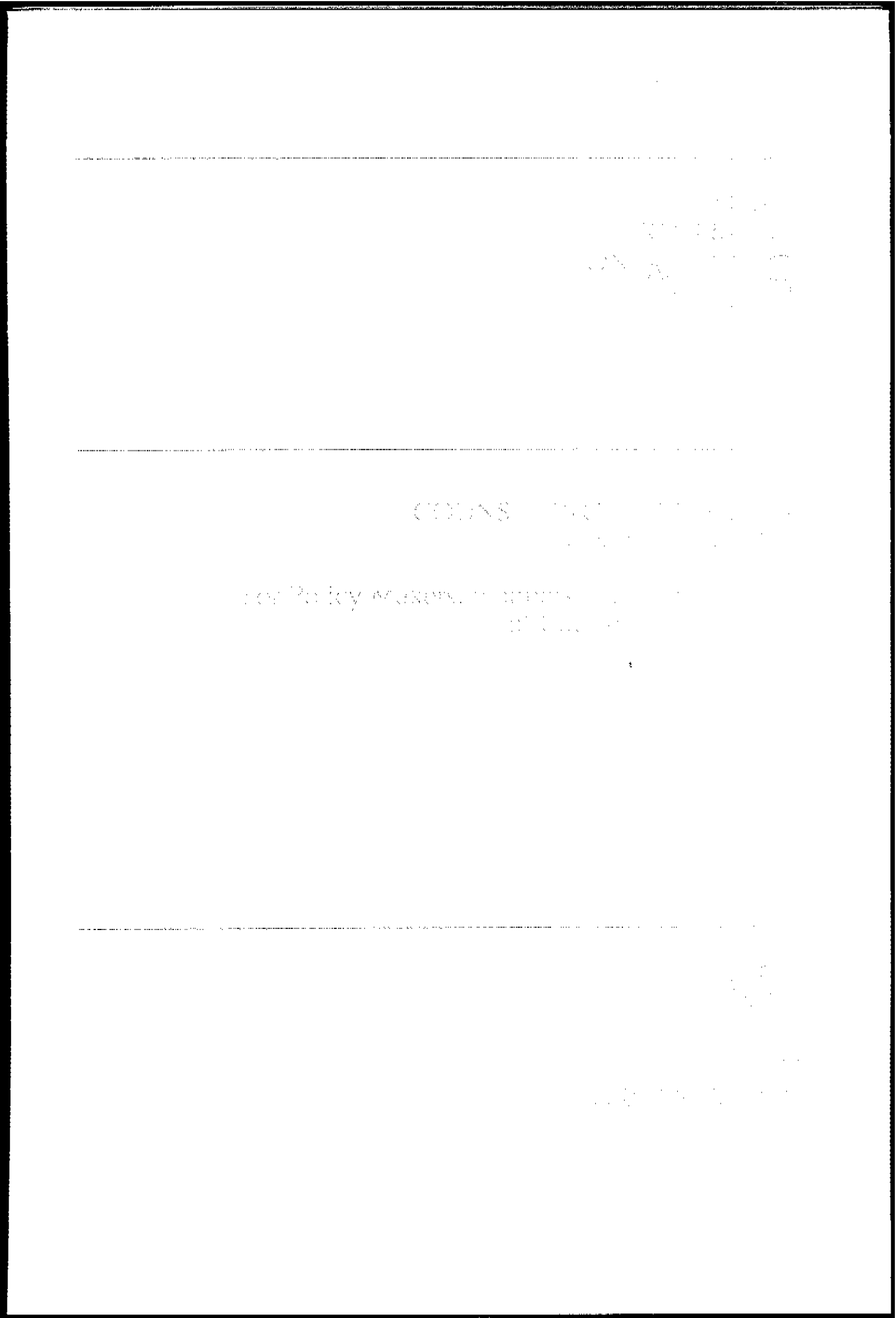

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PREFACE

In 1990 WHO published WHO AIDS Series No. 8 *Guidelines for counselling about HIV infection and disease*. This booklet summarized the then current understanding of the subject, including the nature, role, and principles of counselling, psychosocial repercussions of HIV infection and associated conditions, and special situations in which counselling is called for.

However, during the past five years, our understanding of the psychosocial impact of the epidemic has progressed and recommended approaches to implementing counselling should be accordingly modified. For example, reports and observations from countries with experience in HIV/AIDS counselling indicate that, contrary to previous thinking, HIV/AIDS counselling is most feasible when it is focused towards people living with HIV/AIDS and their families, those undergoing voluntary HIV testing and those worried about their risk of acquiring HIV infection. Resources permitting, voluntary counselling and testing services should be made available at easily accessible sites for these individuals. However, it is not an effective intervention for individuals who are not or who do not perceive themselves to be at risk.

This volume *Counselling for HIV/AIDS: A key to caring* contains updated guidance on general policy issues related to HIV/AIDS counselling, with the aim of facilitating the formulation of national policies. The most valuable sources of information in the revision process have been experiences gained by countries providing HIV/AIDS counselling, and the booklet now includes case studies based on these experiences. It reflects the evolution of HIV/AIDS counselling into an essential element in the provision of HIV-related care, and in promoting safer behaviour among those living with HIV/AIDS.

To supplement the guidance to policy-makers that is provided by this publication, GPA is developing two other resource documents. One, *Source book for HIV/AIDS counselling training* (WHO/GPA/TCO/HCS/94.1) focuses on counsellors and their trainers while the other, *Guidelines for implementing HIV/AIDS counselling* (in draft), is intended for managers of health services.

The updated publication *Counselling for HIV/AIDS: A key to caring* comes at a time when much experience has been gained in the training of counsellors and in the actual provision of counselling. Much more has still to be learned about the feasibility of providing counselling services and sustaining them on a large-scale basis, and the impact of counselling activities. The efforts made by governments and NGOs, in the provision of emotional support and care for those affected by HIV/AIDS or those worried about their risk of acquiring infection, should be applauded. This booklet is dedicated to all those who spend time, at work, in the community, or at home, listening to people and talking with them about the individual consequences of being affected by HIV/AIDS.

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WHO wishes to thank Mr Tom Milroy, an independent consultant specializing in planning of health systems and public health policy, for his invaluable contribution to this publication. The organization is grateful to many people living with AIDS, care-givers and AIDS care services managers without whose work the information presented in this book would not have been generated.

Special mention should also be made of the following people who contributed to the 1990 version and to this revised version of WHO AIDS Series No. 8:

- Mr Alfred Chingono, Clinical Psychologist, University of Zimbabwe, Harare, Zimbabwe.
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INTRODUCTION

Who is this document intended for?

These guidelines are intended to provide **policy-makers and planners** working in health and social service organizations[1] with information to enable them to develop policies that will stimulate, encourage and support the development of appropriate HIV/AIDS counselling services and plan for this service.

This document presents general policy issues in the area of HIV/AIDS counselling. The aim is to encourage countries to develop programme-linked policies and operational guidance for the provision of counselling. It is not intended to give detailed guidance on how to set up and manage HIV/AIDS counselling services or how to design, implement and evaluate training, education or communication programmes. Such guidance is available in other GPA material referenced in the appropriate sections of this publication.

The guidelines are intended to reflect experiences and insights that have been gained in the field of HIV/AIDS counselling since the first version of WHO AIDS Series 8 was published in 1990. As countries develop their counselling services, new ideas and experience will in turn guide the further refinement of services and revision of policies.

Why is it important to have policies on HIV/AIDS counselling?

The existence of sound and clearly stated policies on HIV/AIDS counselling and related areas is central to the establishment of effective counselling services. Policies, in this context, are written guiding principles (including a preferred method of action) issued by the Ministry of Health or other institutions, regarding the provision of HIV/AIDS counselling. Development of policies is particularly important for HIV/AIDS counselling, because

- HIV/AIDS counselling is a recommended prerequisite for HIV testing and, in many instances, HIV testing is a politically sensitive issue. Clear policies are especially important in asserting the role of pre- and post-test counselling.
- HIV/AIDS counsellors, more than any other workers in the field of HIV/AIDS, deal with highly sensitive personal information and with people in their most vulnerable states of mind.

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[1] Readers of these guidelines are likely to include:
- members of national AIDS committees
- planning officers
- programme managers
- training specialists
- managers of institutions providing counselling services
- managers of institutions providing training in HIV/AIDS counselling.

The guidelines are also intended for managers, clinicians and others who may occasionally play a role in the policy-making process or have a special interest in HIV/AIDS counselling.

- Carefully devised policies establishing who qualifies to be an HIV/AIDS counsellor are required.
- Within most health and social services, HIV/AIDS counselling is a relatively new activity and, as such, may meet with different reactions from staff and supervisors. In order to avoid serious negative reactions, policy guidance and approval is needed as to the role and scope of this activity.

The guidelines are presented in three parts:

Part One: HIV/AIDS counselling

The aim of this section is to describe the essential features of the HIV/AIDS counselling process. Examples of the potential benefits of good counselling practice are also given.

Part Two: Policy issues in the development of HIV/AIDS counselling services

This section reviews policy issues pertinent to setting up HIV/AIDS counselling services. Brief examples of ways in which counselling services have been established and/or developed in a variety of different geographical, epidemiological and social contexts are given. Several issues regarding HIV/AIDS counselling services, that will need to be resolved by policy makers according to specific contexts, as well as new issues that may arise, are also discussed in this section.

Part Three: The role of policy-makers and planners

This section suggests what steps can be taken by policy-makers and planners to ensure that policies regarding HIV/AIDS counselling are established. Reference is also made to recent GPA publications on HIV/AIDS counselling.

PART ONE: HIV/AIDS COUNSELLING

What is HIV/AIDS counselling?

The Global Programme on AIDS (GPA) defines HIV/AIDS counselling as "a confidential dialogue between a client and a care provider aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS. The counselling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behaviour".[1]

GPA recommends that HIV/AIDS counselling services be established to meet the needs of individuals and families who may have HIV-related or AIDS-related problems and concerns.

HIV/AIDS counselling is a process that begins with the client's first contact either with HIV/AIDS counselling services or with the care system for HIV-related needs. In the context of HIV/AIDS, the care system includes all health and social service facilities, both formal and informal, where individuals receive care and social support. The counselling process continues through a referral network to various community and social support agencies according to the needs of the individual and the family affected by or worried about HIV/AIDS.

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[1] Further definitions of each of the key words in the GPA definition are as follows:

A client is any person seeking or receiving HIV counselling and/or testing.

A care-provider in the context of HIV/AIDS counselling is any provider who is trained to provide HIV/AIDS counselling services.

Enabling the client to cope with stress, in the context of HIV/AIDS, means:

- providing the emotional support that will help a client to accept the reality (or possibility) of a positive diagnosis of HIV or AIDS of oneself or one's loved one;
- helping the client to identify, explore and select the best options for handling stress;
- helping HIV-positive clients plan for the future by identifying, exploring and selecting available resources in order to meet emotional, medical and social needs that may exist in the life of an individual after a diagnosis of HIV or AIDS.

Facilitation of preventive behaviour means helping the client to identify, explore, select and practise behaviours which will eliminate or greatly reduce the risks of transmission of HIV. This will include helping the client to assess his/her personal risks of transmitting or acquiring HIV and helping the client to plan for a reduction of the risks.

For whom should HIV/AIDS counselling services be provided?

The clients of HIV/AIDS counselling services are likely to be any of the following:

- people with AIDS and their families.
- those who are HIV-positive, and their families;
- those seeking, or agreeing to undergo, an HIV test; and
- those who are concerned that they are at risk or have been at risk of acquiring HIV infection, e.g. those whose partners are HIV-infected or have symptoms of HIV infection, those who may have been exposed through blood, those who have had unprotected sex with multiple partners and those whose regular partners have had unprotected sex with multiple partners.

Box 1. One client's story

He died young and he died with dignity. He was surrounded by his family during his final hours.[1] His workmates visited him regularly right up until the last week of his long illness.

The story had begun several years earlier during a long and arduous business trip. He had visited a bar one evening and had, by chance, met an ex-girlfriend whom he had known while he was a student. They had described their respective lives since they had last met - for example, she told him how she had recently split up with her boyfriend, with whom she had been living for the last two years, because his addiction to drugs was gradually using up all their joint financial resources.

After having several drinks together they had gone to her apartment. They had sex that evening without using a condom.

Several days later he felt pain on urination and noticed a discharge from his penis. He visited a private doctor where, before prescribing an antibiotic for the treatment of his sexually transmitted disease, the doctor gently enquired whether he had considered the possibility that his sexual partner might have been HIV-positive. When he expressed concern that this might be so, the doctor discussed with him several options, including taking an HIV test or not taking a test, but using condoms with his wife. The patient chose to take the test, and the doctor referred him to his colleague who worked in the nearby hospital where an HIV test could be obtained.

[1] Throughout this document the word "family" is used in its broadest sense. Depending on the specific context, "family" may therefore include:
- those living in a committed relationship with the client;
- those living in the same household as the client;
- important members of the client's extended family or community.

When he nervously arrived at the hospital, the doctor there greeted him warmly and referred him to have a conversation with one of the nurses in her office. In the course of the conversation, the nurse asked him why he wanted an HIV test. She listened carefully as he explained his recent sexual history and described his fears. She then asked him what actions he might take if the result of the HIV test turned out to be positive. They also discussed what it would imply to be HIV-positive and what he would do in the interim to protect his wife in case he was already HIV-infected. The patient finally felt prepared to take the test and a blood sample was taken.

Several days later, he returned to find out the results of his HIV test. When the nurse told him that it was "negative" he was overjoyed. The nurse described "the window period"[1] and suggested that it would be advisable to take another HIV test in four or five months and to use a condom for all sexual contacts. However, since it was inconvenient to come to hospital when one was not ill, they agreed that it might be better to take the next test at the anonymous HIV testing site in the capital city.

After almost six months, he travelled to the capital, where there was a walk-in counselling and testing centre that provided HIV tests on an anonymous basis. After a short wait, during which he read about HIV and AIDS in some of the booklets that were available in the waiting-room, he was greeted by a social worker and taken to an office where he and the social worker reviewed the reasons why he had come for an HIV test. They also discussed what action he might take were he to be HIV-positive and he explained how he had a young family who were dependent upon him. He was then directed to the laboratory where a blood sample was drawn.

Five days later he returned to the counsellor's office to receive his test result. The care-provider calmly informed him that the test result indicated that he was HIV-positive. On expression of doubt, the counsellor further explained that there was almost no chance that a mistake had been made. For a while he did not respond: he felt he might lose his senses. When she tried to explain to him that this did not automatically mean that he was about to die, he could not understand. He remembers that she began to plan with him where he would spend the night and what he would do for the next 24 hours until he came back to see her the next day. By the end of the session the client had come to the point of agreeing to return the next day to discuss what the next steps might be. That night he slept in a hotel in the city.

When he returned the next day, he was still distraught. He stated that he feared to return home because he could not face seeing his wife and family. He and the counsellor listed and evaluated all the possible options as to what he should do next. Eventually, after a long discussion of all the options, during which the counsellor listened carefully to all that he had to

[1] The window period is the period between acquiring HIV infection and the appearance of HIV antibodies that can be detected by HIV antibody tests. During this period, individuals are already infectious but their blood tests are HIV antibody negative.

say, he decided that it would be best if he brought his wife to the next counselling session and that the care-provider would be available to help him to break the news.

Before he left her office that day, she asked him to describe how his wife might react; then they did some role-plays in which the care-provider played the role of his wife as he rehearsed how he would break the news. Eventually he gained confidence that with the help of the counsellor he would be able to find the best way to tell his wife.

Because of the preparations that he and the care-provider went through, the counselling session where he told his wife that he was HIV-positive was, in relative terms, a success. His wife accepted to be tested for HIV and luckily she was HIV-negative. After a discussion with the counsellor, the couple decided to use condoms consistently.

The client's next major hurdle was to decide whether he should request his other sexual partner to visit the counsellor with him. After considering all the options, he decided that this was an appropriate step to take and, as a result, she came to the next counselling session during which he informed her of his HIV-positive status. She subsequently decided to receive counselling and eventually opted to have an HIV test which turned out to be positive.

The counsellor (in the city) then referred them to a commmunity-based AIDS support organization in the township where he worked. The counsellor at the organization continued to provide counselling and support to the couple whenever they came in to see her.

During subsequent counselling sessions, in consultation with the counsellor, the client listed and evaluated all of the options for tackling each of the many other problems, both actual and potential, that now faced him. The final product was a comprehensive plan for making sure that his wife and children would be protected from HIV infection and would be adequately provided for when he died. At every step he presented his ideas and plans to his wife and discussed them in detail with her.

It was at work that the client faced his next major challenge. He had noticed, in conversations with his colleagues, that there was a great deal of potential for discrimination against those who are HIV-positive. After discussing this with the HIV/AIDS counsellor, he decided to bring up the subject with the members of the AIDS support organization. They suggested that he should bring up the subject with the nurse at his workplace, who had been trained in HIV/AIDS counselling. He did this, and together they developed a strategy for educating the workforce about HIV and AIDS. The resultant changes that took place in some of his colleagues after a series of difficult and highly emotional discussions gave him the confidence to finally inform them that he was HIV-positive. Not only did they provide him with social support over the coming years, but several of them became active as volunteers in various local organizations that had been set up to combat AIDS.

Throughout the next six years he received varying amounts of ongoing supportive counselling and social support. His wife attended many of these sessions and they continued to

work together in confronting the many challenges of AIDS. Whenever he was most sick, a team of care-providers visited him regularly at his home, and one member of the team played a major role in supporting him emotionally during the most difficult times. Eventually he became very ill and was taken to hospital, where a hospital-based religious worker took over some of the role of providing emotional support to him and his family. Throughout this period, his colleagues at work and members of a local voluntary organization met many of his material needs.

The client's story in Box 1 illustrates a combination of elements of HIV/AIDS counselling and a range of skills which the care-providers put to use in order to support the client and to facilitate preventive behaviour:

- At the private doctor's office, the doctor tactfully enquired about the risks of HIV transmission to which the client had been exposed and presented him with a list of the options regarding what he should do about it, and where he might obtain an HIV test and under what circumstances.
- At the local hospital, the nurse, who had attended a training workshop on HIV/AIDS counselling, helped him to begin to prepare for the possibility that he might be HIV-positive and that he might have to live with HIV infection. This counselling eventually helped him to absorb the shock of the news that he was HIV-positive.
- At the local hospital again, after informing him of the negative results of his HIV test, the same nurse informed him about "the window period". Had she not done this, he almost certainly would never have returned for a second test and would not have become aware of his HIV status in time to be able to learn how to prevent further exposure of his wife to HIV.
- At the anonymous walk-in counselling and testing centre in the capital city, the counsellor presented him with the results of his second HIV test and helped him to come to terms with the initial shock of the news that he was HIV-positive. Had there been no one to support him and to listen to him at this critical time, he might have been unable to cope with the news or might have behaved in a destructive manner such as deliberately spreading the virus.
- At subsequent counselling sessions, once he had come to terms with the reality of his HIV status, the same trained counsellor helped him to consider different options and to make the decision that he must tell his wife that he was HIV-positive and must tactfully request his other sexual partner to visit the counsellor with him so that she too could have the opportunity to receive HIV/AIDS counselling and care. The counselling provided to him and his wife enabled them to know and accept their discordant HIV status and to decide to use condoms.
- At the workplace, the nurse discussed with him the advantages and disadvantages of informing his workmates that he was HIV-positive. As a result of this discussion, he eventually decided not only to inform his workmates of his HIV status, but also to play a role in HIV education. His educational efforts led to changes of attitude to HIV-positive persons amongst

his co-workers and this, in turn, meant that his colleagues were available to provide him with social support at critical times during his illness.

- At his home, a social worker on the home-based care team provided him and his wife with ongoing supportive counselling that helped them to cope with the many crises that had arisen during his long illness.
- At the hospital, religious workers not only attended to his spiritual needs but also helped him to make practical preparations relating to the material and spiritual needs of his wife and children after his death.

In addition to counselling, individuals affected by HIV/AIDS need to receive **social support** from workmates, from members of their family, from members of local voluntary organizations that provide social support for people in need and from members of specific AIDS support organizations that communities may initiate.

What are the main components of the HIV/AIDS counselling process?

The two main components of HIV/AIDS counselling sessions, are:

- the provision of **emotional support**, including helping the client to cope with stress and plan for the future; and
- the **assessment of risks and planning for risk reduction**, including the development of decision-making capacity about options for prevention.

These are supplemented, as necessary, by personalized **information-giving**. For example:

- A health worker who expresses the fear that he or she is at risk of acquiring HIV in the work setting may, as part of the counselling process, be provided with scientifically-based information that:

  * confirms that these fears are a logical response and are not abnormal. Such information is reassuring to the client and can assist in the process of providing the client with emotional support;
  * informs about risks of HIV transmission from various medical procedures. Such information is provided to help the client plan ways of minimizing the risk of being infected with HIV.

- A person with multiple sexual partners who is considering ways of changing his or her behaviour may:

  * be provided with scientifically-based information regarding the extent to which abstinence, mutual fidelity or the consistent use of condoms may reduce the risk of HIV transmission and about ways in which

condoms should be used if they are to be effective in preventing HIV transmission.

* be told that the risk of becoming infected with HIV increases with the number of partners and encouraged to reduce the number of partners.

The relative emphasis placed on each component of HIV/AIDS counselling during a counselling session is determined by the client's particular needs at that time and by the client's readiness to confront the issues that are associated with HIV. Therefore, the well-trained and perceptive care-provider, based on the client's needs, will decide on the relative "weighting" of the two main components of counselling on a session-by-session basis. For example:

- During a counselling session, when a client is first informed of a diagnosis of HIV infection, almost all the emphasis is likely to be placed on the provision of emotional support and on helping the client to come to terms with the consequences of the information that he or she is HIV-positive. Without this emphasis on providing emotional support during the post-test counselling of HIV-positive clients, it is unlikely that the client will subsequently be able to absorb and respond to the risk reduction element of counselling (including, for example, notification of sexual partners of the client's HIV-positive status).
- During a counselling session that takes place after the client has begun to accept and come to terms with the fact that he or she is HIV-positive, it may be more appropriate to place more emphasis on risk assessment and planning of risk reduction. This will enable the client to make appropriate decisions, for example, regarding how to prevent transmission of HIV to his or her sexual partners (or to those sharing needles with the client).

In the particular case of the client whose story is described in Box 1, the relative emphasis of each of these components in the series of counselling sessions involved is shown in Figure 1.

What are the special characteristics of HIV/AIDS counselling?

In order to achieve the objectives of providing emotional support and facilitating prevention behaviour, HIV/AIDS counselling needs to:

- be a **confidential** and personalized process unless and until the client decides otherwise;[1]

[1] Confidentiality in HIV/AIDS counselling implies that only the client and the providers involved in direct care of the client have access to the client's personal information. This information is not furnished under any circumstances to other health care providers, health authorities, family members, employers, insurers, schools or other third parties without the patient's explicit consent.

- **react to the client's needs** and involve conversation and dialogue, without being a didactic process;
- be an **empowering and enabling** process which results in clients taking full responsibility for making those decisions that will directly affect their lives or those of members of their families.

How is HIV/AIDS counselling related to HIV/AIDS education?

HIV/AIDS counselling and HIV/AIDS education have much in common, such as their joint dependence on the ability of the provider to communicate effectively, their role in providing accurate information on HIV prevention and care, the need to be culturally sensitive and the need to assess the knowledge of the receivers before communicating.

The major distinction is that HIV/AIDS counselling is a confidential communication made in response to the needs of the client, providing emotional support to individuals and families who may have HIV-related problems and worries.

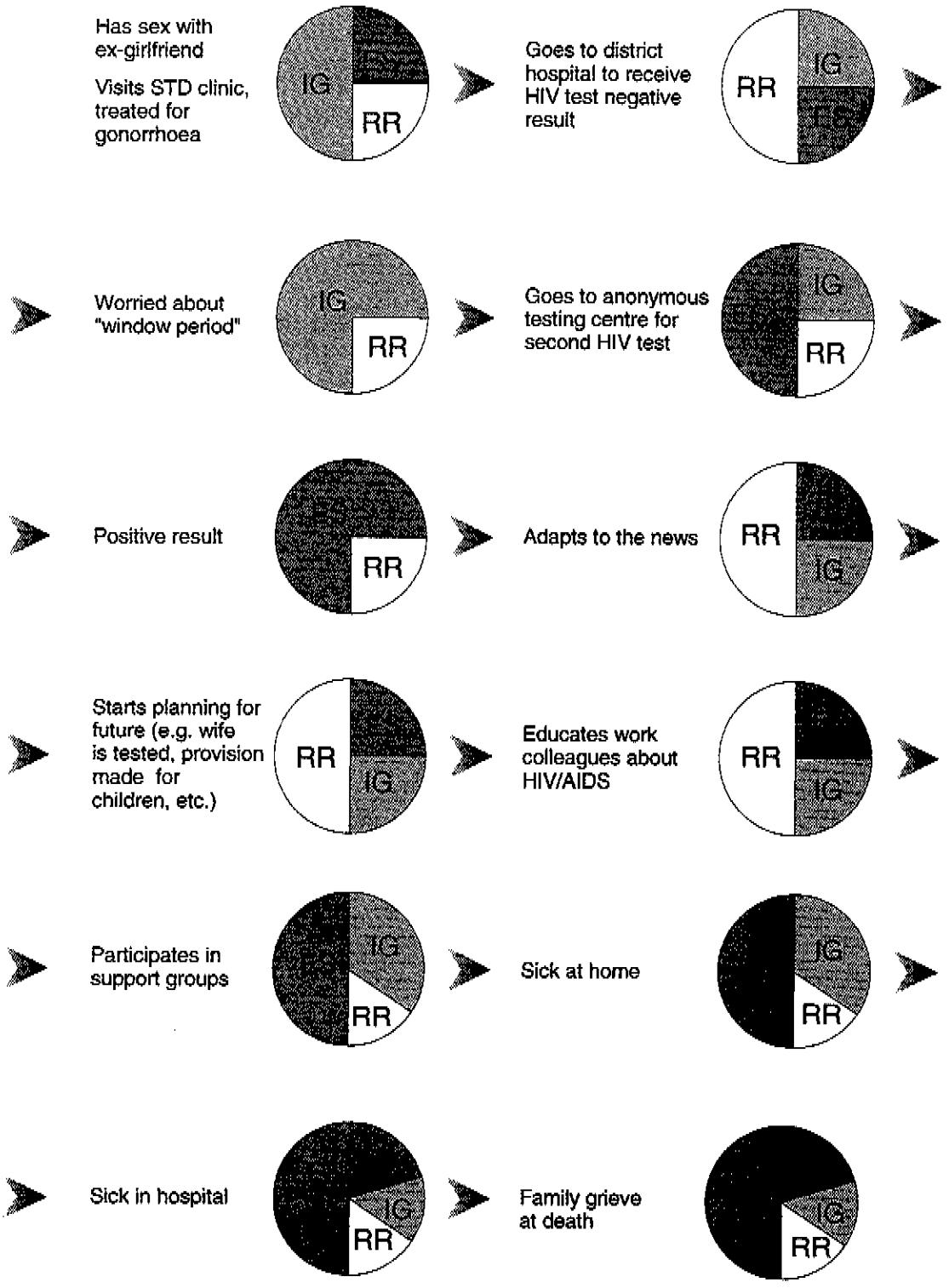
HIV/AIDS education, on the other hand, is a communication that is not usually confidential, is designed in accordance with public health needs and provides information.

The basic skill involved in HIV/AIDS counselling is personalized one-to-one communication relying heavily upon conversational and listening skills.

Educational activities similarly need skills in interpersonal communication but are not necessarily confidential and not geared towards the provision of emotional support:

- HIV/AIDS education, including peer education and one-to-one education;
- communication during clinical and nursing care of AIDS patients and of other patients worried about their risk of acquiring HIV infection; and
- community education and empowerment to make community decisions about HIV/AIDS

Figure 1: Relative emphasis of different components during a series of counselling sessions
(ES = emotional support, IG = information-giving, RR = risk reduction)



In summary

HIV/AIDS counselling:

- is a dialogue aimed at enabling the client to make personal decisions relating to HIV/AIDS;
- is provided to those affected by HIV/AIDS, those seeking or agreeing to receive HIV testing and those worried about their risk of acquiring HIV infection;
- consists of emotional support, personal risk assessment and planning for risk reduction, and is supplemented by personalized information-giving;
- differs from health education in that counselling is targetted primarily towards meeting individual clients' emotional needs and is confidential.

PART TWO: POLICY ISSUES IN THE DEVELOPMENT OF HIV/AIDS COUNSELLING SERVICES

Why is it important to establish HIV/AIDS counselling services?

HIV/AIDS counselling services are established with the goal of meeting the expressed needs for emotional support of individuals who may have HIV-related problems or concerns. HIV/AIDS counselling is a responsive service that should be available to meet the needs for emotional support that are expressed by individual clients.

HIV/AIDS counselling services are important not only for individual clients and their immediate family but also for the community that immediately surrounds the client (including friends and co-workers). In the long run, when affected individuals and families are supported to cope with the effects of and worries about HIV/AIDS and helped to come to terms with the diagnosis, they can talk more openly about their problems to selected members of the community who may provide some help. The wider community benefits through the maintenance of the social fabric and HIV/AIDS counselling tends to have a "ripple effect" on the community.

HIV/AIDS counselling is important for **individual clients** because:

- it helps HIV-positive clients to cope with news of their HIV status and related feelings, develop self-esteem and live productive lives, as well as to seek medical and social support;
- it helps individuals to assess their and their partners' risk of becoming infected with HIV and make plans to reduce the risk.

HIV/AIDS counselling is important to **those who are closest to the client**, such as family or close friends, because:

- it facilitates communication between a client and the family;
- it enables the client's family to be involved in discussions of what measures will be taken to provide care for the client and to prevent transmission of HIV infection.

For these reasons, national AIDS programmes are urged to develop policies that will facilitate the development and implementation of appropriate HIV/AIDS counselling services as part of other HIV/AIDS-related activities.

What factors should be taken into account when developing policies for HIV/AIDS counselling services?

HIV/AIDS counselling will differ from place to place depending on a variety of factors. Planners should take stock of these factors in their local context before developing policies on HIV/AIDS counselling services. Factors which should be taken into account in establishing HIV/AIDS counselling services include:

- **epidemiological factors** such as the current prevalence of HIV infection, its distribution amongst particular groups, and trends in HIV transmission;
- **sociocultural factors** such as current attitudes to HIV/AIDS amongst key groups such as policy-makers, care-providers and community members;
- **historical or political factors** such as the existence of legislation and policies relating to mandatory testing and notification of infectious diseases or the results of any evaluations or assessments of health services;
- **service-delivery** provisions such as the current distribution of health, family planning, counselling and social service facilities and related manpower and the rationale for, and appropriateness of, this distribution.

What are the goals of HIV/AIDS counselling services?

Policy-makers and planners in a country or institution should define the goals of HIV/AIDS counselling services as a guide to implementors.

In the context of a national AIDS programme, the two goals of counselling are usually:

(1) To reduce emotional stress and enable people living with HIV/AIDS and their families and those undergoing linked HIV testing to cope.

(2) To make possible personal confidential risk assessment and to facilitate preventive behaviour for those worried about their risk of becoming infected with HIV and for those living with HIV.

What is the relationship between HIV/AIDS counselling and other activity areas in a national AIDS programme?

HIV/AIDS counselling has a mutually reinforcing relationship with each of the other activity areas in a national AIDS programme. For example, HIV/AIDS counselling positively influences:

- HIV/AIDS **education and information-giving services**, by removing some of the emotional barriers which may impede learning and may also prevent subsequent behaviour changes from taking place. Counselling makes

educational messages more personally relevant as a follow-up to an HIV education campaign. In turn, education and information benefit HIV/AIDS counselling by making clients aware of the availability of HIV/AIDS counselling services and by explaining the role of such services.

- HIV/AIDS **clinical management and clinical care** services, by enabling the client to participate in decision-making regarding different options for care, such as choosing between hospital and home care after consideration of their relative costs, inconvenience to the family and potential benefits. In turn, clinical management services benefit counselling by reducing the physical symptoms of clients, such as persistent diarrhoea, so that clients regain a sufficient level of self-esteem and physical health to enable them to participate in decision-making and planning.
- **social support** services, by encouraging and enabling clients to identify and express their needs for support, thus helping clients to discuss various options. In turn, social support benefits counselling by meeting the clients' needs for material resources, thereby enabling the counsellor to concentrate on meeting the clients' needs for emotional support.
- HIV/AIDS-related **community development** and **community organization** activities, by stimulating more open and informed discussion of HIV/AIDS and of the role that community members might play in care and prevention programmes. This happens when counselling enables individuals and families affected by HIV/AIDS to come to terms with the diagnosis so that they can talk more openly about their problems to selected members of the community who may provide some help. This concept which starts with individual clients can then, through the "ripple effect" of counselling, spread to the wider community. Counselling benefits from community development and the activities of community organizations through the provision of locally available resources and expertise which may often be voluntary and therefore low-cost.
- the **societal response to AIDS**, by providing models of compassionate and informed behaviours that are responsive to the dilemmas and difficulties stemming from the AIDS pandemic.

Where does HIV/AIDS counselling take place?

HIV/AIDS counselling takes place in a wide variety of settings. Regardless of the existing HIV prevalence in a country or region, counselling services should always be available at:

- sites where care is being provided for HIV-positive persons; and
- sites where HIV tests are done and results can be traced to the individual (linked HIV testing).

In countries, or in defined geographical areas within a country, where HIV prevalence is high, HIV/AIDS counselling services should **also** be available at the following sites :

- community sites where ongoing support is provided to those affected by HIV/AIDS;
- health clinics at the workplace; and
- independent sites where voluntary counselling and testing can be sought.

Who takes part in an HIV/AIDS counselling session?

Most HIV/AIDS counselling sessions are confidential and most involve the participation of a single client and a single care-provider. The client has an absolute right to confidentiality and/or anonymity unless and until he or she decides otherwise. However, at the discretion of the client and the care-provider, the following other people may be involved in an HIV/AIDS counselling session:

- members of the client's family;
- a second care-provider with additional counselling skills which may be required to help the client address a particular problem;
- other resource person such as a clinician, a co-worker or religious leader.

Counselling clients in a group can be less time-consuming and therefore less costly than counselling individual clients. However, the circumstances under which more than one client attends a counselling session are subject to careful consideration. The use of group counselling is probably most appropriate at those stages of the counselling process when the educational element is paramount. Group counselling is not appropriate when the emotional support element takes precedence (for example, at a counselling session when a client is to be informed of the positive result of an HIV test) and/or when confidentiality is required.

Because of the greater potential for breaches of confidentiality when group counselling is being undertaken, clients should always be given the opportunity to give their fully informed consent before participating in a group counselling session. Secondly, selection of group members should be sensitive to age, gender and sexuality differences among potential group members. Female sex workers may not find it easy to be in the same group as married women; men who have occasional sex with other men may not relate well with men who identify as gay; men who never have sex with men will relate even less well; and street children may not be understood by moralistic adults.

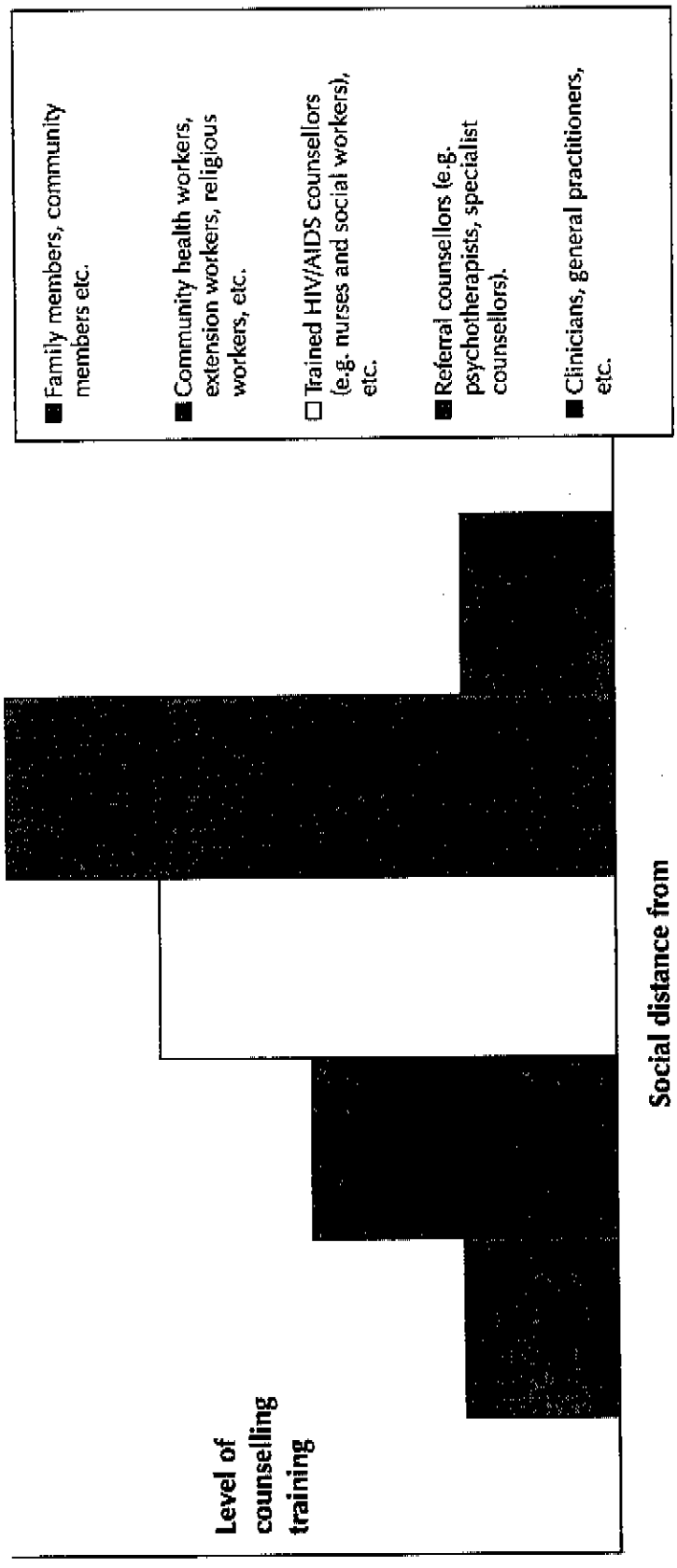
Who undertakes HIV/AIDS counselling?

A wide range of people may play a role in the provision of HIV/AIDS counselling services. They may include:

- nurses, social workers and other care-providers who have been specially trained in HIV/AIDS counselling and who may be either part-time or full-time providers of counselling services at facilities in their country. Some of these trained individuals may also act as "focal points" for counselling services in their country, province or district;
- full-time counsellors (e.g. psychologists and therapists) who have been trained in HIV/AIDS counselling and who may receive clients directly or through referral by other care-providers;
- religious workers and other community-based workers whose work consistently entails the appropriate handling of confidential information and emotional issues;
- community members, and members of AIDS support organizations and people living with HIV/AIDS.

The level of counselling training and the social distance of each of the above categories of care-giver will vary greatly from setting to setting. Figure 2 is an illustration of such variations among different providers of counselling.

Figure 2: Different categories of counselling providers according to level of counselling training and social distance from client



Counselling services are commonly provided by nurses or social workers who have received practical training in HIV/AIDS counselling. A cadre of specialist counsellors may be available for referral or consultation purposes - these will often be trained psychologists, psychotherapists or social workers and nurses who have received specialist training and have gained extensive experience in HIV/AIDS counselling.

Some examples of appropriate patterns of counselling responsibility in different settings are given below:

1. In a setting where HIV prevalence is low, but where the degree of stigmatization against HIV-positive persons is high, there may be a need for a cadre of trained care-providers who can provide the greater emotional and social support that is likely to be necessary for HIV-positive clients in such settings. The role of trained care-providers, such as nurses and social workers, in HIV/AIDS counselling in these settings is likely to be large, whereas the counselling role of peers and community-members at this stage in the development of the epidemic may be less. In such a setting, community members may be trained as peer educators rather than as counsellors
2. In a rural setting where HIV prevalence is high, but where potential clients of counselling services do not have access to health care facilities, more participation of community members in the HIV/AIDS counselling process, usually with leadership and training from relevant counselling organizations that have a presence in the area, may be the only possible way of meeting the need for HIV/AIDS counselling. If HIV prevalence in such settings is particularly high and if the very limited number of overburdened health care workers are unable to take the lead in organizing the provision of counselling services, the community itself may need to take on additional responsibility for organizing and providing counselling services as well as for providing care to AIDS patients.
3. In a setting such as a large city where per capita incomes are relatively high, services for those who can afford them may be provided on a private basis by psychologists and therapist who have developed expertise in HIV/AIDS counselling. Alternatively, if funds are available from the public sector, they may provide services in the public sector whilst providing private services in their spare time, or vice versa.

AIDS "hotlines" have been established in several countries. The main goal of these services is to provide accurate information about HIV/AIDS and, if necessary, to refer clients to trained HIV/AIDS counsellors or HIV counselling and testing centres. Under certain circumstances, clients may request that HIV/AIDS counselling services be provided by telephone. The provision of telephone counselling services is important in settings (where telephone services are widely available) where some clients may have realistic fears about retaining anonymity or where access to face-to-face counselling services is difficult. In any case, telephone counsellors should have previous training and experience as HIV/AIDS counsellors and this should be supplemented by training as telephone counsellors. The giving

of HIV test results by telephone should be discouraged. Box 2 illustrates an example of anonymous counselling provided by means of a "hotline".

Box 2. The AIDS hotline: anonymous counselling

Peter left home at the age of twenty and moved to the city. This was a liberating experience for Peter, who had known for several years that he had a sexual preference for other men. His formative years had been spent in an environment where intense stigmatization against those who practised a homosexual lifestyle and against those who might be HIV-positive was the norm. Soon after he arrived in the city, he established a permanent relationship with another man with whom he lived in a committed relationship for the next six years. During these six years, Peter never communicated with his parents, who did not even know where he was living, because he knew that his father, a senior military officer, would be appalled by the fact that he was living with another man.

During these six years, several friends of Peter and his partner became HIV-positive. Peter started to worry that he too might be HIV-positive. However, since he was well aware of the high level of stigma towards homosexuality, he was reluctant to meet any health officials in order to discuss this risk. He was delighted to learn of the availability of a telephone hotline, through which he could discuss his HIV worries without being identified. After discussing his sexual history over the telephone with a staff member of an AIDS hotline, Peter decided to go for an HIV test at a local counselling and testing centre where he was assured of receiving an anonymous HIV test. The result of the test was positive.

The counsellor who gave him the news of his HIV-positive status provided Peter with emotional support and then referred him to a counselling service, and to an AIDS support organization, that were both nearer to his home. After several months of counselling, and as a result of considering all of the options that were presented to him by the counsellor, Peter decided to make contact with his parents again.

How are providers of HIV/AIDS counselling services trained?

The design of training programmes is based on the specific objectives of counselling service provision in a particular setting and on the pattern of service delivery that is most appropriate for meeting these objectives.

Effective training of providers of HIV/AIDS counselling services always has a closely-supervised practical component. Therefore, counselling training programmes should be designed in such a way that ample opportunity is provided for trainee counsellors to receive this practical training and to learn by sharing their experience with the help of a supervisor.

GPA has published the *Source Book for HIV/AIDS Counselling Training (WHO/GPA/TCO/HCS/94.1)* from which those who plan and/or conduct training for HIV/AIDS counselling service-providers can extract material and adapt it to the needs of the trainees at hand (see Annex 1). Some countries or institutions may then use this adapted material to develop their own counselling training manuals. These manuals can be used by those who have gained expertise in HIV/AIDS counselling to train other providers in counselling skills as the need arises.

Integrating counselling into existing health services

HIV/AIDS counselling is a labour-intensive activity that will consume a significant portion of the already overstretched time of health or social workers. Service planners will need to develop strategies for integrating this new service into existing ones so that counselling is not seen as an extra burden, but rather as a support to other services.

Strategies for integrating HIV/AIDS counselling services include:

- **redefinition of job descriptions** of carefully selected staff so that HIV/AIDS counselling becomes an added role without creating a new post. In many settings, especially those where HIV prevalence is high, this has been done for those cadres of nurses and social workers who are to be trained in HIV/AIDS counselling. If this approach is adopted, great care should be taken to ensure that other essential services do not suffer.

- **involvement and training of volunteers** to provide services. This method has been applied particularly in those countries where there are social workers, school teachers, religious workers, PWAs and other community members who are willing to donate a portion of their time to provide HIV/AIDS counselling services on a voluntary basis. These volunteers have been especially useful in providing on-going community-based counselling to individuals referred to them from the formal health and social services.

- the selection and testing of innovative **alternative approaches** to counselling that may allow a reduction in the staff time required. If this approach is adopted, great care should be taken to ensure that the essential features of the counselling process are not compromised. Careful attention should also be given to ensuring that any alternative approaches that are selected still allow for the necessary interaction and dialogue between the client and the care-giver. This dialogue is the fundamental component of the counselling process. For example, videocassettes, leaflets and group information sessions have been used to provide the bulk of information needed by clients, before they meet the counsellors, so that the counselling session can be shortened. If any of these are used in a supplementary role, their use should be carefully integrated into the ongoing counselling process by a trained counsellor.

- **written procedures for the provision and organization of HIV/AIDS counselling services.** The presence of standard procedures will facilitate supervision and monitoring by making it clear what is expected of the staff of a counselling service. They will enable other staff to know when and where to refer clients who need counselling. Clear procedures on how HIV-related client information is handled will enable high standards of confidentiality to be maintained while at the same time allowing information to flow. In the long run, when staff know what to do and when to do it, staff stress will be minimized.

Boxes 3 and 4 provide examples of how some countries have developed counselling services to respond to the identified needs of their communities.

How do HIV/AIDS counselling services link with other services and other agencies?

For many individuals needing and/or seeking HIV/AIDS care, counselling represents one of the entry points to care. This is true for a client who comes to a walk-in HIV testing centre and requires pre-test counselling, as well as for the client who comes to the health centre with symptoms of AIDS and is referred to a trained counsellor who is responsible for breaking the news that the client has AIDS. The level of trust between the client and the care-giver created during the initial stages of the counselling process will often be a critical determinant of later relationships between the client and the variety of individuals and organizations that play a role in the provision of care, including counselling. The various interactions between the individual and different caregivers within a comprehensive care system are shown in Figure 3.

Some organizations and services which may have links with counselling services are:

- **clinical management services.** For example, a client who receives the information from a counsellor that he or she is HIV-positive may be referred by the counsellor to a clinician who specializes in the care of HIV-positive patients. Similarly, an individual who learns that he or she is HIV-positive may need the help of a counsellor to liaise with clinicians in other specialized clinics, e.g. haemophilia clinics or antenatal clinics, where information about HIV status may be needed but has to be passed on in a confidential manner.

- **family planning services.** For example, an HIV-positive client who wishes not to become pregnant for fear of transmitting the virus to her unborn child, may be referred to local family planning services to obtain contraceptive services and counselling.

Box 3. Country counselling services, Zambia

In order to respond to the great numbers of individuals needing HIV/AIDS counselling, the National AIDS Programme of Zambia has supported the countrywide development of counselling services using existing health and social workers in the following ways:

- a national "focal point" for HIV/AIDS counselling, whose role is to coordinate all HIV/AIDS counselling activities, including the policy development process, has been designated;
- a countrywide programme of training in HIV/AIDS counselling for clinical officers and nurses has been implemented and plans are being developed to set up counselling services as an integral service in all district hospitals;
- advanced training in HIV/AIDS counselling has been provided for carefully selected staff from each Province who can receive referrals from other counsellors and conduct training in HIV/AIDS counselling;
- a walk-in counselling and testing centre, staffed by full-time HIV/AIDS counsellors and providing anonymous testing and counselling, has recently been opened in Lusaka, the capital city;
- mobile teams of trained HIV/AIDS counsellors take their services to workplace settings where counselling services are available as an adjunct to educational programmes about HIV/AIDS;
- members of home-based care teams who visit AIDS patients in their homes (as part of a national policy to make home-based care services available and thereby reduce the number of hospital inpatients) have been trained as counsellors;
- "group counselling" has been introduced at carefully selected phases of the HIV/AIDS counselling process in order to provide some of the educational elements of the HIV/AIDS counselling process at lower cost;
- peer education interventions that are closely linked with HIV/AIDS counselling services and that make increasing use of the contributions of HIV-positive individuals have been introduced;
- counselling services with staff members who are trained in HIV/AIDS counselling to supplement their training in generic counselling skills have been established in the university and in other institutions of higher education.

Box 4. Country counselling services, Myanmar

In Myanmar, the prevalence of HIV infection is high among individuals who are injecting drug users (IDUs) and among commercial sex workers. Initially, many cases of HIV were discovered among blood donors. A surveillance team was formed to follow up these HIV-infected individuals and advise them about prevention of HIV transmission. This team of health workers soon discovered that, whenever they visited the HIV-infected individuals, they had to deal with a variety of emotional and social issues before they could get the HIV-infected individuals to listen to advice about prevention. These emotional and social issues included:

- rejection by the spouse and family and even being thrown out of the house;
- not knowing how to inform their partners and families about their HIV status;
- being ill but reluctant to go to the hospital for fear of being identified as HIV-positive and subsequently being subject to stigmatization.

In the Drug Detoxification Unit of Yangon, where IDUs are admitted to be detoxified and rehabilitated, nearly 60% of the patients are HIV-positive. While the medical social workers at these units were well equipped with knowledge and skills to advise IDUs to stop using drugs, the emergence of HIV raised new issues to be considered. In addition to the issues highlighted above, the medical social workers had to address the following:

- options for prevention of HIV transmission among IDUs did not/were not able to stop injecting;
- how best to tell the family that a person is injecting drugs and is infected with HIV.

Faced with these challenges, the National AIDS Programme requested technical assistance from WHO/GPA to train members of surveillance teams, medical social workers and other health workers in HIV/AIDS counselling. All of these groups were given a five-day basic counselling workshop, followed by six months during which they practised their skills while meeting monthly to discuss cases. After this period they attended a five-day advanced counselling workshop. These health workers are now fully trained and are available to train others in HIV/AIDS counselling in other parts of the country according to the plans and priorities of the National AIDS Programme.

- **blood transfusion services**. For example when pre-donation information and counselling are provided to potential blood donors, counselling facilitates the process of confidential self-deferral and/or deferral of high-risk donors. Those who wish to donate blood primarily for the purpose of knowing their HIV status can be referred to a voluntary counselling and testing site, if it exists (see guidelines for counselling blood donors, listed in Annex 1).

- **clinical and epidemiological research**. If such research includes linked HIV testing, counselling is provided as an ethical obligation and as a care and support service to the study participants. Ongoing counselling also facilitates compliance with the follow-up procedures of the research.

- **local social support organizations**. For example, a client who is no longer able to work may be referred to a local AIDS support organization for emotional support and financial or material assistance.

- **organizations that specialize in meeting specific client needs**. For example, a client who is an injecting drug user may be referred to a methadone programme or to a needle exchange programme. A homosexual client may be referred to a local self-help support and advocacy group of men who have sex with men.

- **religious workers**. For example, an AIDS patient may request help in meeting spiritual needs and be referred to a local religious institution.

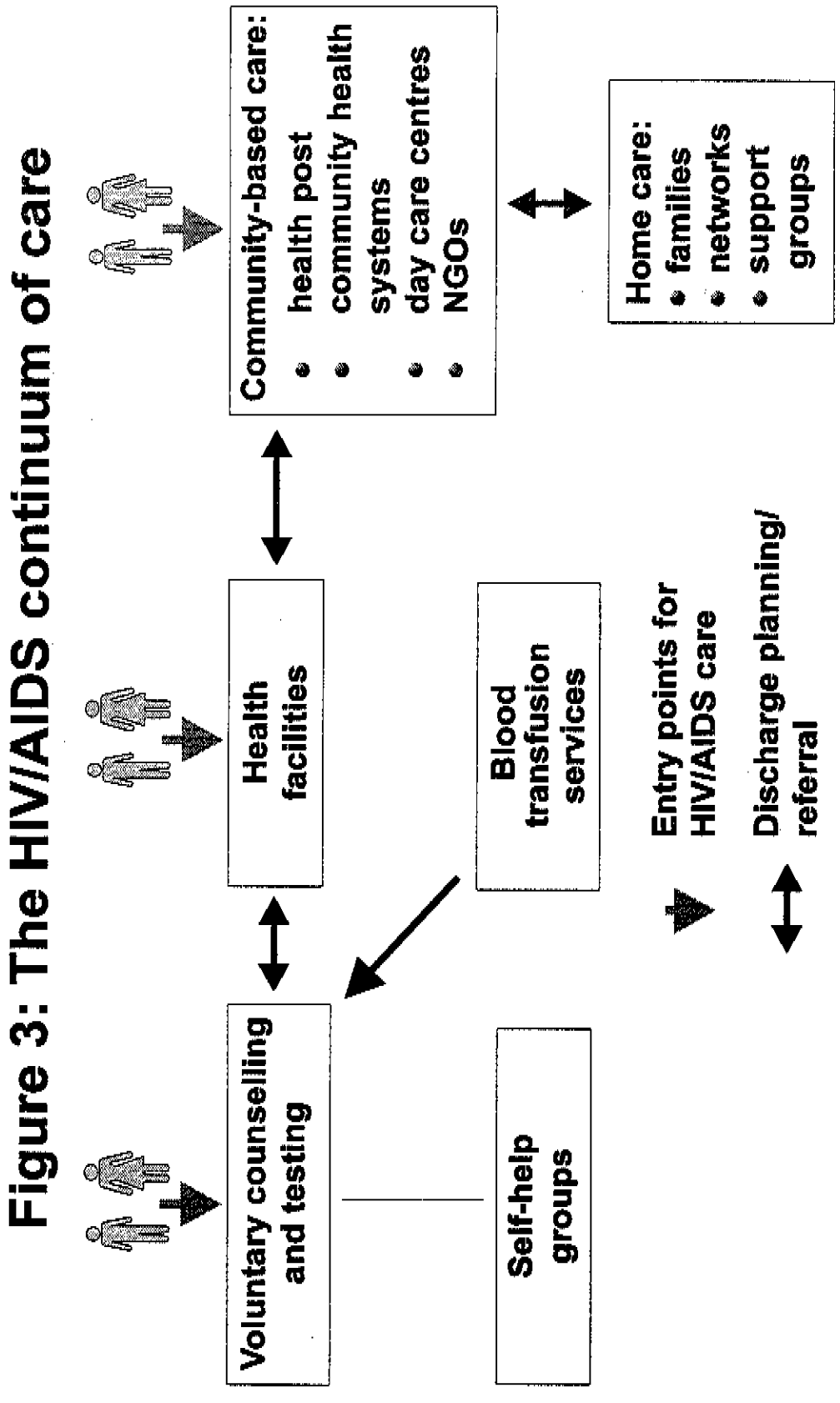


Figure 3: The HIV/AIDS continuum of care
Community-based care:
• health post
• community health systems
• day care centres
• NGOs
Home care:
• families
• networks
• support groups
Health facilities
Blood transfusion services
Entry points for HIV/AIDS care
Discharge planning/ referral
Voluntary counselling and testing
Self-help groups

To be beneficial, voluntary HIV testing, whether initiated by the client or by the health worker, must be:

- part of a comprehensive counselling programme, in which trained counsellors provide counselling before a decision is made about testing (pre-test counselling), and provide counselling together with other supportive services (such as the provision of condoms and safer injecting equipment, where appropriate) or referral after testing (post-test counselling);
- entirely the choice of the individual;
- confidential or anonymous;
- technically sound in terms of laboratory tests used and the quality of the laboratory practices.

See also the statement on testing and counselling listed in Annex 1.

Monitoring and evaluation of HIV/AIDS counselling services

A monitoring and supervisory procedure should be set up to ensure that counselling services are delivered as planned and that any constraints are addressed promptly. This process also enables the professional supervisors of the service to give support to the providers. Evaluations of the impact of HIV/AIDS counselling should be undertaken in order to determine whether the goals of HIV/AIDS counselling have been met. These goals (see page 12) will usually state the purpose for which HIV/AIDS counselling services have been established.

Evaluations should include consideration of the following aspects of the provision of HIV/AIDS counselling services:

- **relevance** (i.e. whether the services are designed to meet a need that has been clearly defined and whether the provision of HIV/AIDS counselling services is the most appropriate way to meet this need);
- **impact** (i.e. whether the services are meeting the intended aim);
- **efficiency** (i.e. whether the services are provided in a cost-effective and timely manner); and
- **progress** (i.e. whether the provision of services is according to plan).

A review of existing documents in the following policy areas at a national or institutional level may form part of the process of the evaluation of HIV/AIDS counselling services:

- policy statements on HIV/AIDS counselling and related areas;

- procedures used in the institutions that are providing services, for example, for counselling and referral;
- standards for the provision of services;
- criteria for monitoring and/or assessing service provision.

The WHO/GPA document *Guidelines for implementing HIV/AIDS* contains guidance on how to establish, maintain and evaluate HIV/AIDS counselling services, including separate tools for setting and monitoring the standard of counselling, evaluating the supportive impact of counselling and measuring the preventive impact of counselling.

HIV/AIDS counselling for women and children

HIV can infect anyone, men, women or children. However, the relative vulnerability of women, children and adolescents will need special attention when counselling services are being developed.

Whilst many of the basic principles of counselling practice are the same for women as for men, several factors should receive special consideration when women are the recipients of HIV/AIDS counselling services:

(1) Since many women are living in **unequal power relationships** with either their sexual partners or the male members of their families, it may be necessary for the provider of HIV/AIDS counselling services for women, to devote additional time to help the woman to assess and strengthen her ability to negotiate arrangements that will prevent transmission of HIV. The care-provider may refer the woman to an organization or self-help group, if available.

(2) Because of their **traditional role as care-givers** rather than receivers of care, many women do not give priority to having their own needs for care met. Counselling of women should therefore include helping them to express their own needs for care.

(3) In many settings whilst reproductive decisions are often made by men, women tend to shoulder the blame and responsibility when things go wrong. The HIV/AIDS counselling process helps women to redress this imbalance providing information, discussing personal difficulties and offering a forum for their partners to become involved in such decision-making.

(4) As HIV can be transmitted from mother to child via **breast-feeding**, this issue needs special attention when counselling women who are pregnant or who have delivered recently. The risks of breast-feeding should be weighed against the risks to which the child may be exposed as a result of bottle-feeding. For example, a child whose mother is HIV-positive and who lives in an

environment where there is no clean water, is probably at higher risk of dying from diarrhoea if bottle-fed than of dying from AIDS if breast-fed. The GPA document *Human immunodeficiency virus (HIV) and infant feeding: Essential issues for decision-makers* (see Annex 1) provides policy-makers with guidance on how to develop counselling policies concerning breast-feeding and HIV/AIDS.

(5) **HIV infection in a child** implies that the mother too is infected, unless the child has other risk factors (e.g. blood transfusion or sexual abuse). The mother needs psychological support to help her face this reality. The child may also face negative reactions from other children and their parents due to stigmatization and irrational fear of casual spread of HIV infection. If the child is old enough to understand, he or she should participate in discussions about issues regarding HIV infection and related episodes of illness and the reaction of other children and the community. The document *Guidelines for the clinical management of HIV infection in children* (see Annex 1) contains a chapter on counselling that covers these issues in detail.

Thus, much more time may need to be allocated for counselling female clients and children than for counselling men.

Counselling of adolescents and young people about HIV/AIDS

An adolescent may him or herself be infected with HIV or affected by HIV because a parent, sibling or other family member, a sexual partner or close friend is infected. The counselling of adolescents and young people presents particular challenges:

(1) The main challenge is that of **balancing the need for confidentiality with the need to meet legal responsibilities towards the young person's family**. For example, a young person who has a tumultuous relationship with his or her parents may not be willing to use services that may inform the parents of drug problems or a history of STDs. This may mean that young clients who could be helped if they were to come forward for counselling may instead retreat from it.

(2) There is a marked tendency to **label the adolescent client who has a problem**. For example, many agencies automatically conclude that the young client with drug problems is also the one with STDs or the one who is likely to become pregnant. This labelling adversely affects young clients so that they gradually lose their self-esteem and their ability to make sound decisions.

(3) There is a need for care-providers to fully comprehend the **culture of young people**. Without this understanding, it is very unlikely that a dialogue, which

is the essential feature of effective counselling, will take place between the care-provider and the client.

(4) **Haemophilia** will present special problems. Mothers may feel guilty because they have not only passed on the haemophilia but, in many cases, have unknowingly injected a contaminated product. When the haemophiliac adolescent has been infected as a young child, the parents have to decide how, when and who will inform the child of this fact. Parents often postpone this until puberty when they say, "sex may come onto the scene". Box 6 illustrates some issues which may arise during a counselling session with an HIV-infected haemophiliac adolescent.

Youth counselling services, where they are available, often have many years of experience in meeting the particular needs of young people and may provide an appropriate location for HIV/AIDS counselling services for adolescents and young people. See the document *Counselling skills training in adolescent sexuality and reproductive health,* listed in Annex 1.

Box 5. Counselling of an HIV-positive adolescent with haemophilia

A family interview with parents and a boy of 15 with haemophilia and HIV infection is used to illustrate how concerns are identified and information that might previously have been kept secret is shared with family members. This is a follow-up counselling session; the boy has already received post-test counselling and he knows he is HIV-positive. His 13-year-old brother is at school and has not been brought to the interview.

Counsellor:	Mr J., what have you told Peter about why we are here today?
Mr J.:	I said we were coming for a check-up and to discuss anything that is worrying us.
Counsellor:	Is this what you understood, Peter?
Peter:	Yeh.
Counsellor:	Mrs J., your husband said you had all come to discuss your worries. Is there anything that you think is worrying your husband?
Mrs J.:	Yes, there is. It is what effect it will have on Peter knowing now that he has HIV. We are worried sick.
Counsellor:	What most worries you, Mrs J.?
Mrs J.:	That he won't be able to marry and have children.
Counsellor:	Peter, did you know that Mum was worried about this?
Peter:	Not really.
Counsellor:	Do you worry about not having children?
Peter:	Not really.

Counsellor:	Peter, I wonder who you think might worry most about this, you, your father, mother, your grandparents or your brother?
Peter:	I don't worry about it. My mother does and so does granny. She only wants me and my brother to have kids.
Counsellor:	So, Peter, you think that your granny puts pressure on your mother?
Peter:	She is always worrying about those things.
Counsellor:	Mrs J., did you know that Peter thinks you and your mother are most worried about this and Peter least?
Mrs J.:	I didn't realize that was how he saw it.
Counsellor:	Mr J., what is your greatest worry today?
Mr J.:	That Peter won't work at school because he won't see the point.
Counsellor:	What do you think about what Dad has said?
Peter:	He just worries that we get a good job. I find work boring at school.
Counsellor:	What would you prefer to be doing?
Peter:	I don't know. There isn't any point, is there, if I'm going to die. You die of AIDS, don't you?
Counsellor:	Yes, you can die of AIDS. Is dying something that worries you?
Peter:	I don't worry about dying. I won't know about anything then. I just want to do what I want.
Counsellor:	What do you want Peter?
Peter:	Not to be nagged all day.
Counsellor:	Just say, Peter, that you keep as well as you are for a good number of years. How would you fill your time?
Peter:	I could get a job.
Counsellor:	Mr J., what is your view about what Peter has been saying? Do any of us know exactly how much time we have got? We could have an accident tomorrow. Do you think that you could discuss with Peter how he might do what he wants, but also show him how difficult it is to get jobs without any qualification? Mrs J., we have heard from Peter that he is not worried about dying. Nor is he worried that he might not marry and have children. He gave me the idea that there are many people who can't have children. Some never find partners, some have other illnesses, and others are infertile. So, although this is your worry now, Peter's worries seem different.

Source: Robert Bor, Riva Miller and Eleanor Goldman, *Theory and Practice of HIV Counselling: A Systematic Approach*, London, Cassel, 1992.

HIV counselling and testing

In order to offer national AIDS programmes guidance on the role of HIV testing, a consultation was held in Geneva in November 1992 (see the statement listed in Annex 1). Its purpose was to review what is known about the advantages and disadvantages of HIV testing, and to develop recommendations on the role of testing and counselling in HIV/AIDS prevention and care programmes. The consultation stressed that testing programmes which do not require and secure an individual's informed consent could damage efforts to prevent HIV transmission and are therefore not in the interests of public health. Voluntary testing and counselling can, however, be useful to initiate care and support of seropositive individuals, provide reassurance and support to seronegative individuals, and relieve anxiety in both groups.

How might future developments in AIDS prevention, testing and care affect the demand for and delivery of HIV/AIDS counselling services?

The following future developments in the area of AIDS prevention, testing and care are likely:

1. The introduction of **rapid HIV tests** in which clients can be informed of their test results within a few minutes will mean that clients may be informed of the results of positive HIV tests before they are emotionally and psychologically prepared to absorb the news. This may lead to additional demands being placed on care-providers. Policies will therefore be needed to ensure that all clients receive adequate pre-test counselling before they are informed of the result of any HIV test.

2. **Self-administered HIV tests**, which could be purchased from pharmacies, could be a popular product in countries where levels of discrimination and stigmatization are highest; for example, in some countries, known HIV-positive status can mean rejection of insurance coverage or loss of job. In such settings, individuals may wish to avoid any possibility of their HIV status becoming public knowledge by purchasing and self-administering HIV tests. Prior to such tests coming on the market, national policies should be put in place to ensure that reference to the need for, and availability of, HIV/AIDS counselling is contained in the instructions and advertisements for such products.

3. Likely **developments in the clinical management of AIDS patients**, leading to prolongation of life beyond what is now the norm, could provide a new rationale for requesting an HIV test. Such developments could lead to an increased demand for voluntary testing and consequently for HIV/AIDS counselling services.

4. **Large-scale trials of vaccines** against HIV will lead to increased demand for HIV/AIDS counselling services. All research protocols for vaccine trials should ensure provision of counselling services for subjects who are involved in the study; such provision should include funds for the necessary training in HIV/AIDS counselling. In countries where vaccine trials are to be conducted, planners will need to put into place strategies to ensure that the increased demand for care-providers with counselling skills is met.

In summary

HIV/AIDS counselling services:

- are necessary to enable affected and worried individuals and families to cope with the effects of HIV infection and with the stress of receiving HIV testing;
- should relate and be linked to other HIV/AIDS activities;
- are usually delivered by providers who have received in-service training in counselling skills to supplement their basic professional training;
- should be established at all sites where care is provided for people with HIV infection and where linked HIV testing is carried out;
- should be integrated into existing health/social/support/religious services.

PART THREE: THE ROLE OF POLICY-MAKERS AND PLANNERS

What are the essential policies and procedures that should be in place before HIV/AIDS counselling services are established?

The HIV/AIDS counselling process is most effective when the following are in place prior to the establishment of services:

- policy statements regarding the objectives and purpose of HIV/AIDS counselling services in the country or institution, including where and to whom counselling should be delivered; and the strategies that are to be followed to ensure that counselling is available/accessible to the desired target group.

- written procedures within each institution or agency providing HIV/AIDS counselling services that will guarantee that testing is confidential and, if requested, anonymous. If needed, there will be procedures for explaining the differences between these two concepts to all clients;

- policies that clearly state that all HIV testing is to be voluntary and to be based on explicit informed consent;

- written policies on who should provide HIV/AIDS counselling: what their professional background should be and what additional training they will need. The role of volunteers as regards different aspects of counselling (pre- and post-test, follow-up counselling) should also be clearly spelt out.

In situations where the above requirements are not met, policy-makers and planners can inform themselves, through discussion with providers of HIV/AIDS counselling services, of the adverse impact of existing policies or lack of policies. This information can be used to gain support for policies and procedures that are consistent with the guidelines contained in this document.

What steps can be taken to develop appropriate policies for HIV/AIDS counselling?

These guidelines have described HIV/AIDS counselling and have answered a series of critical policy-related questions regarding how such services are established and developed. Policy-makers and planners can play a crucial role in the establishment of high-quality HIV/AIDS counselling services. In many settings, a comprehensive review of policies that affect the HIV/AIDS counselling process, and subsequent development and promulgation of new or revised policies, may be necessary. The implementation of the sequence of steps

listed below represents one approach to solving the problem of non-existent or inappropriate policies:

1. Nomination of a coordinator for HIV/AIDS counselling and collection of relevant background information.

2. Identification and prioritization of issues in HIV/AIDS counselling that require policy development or amendment.

3. Detailed analysis of priority issues and selection of appropriate policies to address the issues.

4. Development of draft policy statements.

5. Presentation to and review of draft policies by senior officials.

6. Finalization and dissemination of policies on HIV/AIDS counselling and related issues.

7. Follow-up and monitoring of the implementation of the developed policies.

Step One: Nomination of a coordinator for HIV/AIDS counselling and collection of relevant background information.

Interested members of national AIDS committees, senior planners, and sometimes politicians, will usually take the lead in promoting the development and dissemination of appropriate policies on HIV/AIDS counselling. It may be necessary, as a preliminary step, to nominate a person among this group who will act as a coordinator or focal point for issues pertaining to HIV/AIDS counselling. A first task of this coordinator will be to draw up a list of all those who should be involved in the policy development process. Examples of individuals who might be included on this list are:

- the National AIDS Programme Manager;
- the focal point for HIV/AIDS care;
- the HIV/AIDS IEC focal point;
- interested members of the National AIDS Committee;
- senior planners in the Ministry of Health;
- representatives from institutions that are providing HIV/AIDS counselling services;
- senior psychotherapists;
- senior clinicians; and
- senior representatives of nongovernmental organizations involved in HIV/AIDS care and prevention.

The coordinator will also be responsible for preparing or commissioning the preparation of a report on the current status of counselling services in the country, region or institution for which policies are to be developed. This report will include:

- up-to-date epidemiological information on HIV/AIDS and a brief discussion of the implications of this information for the policy-makers and planners of HIV/AIDS counselling services;
- an assessment of the existing, and likely future, demand for HIV/AIDS counselling services;
- a description of existing services including:
  * details of institutions providing services;
  * details of existing counselling training programmes; and
  * an assessment of the strengths and weaknesses of existing services.

Annexes to the report will include copies of relevant documents that help to describe the current status of services such as:

- written counselling policies that are already operative;
- written procedures that are already in place in locations where HIV/AIDS counselling is being undertaken;
- current counselling training programmes;
- summaries of any reports or evaluations of services that are available.

Step Two: **Identification and prioritization of issues in HIV/AIDS counselling that require policy development or amendment.**

Each of the participants in the policy-making process (such as those listed in step one) should be asked to submit a list of priority issues that require policy development or amendment. This is done after they have read these guidelines and have had the opportunity to consult with colleagues and constituents. It may be appropriate to organize a short workshop at which clarification of some of the issues that are discussed in these guidelines, and of issues that are raised by the participants, is undertaken before a final list of critical policy issues is drawn up and agreed. It is to be expected that issues raised during this step will vary greatly from setting to setting depending on the local context. For example, in a setting where HIV prevalence is high, there may be a need for policy development, particularly as regards the question of "who are the counsellors?" In a setting where HIV prevalence is low, but where levels of potential discrimination against HIV-infected persons may be higher, the main issue may relate to the need for firmly-stated policies on issues of confidentiality and partner notification.

The list of issues identified is then circulated to all participants in the policy development process and each participant asked to rank the items on the list in order of importance. The totals are then collated and analysed and the results used for selecting priority policy issues. It is suggested that only the first five or six items on the list should be included in the final list of priority issues.

Step Three: Detailed analysis of priority issues and selection of appropriate policy tools.

Each priority issue should then be examined in detail and statements made about the content of the policies that will be formulated to resolve each issue. The resulting policies may be general or quite specific. An example of a general policy is: "HIV/AIDS counselling services are to be available in all District Hospitals". An example of a very specific policy is: "HIV/AIDS post-test counselling is to be carried out only by nurses or social workers trained in counselling".

Policies may be implemented by various means:

- **legislation** making mandatory testing illegal;
- **a directive** or order informing all health workers of confidentiality provisions in relation to HIV/AIDS;
- **provision of incentives** allowing health or social workers academic credit for attending workshops on HIV/AIDS counselling;
- **preferential treatment** giving non-monetary rewards to HIV/AIDS counsellors who work on a voluntary basis; and
- **indirect incentives** offering exchange visits by HIV/AIDS counsellors to other institutions.

Some policy issues may best be resolved by using a combination of the above tools.

Step Four: Development of draft policy statements.

Written policies covering each of the issues that have been analysed are then drawn up. However, some circumstances, such as possible public opposition to a particular policy, may necessitate a delay in formulating written policies; even under these circumstances implicit policies can be developed and can be incorporated into counselling training and procedures.

Step Five: **Presentation to and review of draft policies by senior officials.**

The draft policy statements are then presented to the senior officials under whose "imprimatur" the policies will be disseminated. The policies are reviewed by these officials and are either approved or returned for further development or modification.

Step Six: **Finalization and dissemination of policies on HIV/AIDS counselling and related issues.**

After review and approval, the new policies are widely disseminated. Any retraining of HIV/AIDS counsellors that may be necessary to bring their practice into line with the new policies is undertaken at this time. Furthermore, an effort should be made to sensitize managers and staff of sites where counselling is to take place about the status of counselling. HIV/AIDS counselling, being a relatively new domain, is often regarded with suspicion and uncertainty. The role of counselling in HIV testing and in the care of patients will need to be discussed at every counselling site. These discussions, and perhaps seminars, form part of the process of dissemination of policies on HIV/AIDS counselling.

At this time the senior officials may be encouraged to solicit personal testimonials from political figures or other well-known individuals. The positive impact of such testimonials to back up a proposed change in policy, particularly one which aims at reducing the stigmatization to which HIV-positive persons are exposed, has been demonstrated in several countries when very senior politicians have come forward with personal statements about the impact of HIV/AIDS on their family or community.

Step Seven: **Follow-up and monitoring of the implementation of the developed policies.**

Once the policies are disseminated, a mechanism to ensure their implementation is needed. This monitoring process will also be useful in determining which policies need revision and how they can be revised.

Box 6 shows an example of an executive summary of national counselling policy statements.

Technical materials and guidelines for HIV/AIDS counselling and related areas.

In order to implement these policies, programme managers will need to develop more detailed technical guidelines on HIV/AIDS counselling, including how to develop and evaluate services and how to train counsellors. In addition, guidance is needed on how counselling interacts with other aspects of HIV/AIDS care, prevention and research.

WHO/GPA has prepared a series of materials (see Annex 1) giving guidance on specific issues such as:

- how to establish HIV/AIDS counselling services;
- how to train HIV/AIDS counsellors;
- how to incorporate an HIV/AIDS counselling component into blood transfusion services;
- how to advise HIV-positive mothers regarding breast-feeding.

In summary:

- It is essential to develop policies related to HIV/AIDS counselling in order to allow smooth introduction of HIV/AIDS counselling and its acceptance by health professionals.

- Policy-makers should consult widely before prioritizing the policies to be developed.

- Relevant material should be developed to facilitate training and service development in order to implement the policies.

Box 6. An example of a policy statement on counselling: Kenya

It is the Ministry of Health Policy that:

- All health workers should be trained to provide counselling services on a continuous basis.
- Counselling should not be focused on patients alone, but be extended to the family.
- There should be district plans of action for AIDS counselling.
- Confidentiality and ethics should be adhered to at all levels of activities.
- The rights of the individual, culture, social fabrics, etc. should be taken into consideration in AIDS counselling.
- Confirmation of HIV infection or AIDS in an employee provides no grounds for refusal of employment or dismissal.

Source: Kenya, Ministry of Health, *National guidelines on counselling for HIV infection*, December 1988.

Annex 1

WHO/GPA Materials on Counselling and Related Areas

Testing

Statement from the Consultation on Testing and Counselling for HIV Infection, Geneva, 16-18 November 1992 (document WHO/GPA/INF/93.2).

Guidelines for counselling blood donors on HIV (document WHO/GPA/TCO/HCS/94.2)

Training

HIV prevention and care: Teaching modules for nurses and midwives (document WHO/GPA/CNP/TMD/93.3).

Human immunodeficiency virus (HIV) and infant feeding: Essential issues for decision-makers (in preparation).

Living with AIDS in the community (document WHO/GPA/IDS/HCS/92.1 Rev.1).

Source book for HIV/AIDS counselling training (in preparation).

An orientation to HIV/AIDS counselling: A guide for trainers (WHO Regional Office for South-East Asia, New Delhi).

Clinical management and care

Guidelines for the clinical management of HIV infection in adults (document WHO/GPA/IDS/HCS/91.6)

Guidelines for the clinical management of HIV infection in children (document WHO/GPA/IDS/HCS/93.3).

AIDS home care handbook (document WHO/GPA/IDS/HCS/93.2).

Counselling service delivery

Counselling skills training in adolescent sexuality and reproductive health (document WHO/ADH/93.3)

Guidelines for implementing HIV/AIDS counselling (in preparation).

NAP Programme Management Training Course:Module on HIV/AIDS care and social support (1993).

Annex 2

Glossary

Client: The person seeking or receiving HIV counselling and/or testing. In the case of a child or other person unable to consent to testing on his/her own behalf, the client is the parent or other adult with the ethical and legal competence to do so.

Counselling: A confidential dialogue between a client and a care provider aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS. The counselling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behaviour.

Pre-test counselling: Dialogue between a client and a care provider aimed at discussing the HIV test and the possible implications of knowing one's HIV serostatus, which leads to an informed decision to take or not take the test.

Post-test counselling: Dialogue between a client and a care provider aimed at discussing the HIV test result and providing appropriate information, support and referral, and at encouraging risk-reduction behaviours.

Testing:

1) Laboratory testing, i.e. application of an assay (e.g. ELISA) for laboratory markers of HIV infection such as HIV antigen or antibodies. The assay may be used in order to screen blood for transfusion, or organs or tissue for transplantation (see **screening**), or in order to test an individual (see **testing 2**)).
2) More broadly, the testing of individuals with the intention to determine their HIV infection status. All testing in this sense can be categorized according to three sets of criteria:

    a) client-initiated, health care provider-initiated, or initiated or required by a third party for other than health purposes;
    b) with or without informed consent; and
    c) anonymous, confidential, or non-confidential. These terms are defined below.

Client-initiated testing: HIV testing requested by a client on his/her own initiative.

Health care provider-initiated testing: HIV testing initiated by the client's health care worker.

Testing initiated or required by a third party for other than health purposes: HIV testing for other purposes, such as immigration, employment or insurance.

Testing with informed consent: HIV testing performed only after the client has given informed consent to it. **Informed** in this context means that in discussion (pre-test counselling) the client has been made aware of all the ramifications of HIV testing, including the risks and benefits, as well as of alternatives to such testing, in language he/she can understand. **Consent** means the giving of express agreement to HIV testing in a situation devoid of coercion, in which the client should feel equally free to grant or withhold consent.

Testing without informed consent: HIV testing in which informed consent, as defined above, has not been requested and given.*

Voluntary testing: Anonymous or confidential testing initiated by either the client or his/her health care provider and performed with the client's informed consent.

Mandatory testing: HIV testing without informed consent which the individual is compelled to undergo. The term refers both to situations in which the individual clearly has no alternative - as when prisoners are tested involuntarily - and to situations in which refusal of testing is not realistic or would cause the individual undue hardship, as when HIV testing is required prior to employment or marriage.

Anonymous testing: HIV testing in which the blood sample and test result are identified only by code, not by name, with no personal identifiers to link the sample to the donor source.

Linked anonymous testing: HIV testing in which the code is known only to the client.

Unlinked anonymous testing: HIV testing (e.g. for surveillance purposes) after prior removal of all personal identifiers, so that retrospective identification is impossible.

Confidential testing: HIV testing in which only the client and the health professionals involved in the client's direct care know that the test was performed and have access to the test results. This information is not furnished under any circumstances to other health care providers, health authorities, employers, insurers, schools or other third parties without the patient's explicit consent.

Non-confidential testing: HIV testing conducted neither anonymously nor confidentially.

Screening: The systematic laboratory testing of donated blood, blood products, tissue (including sperm) and organs for the purpose of preventing HIV transmission to the recipients. Other specimens, such as saliva, may also be used.

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* The term "Routine testing" is sometimes used to mean the HIV testing of individuals without their knowledge or unless they specifically refuse such testing. Examples are routine testing policies applied by hospitals to patients, and sometimes applied to people attending antenatal or STD clinics. This term should not be used because it does not specify whether informed consent is requested and granted.