saharan Africa, are being stripped of this generation; the labour force is being steadily wiped out, and in severely affected countries, the result could, over another two generations or so, be detrimental to economic and social development ... the key factor here would be the cumulative weakening, from generation to generation of human and social capital ... Within the next five years, every sixth or seventh child in the worst affected sub-Saharan countries will be an orphan, largely because of AIDS ... apart from chronic armed conflicts, such as in the Democratic Republic of Congo ... there is arguably no other cause today of such utter economic and social regress” (Knight, 2008).

Over a decade ago, Jonathan Mann declared that HIV has its worst impact among populations who are already marginalized in any society. Echoing that theme, Knight notes our obligation to work not only with individuals, but also with the institutions that shape their lives. “AIDS flourishes in poor societies because illiteracy and penury make people vulnerable; success against the virus depends partly on broader progress. As President Paul Kagame of Rwanda told the *Washington Post*, ‘there’s no use in giving someone antiretroviral drugs if he has no food’ “ (Knight, 2008).

Check Your Progress III

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

- 1) What according to Hall, are the factors reinforcing or reducing HIV/AIDS? Identify three that are most powerful in the context of your own community. Provide examples of how they might increase or decrease the expression of stigma and discrimination.

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2) Given the influential factors identified above, which organizations or institutions are potential “gate keepers”, reinforcing or responding to them? Name some of the policies or practices shaped by community institutions (governmental, religious, or otherwise) that help or hinder PLHAs access to basic services and resources. How might social workers address stigma resulting from such practices?

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2.4 LET US SUM UP

In essence, social workers must draw on all their skills and training to navigate the deep waters and the challenges posed in the context of HIV/AIDS related stigma. While the experience of being stigmatized or discriminated against is intensely personal, such encounters arise from fears and inequities based in age-old practices and social structures that bind communities together, and give life within them value and meaning. The intrusion of this life-threatening disease into the very fabric of our communities, force us to look more deeply into how we live, what we value, and why. Ultimately, we will succeed or fail in our attempts to control the spread of HIV/AIDS, based upon how clearly we see these connections, and how creatively and respectfully we unravel their more damaging influences on public health.

2.5 FURTHER READINGS AND REFERENCES

1. Abell, N., Rutledge, S.E., McCann, T.J., & Padmore, J. (2007). Examining HIV/AIDS provider stigma: Assessing regional concerns in the islands of the Eastern Caribbean, *AIDS Care*, 19(2), 242-247.
2. Academy for Educational Development, International Center for Research on Women, International HIV/AIDS Alliance (June, 2007). Understanding and challenging HIV stigma: Toolkit for Action (Revised Ed.). Retrieved November 6, 2008 from

http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=255

3. Florida Department of Health, Bureau of HIV/AIDS (2008). *Organizing to survive: The HIV/AIDS crisis among Florida's women*. Retrieved on August 26, 2008 from http://www.doh.state.fl.us/disease_ctrl/aids/Docs/HIV_AIDS_Womens_Report_4_2008.pdf
4. Hall, N. (2007). Why don't we care? Social workers, the profession, and HIV/AIDS, *Social Work, Health, & International Development*, 44(1), 55-72.
5. International HIV/AIDS Alliance (Alliance)(2007a). *Understanding and challenging HIV Stigma: Introduction and Module A*. Retrieved on November 8, 2008 from: http://www.aidsalliance.org/graphics/secretariat/publications/1Stigma_Intro&A.pdf
6. International HIV/AIDS Alliance (Alliance)(2007b). *Understanding and challenging HIV Stigma: Module D & E*. Retrieved on November 8, 2008 from: http://www.aidsalliance.org/graphics/secretariat/publications/3_Stigma_D&E.pdf
7. International HIV/AIDS Alliance in India (September, 2008). *Together now India Newsletter*, 1(1), p. 3. Retrieved on January 24, 2009 from: http://www.aidsalliance.org/graphics/secretariat/publications/Together_now_India_Newsletter1.pdf
8. Kelly, J.A., Amirkhanian, Y.A., Karakchieva, E., Csepe, P., Seal, D.W., Antonova, R., Mihaylov, A., & Gyukits, G. (2004). Gender roles and HIV sexual risk vulnerability of Roma (Gypsies) men and women in Bulgaria and Hungary: an ethnographic study, *AIDS Care*, 16(2), 231-246.
9. Knight, L. (May, 2008). *UNAIDS: The first 10 years*, Joint United Nations Program on HIV/AIDS (UNAIDS): Geneva, Switzerland. Retrieved November 9, 2008, from: http://data.unaids.org/pub/Report/2008/200810_first_10_years_en.pdf
10. Mawar, N., Sahay, S., Pandit, A., & Jahajan, U. (2005). The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma and discrimination and future needs, *Indian Journal of Medical Research*, 122, 471-484.
11. Ogden, J., & Nyblade, L. (2005). 'Common at its core: HIV-related stigma across contexts'. Retrieved September 9, 2006, from http://www.icrw.org/docs/2005_report_stigma_synthesis.pdf#search=%22common%20at%20its%20core%22
12. UNAIDS (April, 2004). "Three ones" key principles, Conference Paper 1, Washington Consultation Retrieved November 9, 2008 from http://www.unaids.org/UNA-docs/three-ones_keyprinciples_en.pdf

2.6 ANSWERS TO CHECK YOUR PROGRESS

Check Your Progress I

1. There is no "right or wrong" answer to this item. As you reflect on it, carefully consider how conditions in the community you imagine might contribute to tendencies to stigmatize a PLHA, and what some of the thoughts or behaviours of community members might be. How would these feelings or actions affect

the PLHA's willingness to share his or her status with others, and to seek the much needed care or support?

2. Again, there is no "right or wrong" answer. Be as honest as you can in identifying ways that family members of PLHA might be treated by neighbours or community members. If this scenario occurred in your own family, what issues would you need to consider, in deciding whether and how to care for someone ill with HIV/AIDS?

Check Your Progress II

1. Think carefully about the spoken and unspoken "rules that cannot be broken" by those who wish to be respected and valued in their communities. Which of these relate most closely to people infected with or affected by HIV/AIDS? Who made these rules, and how are people treated when they break them?
2. After identifying the influential people and institutions in your community, think of how you might begin a conversation with them regarding the causes of HIV/AIDS stigma. Include areas of knowledge they may be lacking, fears that may arise if they misunderstand, or exaggerate basic information about the virus and how it is transmitted. Also consider how you would approach the values, norms and social judgments leaders often believe are important to the well-being of their communities. How would you begin to talk with them about some of the hurtful consequences of such attitudes on the well-being of infected and affected people?

Check Your Progress III

1. This question can be answered in many ways. Consider, for example, whether the state of agriculture or industry in your community supports the needs of those living there. If others migrate into (or out of) your community, what is the impact on the migrants' access to basic needs? How does their presence (or absence) influence the economic and social well-being of themselves or their families? How might this be affected if they were HIV+, or thought by others to be "high risk"?
2. Again, there are many possible answers. What might be the role of police, government, temples, mosques, or churches in recognizing the needs of such people? How likely are they to view them as threats? As deserving or undeserving of support? How might their practices or policies influence the lives and opportunities of PLHA? How might they shape the ways others in your community respond to them? What could social workers do to respond to problems as they arise?

UNIT 3 PROVIDER STIGMA: SOCIAL SERVICE AND HEALTH CARE PROVIDERS

Prof. Neil Abell*

Contents

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- 3.2 Stigma Among Professional Service Providers
- 3.3 Stigma and Discrimination Among Health Care Providers: International Illustrations
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- 3.5 Implications for Social workers
- 3.6 Let Us Sum Up
- 3.7 Further Readings and References
- 3.8 Answers to Check Your Progress

3.0 OBJECTIVES

While we might hope that social service and health care providers, given their HIV/AIDS education and training, would be “immune” to stigmatizing and discriminating, the same is not the case. In this unit, we will:

- appreciate how emotional and socially conditioned views considered to be normal expressions of “human nature,” may trigger underlying tendencies to fear and distance from PLHA;
- consider how these tendencies occur in a wide range of health care and social service providers;
- examine differences and similarities across international settings;
- reflect on how these tendencies have been recognized and responded in India; and
- review issues to be addressed in constructive social service responses.

3.1 INTRODUCTION

In the preceding units, we have seen how HIV/AIDS stigma and discrimination are conceptualized, and gained an appreciation of their critical impact on the global pandemic. In many ways, these dynamics, expressed by individuals, as well as within families, communities and societies, overwhelm scientific and medical breakthroughs. Recognizing this, we have reconsidered the impact of personal fears and concerns, and noted how both individual and structural influences shape the public health environment that PLHA and those considered at risk for HIV encounter.

In this unit, we continue this investigation, examining how health care and social service providers might engage in the same thoughts and behaviours as others in society. As we will see, professionals and paraprofessionals may unintentionally add to the stigma and discrimination felt and enacted in service settings. When they

misbehave with others in these despicable ways, they may undermine their best and most professional intentions. As a result, people who are infected or affected with HIV may disguise their concerns, hide their HIV status, or stay away from settings where they might otherwise receive the information, services, and support they are in dire need of. As noted in the *Framework for Action* developed by the Caribbean Epidemiology Centre (CAREC, 2004), the resultant obstacles include:

- increasing spread of HIV and co-occurring illnesses such as TB;
- reduced use of condoms or other prevention behaviour for fear that doing so will cause others to suspect or reveal another's HIV status;
- forcing people to pretend they are heterosexuals, even if they have same sex relationships (gay);
- preventing communities and families from providing education, care, and support to PLHAs, or those who are vulnerable to HIV;
- negatively affecting the quality of care provided to PLHA; and
- preventing national authorities from getting a true picture of the burden of the epidemic because people will not come forward for testing, care, and support.

The good news is that providers around the world are becoming increasingly aware of these issues, and beginning to take steps to address them. Before turning to intervention strategies (as we will do in Unit 4), let us take a closer look at the nature of HIV/AIDS provider stigma.

3.2 STIGMA AMONG PROFESSIONAL SERVICE PROVIDERS

In many ways, tendencies to stigmatize or discriminate can be understood as “normal” responses to the personal and social fears triggered by HIV/AIDS. Imagining that they might become deathly ill or to be treated as outcasts if they interact with PLHA, health care and social service providers are not immune to reactions that blame or shame those they hold responsible for these risks. After all, we social workers are “only human”. Service providers are, in part, gatekeepers for medical care, social support and prevention education, and beyond their own personal fears and reactions, may also feel they must uphold larger community and social moral standards (Rutledge, Abell, Padmore, & McCann, 2009). Deviating from dominant attitudes or behaviours in their communities can lead to loss of funding for agencies or NGOs, as well as threaten the livelihoods of organizations and workers. Consequently, providers may feel they have little choice but to join in the stereotyping of those who break social taboos, reinforcing views that it is “the ‘will of God’ that homosexuality, marital infidelity, and promiscuity lead to AIDS” (Rutledge et al, 2009).

These pressures are sometimes experienced as emotional reactions to patients’ or ‘clients’ habits and needs, or to the stress of providing services in hostile community environments. Community norms can influence how providers express their emotions in daily interactions, shaping how events are interpreted (i.e. as “good” or “bad”), guiding behaviors that influence other people (for instance, being publicly accepting or rejecting), causing reactions to the events and actions of others (by conveying comfort or distress), and maintaining socially shared interpretations of interactions and events (Varas-Diaz & Marzan-Rodriguez, 2007).

Feelings are very powerful, and may cause providers to think or act in particular ways. Emotions can contribute to stigmatization by indicating whether strong reactions

to PLHA (including violence) are acceptable, and by “keeping unchanged the socially shared negative definitions about (PLHA). Health professionals, as part of (the) social scenario, are also active participants in the use of emotions as sources of meaning and guides of behavior” (2007, p. 1249). Their emotional states may influence how PLHA react to them, and model how PLHA should be thought of or treated by coworkers or other community members. “The truth of living with HIV is a constant reminder of the lack of acceptance and rejection found in our societies. Living with HIV demands silence and secrecy, because even in the best of cases people perceive rejection and lack of acceptance even from health care providers, including psychologists” (Varas-Dias & Toro-Alfonso, 2007).

Check Your Progress I

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

- 1) Consider the obstacles to delivering HIV information, services, and support introduced in the CAREC *Framework*. Reflecting on the communities where you live and work, how much do you believe stigma and discrimination restrict the efforts of national authorities to learn the true extent of HIV? Are members of your community likely to learn their status and disclose it to others? How do these tendencies vary with subgroups within the community and why?

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- 2) Do you accept the notion that social workers are “only human”, and therefore entitled to beliefs or attitudes expressing their fears about contracting HIV or of being mistreated by others because they work with PLHA? What emotions are providers likely to feel as a result of working with such persons in communities with tendencies to blame or shame them?

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3.3 STIGMA AND DISCRIMINATION AMONG HEALTH CARE PROVIDERS: INTERNATIONAL ILLUSTRATIONS

Although it seems illogical, having good information about HIV transmission is not, in itself, enough to guarantee that people will remember and act on that knowledge when encountering PLHA. On an island in the Eastern Caribbean, a well-established leader of an international NGO participating in an anti-stigma workshop once told the story of his own behaviour to a group of student nurses. He described visiting an infectious disease ward in a local hospital, and becoming aware in the middle of his stay that he was walking around with both hands stuck in his pockets. Surprised to find himself behaving in this way, he thought “I know better than this... I am sure I cannot get HIV by touching any of these patients, and yet I am unconsciously ‘protecting myself’ by keeping my hands out of reach.” He was embarrassed to

catch himself acting in such a way, and aware that in doing so he was sending a nonverbal message to patients, their visitors and staff that, he, an educated man, feared the people on the ward. Still, he bravely chose to use himself as an example in the training of the nurses. In this way, he generated a learning experience first for himself, then others, and modelled the courage and compassion of becoming aware of a limitation and growing from it through openness and insight.

Ogden and Nyblade (2005) observed similar disconnects between knowledge and behaviour in their study of health care providers in Africa and South Asia. “This fear of and preoccupation with contracting HIV through impossible or highly unlikely routes persists across all four countries despite high levels of knowledge about how HIV is transmitted. . . . respondents know, or at least can easily recite, the three correct modes of HIV transmission (sex, blood, and mother-to-child). However, correct knowledge does sometimes coexist with incorrect beliefs . . . and there is often a lack of confidence about how HIV is *not* transmitted” (p. 17). A provider in Vietnam stated:

I am a health professional; I know that HIV is transmitted only in three main ways. But when I come into contact with them [people living with HIV and AIDS] I still worry and feel nervous. . . . In my case it is my duty, my responsibility to work with them, to go to them. But in fact, I am fearful.

Differential treatment of PLHA was reported in health care settings, including:

- excessive and unnecessary precautions by health care staff;
- scuffle between providers to avoid caring for HIV+ patient;
- denial of health services;
- provision of treatment below standards;
- use of separate medical tools for people with HIV or AIDS; and
- segregation of patients with HIV, in separate rooms (Ogden and Nyblade, 2005).

In a qualitative study in the Eastern Caribbean, Rutledge et al. (2009) examined whether patterns of stigma and discrimination among health care providers could be mapped using the social cognition concepts introduced in Unit 1. First, they asked whether health care workers labelled PLHAs. They found that female sex workers were referred to as ‘commercial sex workers’, ‘prostitutes’, or ‘skettels’; but the latter term also referred to female promiscuity. When referring to gay men, some participants used (hurtful) terms (e.g., ‘bullers’, ‘chi-chi men’), whereas others used language-neutral expressions (e.g., ‘gay’, ‘homosexual’). Providers also referred to gay men as ‘MSM.’ secondly, they asked whether such labels were associated with *negative stereotypes*. One example included the conclusion that PLHA did misbehave, and acquired HIV as a consequence. In a focus group in Trinidad, two MSM commented on providers beliefs about them:

First participant : “Some people believe [AIDS] occurred from God because they weren’t ‘behaving themselves’.”

Second participant : *You have to understand that we are . . . basically a religious society. . . . either you are gay, or you’re sleeping around . . . you must have committed some great sin and then you’re blamed for having committed this great sin.*

Thirdly, they examined *tendencies to separate “us” from “them”*, and learned that a common view among health care providers in the Trinidad was that AIDS happens to others, not us:

... it was first diagnosed among the same-sex community, and so, it immediately became a disease that was only for same-sex community members ... we got more information on drug use, and they said, ‘Well, I’m not a drug user and I’m not a homosexual, so I’m not at risk for HIV/AIDS’. But even then with the progression of HIV/AIDS in the heterosexual community, we still continue to put up those barriers ... people say, ‘Well, I’ve been married for the past 20 years, I am not at risk because my husband is faithful to me, I’m faithful to him’. But that might not be true and we exclude ourselves. We, of course, exclude ourselves ‘cause we go to the gym and we are fit and we are good Catholics ... there is always something that prevents us from being at risk for HIV/AIDS, but even despite all of that, there is a general negative view of HIV/AIDS and the types of persons HIV/AIDS is associated with.

Finally, they asked whether instances of *discrimination* took place in clinics and hospitals. PLHAs described how, scorn in medical settings, was sometimes expressed non-verbally, with staff demonstrating disgust by the manner in which they delivered routine care. Even seasoned doctors could react badly if taken by surprise.

I went to . . . a place where they treat all sexually transmitted disease. I had a wart on the inside of my gum, and they sent me to this specialist doctor, a lady from India ... there she give me some cream. And after two weeks the cream wasn’t working and I went back to her ... and I went very early ... but [by] 12 o’clock or 1 o’clock nobody wasn’t seeing me as yet. So I see the doctor passing . . . and she didn’t hear me. So I just went and I just touch her like that [gestures touching her shoulder] . . . I say, ‘DOCTOR!’ and she says screaming, ‘Don’t touch me! Don’t touch me!’ I just bolt out from the place. . . . [A]nd she is a doctor in a venereal disease place!” (p. 25).

Another form of discrimination included violating the PLHA’s confidentiality. As is common in small communities, gossip and story-telling about the lives of friends, family and neighbours is common. And as we have seen, providers are in many ways just like others in the community. Because it was very likely that members of the community knew each other, either directly or indirectly, providers who knew someone’s HIV status would sometimes feel a duty to warn others, even when they knew that doing so was unprofessional or even illegal. Several providers discussed this in a focus group.

First participant : The culture is that I know she and she know me so he might be my husband, but the nurse on the ward might be his sister-in-law or my sister-in-law.

Second participant : So information would flow.

Third Participant : By the time I get to him, he would know that I was on the ward and I’m HIV because his sister-in-law would have told either her husband or somebody the husband know.”

When the researchers asked a PLHA in Grenada, a neighbouring island state, how he learned his HIV status, he said as he was walking towards the clinic to get his test results, he saw people on the street pointing to him, exclaiming “There goes ‘The

AIDS Man'!". Despite the health providers 'best intentions (in this case, the lab worker's knowledge that he was legally bound to keep test results a secret), "human nature" and the pressure of community norms, lead to thoughtless and insensitive handling of the PLHAs. It is easy to imagine that as this gentleman told his story to others in his life (who likely were also at risk for the virus), they would "think twice" before deciding whether to go and be tested themselves.

Stigma and discrimination among social service providers: International illustration

In a mixed group of providers throughout the islands of the Eastern Caribbean (Abell, Rutledge, McCann, & Padmore, 2007), participants in a stigma workshop responded to questions about their attitudes towards PLHA. On an analysis, six major constructs pertaining to attitudes emerged. They include:

Warmth: feeling favourably towards infected or affected persons, including children, adults, MSM, IDU, and caregivers;

Comfort: ease in interacting with PLHA, in school, at work, shopping and sharing tableware;

Distancing: minimizing contact or association with PLHAs;

Condemnation: judging or wishing to control PLHA;

Transmyth: (belief that) HIV acquisition (was possible) by sharing glasses, using public toilets, or being coughed or sneezed on; and

Counsel: perceived ability to effectively educate and support others regarding prevention, testing, and treatment.

Participants 'responses were analyzed after sorting them into those who generally were, or were not likely to (physically) touch PLHAs during their normal interactions. Those studied, whose jobs did involve touch, and were generally directly involved in providing health, e.g., nurses, dentists, caregivers; while those whose jobs did not involve touch, and who functioned in a variety of social service roles included Peace Corp Volunteers, police officers, prison officers, HIV/AIDS Counsellors, Social Workers, CEOs, Administrators, and HIV Educators.

Researchers found that despite their professional training, participants across both groups still included significant numbers who were not completely sure that scientists and doctors could be trusted with regard to the truth about HIV/AIDS. Many wonder whether expert opinions about risks associated with casual contact were true. Participants in both groups also were aware that testing for HIV could lead to discrimination, and a significant percentage stated that the risk of being discriminated against would influence their own decision to be tested. Think of the implications: if people whose jobs include counselling others to be tested, or even administering the actual test were themselves afraid to be tested, what emotional message are they likely to convey to their clients or patients? This illustrates the overlap of social and community standards (specifically, the fear of being blamed or shamed by others) on decision making by service providers. Their ability to do their jobs is somewhat compromised by fears of what they would have to manage if they tested HIV+, and of how others would treat them if they knew.

In general, relations among the six constructs conformed with expectations. "More warmth was associated with increased comfort, stronger belief in counselling effectiveness, less distancing and condemnation, and less belief in transmission myths. Greater reported comfort was associated with increased confidence in counselling abilities and reduced tendencies to distance, condemn, or believe in myths.

Respondents with greater counselling confidence were less likely to distance, condemn, or believe in myths, and those who distanced themselves the most from PLHA were more likely to condemn them or believe in myths” (Abell, Rutledge, McCann, & Padmore, 2007, p. 244).

On the other hand, researchers did not expect to find that social service providers (who were less likely to touch PLHA) were also less likely to condemn or distance from them, and more likely to feel comfortable around them. One explanation is that, despite their education regarding HIV risk and transmission, health care providers (who were more likely to touch) continued to feel less safe around, and more likely to judge and reject PLHA.

Check Your Progress II

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) The story told by the NGO director of his surprise to find himself communicating fear and rejection by hiding his hands is a very simple illustration with a powerful message. Can you think of any examples of providers in your community unintentionally conveying other forms of stigma or discrimination to PLHA, their family members or caregivers? If you found yourself engaging in similar thoughts or behaviors, how could you turn it into a positive learning experience?

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2) The perceived “duty to warn” others of someone’s HIV status can be a very strong feeling. How do social work values and ethics help you decide how to act when you feel the need to tell others about a person’s HIV test results?

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3.4 NATIONAL SCENARIO (INDIA)

In India, as elsewhere, “AIDS is perceived as a disease of ‘others’ – of people living on the margins of society, whose lifestyles go against social norms and are often considered ‘wrong’ or ‘sinful’. Social reactions have been quite negative; for example, 36 per cent of respondents in one study felt it would be better if infected individuals killed themselves” (Mahendra, et al., 2007). Given the central role that service settings and providers play in making testing, treatment, and care available to PLHA, it seems critical to understand the damaging consequences of stigma and discrimination and to avoid engaging them as much as possible.

As in other cultures, HIV/AIDS discrimination in India is often perpetrated by well-educated people (Paul, 2006). In Kerala, a parish member who died of AIDS was refused burial rites by a local church, and children found to be HIV+, have been denied admission to schools. Although it is now illegal to refuse employment based on HIV status in India, many organizations still perform HIV screening tests on

prospective employees, and workplace discrimination continues to be reported. PLWHA also continue to face discrimination in hospitals. Gujarat, with a concentrated epidemic, reports an average of three cases of medical discrimination against the PLWHA a month despite the presence of over 5000 physicians trained in HIV management. Similar reports have surfaced from other areas. In addition to being denied timely medical attention, healthcare discrimination forces PLWHA to approach quacks, or to hide their seropositive status from attending physicians (Paul, 2006).

Examining practices by health care workers in hospital settings, Mahendra, et al (2006) uncovered four types of discriminatory practices:

1. Testing patients for HIV without informed consent and proper counselling

“I don’t think consent matters that much. Theoretically, it is nice to talk about consent, but practically it is not possible. Many people do not know how to read or sign. In that case, consent does not really matter”

2. Routinely informing families about a patient’s HIV status

The responses include the following: “If the result is positive, then the doctor tells the patient as well as his relatives;” “Everybody, starting with doctors, nurses, sweepers, to the ward boys, who work with patients, all come to know about the status of the patient;” and “All the staff in the ward knows my status. The doctor tells the nurse, the nurse tells the ward staff, and they tell everyone else about me.”

3. Breaching patient confidentiality by the use of markings or labels on beds and files

Labels such as “High Risk”, “Barrier Precautions”, and “*DANGER*” were posted on top of patient’s beds. A mother wailed, “*Bed labels were put up for my baby. All who could read the label knew the status of my baby.*” A health care provider confessed, “*We move the HIV positive patient outside the room into the corridor so that he is kept separately from other patients.*” According to one doctor, “*You are concerned about human rights of people who are going to die soon ... (but) they are only a small fraction of patients. What about my right as a doctor – don’t I have the right to survive?*”

4. Taking unnecessary precautions

Sometimes, these are due to the lack of adequate supplies for infection management; other times, they appear to be very extreme steps. Some of the responses reflecting this is, “*We burn the linen of the patient. Even utensils of HIV-infected patients are thrown away.*”

Mahendra and colleagues (2006) also reported on health worker attitudes toward PLHA, including blaming, shaming, and disparaging patients’ social class. One doctor commented “high risk population usually means, lower class people – they live in slums, in unhygienic conditions. These people sleep with anybody. Among this class of people, extramarital affairs are common, and so also are drug users and sex workers” (Mahendra et al, 2006).

The International Center for Research on Women, in a study conducted in Andhra Pradesh, focused on community-based health care providers (HCPs), who often provide primary care to PLHAs, who are poor and living in rural environments (ICRW, 2006). Key baseline findings from the study concluded that over 70 per

cent of HCPs avoid treating PLHA, because they fear infection. Some claim that they can cure AIDS, thereby misleading their communities. Most discriminate against PLHAs in hospital settings, and gender-based violence is considered normal and acceptable. One HCP asked “Why are you wasting my time by asking these questions? Men beating their wives is normal, an everyday occurrence. Why are you worried about it?”

3.5 IMPLICATIONS FOR SOCIAL WORKERS

There is an old saying, originating in mindfulness, stating “when conditions are sufficient, something will arise.” Essentially, this means that whatever manifests can be understood better by examining its root conditions. As we can see from topics addressed in this Unit, there is much to be understood, and more importantly, much to do in response to stigmatizing and discriminating circumstances surrounding HIV/AIDS. For social workers, developing an awareness regarding the true nature of the problem is a necessary, but insufficient start. As we will see in Unit 4, strategies and techniques are available, showing the way to addressing these critical social concerns at many levels.

Much good work is underway to counter the disturbing practices of shaming and blaming. The ICRW project goals of increasing knowledge, awareness, and sensitivity of HCPs regarding HIV/AIDS and gender-based violence, building capacities, and commitment of HCPs to address these issues within their practices and their communities, and designing training materials to assist in achieving these ends are but a start. Mahendra and colleagues (2006) are similarly working with the Horizons Program, SHARAN (an Indian NGO), and the Institute for Economic Growth in collaboration with the National AIDS Control Organization (NACO), to improve responses to HIV/AIDS stigma in the Indian context. A registered medical practitioner in the ICRW project states the challenge for social workers clearly:

“We should pass on these ideas to people in the workplace, at the water tap, in tea shops, and in women’s meetings. We can only solve these problems if we get others involved. There will be no change unless the whole community is committed to change.”

Check Your Progress III

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

- 1) As in other cultures worldwide, India is waking up to the crucial challenge of stigma experienced and expressed by health care and social service providers. How do the incidents illustrated in these brief examples make you feel. Are they accurate? Distorted? Who must be involved in discovering the truth of the situation in your community?

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3.6 LET US SUM UP

HIV/AIDS health care and social service providers are, in fact, human just like anyone of us. They live in the same communities, grow up in the same families, and are taught the same values and expectations about leading a good and honourable life. As a result, providers are also prone to the same tendencies to stigmatize and discriminate against PLHA and vulnerable populations. In this unit, we have seen examples of such thoughts and behaviours, and considered their emotional aspects. What we feel often determines how we think and behave, even when it counters our best intentions. We have also seen that education, in itself, is not sufficient to overcome many of these negative potentials. Exposed to a life-threatening virus, and risking judgment and rejection by our communities and loved ones, it is understandable that social workers would sometimes lapse into behavior they know to be irrational and even regrettable.

Through understanding the universal, and cross-cultural manifestation of these responses to fear, we can achieve a starting point in readiness to change. In Unit 4, we look more closely at international projects developed to improve the environment surrounding HIV/AIDS services, identify goals for future work, and consider a model helping us to grow personally as we develop professionally as social workers.

3.7 FURTHER READINGS AND REFERENCES

1. Abell, N., Rutledge, S., McCann, T., & Padmore, J. (2007). Examining HIV/AIDS provider stigma: Assessing regional concerns in the islands of the Eastern Caribbean, *AIDS Care*, 19(2), 242-247.
2. Caribbean Epidemiology Centre (CAREC) (2004). *A health promotion approach to reducing stigma and discrimination: A framework for action*. Retrieved March 21, 2005 from: <http://www.carec.org/pdf/sdframework.pdf>
3. International Center for Research on Women (August, 2006). *Reducing HIV/AIDS stigma, discrimination, and gender-based violence among health care providers in Andhra Pradesh, India*. Information bulletin. Retrieved November 13, 2008 from: http://www.icrw.org/docs/2006_ib-reducingviolenceandstigma.pdf.
4. Mahendra, V. S., Gilborn, L., Bharat, S., Mudoi, R., Gupta, I., George, B., Samson, L., Daly C., and Pulerwitz, J. (2007). Understanding and measuring AIDS-related stigma in health care settings: A developing country perspective, *Journal of Social Aspects of HIV/AIDS*, 4(2), 616-625.
5. Mahendra, V. S., Gilborn, L., George, B., Samson, L., Mudoi, R., Jadav, S., Gupta, I., Bharat, S. and Daly C. (2006). "Reducing AIDS-related stigma and discrimination in Indian hospitals," *Horizons Final Report*. New Delhi.: Population Council. Retrieved November 9, 2008 from: <http://www.popcouncil.org/pdfs/horizons/inplhafriendly.pdf>
6. Ogden, J., & Nyblade, L. (2005). 'Common at its core: HIV-related stigma across contexts'. Retrieved September 9, 2006, from: http://www.icrw.org/docs/2005_report_stigma_synthesis.pdf#search=%22common%20at%20its%20core%22

7. Paul, N. (2007). Discrimination against people living with HIV/AIDS in India: Educated persons as Perpetrators. *Journal of Infection*, 54(1), 103-104.
8. Rutledge, S.E., Abell, N., Padmore, J., & McCann, T. (2009). AIDS stigma in health services in the Eastern Caribbean. *Sociology of Health Care & Illness*, 31(1), 17-34.
9. Rutledge, S., & Abell, N. (2005). Awareness, acceptance, and action: An emerging framework for understanding AIDS stigmatizing attitudes among community leaders in Barbados, *AIDS Patient Care and STDS*, 19, 186-99.
10. Varas-Diaz, N., & Marzan-Rodriguez, M. (2007). The emotional aspect of AIDS stigma among health professionals in Puerto Rico, *AIDS Care*, 19(10), 1247-1257.
11. Varas-Diaz, N., & Toro-Alfonso, J. (2007). Similar epidemics with different meanings: Understanding AIDS stigma from an international perspective, *Interamerican Journal of Psychology*, 4(1), 1-6.

3.8 ANSWERS TO CHECK YOUR PROGRESS

Check Your Progress I

- 1) Consider which “vulnerable populations” are most prevalent in your community (commercial sex workers, MSM, injection drug users, migrants). How are they regarded generally by dominant members of the community? How would the others think of, or treat them differently, if they were known or believed to be HIV+? Do some groups have more internal or external support to help them counter the risk of rejection by the larger community? If so, are they more or less likely to be tested or to disclose?
- 2) Anger, guilt, grief, relief.all of these are possible emotional responses to realizing that “others” have HIV, while “we” do not. Fear and resentment may follow if we fear that one day “we” may become one of “them”, or at least be treated as if we were. Similarly, compassion, empathy, care and concern are possible positive responses to being aware of others HIV status. Which are most common for you?

Check Your Progress II

- 1) All of us are likely to express a feeling or thought, or communicate through our body language. When we notice such behavior or ideas in ourselves or others, accepting them for what they are rather than condemning ourselves for having them is a first positive step forward. Learning to talk about them with others can help everyone learn how to do better in the future.
- 2) The right to self-determination, and respect for the dignity and worth of each person are strong guidelines helping us remember that HIV status is private information, only to be disclosed by the HIV+ person himself, or by someone given specific permission to do so. There can be many seemingly good reasons to try and protect someone who is at risk of being infected from others who are. When we remember the very large impacts of stigma and discrimination on PLHA, we can learn to restrain ourselves and guard their information until they are ready and able to let others know.

Check Your Progress III

- 1) There is another old saying among HIV/AIDS activists: “Nothing about us without us”. This means that if we want to know the truth of a situation, we must be willing, as the authors and researchers in these studies are attempting to be, to look for and seek to understand unpleasant realities. While Ogden and Nyblade have written that stigma is “common at its core”, they also acknowledge that many cultural variations exist. One way to discover the truth is to ask providers, PLHAs, their family members and loved ones to share their experiences in seeking HIV/AIDS information, support, and treatment. Then, we must listen openly and without judgment, to what they have to say, even when it is not easy to hear.

UNIT 4 RESPONSE STRATEGIES FOR SOCIAL WORKERS

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4.0 OBJECTIVES

Working together, governmental and non-governmental organizations (NGOs), have developed a growing number of strategies for measuring the expression of HIV/AIDS stigma, and also in intervening to reduce its impact on the quality of health care and social services. In this unit, we will:

- review existing models tested in national and international contexts
- identify links and references to detailed descriptions of these freely disseminated programs
- learn about the Awareness/Acceptance/Action Model, adapting mindfulness principles to addressing provider stigma and discrimination
- consider implications for social work roles across the spectrum of social service delivery, and
- reflect on the need for long-term strategies addressing this persistent, deeply rooted aspect of the HIV/AIDS pandemic

4.1 INTRODUCTION

In the preceding units, we have examined the roots of stigma and discrimination, and considered how they have evolved in the context of HIV/AIDS. Acknowledging the common features of shaming and blaming across cultures, we have also seen many specific illustrations of how felt and enacted stigma harm both the individuals targeted for discrimination and the settings they may turn to for education, testing, and treatment. The impact is far reaching, and compounded by previously existing tendencies to marginalize those who by tradition, behaviour, or social characteristics are already treated as lower class or outcast. As Knight has noted, “The epidemic will be halted only if AIDS is placed firmly in mainstream development work. Major drivers of the epidemic such as poverty, inequality, especially of women in most societies, and stigma have to be tackled” (Knight, 2008).

In this unit, we shall attempt to look closely at what can and must be done to improve the climate of service and care for PLHA, as well as those thought to be most at risk for HIV. As previously indicated, much good work is already underway, and a rapidly expanding literature, much of it available freely online, offers many guidelines, principles and practices that can be applied or adapted right away. The first obstacle, in many ways, is the lack of will and determination to move forward. Subsequent to the identification and overview of some of the major tools available to confront stigma and discrimination, we will consider factors that inhibit or enhance social workers readiness to better understand their own tendencies and fears, and to act constructively to address them. From these will emerge anti-stigma strategies social workers can consider as they take on more professional and influential roles in their communities.

As we will see, working with stigma and discrimination requires a deeply personal capacity for reflection, understanding, and compassion. Success requires determination to encourage governmental and non-governmental service organizations (NGOs), and the communities they serve, to more fully embrace the needs of those afflicted with HIV/AIDS. This is not an easy job, nor will lasting results be quickly achieved. Success in fighting the social and medical aspects of the pandemic depends upon long-term commitment to individual, institutional, and cultural change.

4.2 EXISTING MODELS: WHAT TO INCLUDE AND WHERE TO START

Over time, successes and false starts with stigma interventions, have begun to yield some “lessons learned”, helping us focus our efforts and move efficiently towards positive change in ourselves, and in our communities. Researchers at the Royal Tropical Institute in The Netherlands have identified a set of stigma reduction strategies associated with specific levels of intervention (see Figure 4.1). Each of these suggest opportunities for social work involvement, and implies points of entry for reducing stigma and creating safer environments for PLHAs. The various strategies link to a range of social work roles, from individual or group counselling, through education,

Level	Strategies
Intrapersonal level	Treatment counselling Cognitive-behavioural therapy Empowerment Group counselling Self-help, advocacy and support groups
Interpersonal level	Care and support Home care teams Community-based rehabilitation
Organizational/ institutional level	Training programmes (New) policies, like patient-centred and integrated approaches
Community level	Education Contract Advocacy Protest
Governmental/ structural level	Legal and policy interventions Rights-based approaches

Figure 4.1: Stigma Reduction Strategies
Source: Heijnders, M., & Van der Meij, S., 2006.

advocacy, and policy-based engagement. Each has a part to play in improving the context of care, and challenges us to understand our own prejudices and fears as we work with others to eliminate obstacles to accessing needed resources.

The Toolkit for Action

In previous units, we introduced the combined efforts of the Academy for Educational Development, International Center for Research on Women, and the International HIV/AIDS Alliance (AED, ICRW, & Alliance, 2007) as an example of progress in confronting HIV/AIDS stigma. Their *Toolkit for Action*, available online at no charge, was founded on broadly-based international research, and designed in its original version to address both individual and structural causes of stigma. In the beginning, workshops were intended to create safe environments where participants could talk freely about difficult issues, and to help them address the following goals:

- exposing stigma and assist in resolving contradictions, such as those between intentions and behavior;
- enhance practical knowledge to reduce fear of casual transmission;
- provide a safe forum to discuss sensitive topics (sex, death, drug use, inequity);
- agreeing to talk about stigma;
- enhancing the capacity of people living with HIV and AIDS (PLHAs) to challenge stigma in their lives;
- provide a process to determine appropriate and feasible individual and community responses to stigma; and
- provide comprehensive, flexible tools for organizations, to strengthen staff skills and develop or strengthen interventions to reduce HIV-related stigma (Ogden & Nyblade, 2005).

As the *Toolkit* has evolved, emphasis has been expanded to include twelve steps to stop stigma (refer Figure 4.2). These steps reflect the awareness that stigma and discrimination, even among health care and social service providers, can only be successfully addressed when the problem is approached comprehensively, including attention to individual, family, and community dynamics. As one registered medical provider in India stated (in terms that clearly apply to social workers),

“We should pass on these ideas to people in the workplace, at the water tap, in tea shops, in women’s meetings. We can only solve these problems if we get others involved. There will be no change unless the whole community is committed to change” (ICRW, August 2006).

Figure 4.2: Twelve steps to stop stigma

1. create a sense of community, and build openness and safety to talk about HIV and AIDS, stigma and sex
2. name the problem - get people to describe how stigma occurs in different contexts
3. getting people to own the stigmatising disease; realising “*We are all part of the problem*” and helping people read and reflect on their own words, attitudes and actions towards PLHIV.
4. help people see the effects of stigma on PLHIV, families, children and communities - how it hurts those stigmatised and indirectly hurts those who are stigmatising

5. analyse the root causes of stigma - e.g. fears and misperceptions about HIV and AIDS, moralising attitudes, power and poverty - and how it particularly affects women, children and poor people
6. address fears and misconceptions about getting HIV through non-sexual casual contact, and what it means to live with HIV and AIDS
7. challenge the judging and blaming built into stigma and help people explore their own attitudes
8. build commitment to changing attitudes, and doing something significant about stigma.
9. help PLHIV overcome self-stigma, build up self-esteem and develop skills necessary to provide leadership on anti-stigma action
10. help family members learn the attitudes and skills needed to provide care and support for PLHIV and children living with HIV and AIDS (CLHAs).
11. develop strategies and plans for taking action against stigma
12. action and the monitoring of action

Source: International HIV/AIDS Alliance (2007). *Understanding and challenging HIV Stigma: Introduction and Module A.*

And as we have seen in previous units, the common experience of “knowing, but not quite believing” that HIV can only be transmitted through specific sex, blood, or mother-to-child exchanges (Ogden & Nash, 2005), must be continually addressed by trusted and powerful sources. Experience shows that repeated exposure to accurate information in a relaxed manner, is essential to overcome providers’ fears that they risk acquiring the virus through casual contact. This “return to basics,” illustrates that stigma interventions must respect subjective interpretations of medical information. Ultimately, while “facts are facts”, what we make of them is more important. Because so much of the stigmatizing process is emotionally driven, and enacted in community contexts, where many strong beliefs compete with evidence in shaping social norms, social workers must frequently re-assess the attitudes and views of their intended audiences. They must tailor their interventions to repeat the basics, as much as needed to establish trust and comfort.

Engenderhealth

With support from the United States Agency for International Development (USAID), Engenderhealth has developed a training module titled “*Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers*” (Engenderhealth, 2004). This document, available free of charge online as both a trainer’s manual and a participant’s handbook, starts with the assumption, that not all the health care provider’s fears are unreasonable. A good many of them are based on “real risks due to their lack of access to supplies and training in infection prevention and standard precautions” (Engenderhealth, 2004). Providers, they note, are subject to the same myths and pressures as their community counterparts, and seldom receive the support they need to rise to the challenges encountered daily in HIV/AIDS services. As a provider in Tanzania said,

“Health workers are expected to know, feel, and act in certain ways. But what has prepared them for this (HIV/AIDS)? Many health workers have the same information the man in the street has... (that) the disease is fatal! Knowledge and skills, yes, that they have. It is part of many training programmes. But what

about preparing them to come to terms with their fears and anxieties about their own sexuality and morality, their prejudices?” (Engenderhealth, 2004)

Driven by such concerns, health care providers are at risk of reacting, by:

blaming or mistreating patients;

breaching their confidentiality;

failing to cooperate with colleagues known to be HIV+;

demanding clients be tested for HIV as a precondition of providing services;

discharging them immediately (regardless of health status), once the test results are known;

segregating or isolating them from other patients, even when there is no clinical compulsions to do so; or

Withholding, or reducing the quality of treatment in comparison to that given those who are not HIV+.

Social workers might raise the same concerns about their professional preparation, and be at risk of similar misbehavior as a way of managing the resulting distress. The Engenderhealth manuals respect the realities of these concerns, and provide many workshop sessions combining elements of theories in social psychology, summarized in earlier units with scenarios and questions designed to encourage greater awareness and understanding. These are paired with small group activities and brainstorming sessions designed to identify not only causes of undesirable reactions, but also possible remedies or alternatives.

In a unit titled “Moving beyond ‘us’ and ‘them’”, for instance, workshop participants would be offered two vignettes, one negative, and another positive. The first vignette illustrated the following (Engenderhealth, 2004):

“A woman came to the hospital in labour. At a certain point in her care, the doctor found out that she was HIV+, and refused to assist in the delivery. He didn’t say anything to her. He just left the hospital. She was forced to seek care elsewhere.”

The second illustration was as follows:

“A man came to the health post because he had a troublesome cough that would not go away. He worried all the way there about telling the nurse that he is HIV+. He thought they might ask him to go away. In the end he told her, and she praised him for doing so, as it was important to know. She treated him just like she would any patient, with dignity and respect, in a caring manner.”

After reflecting on these two stories, participants were engaged in discussion. The first round focussed on feelings, and featured questions such as “how would you feel in this situation”, “what would your reaction be”, and, “if you left, what would you do for care?” The second round encouraged generating solutions, such as “what can we do in our facilities, to make sure that positive experiences are the norm for our clients?”

Materials such as these have been tested in settings around the world, and are showing promise, as tools for raising awareness about stigmatising processes, and encouraging reflection on ways that discrimination can be reduced in healthcare and social service environments.

Check Your Progress I

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

- 1) Imagine a community where there is no opportunity for PLHAs could gather to talk about their worries and concerns. The *Toolkit for Action* emphasizes the importance of creating a safe environment for discussion of sensitive topics. If you were trying to provide a support group that included, for instance, HIV+ grandparents who had been forbidden by their children from touching or even visiting with their grandchildren, what would you need to consider?

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- 2) Reflect on the illustrations contained in the Engenderhealth materials. Think of a story that might more specifically relate to a social work interaction. Show how your story provides opportunities to better understand the viewpoint of the client, and suggest some remedies that might improve his or her experience with the social worker.

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4.3 AWARENESS, ACCEPTANCE AND ACTION: MINDFULNESS PRINCIPLES APPLIED TO PRACTICE

Building awareness of inner thoughts and feelings is not as easy as it sounds. Some social service and healthcare providers are more inclined than others to look within, just like friends and family members in the communities around them. In the same way that our fears may block us from accepting medical information about how HIV is and is not transmitted, they may also inhibit us from fully appreciating the prejudices and attitudes we carry within. And even when we do not notice them, or accept their implications for the quality of our work with others, PLHA and other vulnerable populations are often very aware of how our thoughts and feelings shape our abilities to serve them in a positive manner. As we noted in Unit 3, “when conditions are sufficient, something will arise.” Our awareness of our own internal processes and acceptance of their implications for our treatment of others, creates conditions determining whether positive or negative interactions will follow.

To better understand these dynamics, Rutledge and Abell (2005) proposed the Awareness/Acceptance/Action Model (AAAM) (refer Figure 4.3), introducing three steps for responding to HIV/AIDS stigma. These strategies, based on the Buddhist philosophy, “suggest a strategy for better understanding self and situation as a precursor to responding, rather than reacting, to life experiences” (p. 190).

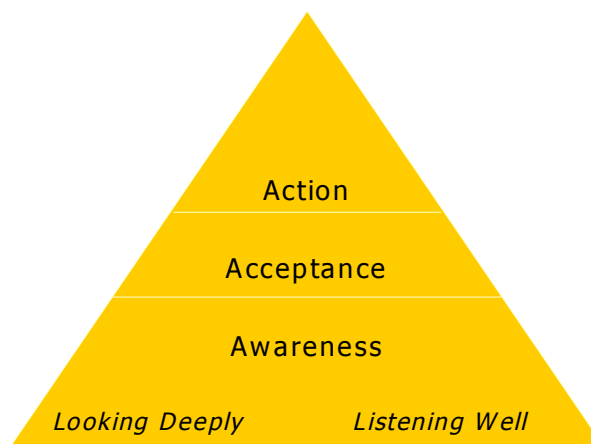


Figure 4.3: Awareness, Acceptance and Action Model

Awareness

As Rutledge and Abell (2005) describe, the AAAM suggests a framework for intentional response in health care and social service settings. Following mindfulness principles, we would concentrate first on cultivating awareness. In mindfulness training, this implies two related steps: looking deeply and listening well.

Imagine a social service provider encountering a PLHA in an advanced stage of HIV-related disease. She or he may appear emaciated, or be actively coughing or sneezing. Looking deeply involves paying attention to the full range of one's initial experience, so as not to respond prematurely. Some of the considerations may include: "How am I feeling?", "What thoughts and associations do I have?", "How are these impacting my choices about how to deal with this person or situation?", "In the beginning of our practice of awareness, these initial questions may seem overwhelming, and understandably so."

HIV/AIDS presents a mixture of triggers uniquely associated with sex and death. One may introspect: "How did this person get this way? Should he or she be blamed?", "What risks am I taking by having contact with him or her?", "Could I become sick, too?", "Am I risking disease, social isolation, or even death for others and myself?" Such serious, normative reactions, can contribute to spontaneous, and sometimes poorly considered choices. While it is tempting to advise the provider to "get over" such responses, or "act maturely," human nature suggests otherwise. In mindfulness, ignoring the full expression of our initial reactions can set the stage for ill-considered and unintentional reactions, leading to discrimination against PLHA, and inhibiting us from effectively performing our roles.

The second step in awareness is listening well. Whereas looking deeply begins with understanding self in encounters with others, listening involves paying undistracted attention to a set of cues communicated by another. When attempting to understand the PLHA's needs and wishes, we must track speech content and tone, emotional expression, and body language. In mindfulness terms, preparation for listening sometimes references the notion of *emptiness*. In this context, it means not a vacuum or void, but a readiness to suspend prior judgments and learn from another through careful observation.

Listening without bias can be exceptionally challenging. Many aspects of HIV/AIDS, filtered through a variety of personal and social lenses, position us to view PLHA with suspicion or fear. Prior assumptions about sexual orientation, drug use, and morality may lead us to prejudge PLHA and their circumstances, restricting our abilities to hear them completely and to respond to their actual, rather than imagined

needs. In contrast, social work values emphasize starting where a client is, rather than where we imagine him or her to be.

Taken together, looking deeply at our own preconceptions, understanding their sources and implications, and listening well to PLHA may reduce the potential for misconceptions, and minimize the initial impact of stigmatizing thoughts and beliefs on service provision. Educating ourselves about the nature of HIV, the routes and means of transmission, the implications for testing, treatment, and caregiving, and the psychosocial complications faced by family, friends, professionals, and community members can enhance our ability to respond, based on facts rather than misinformation.

Acceptance

The second major component of the AAAM recalls a phrase made popular by ACT UP, an AIDS activist organization in the United States that popularized the slogan “Silence = Death.” To this, we add “Denial = Delay” to emphasize that time spent underestimating how we stigmatize PLHA inevitably slows our efforts to provide the best possible service. Whereas acceptance fully acknowledges the true nature of our stigmatizing attitudes and behaviors, denial (and the accompanying silence) represents our tendencies to close our eyes, or turn our backs on unpleasant and frightening realities.

Acknowledging the contradictions between what we know intellectually and feel or enact interpersonally can further complicate accepting the truth of our experience. HIV/AIDS stigma has encouraged many seemingly universal motivations to minimize or ignore the truth about ourselves in relation to others. Imagining that HIV infects and affects only “others” (whom we identify as “deserving” because of who they are or how they behave) delays accepting how generalized an epidemic has become. Furthermore, because “they” are inferior, “we” can justify delays in providing prevention, education, and care. This can be literally fatal to the infected, and unintentionally damaging to those who think they are beyond reach of the virus. Coming to grips with the full extent to which “they” are “us,” calls for a literal transformation of our self-awareness of who we are.

Whereas we might once have thought service to be a one-way transaction, it now becomes part of creating health-enhancing community environments. Consequently, practicing acceptance means that once we have become more fully aware (of the nature and prevalence of HIV, of our own biases and fears, and of the social and cultural attitudes and institutions that keep them going), we may become more focused on creating compassionate communities that support everyone’s well-being and health. This includes acceptance of our own unintentionally hurtful responses to PLHA. Wishing we were free of prejudice seldom makes it so.

Action

The final AAAM component emphasizes translating awareness and acceptance into intentional responses, rather than ill-conceived reactions, to PLHA. On the most personal level, individual action can include deepening awareness of our own prejudices, setting the stage for clearer thinking about HIV/AIDS services. How do my attitudes cloud my ability to see this situation as it *actually is*, rather than as I *imagine it to be*?

On an interpersonal level, action means committing ourselves to a compassionate service option. This includes respecting others as they are, and striving to listen

deeply to their true circumstances before making an action plan. Admittedly, this is extremely challenging when we have limited resources, fearful or hostile families and communities, and demanding or needy clients.

Finally, the AAAM encourages social action. This includes attending to social policies and institutions that, intentionally or otherwise, pose barriers to necessary and constructive responses. In the spirit of mindfulness, action is the necessary translation of awareness and acceptance into constructive and compassionate behavior.

Check Your Progress II

1) As you reflect on your own thoughts and feelings in relation to PLHA or those thought to be part of “vulnerable populations”, what, if any, negative thoughts or feelings do you notice? How easy or hard is it to accept that these are “true” for you?

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2) Compassionate action begins with an awareness that “we” and “they” are ultimately the same. In what ways do you consider yourself to be like or unlike a PLHA? Reflect on your hopes and dreams, and consider how they would or would not likely be shared by a PLHA. How, if at all, does recognizing common needs, desires, or goals change your thinking about treatment you might provide to a PLHA?

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4.4 IMPLICATIONS FOR SOCIAL WORK ROLES IN HIV/AIDS SERVICE DELIVERY

A number of strategies for reducing HIV/AIDS stigma were listed in Figure 4.1. Here, we elaborate on just a few real life situations, emphasizing social work roles and its impact of stigma and discrimination.

Prevention Education and Public Policy

In one North Indian city, a Chief Medical Officer expressed concern that the only way to successfully control the growing HIV/AIDS epidemic, was to quarantine everyone in the country who was HIV+. He knew for sure, that such people were not literally a public health threat to any of the citizens under his care, and that taking such a step would almost certainly backfire by causing those who knew their own status (or feared they might be positive), to hide or keep quiet rather than risk exposure. Still, his fear of being overwhelmed by a rapidly expanding health crisis, caused him to think of drastic reactions, rather than intentional actions. Social workers might be of assistance by helping the CMO see the futility of his proposal, while at the same time expressing understanding for his concerns. Appealing to both his humanity and his sense of reason might ease tensions, so better alternatives for improving his community’s health could be developed.

Counselling

Working with commercial sex workers requires that social workers gain access to hidden aspects of a community, assure those involved in desperate and high risk activities, that social workers can be trusted to concentrate on health concerns above all else, and associate with gatekeepers, who may find social workers difficult to trust. Knowing that sex workers may have grown accustomed to being threatened and mistreated by others, social workers must work hard to overcome presumptions of judgment and stereotyping, and not imagine that clients will quickly trust them with the truth. This is only one example of circumstances reminding us that relationship building is a necessary first step in meaningful counselling, and that it may take repeated contacts over time to establish bonds making it possible for clients to share fears and concerns, and for social workers to offer meaningful resources and support.

Continuity of Care

An HIV/AIDS hospice and treatment center in South India provided excellent, compassionate care. The social worker directing the agency insisted on inclusion of women first as family members responsible for the aftercare of their husbands, and second as primary patients themselves. He appealed initially to concerns about whether women who were excluded could be well-informed regarding the nutritional and other needs of their loved ones, and ultimately refused admission to males who kept their wives away from the health care environment. The result was an array of life-enhancing services for both men and women. Where once there had been only facilities exclusively for helping men in the end stages of AIDS, the community now enjoyed a fully functioning clinic, where some were returned to health and sent home to loving, capable families.

Advocacy

In Northeastern states, social workers found themselves caught in a dilemma. They could only move freely about the urban area they served if they first obtained permission from the insurgents who controlled the local drug trade. On the other hand, the police assumed that if the social workers obtained such permission (which they knew was essential to come and go in the community), then they must be part of the insurgency. In this complex context, the social worker attempting to advocate for the needs of PLHA had to persuade the insurgents that it was in their best interests to allow community members health to be looked after, while convincing the police that in doing so, they were not collaborating in illegal activity.

Advocacy becomes an even more challenging role, when the person is a member of the group being stigmatized within the community. For this reason, social workers need special respect for sexual minorities or others facing serious risks of rejection or punishment when they make their status known while advocating for the rights of PLHA. When these advocates are also HIV+, the risks are further compounded.

4.5 LONG-TERM STRATEGIES FOR URGENT PROBLEMS

Jonathan Mann, writing over twenty years ago on the evolution of the HIV/AIDS epidemic identified three phases (Mawar, Sahay, Pandit, & Mahajan, 2005). First, the silent phase, when the virus spreads unnoticed, and develops over many years without being widely recognized or understood. Second is the epidemic itself, taking years to mature, characterized by the rapid spread of infectious disease within and

across populations. Finally, in the third phase, the virus rises into public awareness, and explosive social, political, and cultural responses are characterized by exceptionally high levels of stigma, discrimination, and denial. These are the circumstances in which we currently find ourselves, and to which this block has been devoted.

In India, HIV/AIDS stigma is now “imposing severe hardships on the people who are its targets and it ultimately interferes with treatment and prevention of HIV infection (Mawar, et al., 2005). While these issues require urgent attention, addressing them will take a long-term commitment. Critical concerns include:

- a) attempting to theologically and morally blame a PLHA
- b) use of presumed “risk group” categories to give false assurance that “they”, and not “we”, are vulnerable to the virus, and
- c) problems related to enforcement of civil and human rights.

The latter lies at the heart of prevention and treatment programme success (Mawar, 2005). Advocacy and enforcement of human rights would minimize erosion of social, economic, cultural and political impacts of the pandemic. As indicated at the start, none of this will be easy. “Human nature” may be as old as the human race, and maturation into a full appreciation of the rights of others as equal to our own, will require stamina and determination to achieve.

Check Your Progress III

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

- 1) Reexamine Figure 4.1, and see if you can identify other roles and strategies for social workers. Can you think of examples of either helpful or harmful roles providers have undertaken in response to HIV/AIDS in your community?

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- 2) Addressing human rights can be intimidating, as it may mean looking beyond work with individual clients and considering larger issues that may pose greater threats to existing authorities. Reflect on issues you have seen regarding discrimination against others in your community based on their social status, gender, or sexual orientation. What would it take to “speak up” about such things publically, and what might you risk in doing so?

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4.6 LET US SUM UP

Social workers play a central role in responding to social problems. In this unit, we have seen that despite their best intentions and motivations, they may also contribute to the very problems they seek to address. Stigma and discrimination are deeply rooted in the human condition, as we seek to manage our fears by identifying targets

to blame and shame for our discomfort and distress. Since the virus takes no notice of our human limitations, the longer we deny the truth of our situation, higher the chances of its spread. In the context of HIV/AIDS, these dynamics have developed into a worldwide pandemic threatening the well-being and stability of entire societies.

Fortunately, as we have seen, there is much that can be and is being done to address the medical and social aspects of this disease. As a result, we have the opportunity to learn much about ourselves as individuals, and to better understand the aspects of our communities and cultures that are truly life-sustaining rather than life-threatening. In turn, as professionals, social workers are uniquely situated to take advantage of this knowledge, and convert it into strategies for confronting the crisis posed by HIV/AIDS. By looking to our own resources and creativity, and drawing liberally from the wealth of resources and strategies now emerging in the professional literature, we have the chance to truly make a difference in the public health challenge of our age.

4.7 FURTHER READINGS AND REFERENCES

1. Academy for Educational Development, International Center for Research on Women, International HIV/AIDS Alliance (June, 2007). *Understanding and challenging HIV stigma: Toolkit for Action* (Revised Ed.). Retrieved November 6, 2008 from http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=255.
2. Engenderhealth (2004). *Reducing stigma and discrimination related to HIV and AIDS: Training for health care workers*. Retrieved November 8, 2008 from: http://www.engenderhealth.org/files/pubs/hiv-aids-stis/reducing_stigma_participant_English.pdf
3. International Center for Research on Women (August, 2006). *Reducing HIV/AIDS stigma, discrimination, and gender-based violence among health care providers in Andhra Pradesh, India*. Information bulletin. Retrieved November 13, 2008 from: http://www.icrw.org/docs/2006_ib-reducingviolenceandstigma.pdf.
4. Heijnders, M., and van der Meij, S. (2006). The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health, & Medicine*, 11(3), 353-363.
5. International HIV/AIDS Alliance in India (September, 2008). *Together now India Newsletter*, 1(1). Retrieved on January 24, 2009 from: http://www.aidsalliance.org/graphics/secretariat/publications/Together_now_India_Newsletter1.pdf
6. International HIV/AIDS Alliance (2007). *Understanding and challenging HIV Stigma: Introduction and Module A*. Retrieved on November 8, 2008 from: http://www.aidsalliance.org/graphics/secretariat/publications/1Stigma_Intro&A.pdf
7. Knight, L. (May, 2008). *UNAIDS: The first 10 years*, Joint United Nations Program on HIV/AIDS (UNAIDS): Geneva, Switzerland. Retrieved November 9, 2008, from: http://data.unaids.org/pub/Report/2008/200810_first_10_years_en.pdf
8. Mawar, N., Sahay, S., Pandit, A., & Jahajan, U. (2005). The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma and discrimination and future needs, *Indian Journal of Medical Research*, 122, 471-484.

9. Ogden, J., & Nyblade, L. (2005). 'Common at its core: HIV-related stigma across contexts'. Retrieved September 9, 2006, from http://www.icrw.org/docs/2005_report_stigma_synthesis.pdf#search=%22common%20at%20its%20core%22
10. Rutledge, S., & Abell, N. (2005). Awareness, acceptance, and action: An emerging framework for understanding AIDS stigmatizing attitudes among community leaders in Barbados, *AIDS Patient Care and STDS*, 19, 186-99.
11. Sartorius, N. (2006). Lessons from a 10-year global programme against stigma and discrimination because of an illness, *Psychology, Health, & Medicine*, 11(3), 383-388.
12. UNAIDS (2007). *Reducing HIV stigma and discrimination: A critical part of national AIDS programmes*. Geneva: Joint United Nations Programme on HIV/AIDS. Retrieved October 2, 2008 from http://data.unaids.org/pub/Report/2008/jc1420-stigmadiscrimi_en.pdf

4.8 ANSWERS TO CHECK YOUR PROGRESS

Check Your Progress I

- 1) This would pose a complex challenge. First, you would need a setting that allows for privacy, and has entrances or exits not easily observed by others. You would also need a way of letting PLHA in the community know such a group was forming, and a way to answer their questions and concerns about joining. Once the group had begun meeting, it would be important to establish understandings about respect and confidentiality, and to demonstrate that you were capable of monitoring group process to support non-judgmental, positive interactions.
- 2) As a brief vignette, imagine a scenario where a PLHA risks embarrassment or mistreatment if his or her HIV status is known. For example, a truck driver concerned about sexually transmitted disease and wondering whether he should use a condom and if so, where to get some. In this context, he might fear that others (i.e. you) would judge him for his immoral behavior, and also assume (even without a test) that he must be HIV+. First, what would your feelings or reactions be to such a person, and how, if at all, could you respond to his requests without condemning or refusing?

Check Your Progress II

- 1) This is not easy, and again, there are no "right" or "wrong" answers. The challenge is to look deeply into your own experience as you imagine or remember interacting with PLHA, and be honest with yourself about what you think or feel. Remember, prejudice and distancing are nearly universal across cultures. If you have difficulty noticing any areas of discomfort in your own experience, consider the possibility that you may not be accepting the truth about your reactions. If this is so, your "denial", intentional or not, may delay your maturation into a truly supportive and useful provider for the PLHA.
- 2) Whatever our differences, almost every human being longs for security, a comfortable home, loving family, and meaningful work. Is this true for you? Do you imagine it to be true for PLHA? If so, would you be more or less willing to listen deeply to their problems and concerns, and respond intentionally? If not,

might you be more likely to react based on prior assumptions about what they deserved rather than what they requested? In either case, how would your beliefs about differences from or similarities with them affect your decision to volunteer appropriate services whether or not they asked?

Check Your Progress III

- 1) There are many possible examples, including empowerment (for instance, working to help women improve livelihoods by generating income through home or communal industry) or community-based rehabilitation (through helping those in recovery from drug addiction to regain their ability to function as contributing members of society).
- 2) Deciding to speak up when we see others systematically deprived of basic rights (including the right to physical safety and security from harm) takes courage, and can be risky. Are you aware of women being subjected to violence in your community? Is this commonly accepted practice among some groups? What would you be risking, personally and professionally, if you chose to become actively involved? What are you risking, ethically and morally, if you do not?

UNIT 5 BEST PRACTICES IN HIV/AIDS PREVENTION AND EDUCATION

Nicole Cesnales*

Contents

- 5.0 Objectives
- 5.1 Introduction
- 5.2 A Brief History of HIV Prevention Programs in the United States
- 5.3 Prevention with Women
- 5.4 Prevention with Drug Users
- 5.5 Prevention with MSM
- 5.6 Prevention with Youth
- 5.7 Let Us Sum Up
- 5.8 Further Readings and References
- 5.9 Answers to Check your Progress

5.0 OBJECTIVES

After reading this chapter the reader will be able to identify the historical roots of HIV prevention methods in the United States with a clear understanding of how and why these interventions began. Furthermore, the reader will be familiar with US experience with empirically supported prevention interventions for high-risk populations, with particular emphasis on understanding of “what works”. Building on the initial ideas regarding interventions presented from the Western perspective, we will emphasize the emerging context in India and consider guidelines for best practices there. The goal here is to evaluate the intersection of these techniques, adapting successful strategies for the unique population and cultural characteristics in India. Finally, the learner will be able to identify the population most at risk for HIV in India and will begin generating ideas for social work supported prevention interventions.

5.1 INTRODUCTION

HIV prevention programs have been developed and tested worldwide since the onset of the epidemic, beginning in North America and spreading across the globe. As we will see in this unit, much has been learned through trial and error about best practices, and so now, the exchange of information is bidirectional, as social workers from around the world strive to learn from each other, on how best to serve their clients. In every country, a primary challenge has been determining what is needed, and adapting methods responsive to the specific cultural, social, economic, and political climates, in which they must be implemented.

In the previous units on HIV/AIDS, we have explored the basics of viral transmission and examined how certain segments of any population come to be seen as at “high risk” for acquiring the virus. Here, we will examine how evidence-based techniques for helping such persons understand their risk and how to minimize it, have been identified and applied. We will note specific techniques developed for women, drug

users, men who have sex with men (MSM), and youth. Briefly, we will overview their origins, use, and demonstrated effectiveness in the United States and India, appreciating the similarities and differences across cultures. Additional readings are identified for those seeking further detail.

5.2 A BRIEF HISTORY OF HIV PREVENTION PROGRAMS IN THE UNITED STATES

In 1981, the first cases of what is now known as HIV were reported in the United States. The populations hit hardest in the United States were men-who-have-sex-with-men (MSM), intravenous drug users (IDU), women (especially commercial sex workers and partners of IDUs), and ethnic minorities. Because of the stigma associated with risk factors for infection, there were (and continue to be) great barriers to overcome in developing effective prevention programs. In the beginning, the Centers for Disease Control and Prevention (CDC) worked to identify the cause of the infection, developed and disseminated treatment guidelines for infection, and worked to prevent the spread of further infections. Historically, these efforts focused on three approaches (Wolitski et al., 2006):

- (1) prevention activities directed at persons at high risk for contracting HIV;
- (2) HIV counseling, testing, and referral services, and
- (3) prevention activities directed at improving the health of persons living with HIV and preventing further transmission”

Primary Prevention

In the United States, prevention activities directed at those most at-risk for HIV started as grass-roots efforts among gay men in large metropolitan areas. The goals of these programs were to increase awareness about HIV/AIDS, dispel myths and ease fears about the spread of the disease, and most importantly, impart knowledge about how people can take precautionary measures against infection.

The CDC followed these efforts in the mid-1980's by generating public health messages tailored to youth, persons at increased risk for HIV including MSM and IDU, racial and ethnic minority populations, pregnant women, as well as health-care workers. These messages stressed the importance of abstinence, the consistent and correct use of condoms, avoiding sharing needles when injecting drugs, perinatal testing and treatment, and universal precautions in the medical field. While these messages were essential in initiating behavior change, infection rates continued to increase among those most at risk for infection. As a result, behavioural interventions were subsequently developed and refined to provide more intensive and targeted prevention techniques. In 1999, the CDC developed the *Compendium of HIV Prevention Interventions with Evidence of Effectiveness* (revised in 2003), to disseminate effective prevention methods to community agencies. The present unit would expose the reader to a brief overview of techniques studied and reported in the *Compendium*, and compares them to current efforts being carried out in developing nations. While each study reviewed here varies on the research methodology, each meets a standard of scientific rigour of best available evidence.

HIV Counseling, Testing, and Referral Services

In 1985, the US Food and Drug Administration (FDA) implemented wide spread testing for HIV-antibodies in blood banks, health departments and health clinics

throughout the United States. Testing of individuals includes anonymous or confidential screening, risk reduction counselling and, on HIV+ results being available, referral for treatment. Originally, testing required two visits. First, the individual was screened for risk factors, counselled on risk reduction, and a blood sample was drawn. In about two weeks, the individual would return for results. This two week long delay, often resulted in attrition, with as many as 50 per cent of the individuals failing to return for their test results (Branson et al., 2006). Since that time, many developments in testing procedures have occurred. Most promising is the development of rapid testing. An oral swab collected during the screening, allowed results to be provided within 20 minutes. During the 20 minute wait, risk reduction techniques are discussed. While this new test has greatly reduced attrition in testing and screening, there was still concern that not all individuals at risk for HIV, were being screened. To address this concern, the CDC has recommended that HIV screening be adopted into routine medical care for all individuals. Recommendations further support the development of programs to make HIV testing and counselling more attractive to those at highest risk. This often involves testing in non-traditional settings such as juvenile detention centers, churches or temples, and on the street through mobile health education.

Prevention with HIV Positive Individuals

Historically, prevention efforts in the United States focused on educating those at risk for infection, aiming to reduce their risk and further prevent the spread of HIV. Public health campaigns and messages were directed to individuals who were not infected, but at risk for infection; gay men, intravenous drug users, and women, for example. However, in 2003, the CDC made recommendations to shift prevention efforts to HIV+ people. Often referred to as secondary prevention, these efforts aim to reduce transmission of infection among those at highest risk for infection (the known partners of HIV positive individuals) and to also reduce the risk of re-infection among positive individuals. The impetus for this change was that despite twenty years of prevention efforts, diagnosis of new infections in the United States held steady at an estimated 55,000 individuals per year for the last decade (Hall et al., 2008). Furthermore, evidence revealed that while individuals reduced their risk for infection after receiving prevention messages and counseling, the change in behavior was not sustained over time (del Rio, 2003). The goals of secondary prevention are to promote self-protection, partner protection, and disclosure to partners, and the early detection and referral for treatment. While studies suggest that prevention with positives is possible in India (Mcgrath et al., 2007) overcoming stigma to implement this type of intervention is a challenge.

Check Your Progress I

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1. In the United States, what three targeted approaches have prevention guidelines focused on?

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2. What is the difference between primary and secondary prevention?

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5.3 PREVENTION WITH WOMEN

United States

Prevention efforts in both the United States and in developing nations have targeted women for many reasons. Women often live in situations that do not afford them the same power as men. Furthermore, women are biologically at higher risk for HIV infection than men, due to more accessible permeable membranes during sexual penetration. Finally, to reduce mother to child transmission, prevention interventions target women who are pregnant or may become pregnant.

Interventions with women in the United States vary. The most frequently employed intervention involves group level cognitive-behavioral risk-reduction skills training. Group interventions that stress gender pride, personal responsibility, sexual assertiveness and communication, condom use, and coping skills showed improvement in consistent condom use among African American women (DiClemente & Wingood, 1995). The most notable of these interventions is the Sisters Informing Sisters About Topics on AIDS (SISTA) intervention. Participants in the SISTA program increased condom use and assertiveness with partners (DiClemente & Wingood, 1995). The overwhelming evidence supporting this intervention has resulted in the CDC adopting and promoting this intervention.

Research demonstrated that group sessions with inner-city, single, pregnant women also resulted in an increase of condom (Hobfoll, Jackson, Lavin, Britton, & Shepherd, 1994) and a decrease in unprotected sex (Kelly et al., 1994). These group interventions incorporated role playing and viewing short videos, and stressed skill building and behaviour change. Baker et al (2003) demonstrated that skills training is more effective in reducing sexually transmitted infections than health education alone.

India

Many socio-economic factors contribute to increased risk for HIV among women in India. Strict gender roles that limit a woman's power in sexual relationships can lead to violence and sexual exploitation. Women in India have limited control in negotiating safer sex practices. Furthermore, women may have limited access to information regarding HIV, and preventive and protective resources, such as condoms and health care. Women living in rural areas of India are not utilizing prenatal testing for HIV (Sinha et al., 2008). Reasons include lack of information and inadequate resources for HIV testing. Another concern is the social costs incurred by women who test positive for HIV. Women are often blamed for spreading HIV to family members and face exclusion from their husband's household. Clearly, the stigma

associated with an HIV diagnosis for women can be devastating. Pant Pai et al (2008) highlighted the barriers to HIV testing, and intervened by providing on-demand rapid testing to all women who appeared at one rural hospital for delivery. Rapid testing was available 24 hours a day, seven days a week. Ninety-eight percent of the women approached for this study accepted HIV testing, with 15 women testing positive. These women were provided with prevention of mother-to-child HIV transmission (PMTCT) measures. As a result, 13 infants were HIV negative at birth, and at one and four months follow-up. Two infants were HIV positive at birth and died within a month of delivery. The implication here is that HIV prevention counselling and testing with pregnant women is essential for the prevention and control of HIV infection among the unborn children. While this most recent study demonstrates that testing of pregnant women in rural hospitals is feasible, The Prevention of Parent to Child Transmission of HIV/AIDS (PPTCT) programme was started in India in 2002. It offers counselling and testing to pregnant women in 11 major hospitals in the five high HIV prevalence states (NACO, Prevention of Parent to Child Transmission section, para. 1).

The National AIDS Control Organization (NACO) in India, has identified female sex workers (FSW) as one of the populations at highest risk for infection, and has developed targeted interventions. These aim to provide awareness of HIV and promote safer sex techniques, through peer-led community outreach and referral for STI treatment; as well as through empowerment involving advocacy, education, crisis management, and “ownership” of prevention services by FSWs.

The most notable intervention with FSW in India is the Sonagachi Project (Jana, Basu, Rotheram-Borus, & Newman, 2004). Based in Calcutta since 1991, the Sonagachi Project addresses community, group, and individual factors. Community level interventions identified sex workers as key stake-holders and stressed political advocacy. Group-level interventions employed peer-outreach workers who develop social relationships with FSW. The outreach workers inquired about the immediate health problems of the FSWs, assisted in resolving them, disseminated HIV information as well as distributed condoms, as well as provided medications to FSW for STIs. Individual interventions emphasize skills and competencies, social cognitive perceptions, and social service delivery to eliminate barriers (e.g. illiteracy and financial stress).

The skills and competencies stressed by the Sonagachi Project include HIV and STI awareness and prevention techniques, including correct and consistent condom use. Outreach workers modelled positive outcomes, most importantly, self-respect. Empowerment of FSW is the foundation for success. Changing perceptions involved adopting a set a rights for FSW. These include the right to speak out, good health, freedom of movement, fulfillment in a relationship, and the right to educate their children (Jana et al., 2004). Changing the FSWs’ self-image resulted in enhanced hope, as well as empowerment to change high-risk behaviors.

Program designers stress that effective prevention efforts, must be cost effective, useful, realistic, evolving, and sustainable (Jana et al., 2004). Until treatment for STIs is more common and available, efforts such as the Sonagachi Project are rare, but essential in changing risk behavior for HIV infection.

Check Your Progress II

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1. What is the most frequently employed prevention intervention for women in the United States?

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2. What population is considered at high risk for HIV infection in India? Why?

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5.4 PREVENTION WITH DRUG USERS

United States

Considering the fact that drug users are at an increased risk for HIV infection, studies have evaluated prevention interventions tailored for them. Though still dramatically stigmatized in the United States, substance abuse treatment is available. Treatment frequently entails inpatient detoxification and psychological counselling. It is during this treatment that HIV counselling and screening may be undertaken. However, many drug abusers do not seek this treatment, limiting opportunities for HIV prevention interventions and requiring creative alternatives. One early study (Des Jarlais, Casriel, Friedman, & Rosenblum, 1992) employed group sessions to non-injection heroin users in a community store front located in a high drug trafficking area. The groups presentations and role playing that ensued, resulted in the participants being less likely to inject drugs. Other effective group interventions include women in methadone maintenance programs (El-Bassel & Schilling, 1992). The five-session curriculum entails HIV transmission and prevention, condom use, and assertiveness training. Assertiveness training advocates for the expression of the right to refuse sexual advances and to negotiate safer sex practices. At the end of the sessions, women reported increased condom use with their partners. While this model may not be appropriate for women living in India, there are components that can be adapted in a culturally sensitive manner to those most at risk.

More recent interventions include the Self-help in Eliminating Life-Threatening Diseases (SHIELD) Project (Latkin, Sherman, & Knowlton, 2003), incorporating social networking and peer outreach among both HIV positive and HIV negative

current drug users. Participants were trained to provide outreach and risk-reduction counselling. SHIELD stresses on developing a sense of community for current drug users, and emphasizes harm reduction aiming to decrease the potential dangers and health risks associated with risk behaviour while at the same time recognizing that the risk behaviour itself may not be eliminated entirely. “Throughout the intervention, participants were encouraged to conduct HIV education and advocate risk reduction among their sex and drug partners, family and friends, and other community members” (Latkin et al., 2003, p. 334). Participants reported less sex and drug risk behaviors six months following the intervention.

India

NACO has identified IDUs as being at highest risk for infection in India, endorsing detoxification and rehabilitation, needle exchange, and access to health services to IDUs to reduce risk and prevent further disease transmission. Partners of IDUs are also at increased risk for infection. A study in Manipur demonstrates how much these individuals are at risk. “Within seven years of the onset of an explosive HIV epidemic among IDUs, 45% of the wives of HIV positive IDUs acquired HIV through sex within monogamous marital relationship” (Panda, Azim, Rehman, Poudel, & Chaudhuri, 2007, p.896). Clearly, prevention interventions among IDUs are needed. Methods to achieve prevention goals are similar to those employed with FSW; peer led community outreach and information dissemination, referral health services, and community-building. Still, the stigma of substance use is a formidable barrier to effective prevention efforts.

Community building calls for involving key stakeholders, including IDUs, local officials, and health care providers to communicate issues and concerns and developing consensus. Hangzo et al. (1997) developed an intervention with IDU in Manipur. To successfully implement the intervention, researchers first worked with community officials to prevent police and military harassment of outreach workers and IDUs. Next, outreach to IDUs utilising the social networks was undertaken and it included family and friends. Outreach workers from varying ethnic backgrounds were trained to conduct prevention outreach in the community. Outreach workers distributed prevention information and made referral for medical care, meeting IDUs in shooting galleries, drop-in centers, treatment centers, and jails. This study clearly demonstrated that a community level intervention with IDUs can be implemented.

Finally, the Society for HIV/AIDS and Lifeline Operation in Manipur (SHALOM) located in Churachandpur, is a community-based organization that conducts a syringe and needle exchange program (SNEP). Components of SNEP include a facility where IDUs can go to exchange used syringes for new ones and get free condoms, and outreach workers who assess social and medical needs. While this program is effective in reaching those IDUs, more than three-fourths of the users of SNEP were HIV positive and reported engaging in high-risk sexual behavior (Eicher, Crofts, Benjamin, Deutschman, & Rodger, 2000). These researchers encourage SHALOM SNEP to expand their outreach efforts to newer IDUs, and to increase sexual risk prevention education.

Check Your Progress III

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1. What is harm reduction? Can you think of several interventions that successfully incorporate harm reduction?

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2. What are some components of effective community building?

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5.5 PREVENTION WITH MSM

United States

In the United States, HIV first involved men-who-have-sex-with-men. The most common empirically supported methods for interventions include outreach in the community and small, peer-led groups. Kegeles, Hays, and Coates (1996) combined community outreach, a social marketing campaign, and a small peer-led group intervention to demonstrate that participants reduced frequency of unprotected anal intercourse. Small group interventions often employ role-playing and lectures to develop risk reduction skills. HIV risk reduction, behavioural self-management, assertiveness skill training, relationship skills and social support development are components of an effective intervention with MSM, resulting in reported reduction of unprotected anal intercourse and an increase in condom use (Kelly, St. Lawrence, Hood, & Brasfield, 1989).

In addition to skills-training, some small group interventions work to promote the social acceptability of safer sex (Valdiserri et al., 1989). Outreach efforts must be creative and adapted for the targeted population and intervention setting. Frequently, interventions take place where MSM socialize. Training gay men to effectively promote HIV risk reduction behaviors followed by disseminating this message to peers proved an effective intervention in gay bars (Kelly et al., 1991).

Other times, individual counselling may be the most appropriate intervention. Because MSM in the United States have been the most frequently targeted population for HIV prevention messages, interventions can become stale. Prevention fatigue has been cited as one possible reason that MSM continue to engage in high-risk behavior. To address this issue, Dilley, et al. (2002) adapted prevention messages during counselling and testing with MSM to create a new intervention with this population.

Participants were asked to keep journals of sexual encounters between counseling sessions, and to indicate reasons for engaging in unprotected anal intercourse. The primary focus was how participants justified unprotected sexual activity. At follow-up, participants reported a decrease in unprotected anal intercourse.

Clearly, both group and individual level prevention interventions MSM are feasible and effective in reducing unprotected sexual risk behavior. Determining whether these reduce rates of infection is harder. EXPLORE (Koblin, Chesney, & Coates, 2004) consisted of ten individual counselling sessions focusing on risk behaviour, including sexual and substance abuse. These sessions were highly intensive, and incorporated motivational interviewing and cognitive behavioral therapy (CBT). On completion, participants registered 18.2% fewer new HIV infections (Koblin et al., 2004).

India

Men-who-have-sex-with-men is a description of a sexual activity between two men. It does not address the sexual identity or orientation of the males involved. MSM may see himself as homosexual, bisexual, or heterosexual. He may have both male and female partners regardless of his sexual identity. If he is a sex worker, he may see his sexual activity as merely a means to earn money and support his family. He may perceive sexual activity between men as an expression of his masculinity or femininity. Regardless of how the MSM thinks of his behavior, often times, MSM are stigmatized, discriminated against, and even criminalized. Complex cultural, religious, moral, and political structures impact the lives of MSM. The result is often an invisible population of men at high-risk for HIV.

The frequent discounting of MSM in India may result in inaccurate or conflicting estimates of the rates of HIV infection. For years, researchers have recognized that government estimates of the number of MSM and their HIV prevalence in India are inexact (Godbole & Mehendale, 2005). In response, a randomized cross-sectional analysis was conducted in Chennai in 2001, demonstrating that 5.9% of the men surveyed reported that they have had sex with men and were more likely to be HIV positive than men who did not report same-sex encounters (Go et al., 2004). Other cross-sectional studies demonstrated that in rural regions of India, nearly “10% of single and 3% of married men had had unprotected anal sex with a man” (Verma & Collumbien, 2004, p. 1854).

In addition, there have been very limited empirically supported studies of HIV prevention for MSM, though there are qualitative and ethnographic studies, often focusing on the anthropological phenomenon of identity development, *Hijras*, and *Kothis* (Boyce, 2007). Other studies explore the sexual behaviors and experiences of MSM in India (Chakrapani, Newman, Shunmugam, McLuckie, and Melwin, 2007; Sri Krishnan et al., 2007).

NACO nevertheless identifies MSM as a high-risk population. Targeted interventions to MSM are designed to minimize the spread of infection to the general population, as was seen with FSW. Prevention interventions with MSM emphasize the importance of peer educators, promotion of behaviour change, access to and the use of condoms. One organization that has been essential in prevention efforts with MSM in India is Naz Foundation International (NFI). Since its inception in 1996, NFI has worked to assist communities in capacity building for the advocacy for the rights of MSM and HIV prevention.

While there are other NGOs that conduct prevention and outreach to MSM (e.g., Sahodaran, The Social Welfare Association for Men and The Indian Community Welfare Organization) there are no identifiable evaluations of the efficacy of these agencies and interventions. One possible explanation is that these agencies face many barriers, including harassment from police and other government officials (Safren et al., 2006).

Still, preventative interventions must continue in order to curtail the spread of HIV. One highly effective intervention is male circumcision. Studies have demonstrated that male circumcision is effective in reducing the spread of HIV. Comparing rates of infection between circumcised and uncircumcised men, one study demonstrated that among Indian men, circumcision resulted in a 6.7 fold reduction in the rate of infection (Reynolds et al., 2004). Clearly, there is a demonstrated need for prevention with this population. Despite the overwhelming barriers faced by MSM and MSM outreach workers, there are interventions that are effective. However, it may be the process of tackling the barriers to prevention with MSM that proves to be the most significant task.

Check Your Progress IV

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1. Which is more effective in reducing risk among MSM, group or individual level interventions?

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2. According to NACO, what should prevention efforts with MSM include?

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5.6 PREVENTION WITH YOUTH

United States

Prevention efforts with adolescents and young adults in the United States began in the 1980s. A large literature exists on effective interventions designed for youth. Youth are at an increased risk for HIV due to biological, psychological and social factors, including peer pressure and the natural tendency to explore a developing sense of sexuality.

Culturally and ethnically appropriate group interventions are often used. One such intervention for adolescent males held at an inner-city school on a Saturday morning incorporated games, videos, and exercises. Students were taught about safer sex practices including condom use and abstinence, and participants reported more frequent condom use and fewer sexual partners (Jemmott, Jemmott, & Fong, 1992). Other culturally appropriate interventions for low-income African Americans have been implemented in recreation centers in public housing developments (Stanton et al., 1996). One involved peer group learning during multiple group sessions. Discussions focused on values, goal setting, HIV transmission and prevention, human development, and contraception. Storytelling and role playing were also employed, and sexually active adolescents reported greater condom use after participation. St. Lawrence et al. (1995) also studied the effects of a cognitive behavioral intervention with African American adolescents. The Becoming a Responsible Teen (BART) intervention is an eight week intervention for inner city youth at a public health clinic for low-income families. Topics included AIDS education, sexual decisions and values, technical skills, social skills, cognitive skills, and empowerment. Findings showed greater condom use, reduced frequency of unprotected intercourse, and delay in sexual activity onset.

Other interventions include adapting school curriculum. Reducing The Risk (Kirby, Barth, Lelan, & Fetro, 1991) addressed the need for HIV education in large school districts. Based on social learning and cognitive behavioral theories, it develops social skills to reduce sexual risk taking behaviour, and employs role playing activities in the classroom. Students learn how to communicate with partners about delaying sexual activity. Students receiving the intervention were less likely to initiate sexual activity and to engage in unprotected sexual intercourse.

These interventions demonstrate that youth can be reached in a variety of settings, including the school, the health care facility, or the neighborhood. A small group intervention to runaway youth in New York City (Rotheram-Borus, Van Rossem, Gwadz, Koopman, & Lee, 1997) was designed based on social learning theory, and focused on reinforcing positive behaviors. Participants were taught about HIV transmission and prevention, used role playing to develop social skills, explored available resources, and discussed attitudes and norms. Results included less unprotected sexual encounters and a reduction in substance use following this intervention (Rotheram-Borus et al., 1997).

Clearly, designing, implementing, and evaluating interventions for youth is challenging. The following guidelines for interventions targeted to youth have been recommended (DiClemente et al., 2008):

- tailor interventions to meet the needs of the population;
- target those behaviors most amenable to change;
- utilising the family as a behavioral change agent;
- expand the scope of STI/HIV intervention programs, beyond individuals;
- incorporate long-term maintenance strategies into interventions;
- incorporate biological outcomes as a measure of program efficacy; and
- translate and disseminate effective STI/HIV interventions.

These recommendations for best practice are clearly visible in the Sistering, Informing, Healing, Living, and Empowering (SiHLE) Project (DiClemente et al, 2004), serving African American adolescent females recruited from community

health centers. The intervention involved four group sessions which stressed ethnic and gender pride, HIV transmission and prevention, skills building, communication and healthy relationships. Participants reduced new sexual partners, and improved consistent and correct condom use. As a result, SiHLE Project has been adopted by the CDC as a model for effective intervention with adolescent African American females (Wingood & DiClemente, 2006).

India

The United States President's Emergency Plan for AIDS Relief (PEPFAR) provides funding for HIV treatment and prevention in developing nations. A key component to PEPFAR funding is implementing the ABC approach to prevention. ABC stands for Abstinence, Be Faithful, and Correct and Consistent Condom Use. While ABC is not an actual intervention or program, it is a fundamental philosophy embraced by PEPFAR to guide population specific interventions globally. The principle components include delaying sexual activity for non-married individuals, ending casual sexual activity, eliminating cross-generational transactional sex, focusing on marital fidelity, adopting correct and consistent condom use and HIV counseling and testing. PEPFAR supports NACO in its prevention efforts, including efforts directed toward youth.

There are a disproportionate number of youth infected with HIV in India; 31% of the identified cases with HIV occur in individuals, between the ages of 15 and 29 years (NACO, Youth section). Young people are faced with many challenges which place them at high risk for HIV including changing bodies, family concerns, social and cultural influences, gender imbalances, economic and financial struggles, and the pressures of a changing world. Globalization and urbanization compete with traditional cultural values and beliefs, and teens are often conflicted. Young girls face different pressures than boys based on differing socially accepted gender norms. Starting at a young age, youth may need to contribute to the family income, be forced to work long hours, and sacrifice formal education for family survival. These contributing factors lead to an increased vulnerability for HIV among youth in India.

To address these needs, several initiatives have been endorsed by the Indian government, including the National Population Policy, the National AIDS Prevention and Control Policy, the National Youth Policy and the Reproductive and Child Health (RCH) Programmes. NACO has created multiple interventions targeted towards youth, both in and out of school, which promote healthy, responsible lifestyles. The Adolescence Education Programme (AEP) incorporates HIV/AIDS prevention education into life-skills training curriculum delivered to school-aged youth. Included in this programme is the School AIDS Education Programme. The curriculum focuses on family life, human growth and development, abstinence, and life skills. Other programs include the Red Ribbon Club, HIV education programmes on college and University campuses, and Youth Unite for Victory on AIDS, providing life skill education and counselling to adolescents.

Recently, a research team conducted brief HIV education intervention in seven villages in Western Rajasthan involving 78 girls between the ages of 12 and 19. Educational sessions consisting of visual aids were presented in local dialects. Topics included HIV transmission, prevention, and management. Myths about HIV were also discussed. A post test revealed significant increases in HIV knowledge among adolescent girls living in rural villages (Trivedi, Joshi, & Levine, 2008).

These examples are just a few of the initiatives and programs designed to address the HIV prevention and education needs of youth living in India. For a more extensive review of these initiatives and other programs not discussed here, please refer to *Young Peoples Sexual and Reproductive Health in India: Policies, Programs, and Realities*, a regional working paper produced by the Population Council (Santhya & Jejeebhoy, 2007). Till date, there are few empirically supported studies evaluating the effects of these education programs, and results vary (Chhabra, Springer, Rapkin, & Merchant, 2008; Ghosh, Chhabra, Springer, & Sharma, 2008). Even fewer identifiable studies examine the efficacy of prevention interventions with high-risk adolescents in India. There is a dire need and great opportunity for social workers to develop, implement, and evaluate prevention interventions with high risk adolescents in India.

Check Your Progress V

Note: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1. What are the seven guidelines for interventions with youth?

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2. What does ABC stand for? What are the components of this policy?

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5.7 LET US SUM UP

This chapter briefly outlines the history of HIV prevention efforts in the United States, and provides an overview of empirically supported prevention interventions for populations at highest risk for infection. Efforts currently implemented in India are also reviewed. The evaluation of the intersection of Western and Indian techniques provides a basis for adapting successful strategies for the unique population and cultural characteristics in India. You should now be able to identify the populations most at risk for HIV in India and begin generating ideas for social work supported prevention interventions for these people.

5.8 FURTHER READINGS AND REFERENCES

1. Centers for Disease Control and Prevention (2001, August 31). *1999 Compendium of HIV Prevention Interventions with Evidence of Effectiveness*. Retrieved September 2, 2008 from <http://www.cdc.gov/hiv/resources/reports/>

hiv_compendium/pdf/HIVcompendium.pdf.

2. Chakrapani, V., Row Kavi, A., Gupta, R., Ramakrishnan, L., Rappoport, C., & Raghavan, S. (2002). *HIV prevention among men who have sex with men (MSM) in India: Review of current scenario and recommendations: Solidarity and Action Against The HIV Infection In India*. Retrieved October 11, 2008 from http://www.indianglbthealth.info/Authors/Downloads/MSM_HIV_IndiaFin.pdf
3. DiClemente, R. J., Crittenden, C. P., Rose, E., Sales, J. M., Wingood, G. M., Crosby, R. A., et al. (2008). Psychosocial predictors of HIV-assisted sexual behaviors and the efficacy of prevention interventions in adolescent at-risk for HIV infection: What works and what doesn't work? *Psychosomatic Medicine*, 70, 598-605.
4. Lyles, C. M., Kay, L. S., Crepaz, N., Herbst, J. H., Passin, W. F., Kim, A. S., et al. (2007). Best-evidence interventions: Findings from a systematic review of HIV behavioral interventions for US populations at high risk, 2000–2004. *American Journal of Public Health*, 97, 133-143.
5. National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India. (2007). *Targeted Interventions Under NACP III: Operational Guidelines, Volume 1, Core High Risk Groups*. Retrieved September 2, 2008, from the National AIDS Control Organisation Web site: <http://www.nacoonline.org/upload/Publication/NGOs%20and%20targetted%20Intervations/NACP-III.pdf>
6. Santhya, K. G., and Jejeebhoy, S. (Eds.). (2007). *Young people's sexual and reproductive health in India: Policies, programmes and realities* (Regional Working Papers: South and East Asia). Population Council, New Delhi, India.
7. Wingood, G. M., & DiClemente, R. J. (2006). Enhancing adoption of evidence-based HIV interventions: Promotion of a suite of HIV prevention interventions for African American women. *AIDS Education and Prevention*, 18(suppl. A), 161-170.
8. Baker, S. A., Beadnell, B., Stoner, S., Morrison, D. M., Gordon, J., Collier, C., et al. (2003). Skills training versus health education to prevent STDs/HIV in heterosexual women: A randomized controlled trial utilizing biological outcomes. *AIDS Education and Prevention*, 15, 1-14.
9. Boyce, M. (2007). 'Conceiving Kothis': Men who have sex with men in India and the cultural subject of HIV prevention. *Medical Anthropology*, 26, 175-203.
10. Branson, B. M., Handsfield, H. H., Lampe, M. A., Janssen, R. S., Taylor, A. W., Lyss, S. B., et al. (2006). Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings [Electronic version]. *MMWR*, 55, 1-17
11. Chakrapani, V., Newman, P. A., Shunmugam, M., McLuckie, A., & Melwin, F. (2007). Structural violence against Kothi-identified men who have sex with men in Chennai, India: A qualitative investigation. *AIDS Education and Prevention*, 19, 346-364.
12. Chhabra, R., Springer, C., Rapkin, B., & Merchant, Y. (2008). Differences among male/female adolescents participating in a school-based teenage education program (STEP) focusing on HIV prevention in India. *Ethnicity and Disease*, 18(Suppl. 2), 123-127.

13. del Rio, C. (2003). New challenges in HIV care: Prevention among HIV infected patients. *Topics in HIV Medicine, 11*, 140-144.
14. Des Jarlais, D. C., Casriel, C., Friedman, S. R., & Rosenblum, A. (1992). AIDS and the transition to illicit drug injection—results of a randomized trial prevention program. *British Journal of Addiction, 87*, 493-498.
15. DiClemente, R. J., & Wingood, G. M. (1995). A randomized controlled trial of an HIV sexual risk-reduction intervention for young African American women. *JAMA, 274*, 1271-1276.
16. DiClemente, R. J., Crittenden, C. P., Rose, E., Sales, J. M., Wingood, G. M., Crosby, R. A., et al. (2008). Psychosocial predictors of HIV-assisted sexual behaviors and the efficacy of prevention interventions in adolescent at-risk for HIV infection: What works and what doesn't work? *Psychosomatic Medicine, 70*, 598-605.
17. DiClemente, R. J., Wingood, G. M., Harrington, K. F., Lang, D. L., Davies, S. L., Hook, E. W., et al. (2004). Efficacy of an HIV prevention intervention for African American adolescent girls: a randomized controlled trial. *JAMA, 292*, 171-179.
18. Dilley, J. W., Woods, W. J., Sabatino, J., Lihatsch, T., Adler, B., Casey, S., et al. (2002). Changing sexual behavior among gay male repeat testers for HIV: A randomized, controlled trial of a single-session intervention. *Journal of Acquired Immune Deficiency Syndromes, 30*, 177-186.
19. Eicher, A. D., Crofts, N., Benjamin, S., Deutschman, P., & Rodger, A. J. (2000). A certain fate: Spread of HIV among young injecting drug users in Manipur, North-East India. *AIDS Care, 12*, 497-504.
20. El-Bassel, N., & Schilling, R. F. (1992). 15 month follow-up of women methadone patients taught skills to reduce heterosexual HIV transmission. *Public Health Reports, 107*, 500-504.
21. The EXPLORE Study Team (2004). Effects of a behavioural intervention to reduce acquisition of HIV infection among men who have sex with men: The EXPLORE randomised controlled study. *The Lancet, 364*, 41-50.
22. Ghosh, S., Chhabra, R., Springer, C., & Sharma, S. K. (2008). A study of knowledge, attitude, and sensitivity about HIV/AIDS among school teachers in northwestern Himalayas. *Ethnicity and Disease, 18*(Suppl. 2), 172-174.
23. Go, V. F., Srikrishnan, A. K., Sivaram, S., Murugavel, G. K., Galai, N., Johnson, S. C., et al. (2004). High HIV prevalence and risk behaviors in men who have sex with men in Chennai, India. *Journal of Acquired Immune Deficiency Syndromes, 35*, 314-319.
24. Godbole, S., & Mehendale, S. (2005). HIV/AIDS epidemic in India: Risk factors, risk behavior & strategies for prevention & control. *Indian Journal of Medical Research, 121*, 356-368.
25. Hall, H. I., Song, R., Rhodes, P., Prejean, J., An, Q., Lee, L. M., et al. (2008). Estimation of HIV Incidence in the United States. *JAMA, 300*, 520-529.
26. Hangzo, C., Chatterjee, A., Sarkar, S., Zomi, G. T., Deb, B. C., & Abdul-Quader, A. S. (1997). Reaching out beyond the hills: HIV prevention among injecting drug users in Manipur, India. *Addiction, 92*, 813-820
27. Hobfoll, S. E., Jackson, A. P., Lavin, J., Britton P. J., & Shepherd J. B. (1994). Reducing inner-city women's AIDS risk activities: A study of single, pregnant women. *Health Psychology, 13*, 397-403.

28. Jana, S., Basu, I., Rotheram-Borus, M. J., & Newman, P. A. (2004). The Sonagachi project: A sustainable community intervention program. *AIDS Education and Prevention, 16*, 405-414.
29. Jemmott, J. B., Jemmott, L. S., & Fong, G. T. (1992). Reductions in HIV risk-associated sexual behaviors among black male adolescents: Effects of an AIDS prevention intervention. *American Journal of Public Health, 82*, 372-377.
30. Kegeles, S. M., Hays, R. B., & Coates, T. J. (1996). The Mpowerment project: A community level HIV prevention intervention for young gay men. *American Journal of Public Health, 86*, 1129-1136.
31. Kelly, J. A., Murphy, D. A., Washington, C. D., Wilson, T. S., Koob, J. J., Davis, D. R., et al. (1994). The effects of HIV/AIDS intervention groups for high-risk women in urban clinics. *American Journal of Public Health, 84*, 1918-1922.
32. Kelly, J. A., St. Lawrence, J. S., Diaz, Y. E., Stevenson, L. Y., Hauth, A. C., Brasfield, T. L., et al. (1991). HIV risk behavior reduction following intervention with key opinion leaders of population: An experimental analysis. *American Journal of Public Health, 81*, 168-171.
33. Kelly, J. A., St. Lawrence, J. S., Hood, H. V., & Brasfield, T. L. (1989). Behavioral intervention to reduce AIDS risk activities. *Journal of Consulting and Clinical Psychology, 57*, 60-67.
34. Kirby, D., Barth, R. P., Lelan, N., & Fetro, J. V. (1991). Reducing the risk: Impact of a new curriculum on sexual risk-taking. *Family Planning Perspectives, 23*, 253-263.
35. Latkin, C. A., Sherman, S., & Knowlton, A. (2003). HIV prevention among drug users: Outcome of a network oriented peer outreach intervention. *Health Psychology, 22*, 332-339.
36. Mcgrath, J. W., Celentano, D. D., Chard, S. E., Fullem, A., Kanya, M., Gangakhedar, C., et al. (2007). A group-based intervention to increase condom use among HIV serodiscordant couples in India, Thailand, and Uganda. *AIDS Care, 19*, 418-424.
37. National AIDS Control Organisation (NACO). (n.d.). *Prevention of parent to child transmission (PPTCT)*. Retrieved September 2, 2008 from http://www.nacoonline.org/National_AIDS_Control_Program/Services_for_Prevention/PPTCT/
38. National AIDS Control Organisation (NACO). (n.d.). *Youth*. Retrieved September 2, 2008 from http://www.nacoonline.org/Quick_Links/Youth/ Naz Foundation International (NFI). (ND). NFI's experience. Retrieved September 2, 2008 from <http://www.nfi.net/experience.html>
39. Panda, S., Azim, T., Rehman, N. U., Poudel, G., & Chaudhuri, A. (2007). Reaching out to regular female sex partners of non-injecting and injecting drug users (IDUs): A need highlighted by research findings and ways to address it demonstrated by a regional HIV intervention project from South Asia. *Substance Use & Misuse, 42*, 895-898.
40. Pant Pai, N., Barick, R., Tulsy, J. P., Shivkumar, P. V., Cohan, D., Kalantri S., et al. (2008). Impact of round-the-clock, rapid oral fluid HIV testing of women in labour in rural India. *PLoS Medicine, 5*, 768-776.

41. Reynolds, S. J., Shepherd, M. E., Risbud, A. R., Gangakhedkar, R. R., Brookmeyer, R. S., Divekar, A. D., et al. (2004). Male circumcision and risk of HIV-1 and other sexually transmitted infections in India. *The Lancet*, *363*, 1039-1040.
42. Rotheram-Borus, M. J., Song, J., Gwadz, M., Lee, M., Van Rossem, R., & Koopman, C. (2003). Reductions in HIV risk among runaway youths. *Preventive Science*, *4*, 173-187.
43. Safren, S. A., Martin, C., Menon, S., Greer, J., Solomon, S., Mimiaga, M. J., et al. (2006). A Survey of MSM HIV prevention outreach workers in Chennai, India. *AIDS Education and Prevention*, *18*, 323-332.
44. Santhya, K. G., and Jejeebhoy, S. (Eds.). (2007). *Young people's sexual and reproductive health in India: Policies, programmes and realities* (Regional Working Papers: South and East Asia). Population Council, New Delhi, India.
45. Sinha, G., Dyalchand, A., Khale, M., Kulkarni, G., Vasudevan, S., & Bollinger, R. C. (2008). Low utilization of HIV testing during pregnancy: What are the barriers to HIV testing for women in rural India? *Journal of Acquired Immune Deficiency Syndromes*, *47*, 248-252.
46. Sri Krishnan, A. K., Hendriksen, E., Vallabhaneni, S., Johnson, S. L., Raminani, S., Kumarasamy, N., et al. (2007). Sexual behaviors of individuals with HIV living in South India: a qualitative study. *AIDS Education and Prevention*, *19*, 334-345.
47. St. Lawrence, J. S., Brasfield, T. L., Jefferson, K. W., Alleyne, E., O'Bannon R. E., & Shirley A. (1995). Cognitive-behavioral intervention to reduce African-American adolescents' risk for HIV infection. *Journal of Consulting and Clinical Psychology*, *63*, 221-237.
48. Stanton, B. F., Li, X., Ricardo, I., Galbraith, J., Feigelman, S., & Kaljee, L. (1996). A randomized controlled effectiveness trial of an AIDS prevention program for low-income African American youth. *Archives of Pediatrics and Adolescent Medicine*, *150*, 363-372.
49. Trivedi, I., Joshi, K. C., & Levine, D. (2008, August). *Effectiveness of short educational interventions in increasing level of HIV awareness among rural adolescent girls in Rajasthan, India*. Poster session presented at the XVII International AIDS Conference, Mexico City, Mexico.
50. Valdiserri, R. O., Lyter, D. W., Kingsle, L. A., Leviton, L. C., Schofield, J. W., Huggins, P., et al. (1989). AIDS Prevention in homosexual and bisexual men: Results of a randomized trial evaluating two risk reduction interventions. *AIDS*, *3*, 21-26.
51. Verma, R. K., & Collumbien, M. (2004). Homosexual activity among rural Indian men: Implications for HIV interventions. *AIDS*, *18*, 1845-1856.
52. Wingood, G. M., & DiClemente, R. J. (2006). Enhancing adoption of evidence-based HIV interventions: Promotion of a suite of HIV prevention interventions for African American women. *AIDS Education and Prevention*, *18*(suppl. A), 161-170.
53. Wolitski, R. J., Henny, K. D., Lyles, C. M., Purcell, D. W., Carey, J. W., Crepaz, N., et al. (2006). Evolution of HIV/AIDS prevention programs—United States, 1981-2006 [Electronic version]. *MMWR*, *55*, 597-603.

5.9 ANSWERS TO CHECK YOUR PROGRESS

Check Your Progress I

1. The Centers for Disease Control and Prevention (CDC) works to develop and disseminate treatment guidelines for infection, and prevent the spread of further infections by focusing on prevention activities directed at persons at high risk for contracting HIV, HIV counseling, testing, and referral services, and improving the health of persons living with HIV.
2. Primary prevention efforts in the United States focus on educating those at risk for infection, aiming to reduce their risk and further prevent the spread of HIV. These include public health campaigns and messages directed toward individuals who are not infected, but at risk for infection; gay men, intravenous drug users, and women, for example. Secondary prevention targets individuals already infected with HIV, aiming to reduce transmission of infection among those at highest risk for infection (the known partners of HIV positive individuals) and to also reduce the risk of re-infection among positive individuals.

Check Your Progress II

1. The most frequently employed intervention targeted to women at highest risk for HIV involves group level cognitive-behavioral risk-reduction skills training. Group interventions that stress gender pride, personal responsibility, sexual assertiveness and communication, condom use, and coping skills, have proven to be effective
2. The National AIDS Control Organization (NACO) in India has identified female sex workers (FSW) as one of the populations at highest risk for infection, and has developed targeted interventions for work with these women. Strict gender roles that limit a woman's power in sexual relationships can lead to violence and sexual exploitation. Women may have limited control in negotiating safer sex practices with their partners. Furthermore, women in India may have limited access to information regarding HIV, and preventive resources such as condoms and health care.

Check Your Progress III

1. The main objective of harm reduction is to decrease the potential dangers and health risks associated with risk behaviour, while recognizing that the risk behavior itself may not be eliminated entirely. Examples of harm reduction include needle exchange programs, injecting drug works cleaning kits, and drop-in centers.
2. Effecting community building calls for involvement from key stakeholders, including consumers, local officials, and health care providers to communicate establish open communication of the issues and concerns, and developing consensus on interventions. An example would be to involve local law enforcement officers, urging them not to harass, or arrest IDUs, after visiting a needle exchange center.

Check Your Progress IV

1. Both group level and individual level prevention interventions are proven effective in reducing risk behavior in MSM. Prevention workers should be aware of

prevention message fatigue, be creative in delivering interventions, and be cognizant of the psychosocial factors that often lead to high risk behavior.

2. Prevention interventions with MSM emphasize the importance of peer educators, promotion of behavior change, and access to and the use of condoms.

Check Your Progress V

1. 1) Effective prevention strategies must involve as far as possible, interventions tailored to the local needs,, 2) Targetting behaviors that are most amenable to change, 3) Utilize the family as a behavioural change agent, 4) Expanding the scope of STI/HIV intervention programs beyond the individual, 5) Incorporating long-term maintenance strategies into interventions, 6) incorporate biological outcomes, as a measure of program efficacy, and 7) translate and disseminate effective STI/HIV interventions.
2. ABC stands for Abstinence, Be Faithful, and Correct and Consistent Condom Use. While ABC is not an actual intervention or program, it is a fundamental philosophy embraced by PEPFAR to guide population specific interventions globally. The principle components include delaying sexual activity for non-married individuals, ending casual sexual activity, eliminating cross-generational transactional sex, focusing on marital fidelity, adopting correct and consistent condom use and HIV Counselling and Testing.