



**POLICY AND
PROGRAMMING GUIDE
FOR HIV/AIDS PREVENTION
AND CARE AMONG
INJECTING DRUG USERS**



**World Health
Organization**

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**World Health
Organization**

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INTRODUCTION

WHY IS A POLICY AND PROGRAMMING GUIDE NEEDED?

The epidemic of HIV infection and AIDS among injecting drug users (IDUs) and its spread from IDU populations to their sexual partners and the wider community is an important but often neglected aspect of the global AIDS pandemic. This neglect has resulted from:

- ▶ ignorance of the existence or extent of the epidemic;
- ▶ cultural, social and political constraints on the development of responses; and
- ▶ prejudice against people engaged in illegal behaviour such as drug use.

Nevertheless, the major reasons these epidemics are so often neglected are the lack of understanding of the importance of controlling the epidemic, ignorance of effective methods for controlling the epidemic and a lack of knowledge about how to develop effective responses.

The evidence is clear: early responses to HIV epidemics among and from IDUs can prevent their spread. Even where epidemics have taken off, they can be contained and reversed. Doing this requires:

- ▶ clarity of vision;
- ▶ concentrating on the approaches that have been effective; and
- ▶ recognizing that many other approaches, although socially and politically supported, are not only ineffective in preventing HIV (and drug use) but can actually promote the transmission of HIV among IDUs.

WHAT IS A POLICY?

A policy is the guiding principles that set the tone and outline the actions required to address a specific issue or issues. A policy may be as simple as “honesty is the best policy” or may, for example, be a complicated document outlining a government’s beliefs about the type of health system it wants to run. A policy can describe a course or line of action to be adopted and pursued by a government, ruler, political party or organization. A policy is important in designing and establishing programmes, as it provides a constant reference point before, during and after a programme is implemented. A programme can evaluate whether its activities are following the principles outlined in the policy.

WHAT IS MEANT BY PROGRAMMING?

Programming turns policy into reality. A policy can outline a specific desired outcome, the ideas or principles behind it and suggestions of how to achieve

these goals. Programming refers to the distinct interventions or activities needed to meet the objectives outlined in the policy. The activities of a programme need to be planned in detail if it is to succeed.

FOR WHOM IS THIS GUIDE INTENDED?

This policy and programming guide is intended to be used by people throughout the world involved in developing policy and programmes on HIV/AIDS among IDUs, such as the members of national AIDS committees and councils and ministries of health. The guide may help these people by offering guidance on how to develop and implement comprehensive prevention responses at the national, district and local levels.

WHAT IS IN THE GUIDE?

The guide concentrates on distilling the principles from policies and programmes that have worked well in responding to HIV/AIDS epidemics among IDUs. These principles can be transferred to other societies, but there is no definitive answer as to what will work. The issues involved in developing and sustaining effective responses to HIV/AIDS and injecting drug use are complex, and every society and community is different. How these principles are expressed in a specific society depends on the characteristics of that society. The guide is just that – a *guide*. It aims to help people in applying principles that have proved effective in dealing with HIV/AIDS and injecting drug use, but it will not be effective unless local circumstances are taken into account.

HOW CAN THIS GUIDE BE USED?

The guide provides an overview of how a society can develop a comprehensive and effective response to epidemics of HIV/AIDS among and from IDUs. It is based on many years of experience in a great variety and number of different countries. This guide should be used in conjunction with the other resources relating injecting drug use and HIV/AIDS, such as the rapid assessment and response guides (Stimson et al., 1998; World Health Organization, 1998a, b) and several WHO publications: *Training guide for HIV prevention outreach to injecting drug users*, *Advocacy guide for effective HIV prevention among injecting drug users* and some policy briefs. This guide shows how the strategies for each part of a comprehensive response are built and fit together; the other resources give more detailed instructions on how to develop and implement these parts.

1. DRUG USE AND THE VULNERABILITY OF INJECTING DRUG USERS TO HIV

1.1. SETTING THE SCENE: HIV AND INJECTING DRUG USE

INTRODUCTION

In 2004, 5 million people became newly infected with HIV, and more than 3 million people died from AIDS. By the end of 2004, an estimated 40 million people worldwide were living with HIV. Since the beginning of the epidemic, close to 70 million people have been infected, and it has become the fourth largest killer globally (UNAIDS, 2002; 2004). Most people living with HIV/AIDS are believed to be between 15 and 24 years old, and most are unaware that they carry the virus.

Epidemics of HIV have been documented for two decades among drug-injecting populations. Injecting drug use accounts directly for an estimated 10% of all reported AIDS cases. By 2000, the cumulative number of HIV-infected drug injectors was estimated to be 3.3 million and rising.

GLOBAL DRUG TRENDS

What proportion of HIV infections around the world are caused by injecting drug use?

Injecting drug use continues to spread around the world regardless of religious persuasion, stage of economic development, social class, environment (urban or rural) or the political system a country adopts. Where injecting drug use occurs, HIV infection associated with the sharing of contaminated injecting equipment quickly follows. Needle et al. (2000) estimated that the proportion of HIV infections caused by injecting drug use is:

- ▶ 50–90% in eastern Europe, central Asia and eastern Asia and the Pacific;
- ▶ 25–50% in North America and western Europe;
- ▶ 10–25% in Latin America;
- ▶ 1–10% in southern and south-eastern Asia; and
- ▶ less than 1% in sub-Saharan Africa.

In 1992, 80 countries in the world reported injecting drug use, with 52 of these reporting HIV infection linked to drug injecting. By 1999, reports came from 134 countries and territories and, of these, at least 114 had identified HIV infection among IDUs (Stimson & Choopanya, 1998; Needle et al., 2000) (Table 1).

Table 1. Globalization of the HIV/AIDS pandemic among IDUs

	1992	1995	1996	1998	1999
	Number of countries reporting				
Number of countries reporting injecting drug use	80	118	121	128	134
Number of countries reporting HIV infection among injecting drug users	52	78	81	103	114
% of total	65%	66%	67%	80%	84%

Source: Needle et al. (2000).

HIV infection spreads from drug distribution epicentres and along distribution routes. This happened in the United States during the early 1980s (from New York), and a similar pattern can be seen in southern Europe (northern Italy, southern France, Austria, Switzerland and the former Yugoslavia) and in parts of south-eastern Asia (Myanmar, China, Thailand and northern India). Drug distribution routes often no longer follow direct geographical patterns. In Nigeria (western Africa), a spillover for local consumption of illicit drugs being trafficked to Europe, coupled with the emergence of an IDU community, gave rise to HIV transmission among IDUs.

However, although drugs are injected and HIV is present, an epidemic of HIV infection among IDUs is not inevitable. HIV epidemics among IDUs can be prevented or reversed.

What has been done to stop the rise of HIV infection among IDUs?

Every year more countries find HIV/AIDS among their IDUs. In many countries, effective programmes have begun to prevent or deal with escalating HIV infection among IDUs and to reverse existing HIV epidemics in IDUs. The strategies these programmes have used include:

- ▶ ensuring access to clean injecting equipment and removing contaminated equipment from circulation;
- ▶ expanding drug dependence treatment (such as providing methadone or buprenorphine); and
- ▶ peer-based outreach to distribute HIV prevention materials and to provide information about HIV testing, counselling and drug treatment.

In most countries, interventions have not been started early enough and/or on a scale large enough to influence the epidemic.

What drugs are being used around the world?

The United Nations Office on Drugs and Crime estimated by end of 2003 that 200 million people used illicit drugs. In 2003, 163 million people used cannabis and 34 million people amphetamine-type substances. An estimated 14 million people took cocaine, 8 million used ecstasy and 15 million used opiates, 10 million of whom took heroin.

Heroin use has increased in eastern Europe, central Asia and south-west Asia but appears to be relatively stable in western Europe. The use of amphetamine-type substances (in particular, methamphetamine) has increased dramatically and is quickly becoming the drug of choice in much of south-eastern and eastern Asia. Between 1990 and 1999, global amphetamine-type substances use grew at about 30% per year compared with an increase in heroin use of 5% per year (United Nations Office on Drugs and Crime, 2001). The injecting of illicit drugs continues to increase throughout the world and may involve as many as 20 million people (Costigan et al., 2003).

Illicit opium cultivation remains concentrated in Afghanistan and Myanmar, accounting for 90% of global production. The opium industry of south-eastern Asia's Golden Triangle, with Myanmar at its epicentre, flourishes but has diversified to include the production of amphetamine-type substances. Many countries in the main drug-producing areas of Asia are crossed by changing trafficking and transit routes linking drug production zones with lucrative consumer markets. Injecting drug use develops rapidly along trafficking routes, creates new drug markets and helps to spread HIV (Reid & Costigan, 2002).

THE SPREAD OF INJECTING DRUG USE AND HIV

Injecting drug use has become a major public health problem throughout the world. It has played a critical role in the spread of HIV infection and other bloodborne infections such as hepatitis B and C, malaria and tetanus. Injecting drug use can also result in other health complications, including drug overdoses and sexually transmitted infections such as syphilis among cocaine users who exchange sex to obtain the drug.

Why has injecting drug use spread?

The reasons for the spread of injecting drug use are complex and include the following.

- ▶ When a drug becomes difficult to get, because of drug control efforts or police activities, it usually becomes more expensive. When a drug user smokes or inhales a drug, much of it is lost in burning or smoke. Injecting a drug uses most of the drug and improves the speed and magnitude of the effect.

- ▶ Communication tools such as the Internet can spread information about how to take drugs, such as details on how to inject drugs.
- ▶ As people migrate and travel, information about new ways of taking drugs travels with them or greets their arrival.
- ▶ Some social groups, because of occupation, are more likely than others to encounter situations to use and inject drugs. This can happen with students or those who work away from their communities (such as truck drivers, fishermen and miners).
- ▶ People with high incomes or social position who have the money to travel and have exposure to other cultures and practices can sometimes introduce new ways of taking drugs.
- ▶ The production, nature and trafficking of drugs is changing:
 - improved transport for trafficking drugs;
 - some traditional opium-growing areas have now also set up heroin-refining factories;
 - injectable forms of drugs are easier to transport and smuggle, less bulky and smelly and are more profitable;
 - increased drug production in some areas; and
 - the emergence of new trafficking routes.

Various combinations of these reasons have brought about an increase in injectable drugs and injecting drug use. New patterns of drug use are influenced by the social, economic and political changes taking place in various parts of the world. The pattern of injecting is dynamic. The size and nature of the drug-injecting population can be influenced by how many drug users take up injecting and also by the number of drug users who stop injecting and take their drugs in another way (Boxes 1 and 2). For example, reports suggest that, in the Netherlands and the United States, the number of drug injectors is declining because of a shift from injecting to non-injecting methods of administration such as smoking or chasing the drug.

Box 1. Myanmar

In Myktyina, the capital of Kachin State in Myanmar, had an estimated 3000 IDUs. In Lashio, the capital of Northern Shan State, the population of IDUs was estimated at 5000. About 500 000 people travelled to and from a nearby jade mining area for work: in this area, heroin was widely available and used by about 5000 IDUs. Heroin injecting was preferred to heroin smoking because it was less expensive, more rapid and had a better effect. In the mining areas it was common for IDUs to go to a shooting gallery, where a professional injector injected numerous customers without bleach or sterilization. Seasonal workers came to this region from various parts of the country and then returned to their home states during the rainy season when it was difficult to get to the mines. The prevalence of HIV among IDUs in both these states was greater than 80%.

Source: Prazuck (1997).

What drugs are being injected?

- ▶ Although not designed for injecting, water-soluble drugs are the most commonly injected.
- ▶ Around the world, heroin and cocaine (produced mainly from illicit refineries) are the most commonly injected drugs.
- ▶ The injecting of amphetamines (bought from pharmacies or from illicit laboratories) is on the increase.
- ▶ Pharmaceutical preparations commonly injected include buprenorphine, dextropropoxyphene compounds, benzodiazepines and barbiturates.

Box 2. Russia Federation

In the early 1990s, eastern Europe and the countries of the former Soviet Union experienced major political, social and economic upheaval. Countries in the region faced increasing unemployment, poverty, widespread labour migration, weakening health care infrastructure and diminishing health care services and preventive health education. This produced an ideal environment for increased injecting drug use and the subsequent spread of HIV/AIDS. As unemployment and poverty increased dramatically after the collapse of communism, the drug trade flourished and many people became involved in drug trafficking. The use of drugs rose as a consequence of hardship, disillusionment and social dislocation. The opening-up of borders resulted in drug trafficking throughout the entire region. Where the drugs travelled, IDU communities emerged, followed by explosive epidemics of HIV/AIDS.

Source: adapted from Open Society Institute (2001).

What are the serious health effects of injecting drug use?

Injecting drugs can have extremely serious health consequences for the drug user. This largely results from:

- ▶ the toxic effects of the drugs used;
- ▶ impurities or contaminants mixed up with the drugs; and
- ▶ non-sterile injecting.

The most important harm from drugs is overdose resulting in death. The other health effects of injecting include:

- ▶ thrombophlebitis or cellulitis at injecting sites;
- ▶ abscesses that can sometimes lead to gangrene and the amputation of limbs;
- ▶ endocarditis, acute and chronic, caused by skin bacteria such as *Staphylococcus aureus*, with fever and the development of heart valve disorders and heart failure; and
- ▶ the “dirty hit”, involving the injection of pyrogenic material, which can lead to an acute febrile reaction lasting 24–72 hours, sometimes associated with rigor and jaundice.

Although these complications are occasionally seen, the most common and widespread adverse health effect of injecting drug use is the transmission of viral diseases such as HIV, hepatitis B and hepatitis C.

THE HISTORY OF SELF-INJECTING

The hypodermic syringe was invented in the early 19th century, and its use spread quickly. Accounts exist of self-administered morphine injections among soldiers during the United States Civil War. By the beginning of the 20th century, recreational drug injecting among specific social groups was reported in western Europe. By the 1920s, self-injecting was reported in Egypt, and a syringe-transmitted epidemic of malaria erupted in 1928; this was probably the first syringe-driven bloodborne disease outbreak on record.

Before the Second World War, about 40% of treatment-seeking opiate users in the United States reported injecting drugs. By 1950, this had risen to between 70% and 90% and was mainly concentrated in New York and other cities in the north-eastern United States. By the 1960s and 1970s, sizeable communities of drug injectors could be found throughout North America and western Europe.

Although many countries in Asia have a long history of indigenous opium use, the emergence and popularity of heroin in the 1960s and 1970s changed the

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nature of drug use. By the late 1980s, drug production and distribution of high-grade heroin in Asia was a reality. Injecting drug use in Asia followed hard on the heels of these opiate epidemics, in part because the cost of drugs increased because of law enforcement but also in response to the “Western” fashion of injecting.

Injecting drug use also swept through the Russian Federation and central and eastern Europe in the 1990s after years of economic crisis and social unrest. At the same time, the habit of drug injecting became more common in various parts of Latin America, largely because of the emergence of heroin as a new drug cultivated by drug cartels. By the end of the 20th century, injecting drug use had arrived in Africa and is now a major problem in Nigeria, Mauritius, Kenya and South Africa.

EXPLOSIVE HIV EPIDEMICS

HIV among IDUs is present throughout the world. In some countries, the highest proportion of all new HIV infections is among IDUs. In parts of southern and south-eastern Asia, epidemics of HIV are truly explosive. These explosive epidemics have occurred in China, Nepal, Thailand, Myanmar, Malaysia, Viet Nam and north-eastern India. The prevalence (the total number of people who have the disease divided by the total population at a particular time) of HIV infection among IDUs has often reached 60–90% within six months to a year of the appearance of the first case of HIV (Fig. 1). In many communities, these explosive epidemics among IDUs then form epicentres for wider spread of the HIV epidemic to other parts of the community. In India, for example, the proportion of non-injecting wives of IDUs with HIV infection increased from 6% in 1991 to 45% in 1997. In some places, up to 60% of IDUs have been infected within their first two years of injecting.

Fig. 1. Prevalence of HIV infection among IDUs in selected locations, 1987–1996

Bangkok, Thailand	34%
Ruili, Yunnan, China	70%
Manipur, India	50-81%
Ho Chi Minh City, Viet Nam	(0.00% - 89.4%)
Myktyina, Lashio, Myanmar	over 80 %

In central and eastern Europe and the countries of the former Soviet Union, the proportion of IDUs among notified HIV cases is equally disturbing: until 1995, the area had been devoid of epidemic outbreaks of HIV infection (Table 2).

Table 2. Proportion of IDUs among HIV-positive notifications in central and eastern Europe and countries of the former Soviet Union, 2000

Country	Percentage of new HIV infections accounted for by IDUs
Belarus	83
Kazakhstan	80
Poland	64
Republic of Moldova	84
Russian Federation	90
Ukraine	74

Source: Honti et al. (2000).

Once HIV prevalence reaches a certain level, often about 5–10% depending on the social organization of the IDUs, it can rise to 40% to 50% or more within a short space of time, as little as 1–4 years. Once the prevalence has reached these levels, it becomes much more difficult to reduce, because controlling a high-prevalence epidemic requires much more change in behaviour than controlling a low-prevalence epidemic. Uncontrolled epidemics of HIV among IDUs provide a core from which sexual transmission to non-IDU sexual partners can fuel more generalized HIV epidemics – especially if significant proportions of IDUs are engaged in commercial sex work. The Asia epidemic model, for instance, indicates that, if uncontrolled, HIV epidemics among IDUs can contribute as much as a 40% increase in the total number of people infected even if other means of transmission are being controlled (Saidel et al., 2003).

HIV prevention works better, and uses less resources, if it is started before the HIV prevalence among IDUs reaches 5%.

1.2. RESPONDING TO HIV INFECTION AMONG IDU'S AT THE LOCAL AND NATIONAL LEVEL – ASSESSING VULNERABILITY

INTRODUCTION

The widespread sharing of injecting equipment has played a critical role in fuelling local, national and regional HIV epidemics. The spread of injecting drug use has also led to rapid and serious public health effects. In many countries,

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HIV infection has spread rapidly among IDUs soon after people started injecting drugs. Once HIV is established in the IDU population, it can then be transmitted to the wider community through sexual contact, blood transfusions or organ donation and from mother to child (Stimson et al., 1998, Chapter 1).

These situations require rapid intervention. The interventions must:

- ▶ respond to local problems;
- ▶ be owned by the local community (by involving key stakeholders and community participation); and
- ▶ be realistic and reflect the local technical and economic resources.

Conventional research can have limitations when it is applied to rapidly emerging public health problems such as injecting drug use. This type of research generally operates from a long-term perspective, which means that quite a long time often passes before interventions are up and running. Rapid situation assessments can potentially generate important public health information and assist and guide decisions about appropriate interventions for health and social problems. Assessments without a corresponding response are not useful, so the two are combined – rapid assessment and response.

WHAT ARE THE MAIN ISSUES TO BE EXAMINED?

Before suitable interventions can be developed to address the issues of HIV/AIDS and injecting drug use, the aims and objectives need to be identified. These include the following.

- ▶ How many IDUs are there? Who are they? Have there have been recent changes in their drug-using behaviour?
- ▶ Why is injecting spreading or about to spread? How is it affecting the health of the IDUs and what is the political and social context of the drug use?
- ▶ What are the risk factors for the health of IDUs (including both drug use and sexual activity)?
- ▶ What is the prevalence of bloodborne viruses (HIV, hepatitis B and hepatitis C), overdoses and other negative health results of drug use?
- ▶ Is there any government policy response to drug injecting? Are there any programmes dealing with or targeting the health needs of IDUs?
- ▶ Are there money and resources (such as staff and organizations) and the ability and desire to intervene?
- ▶ What sort of interventions might work and be acceptable, affordable and ongoing?

RAPID ASSESSMENT AND RESPONSE

What is rapid assessment and response?

Rapid assessment and response is a method or a group of tools used to identify and report on a situation. A rapid assessment and response can identify:

- ▶ the extent, nature and patterns of risk behaviour and associated health effects; and
- ▶ the existing resources and opportunities for interventions to address the problems.

The research tools are adapted from anthropology, sociology, epidemiology and evaluation research. What is distinctive about rapid assessment and response is the way the methods and tools from these various disciplines are combined to identify and develop appropriate interventions and, importantly, to identify potential obstacles to the establishment of a programme.

Rapid assessment happens where there is a commitment to intervene. The rapid assessment and response inherently often creates a mood and environment in which action can happen.

The principles and special features of rapid assessment and response (Stimson et al., 1998) include:

- ▶ speed;
- ▶ cost-effectiveness;
- ▶ use of existing information (data);
- ▶ use of many methods and information sources;
- ▶ practicality and relevance;
- ▶ local community involvement;
- ▶ an investigative approach;
- ▶ inductive method and triangulation (reaching a conclusion by collating and cross-checking a wide range of information);
- ▶ investigation of many levels of a society; and
- ▶ satisfaction with adequacy rather than scientific perfection.

Why is involving the community important?

A community can be defined as a collection of people living together within a fixed geographical location who have a set of social relationships and a shared

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sense of identity. Broad community support and involvement at the early stages of the rapid assessment are essential if the intervention or programme is to be successful.

The extent of community involvement often depends on the level of trust that can be established between the rapid assessment and response team and the community. Drug use is an illegal, stigmatized activity, so there needs to be awareness and understanding of the community's concerns. As community partnership is crucial, the stakeholders need to be convinced of the benefits of rapid assessment and response as a way to stop or limit the negative health and social effects of injecting drug use.

The key stakeholders are the people in the community interested in or connected to the issue. These people need to be identified before rapid assessment and response begins. The stakeholders may be:

- ▶ IDUs and other drug users;
- ▶ former users;
- ▶ their families;
- ▶ school and university teachers and students;
- ▶ youth in general;
- ▶ police and other law enforcement officials;
- ▶ government officials;
- ▶ health professionals;
- ▶ sponsors and funders;
- ▶ religious groups; and
- ▶ anyone who considers themselves as part of the community.

Community participation helps to identify and bring differing opinions together and helps to introduce interventions at a community level. The level of community participation depends on the willingness of the rapid assessment and response team to involve key community members (stakeholders). It also depends on local and national factors such as politics, the economy, social structure and religion. These factors can promote or limit community participation. The underlying principles of community participation are flexibility and the involvement of all stakeholders.

The rapid assessment and response team needs to decide early on who to involve in the initial consultation and who to invite to participate in developing the assessment and intervention or programme. This is called stakeholder analysis (Stimson et al., 1998).

METHODS

What methods are used in rapid assessment of IDUs?

Information for rapid assessment of IDUs is gathered in six major ways. The benefit of using different ways or methods is that it gives the rapid assessment and response team or person the opportunity to check existing information and compare it with newly collected information.

This build-up and cross-checking of information is called triangulation. Various methods are used to collect different types of information (Box 3), which helps to give a comprehensive picture of the situation of HIV vulnerability among IDUs:

- ▶ existing information
- ▶ sampling and access
- ▶ interviews
- ▶ focus group discussions
- ▶ observation
- ▶ estimating techniques.

Box 3. Methods of rapid assessment and response in Cambodia

A rapid assessment was undertaken to determine drug use and concomitant HIV behaviour in Cambodia. Multiple research techniques and activities were used to identify not only what happens to those using illicit drugs but why this happens. An absence of any systematic information about drug use in Cambodia required considering and locating numerous sources of information to build up a picture of the situation. Key informants from government departments (Ministry of Health), nongovernmental organizations (national and international), private and government health care workers, sex workers, street children, border police, fishermen and pharmacy owners were interviewed in various parts of the country. Unobtrusive observations were also used to enlarge and cross-check the information from key informants. These took place in areas where drug trading and drug use were said to occur. Focus groups discussions were used to check and consolidate the information. In the absence of documentation of drug use issues, newspapers were systematically perused that reported on tales of drug trafficking and money laundering. Historical information about drug use in Cambodia was sought from research centres focusing on Asia.

Source: Oppenheimer (1995).

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Existing information. Locating and examining existing information is very helpful for rapid assessment. It saves time, identifies gaps in knowledge and gives useful background. Nevertheless, existing information may be inaccurate or incomplete and does not always satisfy all the needs. The following are useful tips in dealing with existing information.

- ▶ Valuable information and insights can be gathered from routinely collected government statistics, policy documents or local clinic registers and by conducting a literature review.
- ▶ Collect only what is relevant and can be used.
- ▶ Concentrate on the most up-to-date information (up to five years).
- ▶ Note who compiled the information, and watch for bias.
- ▶ Concentrate on who is described in the information and whether the information is representative.
- ▶ Identify gaps in information and monitor changes in the information over time.
- ▶ Cross-check the information through the process of triangulation (see above).
- ▶ Analyse what has been collected.

Sampling and access. Sampling involves systematically selecting a number of cases from a defined study population when the study population has too many cases to interview or test. An epidemiologist or statistician can help to identify a representative sample. The results of the research can be generalized to a larger population.

A representative sample can only be gained when the whole population being sampled is known – for instance, all males aged 15–24 years in a community for which a census exists. In this case, the census is known as the sampling frame. The representative sample is then derived by sampling at random from the sampling frame. With IDUs, a whole population is rarely known, so this style of sampling is usually impossible. However, under special circumstances, such as in a prison, a random sample of all prisoners – if it is truly random – will provide a representative sample, and the results can then be generalized.

The sampling techniques are:

- ▶ purposive: selected cases to quickly help in understanding the wider social processes and activities;
- ▶ opportunistic: cases selected when available;
- ▶ block: picking a series of sample blocks comprising several communities;

- ▶ network: by snowball or chain referrals; and
- ▶ quote: investigating a range of different, theoretically important categories such as prostitution – for example, street workers and hotel workers.

The people to whom the rapid assessment and response team talks are called key informants; they will help to provide sources of information. Employing current or former IDUs as interviewers (gatekeepers to the hidden population) helps with the research process. Putting all the sampling and access information together, called mapping the community, improves knowledge. When people in the area get used to the researchers, maps can be created that will graphically represent complex information.

Interviews. Interviews collect information by asking questions and carefully listening to and noting the answers. There are three types of interviews: key informant (usually one-on-one); group interviews involving several informants but questions are answered individually; and focus group discussions.

Interviews may be formal (such as a questionnaire to be followed) or informal (perhaps a casual chat with a drug user in the street). These are both useful ways to gather information. Interviews can give meaning to events or incidents that need to be explored and understood.

Interviews can occur at any time and place and with different groups or individuals. Interviewers need to know about the subject, have good communication skills, be able to build trust with the interviewees, understand effective questioning and know how to use an interview guide.

Interviewers must:

- ▶ be prepared;
- ▶ understand the importance of confidentiality;
- ▶ use clear and simple language;
- ▶ allow time for the interviewee to think and speak;
- ▶ raise sensitive subjects later in the interview, to give the interviewee a chance to relax and build trust with the interviewer;
- ▶ ensure time for reflection on the answers by interviewees (paraphrase and clarify points);
- ▶ listen;
- ▶ ask why and how;
- ▶ be aware of how long the interview is taking;

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- ▶ collect demographic information (the link between types of people and specific behaviour); and
- ▶ always provide time for any other questions or remarks by the interviewee.

Focus group discussion. A focus group engages in in-depth discussion with a researcher to discuss a specific issue or issues. The people may have common experience, similar background and particular skills. Focus groups encourage individuals to discuss and explore questions among themselves and to share their experiences and beliefs. A focus group is an attempt to understand the perspectives of a certain group of people. Focus group discussions provide substantial information quickly and give the opportunity to identify and explore beliefs, attitudes and behaviour. The problems with focus groups are that the researchers have less control over the discussion than in interviewing one person and that one or two participants can potentially dominate the group.

A focus group may require:

- ▶ incentives to persuade people to talk the researchers, such as a meal or transport costs;
- ▶ a neutral, comfortable, accessible place to hold the discussion;
- ▶ a list of questions;
- ▶ a key informant (the people in a focus group are usually recruited by key informants); and
- ▶ a tape recorder, tapes, batteries, paper, pens, labels and a blackboard or whiteboard.

Observation. Observation allows researchers to experience the relationships and contexts of human behaviour by watching and listening and then describing (Box 4). Aspects that are recorded include:

- ▶ the settings (where people live and where the interview takes place);
- ▶ the people (physical, psychological and social);
- ▶ the activities (what people do and how they do it: that is, drug use);
- ▶ the actions of others;
- ▶ particular events;
- ▶ the goals and connections of the people observed; and
- ▶ any specific activities that are noteworthy for the researcher.

Unstructured observations are conducted at the early stage of rapid assessment and include all prominent features (classified and coded after an event) and often highlight behaviour that is not initially obvious.

Structured observations require the research team to collect information that is most relevant to the rapid assessment. Researchers may use an observational guide, record sheet, field notes, tape recordings, video recording and photographs.

Box 4. Description of an injecting ritual in Mongolpuri, India, January 1993

A took me to his house. We climbed the stairs to the first floor, entered a small room that had things dumped all around. B came up behind us with two ampoules of buprenorphine and one of pheniramine maleate. By this time, A was hunting along cracks in the brick walls, searching for the syringe and needles that he had hidden there.

After a while A found and pulled out a packet. I asked him to let me see his syringe and he handed me the packet. It was a cellophane bag, dusty and crushed. Inside were two syringes, one 2 ml and the other 5 ml. Both were well used, as the movement of their plungers was stiff. There were two used n° 24 needles in their plastic shields. I asked how many times he had used them but he said they were new, bought last week.

A took the syringe and attached a n° 24 needle to it. I noticed his hands were very dirty (he does manual labour) but he seemed oblivious of it. B broke the ampoule with his teeth, handed it to A who drew the liquid into the syringe. He took a strip of cloth hanging from a nail in the wall and wrapped it around his upper arm, pumped his hand up down to raise the veins. He selected one on his forearm and pushed the needle in. Nothing happened for awhile and he withdrew the needle. A thin stream of dark red blood dribbled out of the puncture in his arm.

A sucked at the wound, stanching the flow. I looked at B who was staring intently at the syringe. Once again A tried another spot in his forearm. Presently, a thick stream of blood flowed into the syringe, colouring the liquid inside. He then pressed the plunger all the way in, withdrew the syringe and handed it to B. To stanch the blood flowing out, A used the cloth from the tourniquet, which was filthy and blood stained. He then sat down on the rope bed and smiled at me. I shifted my gaze to B.

Once again B broke the ampoule with his teeth, spat out the shards of glass and drew in the liquid. I noticed he had rinsed the syringe in a small *wati* (bowl) of water before. Then B inserted the needle into the rubber cap of the vial of pheniramine maleate and drew in some more liquid. He shook the syringe. "Cocktail", he announced to me. By this time A began to talk to me and I tried to listen and look at what B was doing too.

With the ease of an expert B tied the tourniquet (the same piece of bloodstained cloth) on his upper arm, selected a vein and pierced the skin of his forearm in one fluid motion. Blood streaked into the barrel of the syringe, B unravelled the cloth from his arm and pushed the solution into his vein. He sighed as he did that, a deep, long sigh. Withdrawing the syringe from his arm he sat beside A.

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They chatted with me awhile. It was late afternoon, winter, the sun low in the horizon. It was chilly in the room. I stamped my feet and looked out of the small window at the narrow alley that was the front to the houses in this block. Children played all over, old people sat on *charpoys* (rope and bamboo beds) and a canal of dirty refuse water ran underneath their beds. The stench was nauseating. When we rose to leave, I glanced back. The syringe lay forgotten on the plastic packet still streaked with *B*'s blood.

Comment: *A* and *B* often inject together and share the same equipment. Sometimes *C* and *D* also inject here, either with different syringes or with a common one.

Source: adapted from Dorabjee (1993).

Estimating techniques. Estimating techniques are used to determine the number of IDUs in an area and the characteristics of the population, such as how the drug use is affecting their health. Estimating techniques rely on data from routine information systems and agencies (such as arrests or incarcerations of drug users and records of overdoses), which is then combined to provide improved overall estimates (Box 5) (Stimson et al., 1998).

Box 5. Using routine data sources for estimates in India

The information in *Drug abuse: consequences and responses* (United Nations Drug Control Programme and Government of India, 1995) was gathered from three activities: a survey carried out by the United Nations Drug Control Programme (now the United Nations Office on Drugs and Crime), a collaborative workshop by the United Nations Drug Control Programme and the Government of India reviewing the situation in India according to available research and related data sources, and further exploration of the available data as well as national and international research. Data were collected from medical and educational institutions, law enforcement agencies and community groups supported by the Ministry of Welfare.

The body of the draft report begins: "Opiates (including heroin, opium, smack/brown sugar and morphine) have been the principal drugs of concern in India for many years." No estimate of the total number of users was posited, although adding the estimates cited produces at least hundreds of thousands and possibly millions. The draft report estimates (without reference to a source) that Delhi had more than 50 000 "heroin addicts" in 1985. This figure is most likely to be at the lower end of the possible number of users, as the report states later that heroin use is increasing and there is no indication that it decreased between 1985 and 1995.

Source: adapted from Dorabjee & Samson (2000).

1.3. KEY DETERMINANTS OF VULNERABILITY TO HIV INFECTION AMONG IDUS

INTRODUCTION

Vulnerability to HIV among IDUs is governed by a complex of factors. Some of these operate at the individual or psychological level and others at increasingly complex and broad levels of society. Assessing the vulnerability to HIV infection of an IDU population requires examining not only the individual's behaviour but also all the influences on that behaviour from the environment in which the person lives. One way to classify these influences is into the microenvironment (in which the person spends all his or her time immediately interacting) and the macroenvironment (although it is not immediately present, it governs the nature of the day-to-day situation) (Box 6) (Rhodes & Hartnoll, 1996).

Box 6. The microenvironment and macroenvironment of injecting drug users

Microenvironment

- ▶ Perceived social and behavioural norms among IDUs
- ▶ Nature and structure of social relationships among IDU networks
- ▶ Immediate social and physical settings in which drugs are used
- ▶ Local neighbourhood and context in which IDUs live

Macroenvironment

- ▶ Public, policy and legal contexts of drug use and its risk management
- ▶ Economic, gender and ethnic inequalities
- ▶ Cultural and religious norms

Source: adapted from Rhodes & Hartnoll (1996).

It is useful when assessing vulnerability to examine the individual and the peer group as comprising the microenvironment and social, cultural and structural factors as comprising the macroenvironment.

Individual and peer group determinants of HIV vulnerability among IDUs

Individual and peer group vulnerability to HIV among IDUs depends on individual and shared behaviour, which in turn depends on individual and group attitudes, practices and knowledge. Ignorance about the risks of injecting, especially of HIV transmission, or lack of concern about these risks because of more pressing life concerns creates psychological vulnerability to participate in unsafe injecting practices that increase the risk of HIV infection. The degree of dependence, and therefore the severity of the withdrawal syndrome, also markedly affect the ability of the individual IDU to make safer injecting decisions.

In addition, the social organization of IDUs may increase or protect against vulnerability to HIV infection and is important in designing effective interventions. IDUs are generally socially marginalized; where this has led to the formation of IDU subcultures, alienated from the mainstream community, IDUs often do not have access to or do not trust mainstream education or health care systems. This may have the effect of increasing their vulnerability to HIV. If IDUs remain more socially connected – through family or other ties – they may have greater access to the means to protect themselves against HIV. In any case, the social and often legal stigma experienced by the vast majority of IDUs guarantees that much of their lives is hidden from the community, making programme development more difficult and decreasing their access to and involvement in protective community activities.

However, individual behaviour results from complex influences and pressures acting on the individual from many different social levels and sectors. Researchers need to examine the larger context, or circumstances and facts of life, of drug injecting and the public health response to understand the factors that influence drug injecting. Beyond the individual level, these are called the structural context and the social and cultural context. These contexts are usually beyond the immediate control of the individuals themselves and sometimes beyond the control of government, welfare and health institutions. The structural context and the social and cultural context do interact with each other and exist at the same time. From the beginning of rapid assessment and response, researchers need to understand that drug use and risk behaviour are not just the result of individual risk taking but are influenced by environmental factors. Interventions can potentially occur at any level, so an assessment needs to include all the levels of influence on the end result – the behaviour of the individual IDU.

A way of thinking of these influences is to work from the individual to the national level, considering all the potential factors that might influence the IDU as a social being and therefore his or her behaviour. This requires examining key determinants of HIV vulnerability among IDUs at each level – individual, family and social groups, the community and higher levels. This examination should then help in understanding which factors can be influenced by what strategies and at what level and which factors are beyond the control of the interventions.

What is the structural context?

The structural context means the basic structure of a country, city or community. The factors that influence the structure include:

- ▶ population;
- ▶ demographics;
- ▶ migration and mobility;
- ▶ the political, legal and economic situation; and
- ▶ the national transport and communication channels.

These factors are not easily changed in the medium or short term.

Key structural determinants of HIV vulnerability among IDUs

The structural determinants of HIV vulnerability among IDUs are the factors in broader society that set the context for social organization and community functioning, such as laws, economic systems and infrastructure. Those that increase vulnerability of IDUs to HIV infection include:

- ▶ repressive laws that target IDUs and their behaviour, such as paraphernalia laws that make possession of needles and syringes a crime or at least an excuse for police harassment, and laws establishing the mandatory reporting and incarceration of drug users;
- ▶ economic systems that deprive some people of meaningful employment opportunities, encouraging them to become involved with drugs and removing hope of a more productive, alternative future; and
- ▶ unintended and adverse effects of drug policy: for instance, a crackdown on the availability of smokable drugs may lead to an increase in injection, with subsequent increases in the risk of HIV transmission.

What questions need to be asked to determine the structural context of a country, city or community?

- ▶ *What are the factors that make up the local structural context?* A basic description of the country, city or community, including migration and mobility, employment levels, literacy levels, educational levels, civil unrest, the extent of poverty, the quality of housing and other factors.
- ▶ *How do structural factors influence health and living conditions?* An overview of the city or community's general health and living conditions, the social and geographical distribution of disease,

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including HIV and sexually transmitted infections and other adverse health conditions associated with drug use.

- ▶ *How do structural factors influence the patterns of drug use?* An overview of the country's or city's patterns of drug use, the extent and nature of drug use and new trends in injecting drug use (such as moving from smoking drugs to injecting them) (Box 7).
- ▶ *How do structural factors influence patterns of risk behaviour?* Examine issues such as the impact of poverty, legislation, law enforcement and criminal justice.
- ▶ *How do structural factors influence the development of health policy and health interventions?* Examine the various factors that influence the feasibility and setting up of health policies and interventions. The factors may range from general health and living conditions to the political and economic situation of the country.
- ▶ *What factors promote increased risk or protection?* The answers to these questions may identify structural factors, or combinations of them, that may increase or protect drug users from the risk of drug use.

Box 7. Social structural factors and the impact of development on drug use in traditional societies: Thailand

A study of villages in northern Thailand found that the more "developed" villages were more likely to contain residents that use illicit drugs. It found that villages reporting "good access to primary school education" – villages that had undergone more development – were much more likely to have both methamphetamine users and young adult opium users in the village, but that less-developed, more traditional villages tended to have more older opium users present. The author concluded that "Change from a traditional to more developed status brings with it an increased likelihood of illicit drug use in highland tribal villages."

Source: Barrett (2003).

What is the social and cultural context?

The social and cultural context is how people organize their social relations, their social activities and the setting where drug use happens. This includes drug use, sex and people's values. These factors may be able to be changed in the medium or long term.

Individuals behave within a social context. Their interactions with other members of their society and community are largely influenced by this social context, which includes adherence to cultural and religious norms. Significant social influences on individual behaviour include:

- ▶ religious and cultural attitudes towards drug use – whether drug use is seen as a problem or not, and if so, whether it is seen as a psychological, medical, legal, moral, religious problem or a combination of different aspects strongly influencing how drug users are treated;
- ▶ social welfare and health systems that may be more or less accepting of drug users, or even exclude them from access to services, which heightens their vulnerability to many harms, including HIV; and
- ▶ stigma and discrimination, often rooted in moral and religious beliefs, which are common (almost universal) reactions to illicit drug use, and injecting in particular.

What questions need to be asked to determine the social and cultural context of a country, city or community?

- ▶ *What is the drug-using community like and how does this influence the way drugs are used?* Look at the social acceptability of drug use and the differences between specific social groups. For example, what drug use is considered socially acceptable or unacceptable in the study community? Alcohol use may be common and fine, whereas injecting drugs may not.
- ▶ *How do the places where drugs are used and other risk behaviour happens influence the patterns of drug use and risk behaviour?* Look at the social relationships and physical places where drug use and risk behaviour happen. For example, what are the social relationships like between people in drug-using networks? What types of risk behaviour happen (such as sharing injecting equipment)? Does the actual place where people use drugs lead to unsafe practices (such as a lack of water to even rinse injecting equipment and poor light for injecting)?
- ▶ *How do the social beliefs, values and settings influence the development of health policy and interventions?* Social and cultural factors may influence the development, feasibility and implementation of health policy and other intervention responses. How do the social beliefs and values about drug use influence institutions, politicians, public health policy and interventions?

HEALTH IMPACT ASSESSMENT

What is health impact assessment?

Health impact assessment examines the type of health problems IDUs experience, the extent of these problems and any trends that have emerged. The health assessment also provides important information about the factors that contribute to these health problems, which can help in developing policy

and programmes. Health problems are a consequence of injecting drug use and the policy and social context in which drug users live.

The main focus of the health impact assessment is the occurrence and management of infectious and other diseases, especially HIV infection and sexually transmitted infections, mental health and trauma associated with drug use. The main method used in the assessment is compiling existing information, and assessing the quality and accuracy of the information is important.

What is risk behaviour assessment?

Risk behaviour comprises how IDUs behave and the activities in which they engage that put them at risk of injury and illness. The areas to look at include:

- ▶ the extent and nature of health-related risk behaviour;
- ▶ why IDUs engage in risk behaviour;
- ▶ the factors that make it difficult (or easy) for IDUs to protect themselves from risk practices and activities; and
- ▶ the behaviour of others (friends or sexual partners of IDUs).

What influences risk behaviour among IDUs?

Three main areas that coexist can influence risk behaviour among IDUs:

- ▶ individual risk behaviour;
- ▶ community norms and context (when drug injectors' behaviour is influenced by wider peer group or community norms); and
- ▶ policy, law and the environment.

The key questions to ask vary according to which methods are used, the type of information available and the local context. The methods (structured or unstructured interviews, focus groups, observation and existing information sources), information sources (IDUs, their friends, sexual partners, mass media, official documentation and policy planners) and examples of the type of questions and results to be entered are in *The rapid assessment and response guide on injecting drug use (IDU-RAR)* (Stimson et al., 1998).

The information from the key questions needs to be summarized and then put together to form a strategic plan (or action plan). The strategic plan requires:

- ▶ the key findings on risk behaviour;
- ▶ assessing how this risk behaviour is influenced by the three main areas mentioned above and, if possible, ranking them from low to high; and

-
- ▶ suggesting what action is required to address this risk behaviour.

How should the key findings be analysed and presented?

The results and conclusions of the different assessments are analysed, and this information is placed into assessment grids.

An assessment grid (Box 8) creates a framework for thinking about the key areas influencing HIV vulnerability among IDUs. It should provide:

- ▶ a guide to the interpretation and organization of the collected information (data);
- ▶ a guide to writing field notes throughout the rapid assessment; and
- ▶ a guide to presenting the key findings once the rapid assessment is completed.

Box 8. Example of a risk behaviour assessment grid

What types of injecting behaviour among IDUs increase the risk of infectious disease?

- ▶ List the types of injecting behaviour in which IDUs engage that carry the risk of infectious diseases.
- ▶ Provide a local description of the behaviour.
- ▶ Describe the sources of information used and assess the validity of the data.

Injecting risk behaviour	Local description	Sources of information and validity of data
Sharing needles or syringes	There is a long history of needle and syringe sharing in the city; most IDUs use syringe barrels with detachable needles	Confirmed by multiple data sources: research documents; interviews with IDUs; focus groups; observations; and key informant interviews
Buying ready-filled syringes	Some IDUs mentioned buying their drugs from dealers in ready-filled syringes	Confirmed by sources: observations; key informant interviews; and interviews with IDUs
Sharing drug solutions	There is a long history of IDUs making a cocktail of pharmaceutical drugs and withdrawing the drug from the same container	Confirmed by data sources: observations, interviews with IDUs and key informants from outreach programmes
Use of professional injectors	There is a long history of IDUs visiting people who provide drugs, the injecting equipment and within the fee also inject a person – the use of a clean needle and syringe between clients is uncommon	Confirmed by multiple data sources: observation; and interviews with IDUs and professional injectors
Etc.	Etc.	Etc.

Source: adapted from Stimson et al. (1998).

The development of policy and programmes will be based on the findings of the assessments. The rapid assessment and response outcomes must therefore be clear, understandable and locally appropriate (World Health Organization, 1998).

Finally, it is strongly advised that at least one community consultation (of both the target groups and the larger community) be held to:

- ▶ provide the community with the information that has been gathered;

- ▶ to discover community-based ideas for interventions or responses; and
- ▶ to gauge support for the suggested interventions or responses.

SUMMARY

Rapid assessment and response is a fast way to determine the following.

- ▶ What are the problems? What sort of drug use exists, how much of it is going on, what sort of risky behaviour are drug users involved in and what are the health effects?
- ▶ What resources and people exist to deal with these problems?

A rapid assessment and response team will use varied methods to determine this that may include:

- ▶ collecting existing information;
- ▶ formal and informal interviews;
- ▶ focus groups;
- ▶ observation; and
- ▶ estimating techniques to provide statistics.

A rapid assessment and response:

- ▶ produces a snapshot of drug use in the particular country, city or community;
- ▶ identifies the urgent and developing problem areas; and
- ▶ suggests the response or interventions needed

The suggested response or intervention will aim to:

- ▶ help people change their behaviour (individually); and
- ▶ help to change communities in their attitudes, reactions and the environments in which drugs are used.

2. POLICY DEVELOPMENT

Policy can be many things. In its broadest sense, it is the position, stance or view a government or organization takes on an issue. It can be written or unwritten. It can be formally endorsed in law or presented in a position paper. It can be as simple as endorsing a set of recommendations in someone else's report.

Policy is not a static thing. It is as much a process of research, investigation, discussion and decision-making as it is a piece of paper. In a field such as HIV/AIDS, it can be constantly changing as information and/or technology changes.

The policy development process can be as useful as the policy itself. Getting people together to debate an issue, presenting them with the best available knowledge and evidence on the issue and assisting them in reaching a consensus on how to move forward can be part of solving the problem.

This section sets out the parts or components of a comprehensive policy to reduce HIV transmission among IDUs. It also provides a guide to the policy development process, describing the steps that can be followed to develop and revise policy. It finishes with a discussion about the policy needs of especially vulnerable groups.

2.1. COMPONENTS OF A COMPREHENSIVE POLICY TO REDUCE HIV INFECTION AMONG IDUS

The following are needed to create an effective policy to reduce HIV/AIDS among IDUs:

- ▶ research and a link between research and practice;
- ▶ integration of prevention and care initiatives;
- ▶ access to the means of prevention;
- ▶ health education;
- ▶ changes in laws and in the practices of the police and public security;
- ▶ bringing major policies and strategies together (such as the national illegal drug strategy and the national AIDS strategy);
- ▶ prevention of sexual transmission;
- ▶ attention to issues of poverty, homelessness, unemployment, violence and vulnerability;
- ▶ evaluation of the success of the response;

- ▶ national and political support;
- ▶ support of other parts of society; and
- ▶ community education.

Some of the successful approaches various countries have used to address HIV infection among IDUs include:

- ▶ comprehensive and multisectoral HIV prevention efforts started when seroprevalence among IDUs was generally 5% or less;
- ▶ targeting HIV prevention activities to the population at risk;
- ▶ involving the affected community – drug users and their families;
- ▶ community outreach and peer education to share HIV/AIDS information, provide risk reduction supplies (such as clean injecting equipment, bleach and condoms) and building trust between outreach workers, peers and the IDU community;
- ▶ creating links between traditional drug treatment and substitution programmes and providing HIV counselling and testing; and
- ▶ providing comprehensive access to sterile injecting equipment.

RESEARCH AND A LINK BETWEEN RESEARCH AND PRACTICE

Policy is about solving problems. Policy-makers must clearly understand the problem the policy sets out to solve. Sufficient information needs to be available about the exact nature of the problem in the local setting (country, city or community). This information can be made available through rapid assessment and through a programme of ongoing social and epidemiological research (see section 1.2).

This research not only provides valuable information in the initial development of the policy but is also a central part of the ongoing response. The information collected through the research gives policy-makers and people establishing programmes essential information about:

- ▶ changes in the patterns of risk and infection;
- ▶ emerging at-risk groups; and
- ▶ the impact of prevention and care initiatives.

Epidemiological studies that count new infections and collect minimal information about risk categories need to be complemented by more comprehensive social research studies. This research reveals:

- ▶ the context of drug use and risk among vulnerable populations;
- ▶ the impact of prevention strategies; and
- ▶ the barriers that exist that stop IDUs from using programmes, adopting safe sex practices and heeding safer needle use messages.

Researchers, policy-makers and the people actually establishing and working in programmes should be linked (Box 9). Policy-makers and programmers can help researchers in designing appropriate questions for research, designing effective research methods and making contact with marginalized communities. This partnership means the researchers will have the right questions to ask and the programmers will have access to the research to assist their programmes.

Box 9. How can a partnership be developed between research and practice?

- ▶ Have front-line prevention workers on research advisory committees.
- ▶ Make sure that research institutions consult with communities and programme workers when developing their research studies.
- ▶ Commission research that can guide the programme rather than just allowing researchers to develop their own priorities.
- ▶ Hold workshops at the national or provincial level to bring researchers and programme practitioners together to discuss research findings and to plan future research.
- ▶ Involve IDUs in research design and in delivering the research findings to IDU communities.

INTEGRATION OF PREVENTION AND CARE INITIATIVES

Working with and supporting people with HIV/AIDS and their families helps to stop the spread of HIV/AIDS. Preventing HIV/AIDS and caring for those infected are often seen as separate and requiring different policies, involving different stakeholders and different strategies. There are good reasons for integrating prevention and care policies related to HIV/AIDS.

- ▶ HIV-positive IDUs who are provided with support, counselling and access to peer education, drug treatment and drug substitution programmes are less likely to engage in risk behaviour and pass the virus on to others.

- ▶ IDUs are often discriminated against or poorly treated by health services. Frontline harm reduction workers can gain the trust of marginalized IDUs with HIV and can act as a bridge for them into care services.
- ▶ Providing access to HIV treatment for peer workers indicates that they are valued members of staff, assists them in being productive and sends a message to clients that they are also valuable.
- ▶ HIV prevention is not just about distributing clean needles; sustainable prevention means improving the overall health and welfare of IDUs and therefore has to be linked to care and support services.
- ▶ IDUs with HIV, if mobilized and supported, can become highly effective agents for change and/or peer educators in their communities. They are often the best people to reach marginalized IDUs at risk who are suspicious of health workers, community workers, government officials and others.

ACCESS TO THE MEANS OF PREVENTION

One of the most essential elements of an HIV prevention strategy among IDUs is providing access to clean injecting equipment. This can also be one of the most highly debated areas of policy among governments, the mass media and communities. The compromise is sometimes a policy of needle availability: either distributed free of charge by nongovernmental organizations or sold at a low cost through pharmacies (Box 10). In this area, policy-makers should think about what they are trying to achieve.

- ▶ IDUs (who are usually spending all of their available money on drugs) should get and use clean needles and not share them with other people.
- ▶ People who cannot get a clean needle (because they have no money, are in prison, in an isolated area or injecting late at night) should not share their used needle and syringe with anyone or should clean it somehow before someone else uses it.
- ▶ People should know how to inject in a more healthy way, by rotating injection sites, using clean water to mix the drugs and other ways.
- ▶ This behaviour should be sustained and consistent, so the policy needs to address the barriers that will make IDUs return to needle-sharing and the repeated use of old equipment.

Policy-makers must understand how, when and where people inject drugs in their communities. They need to devise policies that make it as easy as possible for people to incorporate the use of a clean needle into this pattern of drug use. Simple policies that state that a needle will be available at a cost from a shop will not necessarily lead to sustained safer injecting. For example, many IDUs are wary of identifying themselves as a drug injector to anyone, let alone a pharmacist.

Box 10. Example of needle and syringe programme in Dhaka, Bangladesh

In Bangladesh, the SHAKTI Project of CARE Bangladesh began a needle syringe programme for IDUs. There were an estimated 7000 IDUs, mainly men, in the capital city of Dhaka. Although a baseline serosurvey among IDUs showed that none had HIV, 20% sold blood and most shared their needles regularly. Needles were available in pharmacies, but few IDUs would invest in them. Bangladesh has no paraphernalia laws, which meant that no one could be arrested simply for carrying needles. The SHAKTI Project therefore felt that a needle syringe programme was not against the law and established one in 1998. The Project trained peer educators who were active IDUs to assist in distributing clean injecting equipment, and this was seen as an extremely practical approach to accessing the IDU community. In 1999, serosurveillance found that, although the HIV prevalence among IDUs was 2.5%, up to 93% shared their needles. By 2000 the programmes were expanded and SHAKTI claimed to cover 3500 IDUs, providing three needles and one syringe daily free of user charges. The return rate of injecting equipment to the peer outreach educators was about 80%. The Inspector General of the Police was provided with an explanation of the programme, and the reception towards this type of work was very positive. He advocated that all wards in the city cooperate with such programmes. Although the work of the project staff was generally free of police harassment, this was unfortunately not the case for IDUs that made contact with the needle syringe programme. Advocacy for policy change is essential, but the conditions of police work, including poor salaries and entrenched corruption, make it unlikely that top-down policy work will be sufficient. Other ways need to be examined. The needle syringe programme has continued to grow, however, and in 2003 there were 11 drop-in centres for IDUs, with more than 40 peer outreach workers providing clean needles and syringes to the city's IDU community.

Sources: Jenkins & Jana (2001) and personal communication, Shamim Rabbani, SHAKTI Project, CARE Bangladesh, 2003.

PROVIDING DRUG TREATMENT OR DRUG SUBSTITUTION

Policy-makers need to look at how to make it easier for IDUs to get into drug treatment programmes so that they can stop injecting drugs. Options need to be expanded to help IDUs reduce their drug injecting. Some drug users reduce or stop needle use by moving on to non-injectable drugs. Policies that provide for the availability of drug substitution programmes such as methadone and buprenorphine are important elements of HIV prevention.

Other IDUs stop or significantly reduce their injecting drug use by attending drug treatment centres or participating in drug treatment programmes based on the 12 steps (Narcotics Anonymous) and other models. The reality is that relapse rates are high, and no one programme is successful for all drug users. Many move in and out of programmes and drug treatment centres before they find a solution that works for them. Some people never find a successful way to stop drug use.

Effective policies need to be realistic about drug use. Policies should acknowledge that at any point in time some people are:

- ▶ currently injecting;
- ▶ responding well to treatment or substitution programmes;
- ▶ former participants in programmes who have started injecting drugs again;
- ▶ new people experimenting with drug use; and
- ▶ people moving out of drug use.

An effective policy tries to take all of this into account and provide an environment that minimizes HIV transmission for all these groups.

HEALTH EDUCATION

Apart from providing the physical means of HIV prevention (such as clean needles, bleach and condoms), an effective policy needs to show how learning about HIV and health and acquiring the skills for safe behaviour will help IDUs. IDUs are often marginalized in communities.

- ▶ They are in conflict with police and public security.
- ▶ They are often denied access to or receive poor treatment from health and welfare services.
- ▶ They move in and out of prisons and compulsory rehabilitation centres.
- ▶ They are shunned by communities as they are often involved in crime to support their drug use.

This creates a challenge for providing health education and skills training to IDUs, as they are not likely to trust health professionals who try to carry out this work. Policies that support nongovernmental organizations who are already working with IDUs and have their trust are more likely to succeed. In many countries, IDUs have formed their own peer education and support organizations. These can be particularly effective as they:

- ▶ know about the reality and context of drug use and risk;
- ▶ can speak the language of drug users and understand the drug-using culture;
- ▶ are trusted by drug users and the health messages are therefore more likely to be believed.

Setting out a legitimate role for nongovernmental organizations and IDU groups in national or provincial AIDS policy can be a good way of making sure that these groups are provided with resources and are involved in planning and implementing the overall response. Policies that spell out a partnership

between government, health services and the affected groups (represented by nongovernmental organizations and user groups) provide legitimacy for these groups to contribute.

Policy needs to be based on evidence (Box 11). A growing body of evidence shows that peer education is an effective tool. It shows that supporting IDU organizations in producing health promotion materials and support and education programmes represents best practice in HIV prevention among IDUs. This evidence needs to be collected and used to justify and defend policy directions.

Box 11. Peer education in Dhaka, Bangladesh

Forty trained peer outreach workers have been placed in different areas of Dhaka, Bangladesh, where IDUs gather, and they educate, offer health services and give out new needles. The used needles are collected and exchanged for new ones. Condoms are also distributed along with information on HIV. These peer outreach workers are current drug users who do not carry or inject drugs during work hours. They promise not to be involved in petty crime as well. These men carry outreach worker identification cards while they work.

There are also more than 200 trained peer educators. These are other IDUs who are not on staff and do not carry identification cards but who serve to spread information to other IDUs. The peer educators and outreach workers are also encouraged to participate in various social activities. They actively participated in the flood response activities during the two months of devastating floods in 1998. That helped them to gain confidence, self-esteem and social acceptability among the communities they served.

Source: adapted from Beg (1999).

CHANGES IN LAWS AND IN THE PRACTICES OF THE POLICE AND PUBLIC SECURITY

Some of the laws that have been put in place to stop or reduce illegal drug use have the potential to work against HIV prevention. In some countries, a person can be arrested as a suspected illegal drug user if he or she found to be carrying injecting equipment. This may be seen to be a justifiable law in relation to a country's illegal drug strategy, but it works against a harm reduction strategy that tries to get IDUs to have clean equipment with them so that they do not share needles and syringes.

Developing good policy requires negotiation between public health and law enforcement personnel so that efforts to reduce illegal drug use can work together with strategies to reduce the spread of HIV. The potential conflicts can be resolved, although the negotiations can be difficult. Some countries have succeeded in establishing common ground between these groups by setting up intersectoral HIV/AIDS advisory groups in which these issues can be discussed and resolved.

In some countries, the law remains unchanged, but public security and the police have agreed to allow nongovernmental organizations to distribute needles and syringes and have not prosecuted people for carrying clean injecting equipment. Other areas of the law can be examined and reformed to support HIV prevention, such as:

- ▶ anti-discrimination laws;
- ▶ public health laws; and
- ▶ laws of evidence.

Multisectoral AIDS legal working groups have been established in some countries to consider reforming laws and policies to assist in HIV prevention strategies (Box 12).

Box 12. Australia – review of legal and regulatory frameworks

In 1989, the Australian National HIV/AIDS Strategy made recommendations covering multiple aspects of Australia's response to HIV/AIDS, including the need for legislative reform. The legislative recommendations of this Strategy were largely based on the report of a Panel on Discrimination and other Legal Issues that held public hearings in capital cities. The Strategy recommended the establishment of a Legal Working Party to report to the Intergovernmental Committee on AIDS of the Australian Health Ministers' Advisory Council.

The Legal Working Party was established as a subcommittee of the Intergovernmental Committee on AIDS, and the first meeting was held in February 1990. The Working Party was made up of legal policy specialists representing the Commonwealth, state and territory departments of health and attorneys-general and the Australian National Council on AIDS.

The discussion papers prepared by the Legal Working Party were released as soon as possible after approval of the Intergovernmental Committee on AIDS between February 1991 and April 1992. Public comment in the form of submissions on the preferred options for reform identified in the discussion papers was invited. The papers were widely circulated; about 13 000 copies were distributed. Over 300 submissions were received from 111 organizations and individuals, and the recommendations were redrafted on the basis of these submissions.

The process undertaken by the Legal Working Party was remarkable; no other country has produced a comprehensive set of discussion documents on legal issues and HIV/AIDS, although many recognize the need for such a process. The discussion papers of the Legal Working Party have had an enormous impact on legal and regulatory reform in Australia and many other countries.

Source: adapted from Department of Health Housing and Community Services (1992).

BRINGING MAJOR POLICIES AND STRATEGIES TOGETHER (SUCH AS THE NATIONAL ILLEGAL DRUG STRATEGY AND THE NATIONAL AIDS STRATEGY)

This has been a difficult area of policy in many countries. Many countries with significant illegal drug use problems have introduced national drug strategies or policies to reduce illegal drug use. These are often coordinated by the police, public security and the justice departments. Many of the people involved in developing and implementing these strategies hold the view that harm reduction and public health strategies to reduce HIV infection work against the principles of the drug strategy and in fact encourage or condone illegal drug use. This clash of principles needs to be resolved so that all the sectors work together.

There is no reason why the strategies that work to reduce HIV spread should threaten the national efforts to reduce drug use. Strategies to reduce illegal drugs can work alongside strategies to prevent HIV infection. One way to encourage the people associated with each of these areas to work together is to set up workshops at which they can present their perspectives and debate issues. These workshops and meetings can examine the international evidence for harm reduction and can also allow people from other countries to show how these strategies are working well in their countries.

PREVENTION OF SEXUAL TRANSMISSION

In many places, strategies implemented to reduce sexual transmission are not aimed at IDUs. There seems to be a belief that IDUs do not have sex. This is not the case. The assumption comes from putting people into particular “high-risk” groups. So sex workers are often seen as being at high risk of sexual transmission of HIV and IDUs at high risk of needle-associated transmission. The reality of people’s lives is more complicated than this, and policy needs to reflect this reality. Sex workers use illegal drugs; IDUs have sex. People do not fit neatly into high-risk groups, and prevention strategies for IDUs therefore need to look at sexual transmission as well as needle-sharing.

It is just as important to prevent the spread of HIV from one IDU to another through needle-sharing as it is to prevent transmission from an IDU to his or her sexual partners or children. Policies need to reflect all possible risks and support strategies that attempt to reduce transmission in all situations.

ATTENTION TO ISSUES OF POVERTY, HOMELESSNESS, UNEMPLOYMENT, VIOLENCE AND VULNERABILITY

Creating a policy to reduce the risk of HIV among IDUs is not simple. It does not mean just creating policies and strategies to reduce needle-sharing. It is easier to devise policies and strategies that see HIV risk as needle-sharing only and to see the answer as clean needles. But the whole context of drug use needs to be examined. This means looking at the wider social context of the lives of IDUs. Policies must take into account and address issues such as:

- ▶ poverty;
- ▶ vulnerability;
- ▶ homelessness; and
- ▶ unemployment.

IDUs need to be in the best possible position to either avoid injecting drug use or adopt safe injecting behaviour. Taking this more holistic approach acknowledges the complexity of the task of health promotion. There is ample evidence in other areas of health promotion to show that paying attention to the social context is as important as looking at the specific behaviour that contributes to poor health (sharing needles in this case). Human behaviour is complex. If the goal of policy development in this area is to establish an environment in which people make consistent safe choices in relation to injecting drug use, then the policy needs to find a way to look at all the factors that contribute to that decision-making.

These go well beyond the availability of a clean needle and syringe. They can be linked to the availability of:

- ▶ adequate food and shelter;
- ▶ purposeful work;
- ▶ substitute drugs; and
- ▶ education.

A comprehensive policy needs to take account of these complexities.

EVALUATION OF THE SUCCESS OF THE RESPONSE

Evaluation is an essential component of any policy. Policies need to be regularly reviewed to make sure that they are contributing to solving the problems for which they were developed. Many governments make the mistake of developing a policy and then putting it on the shelf, never looking at whether it was implemented effectively or at whether the approaches actually solved the problem they were designed to solve.

Evaluation can be done externally or internally. External evaluations provide an opportunity for an objective analysis of the success of a policy. Internal evaluation gives those involved a chance to look at the successes and failures of a policy and to make modifications. Both strategies are useful at different times. The main purpose of evaluation is to provide an opportunity to revise policies so that they remain relevant to the changing context of AIDS and to test whether the principles behind the policy are effective. Evaluation should be continuous and should be used to bring about change and reform.

NATIONAL AND POLITICAL SUPPORT: WHY IS IT IMPORTANT TO GAIN SUPPORT FROM GOVERNMENTS AND OPPOSITION PARTIES?

If HIV transmission is to be prevented in the long term, countries and provinces need to set up policies that are long-lasting (Box 13). Strategies therefore need to be protected against changes of government. The best way to ensure this is to get support for HIV policies from all political parties. This has been achieved in some countries by declaring that the HIV emergency should be free from politics and by setting up a parliamentary group with membership from all political parties. If provincial governments have to implement the response, establishing an intergovernmental committee that has representation from all provincial or state governments may also be useful.

These structures promote involvement and can be used to educate members of parliaments and other elected officials so that they can defend the principles of the AIDS policy.

Box 13. Australia – a multisectoral, nonpartisan approach

By the time the first Australian case of AIDS was made public in 1983, there was already a high awareness of the epidemic in the United States, a legacy of an active community health movement and an organized and politically active gay community. The federal Health Minister led the development of a national response. This response was guided by an AIDS task force providing medical advice and a national advisory council broadly representative of community interests, including representation from all major political parties. The first national AIDS strategy, released in 1989, was built on the existing tripartite involvement of government and bureaucracy, the medical and scientific professions and the most heavily affected communities: men who have sex with men, sex workers and injecting drug users. The early Australian response was nonpartisan, untraditional and comprehensive.

The federal Health Minister raised the magnitude of Australia's response, convoking state and territory health ministers to develop a national response. Considerable political effort was invested in the development of a policy consensus. The federal Health Minister was determined to enshrine the policy consensus and to obtain agreement from the more conservative states. He set out to obtain long-term federal funding and, by an elaborate and inclusive process of consultation, to formulate a comprehensive national strategy.

Sources: adapted from Crofts & Ballard (1998) and Crofts et al. (1994).

SUPPORT FROM OTHER PARTS OF SOCIETY

Other parts of society can also play a key role in supporting AIDS policies or they can work against the policy by criticizing it publicly. Community leaders such as church or religious leaders, labour union leaders, private sector leaders and people from nongovernmental organizations can be part of the process of developing and reviewing policy. Making them part of the process often means that they are less critical of the policies developed and also raises their level of

knowledge about HIV/AIDS. It provides an opportunity for them to bring their resources to the HIV/AIDS response.

There are many ways to involve various groups in the society. If there is a range of religious and spiritual groups in the country, a forum where representatives of all faiths come together is a good way to get them to support the AIDS policy. They can also be challenged to look at how their health and welfare institutions can become involved. Labour unions can introduce AIDS training into their workshops to reduce discrimination and promote safe behaviour. Business can be challenged to provide goods at reduced cost, to provide worker training and to introduce HIV-friendly workplace policies.

COMMUNITY EDUCATION

Educating the wider community about the need for harm reduction strategies is important to minimize HIV transmission among IDUs. A community will often react negatively to the idea of IDU services in their neighbourhood. They fear that it will cause an increase in crime or encourage their young people to start using illegal drugs. Communities can be worked with to bring them to an understanding of the need for services. The mass media can play an important role in community education. Educating the media can be a useful strategy to improve the quality of the mass-media coverage of AIDS policy issues (Box 14). Strategies may include:

- ▶ briefing the mass media on the rationale for policy decisions;
- ▶ encouraging journalists to attend workshops to explain policies; and
- ▶ providing a mass media guide that sets out the evidence for harm reduction policies.

Box 14. Southern African AIDS Information Dissemination Service (SAfAIDS)

Established in 1994, SAfAIDS is a regional organization with the mission of strengthening understanding of HIV/AIDS as a development issue. SAfAIDS' mass-media programme acts as a catalyst for providing and disseminating information to journalists, editors, reporters, media managers and information officers, people living with HIV/AIDS, nongovernmental organizations and others.

A key area of SAfAIDS' work is producing materials. Investigative stories are packaged to suit mass-media needs as well as to depict the human face of HIV. Stories are set in localized contexts to which communities can relate, with an emphasis placed on real life issues, rather than statistics.

SAfAIDS aims to increase the quality and quantity of mass-media reporting on HIV through the training of mass-media practitioners. Training focuses on the reduction of stigma; addressing personal attitudes; changing stereotypes; focusing on evidence-based stories; reducing sensationalist coverage and headlines; and addressing wider issues such as gender

imbalances, misconceptions and cultural practices. An important strategy is to target stakeholders who have editorial autonomy and can change newsroom policy, promote new concepts and influence training curricula.

Source: adapted from United Nations Fund for Population Activities (2002):60–61.

2.2. THE POLICY-MAKING PROCESS

INTRODUCTION

Policy can take many forms. It can be a simple expression defining the approach to be taken or it can be a lengthy and detailed document setting out all the issues relating to a particular topic and stating the position of the government, province or institution on these issues.

This section sets out some of the approaches that can be taken to develop and revise policy. Policy is not a static thing that is developed once and placed on a shelf. It should be under regular review and flexible enough to change as circumstances change. This is especially important in HIV/AIDS, where changes are occurring all the time and often rapidly.

THE POLICY DEVELOPMENT PROCESS¹

Several questions can be asked in the policy development process to help people and agencies. These include:

- ▶ What problem needs to be solved?
- ▶ How will this policy help?
- ▶ What new problems will the policy create?
- ▶ What are the consequences of not having a policy?
- ▶ Who will be affected by this policy?
- ▶ What evidence exists for the range of possible interventions?
- ▶ What policy already exists that will complement or conflict with this policy?
- ▶ What needs to be done to build political support for the policy?

¹ Adapted from Australian Federation of AIDS Organisations (1999).

What problem needs to be solved?

This sounds like a simple question, but it can be quite complicated. If the problem is not identified correctly, then the solution is likely to be wrong. Many people start by saying that the problem is drug use. Illegal drug use can certainly severely affect individuals, families, communities and countries. Countries and communities struggle with the complexities of reducing drug supply, demand and use.

Many countries have taken the approach that the problem of illegal drugs is a long-term problem requiring long-term solutions and that the AIDS epidemic is an immediate and urgent problem requiring immediate intervention. The two objectives of preventing HIV infection and reducing drug use do not have to work against each other. In many places they work side by side.

The immediate problem in terms of AIDS is the transmission of HIV from one person to another. The main way HIV is spread in IDU communities is by sharing injecting equipment. The immediate solution is to make sure that needle-sharing is minimized. This generates a whole series of problems. The barriers to establishing a policy that aims to stop needle and syringe sharing can be discovered and explored. These barriers will indicate what the problems are that the policy needs to address. Remember to revisit the problem from time to time to make sure that it has been identified correctly and that circumstances have not changed so much that the problems have changed.

How will this policy help?

This is another important question. Having a policy in place may or may not help. If the policy is ignored or if no-one has the resources to get it started, then it is not likely to be successful. If the policy development process creates more conflict between the various stakeholders, then it may not be useful. Developing the policy requires clear ideas about how the policy can be used to overcome the identified problems.

What new problems will the policy create?

All changes achieved will affect other areas of policy and programming. This needs to be considered when developing new policies. The obvious question for HIV prevention among IDUs is the link with policies on illegal drugs. These conflicts need to be discussed so that both policies can work together rather than against each other.

Other new problems need to be taken into account. For example, a policy might be introduced of making needles and syringes available through chemists or pharmacies. This might lead to the police setting up observation points around busy pharmacies to arrest drug users who come in for the clean needles and syringes. Injecting drug users may face more discrimination if pharmacy staff are not trained and supported to carry out this new job. This new policy may also increase the number of syringes discarded by IDUs in parks and other secluded places around the pharmacies. This, in turn, may lead to needle-stick

injuries in children playing in the nearby park, which would bring about public outcry against the policy. Planning exercises can help the policy development group to anticipate such problems as these that may arise.

What are the consequences of not having a policy?

As the complexities of the policy development process unfold, some people might suggest that staying with an informal policy is better than trying to make it formal. The consequences of leaving the situation as it is, without a policy, need to be examined. For example, some places have an informal arrangement between IDUs, nongovernmental organizations and the police. The arrangement may be that police will not interfere with the work of the nongovernmental organization when the workers are giving out needles and syringes and educating drug users. This might work reasonably well with only the occasional problem emerging when police or public security decide to crack down and start arresting or harassing IDUs when they are interacting with the staff of the nongovernmental organization.

The problem with this arrangement is that the parties do not formally agree on it, and it depends on an agreement between individuals in the police and the nongovernmental organization. Changes in personnel might lead to changes in the arrangement. Arrests and harassment erodes the trust that the nongovernmental organization workers are trying to develop with the IDUs. The whole arrangement is fragile, and it is not clear how it can lead to sustained success.

Who will be affected by this policy?

If the policy is to have the best chance of being relevant and successful, it needs to be developed in collaboration with the people who will be most affected by it. IDUs themselves, and the nongovernmental organizations who work with them, are the most likely people to understand how the policy will affect them. They are in a good position to examine:

- ▶ how the policy will be interpreted in the field;
- ▶ the barriers that exist;
- ▶ the people most likely to oppose it; and
- ▶ the problems it will create.

Involving IDUs and the nongovernmental organizations that work with them in the development process also means that they will be more likely to support the policy and work together to ensure its success.

What evidence exists for the range of possible interventions?

The people involved in the policy development process need to have some evidence that the policy options about which they are thinking actually do

work. Good policy should be based on a combination of local knowledge and evidence of success in other towns, cities or countries. Importantly, this evidence of success can also be used to promote the policy and defend it from critics. For example, in the case of preventing HIV among IDUs, a government may be contemplating a policy of making clean needles and syringes available. Needle and syringe availability has been started in many different ways in different settings. Some of these include:

- ▶ funding nongovernmental organizations to train and support peer educators to distribute needles and syringes along with health education, advice about safer injecting and so on;
- ▶ setting up vending machines on railway stations and in other places where people inject; and
- ▶ having needles and syringes available for sale in pharmacies and clinics.

Governments need to look at the evidence for the range of possible approaches and adopt a policy based on the clear evidence of success (Box 15).

Box 15. Evidence for needle syringe programmes

Since the early 1980s, needle and syringe programmes have emerged as particularly important in preventing HIV infection among IDUs, but their widespread implementation has often been limited by uncertainty about their effectiveness. Many studies have been undertaken that clearly indicate that needle and syringe programmes are not only effective in reducing risk behaviour change but also prove extremely cost-effective. In 2002, a seminal report from Australia showed the level of investment and return from needle and syringe programmes over a period of 10 years. The report found that, between 1990 and 2000, nearly Aus\$ 150 million had been invested in needle and syringe programmes. This level of investment and return from needle and syringe programmes over 10 years has :

- ▶ avoided an estimated 25 000 cases of HIV;
- ▶ avoided an estimated 21 000 cases of hepatitis C;
- ▶ saved an estimated number of lives exceeding 5000 by 2010; and
- ▶ provided an estimated return of somewhere between Aus\$ 2.4 billion and Aus\$ 7.7 billion on an investment of Aus\$ 150 million.

As was stated by Major Brian Watters of the Salvation Army, Chairman of the Australian National Council on Drugs, "it is hoped this report will further enhance the public's awareness of the purpose and value of needle and syringe programmes and help in overcoming the misunderstanding that these programmes somehow condone and encourage the injecting of illicit drugs".

Source: adapted from Commonwealth Department of Health and Ageing (2002).

What policy already exists that will complement or conflict with this policy?

Looking at the existing policy, laws or practice that will conflict with the proposed policy and may cause problems in adopting the policy and setting up programmes is also helpful. This is also a good opportunity to see what the policy has in common with other policies and laws as a way of building the case for a government to take on the policy.

What needs to be done to build political support for the policy?

Policies that address HIV/AIDS issues are often controversial, and those relating to drug use are often even more so. Strategies that can help gain political support for the policy include:

- ▶ working with politicians who already support the policy and giving them a role in talking to their colleagues about the policy;
- ▶ giving key leaders an opportunity to see the policy being implemented in other countries;
- ▶ bringing in trusted and influential people to assist in promoting the policy; and
- ▶ preparing written materials and videos specifically aimed at gaining political and community support.

THE STAGES IN THE POLICY DEVELOPMENT PROCESS

A government or organization can follow several stages in the process of developing policy.

- ▶ Define the problem to be solved.
- ▶ Gather together the people most likely to be able to assist in developing the policy.
- ▶ Conduct research to establish the local context and to gather evidence on successful policy approaches in other countries, cities and communities.
- ▶ Prepare a discussion paper setting out the problem, analysing the potential policy positions that could be taken and making recommendations about the most appropriate approach.
- ▶ Circulate the discussion paper to stakeholders and the people likely to be affected by the policy for comment.
- ▶ Incorporate the comments into the final policy.

- ▶ Launch the policy along with education and mass-media materials.
- ▶ Develop an implementation plan for the policy to ensure that it translates into practice.
- ▶ Set out how the success of the policy will be evaluated and how the policy will be revised.
- ▶ Revise the policy.

Fig. 2 shows an example of how to use these stages.

Fig. 2. The policy development process

NGOs are working with IDUs and want to start distributing clean needles and syringes. Public security and police are arresting people carrying needles and registering them as drug users.

Yes	Government sets up a committee of public health officials, NGOs and international advisers to examine the issue and allocates a government employee to assist
No	Government decides that the current informal arrangement should continue
	Committee meets, briefs employee on the research required, identifies key groups with which to consult and identifies key people who will support or oppose the policy
	Consultation with key stakeholders: workshop held to discuss problem and issues
	Employee assists committee in drafting a position paper that summarizes the evidence for various approaches to HIV prevention among IDUs and summarizes the issues involved in setting up harm reduction and needle and syringe programmes
	Discussion paper with options and recommendations circulated for comment
	Comments collected and incorporated into final policy
	Policy launched along with education materials, an implementation plan and the identification of resources to implement
	Data collected on the effectiveness of the policy
	Policy reviewed and revised

Source: adapted from Australian Federation of AIDS Organisations (1999).

2.3. ADDRESSING THE VULNERABILITY TO HIV INFECTION OF SPECIFIC IDU GROUPS

INTRODUCTION

This section concerns more advanced policy-making in addressing the needs of the vulnerability of IDUs to HIV infection. It moves beyond basic policy and planning to look at the needs of specific groups at risk of HIV through injecting drug use. The question is: how can basic HIV/AIDS policies for IDUs be improved and the policies made more responsive to the needs of special IDU populations?

This section provides some strategies and principles for involving marginalized and vulnerable groups and communities in the process of developing and implementing policy.

SPECIFIC RISK GROUPS

How can specific groups be contacted?

The first step in examining the policy needs of specific groups is to find a way to get access to the group. Some of the vulnerability of these groups stems from their isolation or marginalization from mainstream society. Members of these groups are often suspicious of health professionals or government officials and have often suffered stigma and discrimination from these people. The most effective way to get access to these groups is to find people who already have the trust of the group and to work through them to get access to the other group members.

Why do these groups need to participate for effective policies and programmes to be developed?

Programmes or policies that are developed without the involvement and support of the people they are attempting to assist or serve are less likely to succeed. This is because they are unlikely to be based on the actual needs and priorities of the group. People use words such as targeted to demonstrate that they are aiming their intervention or policy at a particular group.

It is more effective to talk about the participation or involvement of the vulnerable group members rather than just seeing them as passive targets of interventions. There are many examples of effective partnership approaches to HIV prevention and care that have the involvement of the vulnerable groups as a key feature.

Who are the specific groups?

Some especially vulnerable groups of IDUs include:

- ▶ prisoners and their families (Box 16);
- ▶ sex workers;
- ▶ men who have sex with men;
- ▶ ethnic minority populations;
- ▶ refugees and mobile populations (Box 17);
- ▶ women in general;
- ▶ pregnant women;
- ▶ street children; and
- ▶ slum populations.

Box 16. Prison syringe exchanges

The first prison syringe exchange programme started in 1992 in Switzerland. As of March 2004, over 50 prison exchange programmes were operating in 6 countries (Switzerland, Germany, Spain, Moldavia, Kyrgyzstan, Belarus) Most of them in Spain. There have been evaluations of prison syringe exchange programmes, and all have been favourable. Reported drug use decreased or remained stable over time. Reports of syringe-sharing have declined dramatically. No new cases of HIV, hepatitis B or hepatitis C transmission were reported. The evaluations found no reports of serious unintended negative events, such as initiation of injection or of the use of needles as weapons. Staff attitudes were generally positive, but the response rates to these surveys varied. Overall, this review indicated that prison syringe exchange programmes are feasible and do provide benefit in the reduction of risk behaviour and the transmission of bloodborne infection without any unintended negative effects.

Source: adapted from Dolan et al. (2003) and Rick Lines et al (2004).

Box 17. Working with refugees in Hong Kong

In 1996, Médecins Sans Frontières established a harm reduction programme among Vietnamese refugees in the Pillar Point refugee camp in Hong Kong. The initial concerns were not only the high number of opiate-dependent people but also the numbers of discarded syringes with which children used to play. The programme worked to distribute and collect clean needles and syringes for IDUs in the camp. Drug users were also offered counselling, methadone maintenance and peer-based education on HIV and other bloodborne viruses.

Source: Nemayechi & Taveaux (1997).

Why are they so vulnerable?

People from these groups are especially vulnerable to HIV infection for several reasons:

Mobile populations, refugees and minority ethnic groups also have barriers of language and culture.

What is risk mapping?

Vulnerability varies from place to place and from time to time. Rather than accepting external definitions of vulnerability, programme and policy developers should become familiar with HIV vulnerability in each environment.

WORKING WITH VULNERABLE GROUPS

Once the range of vulnerable groups has been established, the task is to work in partnership with these vulnerable groups to determine what policies and programmes would best reduce HIV vulnerability. Previous sections of this guide show that policies come in a variety of forms, including:

Outsiders can best work with vulnerable groups by:

- ▶ working to build trust;
- ▶ using uncomplicated language;
- ▶ being patient;
- ▶ being reliable;
- ▶ avoiding exploitation;
- ▶ sharing power;
- ▶ identifying and breaking down barriers to participation; and
- ▶ reporting back to communities.

Working to build trust

Remember that trust is something that is constantly assessed by both parties in a relationship, so behaviour has to be consistent if trust is to be maintained.

Using uncomplicated language

One of the biggest barriers to involving marginalized groups in the policy process is the use of complicated language. Some experts use technical language, or jargon, to show their superior knowledge and education. But this can be extremely alienating to people in marginalized groups.

Policy-makers must take the time to determine what language a vulnerable group uses when they are trying to build a partnership. Many groups have their own expressions and idioms that are a part of their culture. Minority ethnic populations are often forced to communicate in a language that is not their native language. Successful policy and programme design is based on good communication, and communication is most effective when both sides clearly understand the topics being discussed.

Preparing written materials in plain language is a skill. Help can be obtained from people who are skilled in translating complex technical jargon into simple language. Documents for discussion can be tested on a small group of people from the vulnerable community to make sure that the documents are easy to understand.

Being patient

Sometimes the quickest way to make policy is to sit in an isolated room and write a policy document. Some policy-makers complain that involving communities creates unnecessary complications and makes the policy development process too long. Policy-makers are sometimes tempted to think that they understand the vulnerable groups and therefore do not need to involve them.

That would be fine if policies did not need to be implemented. Effectively implementing policy requires that the people affected by the policy participate and that the community have some level of ownership of the policy. This usually only happens if the community has had some involvement in the policy development process. For this to happen, policy-makers need to:

- ▶ be patient, as community participation takes time;
- ▶ reach agreement or consensus, as these cannot be forced; and
- ▶ set out realistic time frames for developing, agreeing on and implementing policy.

Communities need time to discuss the issues and how new policies and programmes will affect them.

Being reliable

Many people in vulnerable groups have seen people from government and health services come and go, making unrealistic promises about how their lives will change. Building trust with people requires being reliable. Reliability can be demonstrated by such actions as:

- ▶ keeping appointments;
- ▶ being on time;

- ▶ not promising things that cannot really be delivered;
- ▶ telling the truth, even if the news is bad or disappointing; and
- ▶ keeping promises or delivering on undertakings.

Avoid exploitation, and protect the community with which you are working from outside exploitation. Many people from vulnerable groups have been exploited, often many times. Securing their involvement in HIV/AIDS policy and programmes can also be exploitative unless policy-makers take steps to reduce or avoid exploitation. Exploitation has many forms. For example, people with HIV may be encouraged to speak out publicly but may find that the mass media exploits them and increases the levels of stigma and discrimination they experience. Further, researchers may get the support and voluntary labour of people from vulnerable communities but may not share with the community members any of the rewards that flow from the research, such as attending international conferences and career advancement.

Even if people from vulnerable groups are involved voluntarily, policy-makers can take steps to ensure that the effort of people from vulnerable groups is respected and acknowledged.

Sharing power

Marginalization is accompanied by a lack of power: both individual power and community power. Policy-makers and programme directors are often in a position of power in societies. Establishing an effective partnership with vulnerable groups requires that policy-makers and people in government share some of the power they have, allowing and helping marginalized communities to increase their control over the factors affecting their own lives. This need not necessarily diminish the power of policy-makers and people in government, because forming effective working partnerships with marginalized communities can lead to an increased ability of all groups to achieve their aims. This is clearly more the case where goals are common.

Power can be shared in many ways. It can be the key to a genuine understanding of the perspectives and needs of the communities vulnerable to HIV/AIDS. Power-sharing may involve:

- ▶ encouraging people from vulnerable communities to take the lead in setting the agenda or the priorities for policy development;
- ▶ taking the advice people from the groups provide about the best way to establish a programme;
- ▶ the way that people in power behave towards the people with whom they are dealing;
- ▶ trust and a generosity of spirit;
- ▶ sharing credit and opportunities;

- ▶ paying attention to overcoming barriers to participation;
- ▶ setting up and maintaining transparent decision-making processes; and
- ▶ being open and responsive to criticism and feedback.

Identifying and breaking down barriers to participation

People from vulnerable groups are prevented from participating in the process of developing and implementing policy in many ways. People from marginalized groups often need to spend much of their day just meeting their basic needs, such as food, shelter and safety. The successful participation of people from marginalized groups in the process of policy development depends on the extent to which the policy developers work to break down the barriers for people from these groups, including:

- ▶ a lack of trust in government and authority structures;
- ▶ the need to spend time earning money, finding food and shelter or a supply of drugs each day to survive;
- ▶ fatigue from long hours of work, street life and other factors; and
- ▶ unfamiliarity with the processes related to meetings and policy development.

Knowledge, planning and patience can result in many of these barriers being overcome, and the participation of people from marginalized groups can be maximized.

Reporting back to communities

Communities often feel exploited when people come in to seek information, to consult or to carry out research but never return to provide feedback, to report on research findings or to include the community in starting a programme. There are many effective ways to maintain communication with communities.

Producing long reports in technically complicated language is probably the least effective method. People often find reading beyond the first few pages difficult. If a report is necessary, then plain language is essential and the report must have a concise summary at the beginning.

Other effective ways to report to the community include:

This section has not dealt in detail with the needs of specific vulnerable groups. Many publications can assist policy-makers in identifying these needs; Annex 2 includes web sites to assist with this.

3. PROGRAMME DEVELOPMENT AND IMPLEMENTATION

3.1 TRANSLATING STRATEGIES INTO ACTION

INTRODUCTION

Once a policy has been developed to address HIV infection among IDUs, it needs to be translated into action. A policy that sits on a shelf and is never turned into reality is not of much use. Strategies to deal with IDUs and HIV/AIDS should result from a policy. A strategy is a plan of activities that aims to address the specific situation or problem identified in the policy. The strategy leads to the programme and then specific projects: for example, needle and syringe exchange may be one of the projects in a programme.

If a rapid assessment and response exercise has been conducted, it will have identified both the problems relating to a specific country, city or community and also possible activities that may help to solve the problems. If these interventions are adopted, they will make up the programme.

Section 3 examines:

- ▶ how to select the best interventions for a specific community;
- ▶ the characteristics of effective programmes; and
- ▶ how to establish and sustain a programme.

SELECTING THE BEST INTERVENTIONS

How can the best range of interventions be selected for a specific country, city or community?

The interventions programmes use vary. Some target individual behaviour, whereas others may focus on national policies and legislation. There are many possible interventions and usually limited resources available, and planners and decision-makers must therefore select the best possible combination of interventions. They need to work out what the priorities are in the particular community. The priorities may be determined by thinking about:

- ▶ the feasibility of the intervention – whether what needs to be done really can be accomplished;
- ▶ the acceptability of the intervention – communities may be completely unwilling to accept certain activities or they may be culturally inappropriate: for example, in some communities, men delivering key information or equipment to women;

- ▶ the effectiveness of the intervention and whether it will work in the specific local context; and
- ▶ the stage and nature of the HIV/AIDS epidemic in the community.

Understanding the local context is crucial if a programme is to have any chance of success. A good rapid assessment and response will point the way and is sound investment before deciding on and investing in interventions (section 1.1). The priorities will differ for:

- ▶ the countries with a very low prevalence of HIV infection;
- ▶ those that have concentrated epidemics among specific populations (such as IDUs or sex workers); and
- ▶ those that have generalized epidemics.

What steps can be taken to initiate action on the intervention priorities for a community?

The steps for initiating action on the intervention priorities for a community include assessment and monitoring, advocacy, policy and legislation, information and education, training, providing services, action in prisons and HIV/AIDS care.

1. Assessment and monitoring

- ▶ Perform rapid assessment and response and/or a local situation assessment to identify what the situation really is and where the problems are so that the interventions are based on reality.
- ▶ Develop a sentinel surveillance system to monitor risk behaviour and the prevalence and incidence of HIV among IDUs.

2. Advocacy

- ▶ Educate politicians, community and religious leaders and other decision-makers about the urgent need to respond to HIV/AIDS with specific interventions for IDUs.
- ▶ Provide evidence and experience from other relevant countries. (Organizing study tours for key decision-makers to expose them to other programmes is a good idea.)

3. Policy and legislation

- ▶ Talk to and negotiate with the local authorities (such as police) to achieve a pragmatic and flexible application of the laws and regulations (such as possession of injecting equipment). This may help IDUs to

interact with people who may be able to assist them in reducing their risky behaviour (such as peer workers or health professionals).

- ▶ Commission a policy research study to review the existing laws and regulations that are a barrier to implementing HIV prevention strategies.

4. Information and education

- ▶ Develop targeted information and education programmes for IDUs, sex workers and other vulnerable populations, using peer networks.
- ▶ Develop public education to reduce the stigmatization and discrimination experienced by most IDUs (Box 18).

Box 18. Turning an obstacle into an opportunity

In 1992, a young Brazilian girl was kept out of primary school because she was HIV positive. This happened in São Paulo, where the bulk of Brazil's AIDS cases were concentrated at the time, and put the spotlight on discrimination against all people living with HIV/AIDS.

AIDS activists inside and outside the government joined with the mass media to bring the case to public attention. They used it to build public pressure for a more supportive environment for people living with HIV/AIDS. The São Paulo school system was especially responsive – it has now developed a comprehensive syllabus for sexual health education and supports access for children affected by HIV.

The pressure built around the case continues to have an effect; although the girl has now died, an annual award is given in her name for work in reducing the transmission of HIV and its impact.

Source: UNAIDS (1999).

5. Training

- ▶ Develop a workforce of outreach workers and other staff skilled in working with IDUs.
- ▶ Provide training to relevant health professionals and social service personnel who come into contact with IDUs.

6. Providing services

- ▶ Make sure that IDUs can easily access sterile injecting equipment, condoms, voluntary counselling and testing and user-friendly prevention and treatment services for sexually transmitted infections.

- ▶ Develop and expand drug treatment services using a range of different options.

7. Action in prisons

- ▶ Provide training for prison staff and prisoners.
- ▶ Talk to prison authorities and negotiate for a set of broader interventions, such as drug substitution, a needle syringe programme, bleach and condoms.

8. HIV/AIDS care

- ▶ Ensure that IDUs are able to get treatment and care and are not discriminated against because they are IDUs.

HOW MUCH INTERVENTION IS ENOUGH?

In some cities around the world, HIV epidemics have occurred among IDUs even though harm reduction interventions had been implemented for some time. In Kathmandu, the needle syringe programme covered less than 10% of the IDU population. Harm reduction education of IDUs and substitution drug treatment were scarce. There was no user group. A change from injecting heroin to injecting buprenorphine, along with other changes, made HIV infection explode through the Kathmandu Valley in 1997. In several Canadian cities, the needle syringe programme had more than 10% coverage but, in retrospect, the coverage was insufficient. A switch from heroin to cocaine injecting and increased restrictions in cheap hostels in Vancouver and a weak substitution drug treatment system and needle syringe programmes in several Canadian cities all contributed to an explosive HIV epidemic in the mid-1990s. These kinds of experiences led policy-makers to ask how much intervention was needed.

This can easily be worked out with needle syringe programmes as an example. Assume that 100 000 heroin injectors live in a city called Drugland. The average frequency of heroin injecting is just under twice a day. The number of injecting episodes in Drugland in the next 12 months is therefore going to be around 2 times 365 times 100 000 = 73 million. UNAIDS suggests as a guide that 60% of the population needs to be covered to control HIV. This means that about 44 million sterile needles and syringes need to be distributed – each year – in Drugland to control HIV.

Countries or cities in which the prevalence of HIV infection among IDUs is high may have to even surpass 60%, whereas cities or countries with much lower HIV prevalence might get by with a lower figure. Providing 44 million needles and syringes to 100 000 IDUs each year is not easy. It requires substantial planning. Authorities might set a target of getting back 60–70% of used needles and syringes. The programme needs to be quite diverse. So some outlets might be pharmacies, some might be fixed-site free needle exchange, and outreach

might be provided for some especially vulnerable populations of IDUs. Planners might think about setting up 20 major outlets each with an annual throughput of 200 000 needles and syringes a year. That might require 80–100 staff who need to be trained and supervised. Policy and procedure manuals need to be written and some central administrative support provided. Accommodation needs to be provided, concentrating especially on areas where IDUs already tend to congregate. This structure cannot be set up overnight. It might take as long as five years to reach this level. Goals and targets should be made for points along the way. Starting from scratch, achieving an annual throughput of 800 000 in the first year and doubling every year will mean that the target of 44 million can be achieved after seven years.

3.2 CHARACTERISTICS OF EFFECTIVE PROGRAMMES

INTRODUCTION

Drug users need to reduce or eliminate the behaviour that places them and others at risk to prevent the spread of HIV and other bloodborne infections. Research shows that relevant and well-designed prevention programmes can reduce the transmission of HIV and other bloodborne diseases, such as hepatitis B and hepatitis C and sexually transmitted infections.

WHAT ARE THE PRINCIPLES BEHIND EFFECTIVE PUBLIC HEALTH RESPONSES?

Successful responses to public health crises have guiding principles that have helped to develop the programmes or interventions.

Adopting a step-by-step approach to behaviour change. This approach attempts to change behaviour:

- ▶ by increasing drug users' awareness of the risks and harms of drug use;
- ▶ by reducing the health risks and harms associated with drug use;
- ▶ by providing treatment and care to drug users;
- ▶ by encouraging and assisting a reduction in drug use and risk behaviour; and
- ▶ by encouraging and assisting the stopping of drug use and risk behaviour.

A pragmatic approach. A pragmatic approach suggests that preventing HIV epidemics requires giving greater priority to reducing the risks associated with drug use rather than focusing solely on preventing drug use.

Multiple and integrated strategies. The focus is not on one aspect of society or one possible intervention. Successful public health responses need to focus on the need to encourage change at various levels of society. The focus may need to include: individuals' lifestyles; health service delivery; the immediate community context; the wider social environment; and public policy.

Providing the means for behaviour change. Behaviour change is more likely, and effective, if people are made aware of the health risks and of methods or ways of reducing the risks. This works best if they are also provided with the means to change behaviour, such as making condoms or clean needles available.

Changing service delivery. Improve the health services available to IDUs and make them easier for IDUs to use and approach. Health services need to be able to attract IDUs to them, establish some trust and maintain contact with IDUs.

Community-based intervention. Interventions targeting hidden populations (such as IDUs) must involve local agencies and organizations and should also use individuals to make contact with drug users, often called outreach.

Community-oriented intervention. Community ownership and participation is essential in developing effective responses to HIV/AIDS and drug use. Key members of the local community, including drug users and law enforcement authorities, need to be involved and educated about the need for change. They need to be involved from the start with the rapid assessment and response and onwards to the development of the intervention or programme.

Changing the social and political environment. Public health interventions require help from those who can influence public policies (for example, government health officials) and from those who support risk reduction and behaviour change.

Changing policy. Existing public policy must be examined to determine whether specific parts of the policy need to be changed for intervention to work. For example, a public policy that forbids distributing clean injecting equipment or providing condoms may have to be targeted.

The rapid assessment and response guides (Stimson et al., 1998; World Health Organization, 1998a, b) give technical details for assessing and developing appropriate health interventions for drug use.

CHARACTERISTICS OF EFFECTIVE PROGRAMMES

What makes programmes effective?

A programme may be effective for many reasons. Experience suggests that effective programmes include some or all of the following principles:

- ▶ Start HIV/AIDS prevention programmes as soon as possible.
- ▶ Provide a comprehensive range of well-coordinated and flexible services.
- ▶ Involve the community in planning and implementing interventions and services.
- ▶ Prevention programmes must be based on a thorough, continuing assessment and understanding of local community needs, and the effectiveness and impact of programmes must be continually assessed.
- ▶ Services should be available in a wide variety of locations with different operating times.
- ▶ Community-based outreach is an essential component of HIV/AIDS prevention and must be provided to drug users in their own neighbourhoods.
- ▶ Drug users and their sexual partners must be treated with dignity and respect and with sensitivity to cultural, racial, ethnic and gender-based characteristics.
- ▶ HIV prevention programmes should ensure that IDUs have easy access to sterile injecting equipment to reduce the reuse of injecting equipment.
- ▶ Ensure adequate coverage of target populations with information and services for risk reduction.
- ▶ Interventions to reduce the risk of HIV/AIDS must be ongoing and sustained over time.
- ▶ Create political willingness for a supportive and enabling environment.
- ▶ Prevention and treatment efforts should target IDUs who are already HIV-infected and their sexual partners.

Start HIV/AIDS prevention programmes as soon as possible. Programmes must be started before HIV enters the target population or when prevalence is below 5%. Nevertheless, even when HIV is established in a community, prevention programmes can significantly limit further spread.

Provide a comprehensive range of well-coordinated and flexible services. IDUs are individuals, and no single prevention strategy will work for everyone. A comprehensive approach that readily adapts to changing needs and circumstances is the most effective approach for preventing HIV/AIDS and other bloodborne infections in IDUs, their sexual partners and their communities. This approach should include:

- ▶ community outreach;
- ▶ HIV testing and counselling;
- ▶ drug treatment;
- ▶ easy access to sterile syringes and needles;
- ▶ services delivered through community health and social service providers; and
- ▶ carefully coordinating all these services.

Involve the community in planning and implementing interventions and services. Involving IDUs and the local community increases the chances of developing and putting in place culturally appropriate HIV/AIDS prevention strategies. These strategies are more likely to be acceptable to the community and reach the IDUs and their sexual partners in their own environments.

Prevention programmes must be based on a thorough, continuing assessment and understanding of local community needs, and the effectiveness and impact of programmes must be continually assessed. The nature and extent of drug use and the HIV/AIDS epidemic varies widely, and prevention strategies must therefore be adapted to local community needs and resources. Local drug use and HIV/AIDS risk-behaviour patterns must be constantly monitored to refine programme approaches and strategies over time and to evaluate programme outcomes (Box 19).

Box 19. Ongoing monitoring in Delhi, India

The 1998 rapid assessment of injecting drug use in Delhi revealed hot spots of injecting drug use all over Delhi. The SHARAN Drop-in Centre was established in 1999 at the Yamuna Bazar area after a baseline survey of IDUs and a needs assessment among drug users in that area. Initially, buprenorphine substitution, needle exchange, primary health care, wound and abscess management, counselling, peer education and outreach activities were carried out from the Drop-in Centre. A few months later, outreach workers reported hearing of some clients crushing and injecting the take-away buprenorphine tablets, sometimes resulting in painful abscesses.

To prevent this, it was decided to crush the tablets into powder and make the clients take the dose in front of the dispenser as directly observed therapy. Clients had to sit down in the buprenorphine dispensing room for a few minutes and open their mouths to show

3. PROGRAMME DEVELOPMENT AND IMPLEMENTATION

staff that the dose had been ingested before leaving. Even then some clients got away with spitting the powder into their hands and hiding the hand under thick blankets they wore to protect themselves from the winter cold.

Ongoing monitoring through outreach and interviews with randomly chosen IDU clients revealed that, after concealing their buprenorphine doses, clients would take needles and syringes from the needle syringe programme counter and inject the buprenorphine powder mixed with pheniramine maleate in the parks surrounding the Drop-in Centre. As a result of this information, clients on buprenorphine substitution were not given needles and syringes at the Centre, and this practice continued until there were no more reports of tablet injecting.

Source: personal communication, Jimmy Dorabjee, Centre for Harm Reduction, Macfarlane Burnet Institute for Medical Research & Public Health, Australia, 2003.

Services should be available in a wide variety of locations with different operating times. Harm prevention and support services need to be available in a wide range of settings, as IDUs are dispersed throughout communities. These settings may include community health and social service agencies, hospitals and clinics and drug treatment and correctional facilities. The opening hours at these places need to suit to drug users. This approach increases the impact of interventions and reduces the unnecessary duplication of services.

Community-based outreach is an essential component of HIV/AIDS prevention and must be provided to drug users in their own neighborhoods. Drug use is usually a hidden activity, which makes it difficult to contact drug users and their sexual partners through traditional health and social services. Outreach workers who are local and familiar with the drug subcultures and their communities help to produce behavioural change and to refer drug users to service agencies and drug treatment facilities.

Drug users and their sexual partners must be treated with dignity and respect and with sensitivity to cultural, racial, ethnic and gender-based characteristics. Successfully involving drug-using populations in programmes requires that outreach workers and service providers show that their concern for drug users is genuine and that they believe that drug users are capable of changing their HIV-related risk behaviour. Outreach workers and service providers should use socially and culturally appropriate, nonjudgemental approaches to work with and keep drug users and their sexual partners involved.

HIV prevention programmes should ensure that IDUs have easy access to sterile injecting equipment to reduce the reuse of injecting equipment. IDUs are at risk for HIV and other infections if they share or reuse syringes or other injecting equipment, including cookers, cotton and rinse water. Research has shown that easy access to sterile syringes, one component of a comprehensive approach to HIV prevention, effectively reduces syringe-sharing and prevents the spread of HIV, without increasing the number of people injecting drugs.

Ensure adequate coverage of target populations with information and services for risk reduction. The scale of adequate coverage depends on the HIV prevalence among the different communities of IDUs. However, providing most IDUs, their networks and sexual partners with prevention services is essential.

Interventions to reduce the risk of HIV/AIDS must be ongoing and sustained over time. Research has shown that brief interventions have significantly reduced the risk of HIV and other infections among substantial numbers of IDUs and their sex partners. Nevertheless, brief interventions are usually not adequate. Sustained and repeated interventions are usually needed.

Create political willingness for a supportive and enabling environment. Behaviour change occurs when a person acknowledges the risks of his or her own behaviour and the tools for behaviour change are provided. An environment that is supportive and practical is crucial in this process. Advocacy is required to promote environments that will help programmes to become effective.

Prevention and treatment efforts should target IDUs who are already HIV-infected and their sexual partners. People who are HIV-infected may need help to gain access to services and to adhere to therapy to prevent HIV from progressing to AIDS. Research has demonstrated that HIV-positive IDUs can make the necessary major behavioural changes to protect their injecting and sexual partners from contracting the infection.

What other issues affect programmes?

Programmes are also affected by issues related to:

- ▶ infrastructure;
- ▶ quality of staff;
- ▶ training and capacity-building;
- ▶ programme management;
- ▶ programme structure, including opening and closing times, user-friendly service delivery and clients' ability to accept the treatment regimens;
- ▶ monitoring and evaluation; and
- ▶ sustainability.

Programme managers need to consider these issues carefully throughout the life of the programme and be prepared to be flexible and adapt to changing situations as they arise.

3.3 ESTABLISHING AND SUSTAINING A PROGRAMME

PLANNING INTERVENTIONS

What information will the rapid assessment and response provide that can help to plan a programme?

If a rapid assessment and response on drug injecting and HIV risk transmission shows the need for intervention activities, programmes need to be devised to deal with these issues. The rapid assessment and response information should provide a clear idea about who needs to be targeted. Target groups may include:

- ▶ non-injecting and/or injecting drug users;
- ▶ urban and/or rural people;
- ▶ youth;
- ▶ drug users in or out of treatment;
- ▶ prisoners; and
- ▶ sex workers.

The rapid assessment and response will also identify the problems that need to be addressed. These problems may include:

- ▶ little knowledge of HIV/AIDS;
- ▶ insufficient treatment facilities;
- ▶ stigmatization of IDUs; and
- ▶ legal constraints, such as legislation that prohibits the sale of needles and syringes.

The selected sites for the intervention activities to occur may include towns, cities, prisons and brothels. The rapid assessment and response may identify local organizations, especially nongovernmental organizations, which may have access to drug users or be running a programme that could complement the desired programme. This can also avoid duplicating services.

A project could operate within an existing programme or institution. Although this can be helpful (for example, by using their building and meeting rooms), a disadvantage can be the host organization attempting to influence a programme's activities (for example, by not permitting distribution of injecting

equipment from the premises). If the programme is established independently, networking with other drug-related HIV/AIDS organizations during and after the implementation of the programme is still crucial.

What is the programme aiming to achieve and how will this happen?

During the planning process, getting a sense of what the programme is trying to achieve and how it plans to do this is essential. This is why establishing aims (what is desired to be achieved) and objectives and targets (ways of bringing about the aims) are important. Aims, objectives and targets can then act as a reference in starting up the programme. Activities are then implemented to achieve the objectives and targets. Lastly, strategies establish a set of activities to be undertaken to meet a specific objective or target.

DRAWING UP A PROGRAMME PLAN

What is a programme plan?

A programme plan identifies what is needed to get the project up and running and the stages for the development of the programme. Interventions often consist of more than one activity, and each component therefore needs to be planned. A programme plan usually includes:

- ▶ the order and timetable of activities;
- ▶ job descriptions and individual staff responsibilities for the various activities;
- ▶ identification of the supplies needed and how they will be distributed; and
- ▶ guidelines for reporting the programme.

As several programme activities may be running at the same time, drawing up a flowchart to display changes during the life of the programme can be helpful. This may help to assess the need for different resources at different stages.

Where can the money be obtained?

Planning a programme requires identifying where money may be found to get the project up and running. Money may be required for various costs ranging from funding staff salaries to purchasing office equipment. Wherever the funds are being sought (for example, local and national governments, international organizations and private trusts and foundations), a written proposal to a potential funder is usually necessary. A budget plan will be able to identify where money can be located and then indicate how it is to be spent when it is received. Categories in the budget include programme staff, non-staff costs, programme support costs and programme overhead costs.

IMPLEMENTING THE PROGRAMME PLAN

Who is involved in running the programme?

Most programmes have a coordinator or supervisor to oversee and direct the programme. A management team or committee may also be invited to oversee the running of the programme: the team may include community representatives and experts.

Staff members employed by the programme need to be nonjudgemental, noncoercive and able to maintain confidentiality. Finding the right staff to work in peer education and outreach can be difficult. As a result, many NGOs often find their workers in the IDU community. Once staff have been recruited, they need basic training sessions on such issues as:

- ▶ HIV/AIDS and related risk behaviour;
- ▶ safer injecting;
- ▶ safer sexual activity;
- ▶ their job responsibilities; and
- ▶ the aims, objectives and targets of the programme.

Staff should also discuss issues relating to stereotypes, prejudice and the discrimination of drug use and drug users.

What are performance targets?

Performance targets show the change desired to be achieved in a given period of time. They may indicate:

- ▶ the success of either implementing activities: for example, the number of staff trained; or
- ▶ the impact of activities: for example, the proportion of IDUs using sterile injecting equipment.

The benefit of performance targets is that they help a programme to analyse how a project is progressing and, depending on this progress, to assess what changes need to be made.

MONITORING AND EVALUATION

What are monitoring and evaluation and why are they important?

Monitoring and evaluation are essential and should be taken into account from the design stage of a programme. They provide information on the programme's progress and show what is working and what is not.

- ▶ Monitoring is the continuous collection of information to determine whether activities are being carried out as planned.
- ▶ Evaluation involves a process of regular (at least annually) collection and analysis of information. The main purpose is to determine whether the aims and objectives are being met and whether the interventions can be changed to make the programme more effective.

What types of evaluation are there?

Implementation (or process) evaluation looks at the extent to which intervention activities are developing as planned (UNAIDS, 2000). For example, has the programme employed, trained and supported the requisite number of outreach workers?

Impact evaluation determines the extent to which the intervention has had the desired impact. For example, have the drug users changed their behaviour in response to the programme intervention?

Where can the information be obtained?

The information for evaluation comes from the programmes themselves. Programmes usually routinely collect information that is reported in project reports and other publications. The information also helps managers to monitor and review the progress of the project and can be useful for advocacy purposes. The people responsible for collecting information include programme staff, external evaluators and community members. The information may include details about how many clients are using new injecting equipment, the number of clients seen and the needs of the clients. The information is usually collected throughout the life of a programme.

How is the information analysed?

The way the information is analysed depends on the type of information. Quantitative data (numbers, rates and ratios) are analysed statistically, whereas qualitative data (interviews and impressions) are categorized and summarized.

The information is best analysed by or in conjunction with those who most need the information – those involved in implementing and managing the programme. Evaluation information helps programme managers and staff to reassess the programme, make activities more appropriate and plan a programme for the future. For detailed information about evaluation, see section 5.

4. MAJOR INTERVENTIONS

INTRODUCTION

The rapid assessment and response and the planning and development stages of implementing a programme should result in a detailed plan of the people the programme will target and how it will do this. Section 4 discusses the elements needed to produce a comprehensive and effective programme. Not all programmes have the same focus, as much depends on what is needed and suitable for different countries and communities. The following interventions would comprise a comprehensive programme of HIV prevention among IDUs.

THE COMPONENTS OF A COMPREHENSIVE PROGRAMME

The most important parts or components of a comprehensive programme of HIV prevention among IDUs are:

- ▶ outreach;
- ▶ information, education and communication;
- ▶ risk reduction counselling;
- ▶ HIV testing and counselling;
- ▶ disinfection programmes;
- ▶ needle and syringe programmes;
- ▶ disposing of used injecting equipment;
- ▶ availability of drug treatment services;
- ▶ agonist pharmacotherapy programmes (drug substitution treatment);
- ▶ HIV/AIDS treatment and care;
- ▶ primary health care; and
- ▶ peer education.

OUTREACH

Outreach is an essential component of a comprehensive HIV prevention programme. Community-based outreach is organized to reach the optimum number of people in the population at risk on a continuous basis in a range of high-risk environments at various times, especially times of greatest risk.

Outreach also aims to provide drug users with the information to reduce their risk behaviour, which may include information about reducing the risks associated with drugs, safer injecting and sexual practices and preventing overdose. Outreach also aims to provide the means to reduce risk behaviour

through condoms, bleach, needles and syringes and referrals to a range of health and social services.

INFORMATION, EDUCATION AND COMMUNICATION

Information, education and communication can be defined as specially developed materials that focus on providing explicit information. They should be written in clear and simple language and may focus on:

- ▶ the risks of sharing injecting equipment;
- ▶ health issues;
- ▶ safer sex;
- ▶ safer drug using; and
- ▶ taking better care of oneself.

Information, education and communication can be in the form of pamphlets, posters, handouts, charts, billboards, graffiti and other media. These materials are distributed among drug users and put up as posters at drop-in centres and other places where IDUs are likely to congregate.

Information, education and communication materials are most effective when they:

- ▶ are developed by drug users for drug users;
- ▶ use the language of the setting;
- ▶ are simple to read and understand; and
- ▶ are widely disseminated and available.

In essence, they enhance the ability of IDUs to care for themselves.

RISK REDUCTION COUNSELLING

Risk reduction counselling is usually conducted by trained counsellors using information, education and communication materials and aims:

- ▶ to educate IDUs about the risks of sharing injecting equipment, overdose, unprotected sex and other risks;
- ▶ to help individuals to clarify their feelings and thinking; and
- ▶ to help IDUs to better understand their behaviour and environment so that they can take action to protect themselves from the risks of injecting drug use.

Counselling also plays an important role in providing psychosocial support to IDUs living with HIV/AIDS. It also helps them to protect their health and minimize or eliminate HIV transmission to their sexual and drug-using partners and, in the case of pregnant and breastfeeding mothers, to their children.

HIV TESTING AND COUNSELLING

HIV testing and counselling programmes seek to change risk behaviour related to HIV/AIDS among drug users. These programmes can also be used to help prevent injecting-related and sexual transmission of HIV to partners. The knowledge of a person's HIV status can help prevent transmission of the virus. Such knowledge can also result in lifestyle changes that improve general health, including seeking treatment for opportunistic infections. It also allows forward planning in relation to families and other commitments and opportunities for preventing the vertical transmission of HIV from an infected mother to her child.

DISINFECTION PROGRAMMES

Disinfection programmes promote the cleaning of used needles and syringes with bleach and other disinfection methods. This aims to reduce the likelihood of spreading HIV and other bloodborne viruses among the IDU community. Bleach-and-teach programmes aim to teach drug users to disinfect used syringes and needles and to ensure that, if infected syringes are reused, the amount of virus inside is considerably diminished and consequently reduces the chances of further spread.

NEEDLE AND SYRINGE PROGRAMMES

Needle and syringe programmes provide IDUs with sterile injecting equipment, along with other risk reduction materials, to ensure that every injection happens with a fresh needle and syringe. They also reduce the availability of used and/or contaminated equipment and encourage safe disposal. Needle and syringe programmes are one of the most effective interventions to date in the HIV prevention catalogue. Needle and syringe programmes have been intensively evaluated in different settings and have conclusively shown that needle and syringe programmes do not promote injecting drug use.

DISPOSING OF USED INJECTING EQUIPMENT

Collecting and safely disposing used injecting equipment is a very important aspect of needle and syringe programmes because it eliminates the possibility of potentially infectious equipment being reused and removes a potential source of accidental transmission to non-IDUs, especially children.

AVAILABILITY OF DRUG TREATMENT SERVICES

There are many models of abstinence-oriented drug treatment services, ranging from:

- ▶ institutional short-term and long-term detoxification with or without medication (cold turkey);
- ▶ residential rehabilitation;
- ▶ outpatient detoxification; and
- ▶ community-based detoxification camps.

Drug treatment aims to improve the health of drug users by providing treatment for their addiction as well as for their general health. The time out from continuous drug use while in treatment gives users space to deal with other issues in their lives and creates a breathing space from the daily cycle of buying and using drugs.

AGONIST PHARMACOTHERAPY PROGRAMMES (DRUG SUBSTITUTION TREATMENT)

Agonist pharmacotherapy treatment (drug substitution treatment) usually has two aims: treating drug dependence syndrome and reducing the health risks and negative health effects (such as HIV infection) of drug use. Drug substitution treatment encourages a transition from injecting to non-injecting drug use in the form of supervised prescribed treatment. Engagement and retention in drug dependence treatment also provides opportunities for counselling and advice on reducing the risk of HIV transmission and for managing other health and social problems.

Agonist pharmacotherapy involves treating drug-dependent people with a drug that has a similar action to the drug on which they are dependent, thereby preventing a withdrawal syndrome and craving. Most substitution programmes rely on replacing an injected illicit drug (such as street heroin) with an oral legal drug (such as methadone or buprenorphine). This is done under medical supervision and reduces the risks associated with injecting, such as transmission of HIV, overdose and damage to veins.

HIV/AIDS TREATMENT AND CARE

Health care for IDUs and their families, both primary health care and support and treatment for HIV-related illness, can be carried out anywhere. This may be in the home, the street, primary health care facilities, clinics for sexually transmitted infections and other clinics, drug treatment centres and hospitals.

In most situations IDUs, and often their families, have poor or little access to health care. They often lack comprehensive treatment for HIV and for AIDS-related conditions. Treatment may not be available or is unaffordable. Alternative strategies for providing this health care and support are needed to reach these extremely marginalized communities. At the same time, advocacy is required to improve the acceptance of the health care needs of IDUs by mainstream health services and authorities.

PRIMARY HEALTH CARE

Most drug users are concerned about their health. Nevertheless, since drug use is a crime in most societies, drug users are reluctant to approach mainstream health services for fear of discovery and punishment. Primary health care for IDUs attempts to provide health services and/or referrals to appropriate services that suit the needs of drug users and protect the general health of drug-using communities. Nurses or trained peer workers generally provide primary health care through outreach or drop-in services. Primary health care includes attending to injecting-related wounds and abscesses, minor opportunistic infections, tuberculosis, diarrhoea and other HIV-related conditions. Home-based supportive and medical care is the next step and involves the families and community in the care of their family members living with HIV/AIDS.

PEER EDUCATION

Many IDUs do not trust traditional and mainstream health services. IDUs are usually marginalized in society and experience and fear harassment and possible arrest. The use of peer educators, peer outreach workers and peer networks increases the reach of HIV prevention services to the most marginalized and hard-to-reach IDUs and helps to establish trust between IDUs and health services. Involving current and ex-drug users in designing, promoting and delivering services to IDUs is an important principle for HIV prevention programmes and is based on the general principles of community involvement.

5. MONITORING, EVALUATING AND REFINING POLICIES AND PROGRAMMES

INTRODUCTION

Evaluation is a structured, staged process of identifying, collecting and considering information... [and] will help you to describe and understand the goals, progress and outcomes of many types of promotion and prevention initiatives. (Commonwealth of Australia, 2001)

Evaluation is a crucial part of any programme. It provides information about how the programme is progressing and highlights what is working well and what is not. Evaluation should not be an afterthought; it needs to be taken into account, planned, agreed to and budgeted for from the very beginning of the programme. Monitoring and evaluation should be seen as an integral part of day-to-day management and practice.

MONITORING AND EVALUATION OF PROGRAMMES

What are monitoring and evaluation?

Once a programme is planned and begun, determining whether the activities are being carried out as intended is important. This process is called monitoring and is essentially the ongoing collection of relevant information about the programme. It can ensure a coordinated and organized schedule of supervision of work and workers and produce the information that funding agencies (and stakeholders) want in regular programme reports.

Monitoring and evaluating a programme has three main phases:

- ▶ identifying the indicators that can be used to monitor the progress (indicators are measures that can show whether the intended changes are happening);
- ▶ collecting and analysing information (data); and
- ▶ modifying existing interventions and/or developing new ones.

Two types of evaluation

The *Manual for reducing drug related harm in Asia* (Costigan et al., 2003) recommends two types of evaluation: implementation evaluation and impact evaluation.

Implementation evaluation involves assessing the extent to which the programme or intervention activities have been developed as planned. The questions that need to be asked are the following.

- ▶ Has the project been established successfully?
- ▶ Is the project reaching or attracting the target population?
- ▶ Is the project delivering the programme objectives as intended?

Impact evaluation involves assessing the extent to which the programme or intervention has had the desired impact on the target population. The questions to be asked are the following.

- ▶ Has the desired change in the target group occurred as a result of the intervention?
- ▶ Is the intervention an effective use of resources?

Why is this process necessary?

This process is necessary to collect information:

- ▶ to assist programme managers;
- ▶ to provide content for programme reports, articles and other publications;
- ▶ to inform the community and stakeholders of what is going on and how the programme is working;
- ▶ to inform funders (those who have provided the money for the programme); and
- ▶ to provide material for advocacy (promoting this approach).

Who should collect the information?

Programme staff usually collect the information for the regular monitoring of the programme. Programme managers must recognize that this requires time and, sometimes, specific training. The time and training should also be allowed for in the project or programme budget.

Other people who can participate in the collection include:

- ▶ programme clients: for example, by keeping personal records or journals about their drug use, practice, needle exchange, etc.;
- ▶ an external evaluator: someone from outside the programme who can bring a highly objective view to the evaluation, and who can, for example, receive input from people participating or outside the programme without perceived bias; and
- ▶ participants: this allows community members, stakeholders, clients and others to participate in and contribute to the programme.

What information should be collected?

Only information that can be used should be collected! Information that is collected but unused wastes the time and resources of participants or staff. The information to be collected, depending on the programme, may include:

5. MONITORING, EVALUATING AND REFINING POLICIES AND PROGRAMMES

- ▶ the use of new injecting equipment;
- ▶ the number of clients in a programme (such as methadone or needle and syringe programmes) and their responses;
- ▶ the adoption of cleaning practices;
- ▶ client health; and
- ▶ condom use.

The information may be found in:

- ▶ schedules for workers;
- ▶ field diaries or journals;
- ▶ account books;
- ▶ computer spreadsheet programs;
- ▶ minutes of meetings; and
- ▶ project correspondence and reports.

Seroprevalence information

A HIV seroprevalence study may be established in programmes that specifically set out to reduce the transmission of HIV among IDUs through a number of interventions. Such a study measures the prevalence of HIV infection among IDUs before the programme started and the prevalence of HIV infection among IDUs periodically thereafter, usually on an annual basis.

The prevalence of HIV infection measures the total numbers of people infected with HIV among the populations being studied (such as IDUs enrolled in a programme) at a specific time. This can then be repeated at regular intervals, such as at the same month every year.

In a very large programme, involving a state or large district, HIV prevalence may be measured in a number of regions among selected groups of people (referred to as sentinel groups) who are at high risk of HIV transmission. Such a programme is carrying out sentinel surveillance. Thus, trends in HIV infection are monitored over time, by group and place.

When should the information be collected?

Although information will be collected throughout the life of the programme or project (monitoring) and periodically (evaluation), it must be planned for during the planning stage to allow for time and resources to be allocated in the budget.

Baseline surveys are usually carried out at the very beginning of a programme. This allows for comparison, which then provides a measure of progress (an indicator) towards achieving the programme's objectives and targets.

Monitoring implies that the information is collected on a regular basis. Some information may be collected daily (for example, IDU attendance at the needle and syringe programme or methadone dispensary) or monthly (for example, records of the monthly staff planning meeting).

How is the information analysed and by whom?

The method of analysis depends on the form and content of the information. If it is quantitative (numbers, rates and ratios – the measurable data), it may be analysed mathematically and statistically, manually with a calculator or on a computer. Qualitative information – words, stories, anecdote, impressions and context – is usually collected in interviews, during conversations, observations and group discussions and does not lend itself to statistical or mathematical analysis. This information can be categorized, summarized and used anecdotally (such as the case studies in this guide).

MODIFYING EXISTING INTERVENTIONS AND DEVELOPING NEW ONES

How can monitoring generate reports?

Reports are a feature of all programmes, and their nature and format vary from project to project. Demands for reports most likely arise from several sources, including donor agencies, governments, the host community, clients and beneficiaries and programme staff.

How does monitoring stimulate feedback?

Programmes are accountable to their donors, target groups, stakeholders and others. Feedback to those intimately associated with the programme (such as IDUs) creates an opportunity for greater involvement and ownership and a greater sense of participation.

Monitoring and review processes allow for this feedback, which can be presented in a variety of formats and venues.

What are the benefits of conducting an evaluation?

The benefits of evaluation could include:

- ▶ creating a regional approach by sharing information with other programmes;
- ▶ providing an opportunity to be culturally appropriate rather than always adopting strategies from other countries' programmes;

5. MONITORING, EVALUATING AND REFINING POLICIES AND PROGRAMMES

- ▶ establishing self-help groups by bringing together various stakeholders and agencies involved with the programme;
- ▶ providing social research on the situation;
- ▶ providing material for publication; and
- ▶ providing opportunities for networking using the information and the results from the evaluation both locally and internationally.

How can evaluation result in changes to the programme?

The evaluation report may show, for example, that an intervention has not been established as planned and/or that it is not having the desired impact on the target group. The evaluation information will help the programme manager or coordinator and staff to reassess the intervention or the larger programme, and modify accordingly, to make the activities more appropriate.

An evaluation of the progress of a programme offers the chance to review and to preview. The lessons learned are brought to light by an evaluation and these lessons, together with an understanding of the actual progress made toward achieving the programme's objectives, help to plan the programme for the future.

An evaluation allows for change – to objectives, targets and strategies – and justifies it to the community, the clients and the funders.

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ANNEX 1. GLOSSARY

3 by 2 by 6 Method for cleaning used needles and syringes:

- ▶ drawing clean water into the syringe, shaking it and emptying it three times;
- ▶ drawing bleach (or a similar cleaning or disinfecting agent) into the syringe, shaking it and emptying it twice; and
- ▶ drawing clean water into the syringe, shaking it and emptying it, six times.

This process is recommended when injecting equipment has to be reused and/or shared because sterile needles and syringes are not available to the user. It is not guaranteed to rid the syringe of HIV or any other virus if an infected person has used it previously.

Acquired immunodeficiency syndrome (AIDS) A syndrome defined by the development of opportunistic infections resulting from immune system damage caused by advanced human immunodeficiency virus (HIV) disease.

Acute infection Any infection characterized by signs and symptoms that last for a short period. Acute infection with hepatitis C is often very mild, lasts less than six months (often less than three months) and goes unnoticed for most people.

Agonist (agonist pharmacotherapy treatment or drug substitution treatment) Endogenous substance, liquid or drug that acts on and binds to receptors, initiating a physiological, pharmaceutical or biological response characteristic of that receptor, such as contraction, secretion or relaxation. Agonist drugs (such as heroin) activate or bind to a specific opioid receptor and mimic the body's natural chemicals. Agonist drugs such as methadone, clonidine and levo-alpha acetyl methadol (LAAM) can also provide a substitute for a drug of abuse and assist withdrawal. A full agonist is capable of producing a maximal response and has high efficiency, such that every drug receptor interacts and is capable of contributing to that response. See **Antagonist**.

Alcohol The intoxicating element in wine, beer, spirits, etc. Can cause damage to all or some of a body's organs, especially the liver.

Amphetamine (amphetamine-type substances) Generic term for a range of synthetically manufactured illicit psychostimulant drugs or central nervous system stimulants.

Antagonist Drug or compound that binds, or has an affinity for, a receptor site but opposes or blocks the actions of the body's natural (or externally administered) chemicals. For example, naltrexone, an opioid antagonist, blocks the effects of morphine or heroin at opioid receptors. A short-acting formulation, naloxone, is commonly administered to people suspected of having an overdose, as it blocks the receptor sites to which heroin normally binds and reverses the effects of overdose. Antagonist drugs occupy the same receptor sites in the brain as specific drugs of abuse, such as heroin. However, they do not produce the same effects as abused drugs and are non-addicting. Antagonists may be used for people who do not want to be maintained on drug substitutes (for example, agonists such as methadone). See also **Agonist**.

Antibody A protein secreted by cells of the immune system in response to infection. The antibody binds to an enemy molecule. This is meant to prevent the virus from infecting other cells, and may destroy it. As with other viral infections, the presence of antibodies does not necessarily mean a virus will be eliminated from the body.

Antibody test Initial screening test. This is a blood test for antibodies to the virus and not for the virus itself.

Antigen A substance, usually a protein, that causes the formation of an antibody and reacts specifically with that antibody.

Antiretroviral drug A drug that inhibits the replication of retroviruses such as HIV.

Antiviral drug A drug that is effective against viruses.

Asymptomatic Having no symptoms or signs of illness.

Biopsy The examination of tissue removed from a living body to determine the presence, cause or extent of a disease.

Blood and blood products Components of blood including red cells, platelets and plasma, which are separated out by blood banks. **Plasma** is processed and purified to produce specific medical products, such as Factor VIII.

Blood awareness Being alert to the potential or actual presence of blood in any situation or environment.

Bloodborne virus A virus that is transmitted by blood or body fluids that contain blood. Examples include hepatitis B, hepatitis C and HIV.

Blood-to-blood Where blood from individuals meets, such as where one person's blood comes into contact with another person's through an open wound, cut or graze or via used injecting equipment.

Body art permanent, semipermanent or temporary physical decoration such as tattooing, skin or nail piercing, hair dyeing or colouring, make-up, scarification, etc.

Buprenorphine Partial agonist used to treat withdrawal from heroin; used in maintenance treatment to block the effects of other opioids (with a duration of action from 24 to 48 hours).

Chronic infection An infection that is ongoing for more than six months. It does not refer to the severity of the infection.

Clonidine Antagonist drug that reduces the withdrawal symptoms of heroin, cocaine and methadone. It is taken orally and rapidly absorbed; being lipid soluble, it concentrates in the brain, lungs and other fatty areas of the body. Clonidine is increasingly used in combination with naltrexone during rapid opiate detoxification. Side effects include postural hypotension and/or sedation.

Cocaine Potent and highly addictive central nervous system stimulant derived from coca leaves.

Coinfection A general term referring to infection with two or more infectious agents. HIV coinfection refers to HIV and another bloodborne virus such as hepatitis B and/or hepatitis C.

Combination treatment or therapy The use of two or more types of treatment in combination, alternately or together, to achieve optimum results and to reduce toxicity (harmful side effects and poisoning).

Communicable disease An illness caused by a specific infectious agent or its toxic products that arises through the transmission of that agent or its products from an infected person to a susceptible host.

Community development Any activity that aims to empower individuals (within their community) to participate effectively, make decisions and take action to optimize their own health and quality of life.

Complementary therapies Various systems of healing the medical profession does not regard as part of orthodox treatment. In relation to HIV/AIDS, complementary therapies are mainly used to reduce symptoms and can include acupuncture, homeopathy, therapeutic or relaxation massage and other touch therapies, aromatherapy and remedial massage.

Crack Street name for a smokable form of potent, concentrated cocaine.

Demography The study of the statistics of births, deaths, disease, etc. to illustrate the conditions of life in communities.

Disclosure The act of a person living with HIV/AIDS who informs other people about this. Disclosure to partners, family, friends, employers, insurers and health workers is a personal and potentially difficult decision. Expectations of disclosure differ throughout the world.

Discrimination Any unfavourable treatment based on known or implied health status; any action or inaction that results in a person being denied full or partial access to otherwise generally available services or opportunities because of known or implied health status. The definition includes discrimination based on known or imputed membership of specific groups that are commonly associated with the health matter in question.

Ecstasy 3,4-methylenedioxymethylamphetamine (MDMA), an illicit designer drug manufactured and sold in tablet or capsule form.

Epidemic A widespread occurrence of a disease in a community at a specific time; an increase in the number of cases of a disease over baseline or over what is expected.

Epidemiology The study of patterns of disease in human populations; the basic science of public health.

Haemophilia A hereditary blood disease in which blood fails to clot and abnormal bleeding occurs. It almost exclusively affects males and is treated by injections of Factor VIII.

Harm minimization The primary principle underpinning Australia's National Drug Strategic Framework. The term refers to policies and programmes aimed at reducing drug-related harm. Both licit (such as alcohol, tobacco) and illicit (such as heroin, cocaine) drugs are the focus of Australia's harm minimization strategy. Harm minimization includes preventing anticipated harm and reducing actual harm, involving a balance between demand reduction, supply reduction and harm reduction.

Harm reduction Harm reduction aims to reduce the harm associated with potentially risky activities rather than preventing people from performing those activities. Harm reduction is a pragmatic concept that recognizes the reality of drug use and maintains that individuals and the community may be better served by diminishing the harms associated with drugs than by attempting to stop drug consumption.

Health A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Health promotion Health promotion is the process of enabling people to increase control over, and to improve their health

Hepatitis General term meaning inflammation of the liver.

Hepatitis A virus Most infectious type of hepatitis. A viral disease that can be spread by contaminated food and drink, person-to-person contact, and other environmental sources.

Hepatitis B virus Potentially life-threatening bloodborne viral disease of the liver, transmitted primarily by sexual activity or exposure to blood. Hepatitis B is common worldwide, with no cure at present. A course of three vaccinations is available, provided in a schedule of injections, and continued immunity requires booster vaccination. Hepatitis B is transmitted via body fluids, and the most common form of transmission is via contaminated blood and sexual excretions. Injecting drug users are at especially high risk through exposure to dirty and shared needles.

Hepatitis C virus An RNA virus transmitted through blood-to-blood contact that causes inflammation of the liver and may cause severe, life-threatening liver damage. Hepatitis C is a particular risk to heroin users; for example, the prevalence of hepatitis C infection among Australian IDUs was estimated at 60–90% in 1999. It is also very prevalent in prisons because of the incarceration of IDUs, needle-sharing and unsafe practices.

Heroin Illicit drug manufactured from diacetylmorphine hydrochloride or codeine. As with other opioids, heroin is a depressant drug that slows the activity of the central nervous system.

Human immunodeficiency virus (HIV) The human retrovirus that can cause AIDS.

Immune system The body's defence against the effects of drugs, toxins and cancer cells.

Incidence The number of new cases of a disease in a defined population over a defined period (usually measured annually).

Informed consent Permission obtained without force, fraud or threat and with knowledge and understanding of the consequences of the matter to which consent relates. In this context, informed consent often means permission from a person to perform a specific test or procedure. In relation to HIV, the health care worker should seek informed consent from the person involved before any medical intervention – such as testing, biopsy or prescribing of treatment – takes place.

Injecting drug user (IDU) User of illicit drugs injected intravenously.

Methadone A potent narcotic analgesic drug used to relieve severe pain, as a linctus to suppress coughs and as a substitute for morphine or heroin.

Methadone maintenance treatment The measured and prescribed use of methadone in a course of treatment as a substitution therapy for heroin addiction.

Methamphetamine An amphetamine derivative with quicker and longer action, used as a stimulant.

Mother-to-child (vertical) transmission The transmission of an infectious organism from mother to child during pregnancy, delivery or breastfeeding.

Natural history Progression of a disease in the absence of any medical treatment or other intervention over a designated period.

Needle and syringe (exchange) programmes Authorized programmes that distribute, safely dispose of or sell needles, syringes and other injecting equipment and provide public health information to people who inject drugs. Some programmes (for example, in Australia) do not make the return of used equipment a condition for receipt of clean equipment, nor are the numbers of needles and syringes handed out limited to the number returned. Clean equipment will be distributed even without the return of used equipment, and hence exchange is no longer used in the programme title.

Needle-sharing The practice of reusing or sharing needles and syringes in both the licit and illicit setting. Needle-sharing is one of the most efficient ways to transmit HIV and hepatitis C.

Needlestick injury An injury with a needle or other sharp implement.

Non-injecting routes of administration Administering drugs by means other than injecting. Examples include smoking, inhaling and suppositories. Promoted as an alternative to the high-risk practice of injecting illicit drugs.

Opiates Containing or coming from opium.

Pandemic A disease affecting or attacking the population of an extensive region.

Paraphernalia Injecting equipment, including needles, syringes, spoons, filters, sterile water and tourniquets.

Paraphernalia laws Laws pertaining to the carrying of paraphernalia.

Parenteral Administered or occurring elsewhere than in the alimentary canal.

Pathogen Any organism or substance capable of producing a disease.

Peer education An educational process that is self-directed and devised, implemented and owned by members of a group or subculture in which the desired outcome is that peer support and the culture of the target group are used to effect and sustain changes in attitude and behaviour.

People living with HIV/AIDS Anyone living with HIV infection or an AIDS-defining illness.

Prevalence The total number of all people who have an attribute or disease at a particular time divided by the total population at that time.

Prophylaxis Strategy, treatment or drugs intended to prevent an infection or disease.

Postexposure prophylaxis The provision of antiretroviral treatment following any incident that has resulted in potential exposure to HIV infection, such as following a needlestick injury, the use of shared injecting equipment or unprotected sex with a HIV-positive partner.

Protease inhibitor An antiviral drug that inhibits protease – an enzyme HIV needs for replication.

Pyrogenic Fever producing.

Rapid assessment and response A method or group of tools for identifying and reporting on a situation (see section 1.3). Rapid assessment and response can identify the extent, nature and patterns of health risk behaviour and associated health effects and the existing resources and opportunities for interventions to address problems. The research tools are adapted from anthropology, sociology, epidemiology and evaluation research.

Risk practice Any behaviour, sexual or otherwise, that can transmit disease.

Safe(r) sex Sexual activity in which there is no exchange of body fluids such as semen, pre-ejaculate, vaginal fluids or blood.

Seroconversion The development of a detectable level of antibodies that occurs after a person has been exposed to and become infected by a virus such as HIV or hepatitis C.

Sexually transmitted infection (formerly sexually transmitted disease) An infection that can be passed on by sexual contact.

Sharps Needles and syringes; used needles and syringes.

Shooting gallery Venue where many IDUs inject or are injected using the same needle and syringe by a dealer or professional injector. Most have no or only rudimentary sanitation and a needle and syringe can be used many, many times without cleaning between uses.

Stakeholders Anyone or any agency with an interest in an issue or strategy but not necessarily closest to it or involved in its management or implementation.

Sublingual Under the tongue.

Surveillance The continuing tracking of all aspects of a disease, including occurrence and spread, pertinent to its effective control.

Transmission The movement of a viral infection or other infection from entity to entity. (Vertical transmission – see **Mother-to-child**)

User groups Community-based organizations representing the interests of (and usually operated and managed by) people who inject or otherwise use illicit drugs.

Vaccine A substance that stimulates an immune response and renders a person immune to a specific infection. There is no vaccine for hepatitis C or HIV, but vaccines are available for both hepatitis A and hepatitis B.

Viral load The amount of virus circulating in the blood.

Virus A vast group of minute organisms, composed of a sheath of protein encasing a core of nucleic acids, which are the building blocks of RNA and DNA. They are capable of infecting almost all members of the animal and plant kingdoms, and are so small that they can even infect bacteria. Viruses are characterized by a total dependence on living host cells for reproduction and lack independent metabolism. Most viruses only infect one species.

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WEB SITES

Asian Harm Reduction Network

<http://www.ahrn.net>

Australian Drug Foundation

<http://www.adf.org.au>

Australian National Council on Drugs

<http://www.ancd.org.au>

Bureau for International Narcotics and Law Enforcement Affairs

<http://www.state.gov/g/inl/narc>

Canadian Harm Reduction Network

<http://www.canadianharmreduction.com>

Centre for Harm Reduction

<http://chr.asn.au>

Centre for Drug Research, University of Amsterdam

<http://www.cedro-uva.org>

DRCNet Online Library of Drug Policy

<http://www.druglibrary.org>

Drug Info Clearinghouse

<http://druginfo.adf.org.au>

Drug Policy Alliance

<http://www.drugpolicy.org>

Family Health International

<http://www.fhi.org>

François-Xavier Bagnoud Center for Health and Human Rights

<http://www.hsph.harvard.edu/xfbcenter>

Global HIV/AIDS and STD Surveillance

<http://www.who.int/emc-hiv>

Harm Reduction Coalition, New York

<http://www.harmreduction.org>

International Harm Reduction Association

<http://www.ihra.net>

International Narcotics Control Board

<http://www.incb.org/e/index.htm>

Open Society Institute

<http://www.soros.org/harm-reduction>

Trimbos Institute – Netherlands Institute of Mental Health and Addiction

<http://www.trimbos.nl/indexuk.html>

UNAIDS

<http://www.unaids.org>

United Nations Office on Drugs and Crime

<http://www.unodc.org/unodc/index.html>

United Nations Office on Drugs and Crime, Regional Centre for East Asia and the Pacific)

<http://www.unodc.un.or.th>

United States Centers for Disease Control and Prevention – HIV prevention among injection drug users

<http://www.cdc.gov/idu/default.htm>

United States Drug Enforcement Agency

<http://www.usdoj.gov/dea>

United States National Institute on Drug Abuse

<http://www.drugabuse.gov/NIDAHome.html>

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