PART

1

Why work in groups?

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© Gideon Mendel/Network

"I wanted to see other people with HIV. We gained strength just from knowing each other." South Africa

Groups of friends or colleagues often develop naturally – in the home or community. We are used to working or socialising in groups – in our family, at work or sports clubs, for example. Groups can also be set up for people to share feelings, or organise activities, about particular subjects of concern to them.

HIV and AIDS usually raise difficult and personal issues such as health, relationships, financial security, death or feelings about sexuality. Other people's prejudices and discrimination and wider social and economic issues also cause many problems for people affected by HIV.

Many people affected by HIV – both those of us with HIV and those of us who are family or carers – feel that support or self-help groups can reduce some of these pressures. Working together and sharing ideas and problems can help people in many emotional and practical ways.

Self-help, support and action

Groups of people living with HIV are called many names – 'self-help', 'support' and 'PWA groups'. These names vary in different areas, so in this manual we use these different names – all of which mean groups run by, or for, people living with HIV. A group (self-help, support or PWA) can provide a chance for people to talk freely, in confidence, and be listened to and encouraged. A self-help group should encourage its members to reflect and learn from themselves and from each other. It may sometimes challenge members' attitudes, but in a safe and supportive environment.

To form a support group, or self-help group, it is important to be clear about why you want to get together. Some groups may be formed simply for members to have a place to talk to each other and share feelings and experiences. Other groups of people may join together to work towards a common goal or need, such as campaigning for improved medical care or providing information about HIV and safer sex. Groups may work with or without a particular leader or organiser, but it usually helps if everyone is clear about how the group should work.

Working as a group can:

- help people feel that they are not isolated and alone with their problems
- provide a way to meet people and make friends

- help individuals to become more confident and powerful
- provide a basis to organise activities led by the members
- make links between people from different backgrounds and increase understanding and tolerance
- help to share resources, ideas and information, for instance about the latest available treatments or local support services
- make others in the community more aware of the situation facing people in the group by increasing the visibility of people living with HIV
- lead to change by creating a public or political voice.

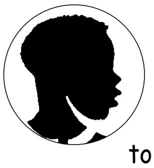
> 'It helps me to be in a group like Pinoy Plus because it means we have one voice. If you're just an individual person living with HIV you have no power. You don't know where to go if you experience discrimination in your own town. For me it's very nice to have this organisation because it gives us all a place to go. It gives us one voice to fight for our human rights and to show that we're still productive and no different from anyone else. We look just like everyone else. The only difference is that we have a virus which is not a reason to discriminate against us.'
>
> **Archie Rivera, Pinoy Plus, Philippines**

Working together as a group can help people to become more aware of their own power. Even when people's ability to change their circumstances is limited by poverty or ill-health, there are ways to make the most of their personal skills and experience. A group has more influence than individuals working alone.

Safe space

'As soon as I met her (another woman with HIV) it changed my life. I realised I hadn't done anything wrong. I wasn't a criminal. We've become firm friends. We have good laughs which is what – when you're HIV – you tend to lose... We've formed a woman's group. We used to go to a mixed group, but we found we were looking after the gay men there... and not getting anything out of it for ourselves.... I can talk about problems that have happened. Not just to do with HIV, but the children or if I've not been well. Just supporting each other, having good fun, having a laugh.'

Sarah, England



Reducing isolation

'I thought, I can't deal with this alone. I have to tell somebody... It took me about a month to build up the courage to do that. I went to see these people called Body Positive. It was very informative, each week was structured, they dealt with issues of bereavement, dying, all the medical issues and how and when to tell partners, family and friends. I also met other men who are in my same boat.'

Winston, Canada

'For me, at the start, the group was a movement – a kind of family – where we meet each other every day to exchange experiences, to talk about our feelings... to help each other psychologically.'

Group leader, Lumière Action, Côte d'Ivoire

Action for change

'If the families of other sick people are taught about self-care it would help boost the morale of the sick and increase their life-span... I do home visits, giving moral support, providing education on self-care and co-ordinating with hospitals when people become ill. Through making home visits I have come to realise that people with HIV have an important role to play. If they make home visits or give talks, the people who are sick begin to confide in them. Now the ones who do home visits are able to understand more about the problems faced by people with AIDS.'

Phimchai Inthamun, Chiang Mai, Thailand

Providing optimism

'Care should be taken that the group does not reinforce negative aspects of HIV, what we call in Spanish the groups that get together to 'tejer y contar los achaques' (knit and relate your aches and pains)... We share what we feel in order to get better and live well.'

Corporación Chilena de Prevención del SIDA, Chile

'I started attending the day centre for comfort because my baby had died. I learned tailoring, handicrafts, sharing experiences with existing clients and helping where needed. The whole sense of death from AIDS disappeared; I made up my mind to plan for the future of my children... We HIV-positive mothers have a common financial problem. A club was formed to meet our needs and from discussions, income-generating activities were suggested. There are handicrafts, poultry farming and breadmaking.'

Jennifer, Uganda

Learning more

'Some club members have been HIV positive for a long time. They are like veteran soldiers, and they can explain to the newcomers how they've been able to live so long with the virus... The club organises informal counselling for patients at the hospital. The club has organised training and practice sessions in Buddhist meditation which have helped some members to attain greater peace of mind... Members contribute articles, letters and drawings to the quarterly magazine *No-name* which is distributed to members and to health institutions as a means of sharing experiences and providing practical information about common problems among people living with HIV.'

Wednesday Friends Club, Thailand

Not always easy

There may be problems in working as a group, as well as benefits:

- in some places it is not possible to be public about HIV status, which makes people reluctant to join a group in case other people find out
- many groups fail because the biggest need of their members is money and other material and economic support – a small self-help group is unlikely to be able to solve this problem
- group members often have different needs and expectations, which can lead to conflict and disappointment
- often a few dynamic individuals set up the group and, when these people are no longer involved, the group can lose its way

- group members can 'burn out', especially if the few openly HIV-positive people have many demands made on them for public speaking, planning services and other activities.

Making sure that the aims of the group are very clear to everyone involved is a good way to minimise problems. Part 2 addresses these practical issues.

Doing it ourselves

Many support groups are set up by 'professionals' – counsellors, nurses, religious leaders – who care for people with HIV and see the need for their 'clients' to meet other HIV-positive people. This can often be valuable because it may enable a person with HIV to meet others who have HIV for the first time. However, many groups established in this way do not succeed because people with HIV are not involved in deciding how the group will run and what it will do. If a group is run by, or involves people who are not HIV positive, it is essential that the people with HIV feel that meets their needs.

> 'When we started doing prevention work in the late 1980s, a few people shared the fact that they had HIV. Eventually they asked to meet separately. They were worried about confidentiality, so they insisted no one be in the office when they had their meetings. In the end we didn't know what they were doing or thinking or even who they were. Eventually they splintered into a lot of different groups but none of them ever really got off the ground...Now the situation has changed, there are hundreds of people with HIV in Santiago! There are treatments and people want to work on getting access to them. We have sponsored a self-help group again.'
>
> **Corporación Chilena de Prevención del SIDA, Chile**

Change for the better

Groups can help to make changes in people's personal lives and in the wider world. They can improve group members' personal situations – by reducing their sense of isolation, providing them with support and information, or improving their chances of economic security. They can also improve the broader situation of people with HIV – and of people vulnerable to HIV – by challenging and lobbying for change in factors which lead to poverty and discrimination.


© Cedric Nunn

Poverty and discrimination increase vulnerability to HIV, such as the factors which make people have to leave home for work.

Communities, including communities of people living with HIV, are made up of different people with many different concerns and priorities. People may see themselves as being members of several different groups – defined by their family, religion, race, workplace or age for example. Within any community some groups of people are discriminated against. HIV has greatest impact on people already discriminated against – women, gay men or sex workers, for example. But those who are less visible, less powerful and less assertive are often not involved in actions for change. This may mean that groups need to consider working on issues that are not just about HIV but are about broader issues, such as gay and lesbian rights, improving working conditions for sex workers or enabling women's access to education and employment.

It may be helpful to think about the factors which affect both ourselves as individuals and our position in the wider community:

- **knowledge** – what we know or don't know
- **skills** – what we know how to do
- **beliefs, attitudes and self-esteem** – what we think or feel, and what we feel able to do
- **peer pressure and social influences** – how other people around us behave, think and feel
- **the wider environment** – culture, religion, economic opportunities, health policies, legislation and service provision.

Information and knowledge are necessary but we also need the skills to put this information into use. Without a belief in our values and confidence in ourselves it is difficult to make changes – for example, having the confidence to be assertive about our treatment options when dealing with health professionals.

However, when we decide that we want to make changes – either in our own life or more broadly – we will need support and help from other people. This means building on existing social and cultural beliefs and practices that provide a positive social environment, where people with HIV are accepted as equals and others feel able to reduce their risk of HIV infection. It also means living in an environment where having HIV, and taking steps to reduce the risk of HIV is easy, acceptable and seen as 'normal', and where resources exist to make these choices possible.

> 'On December 1 1996, a young man, who wishes to be known as Jean Paul, became the first person in Burkina Faso to talk on television about being HIV positive. Jean Paul was informed of his diagnosis two years previously, at a time when few people in Burkina Faso who happened to be tested were actually told their diagnosis. Unfortunately, his status soon became public knowledge and many of his friends and neighbours shunned him leading to intense solitude. Finally, out of desperation, he wrote a letter to a daily newspaper sharing his difficulties. The president of a local youth group responded to the letter and invited Jean Paul to join the group anonymously.
>
> However, the silence surrounding people with HIV continued. When the National AIDS Programme looked for someone with HIV to go public, they could not find anyone. Eventually, Jean Paul agreed because "it could help others in my situation".
>
> **Source: Vin-Khim Nguyen, International HIV/AIDS Alliance**

ACTIVITY
1.1

© Mark Edwards/Still Pictures

Affordable condoms are necessary for both HIV-positive and HIV-negative people.

PLACING YOURSELF IN A BROADER PICTURE

AIM To explore barriers to change and possible strategies for overcoming them, and consider their influence on your group.

The diagram on pages 14-15 divides the factors that influence our lives and our position in the community into five different levels. It lists both barriers to change and possible strategies for overcoming them. In your group you can think about the factors that affect your own situation – the examples listed here are just some ideas.

This activity can also be used as a planning activity (for more information on planning see Part 4) or as an awareness raising training activity to make others aware of the situation which HIV-positive people face.

❶ On one large sheet of paper, write the headings from the 'causes of problems' section. Leave another sheet blank. On a third sheet, write the headings from the 'positive changes' section.

❷ Ask group participants to suggest the main things that cause problems for people with HIV. Write up all the suggestions randomly on a blank sheet.

❸ Ask participants to group these suggestions under the relevant headings on the 'problems' sheet. Ask them to suggest more if necessary.

❹ Finally, think of ways to overcome these problems and write them down on the third sheet under the relevant heading.

Change for the better

Causes of problems for people living with HIV

Individual ↕ Community ↕ Society

❶ Lack of knowledge

- lack of knowledge about care and treatment options for HIV and opportunistic infections
- limited access to information

❷ Lack of skills

- limited opportunities for learning skills
- lack of opportunities for practising skills e.g. condom use
- lack of practice in safer sex

❸ Unhelpful attitudes and beliefs

- belief that women should not be independent or make their own decisions
- fear of being seen as different
- denial of HIV
- fear of people with HIV
- belief that young people should not know about sex

❹ Social and cultural pressures

- men expected to be decision makers
- stigmatisation of people with HIV
- discrimination and blame e.g. against sex workers and gay men

❺ Restrictive environment

- inappropriate policies, e.g. mandatory HIV testing
- uninformed and inaccurate media
- poverty and lack of resources
- limited access to medical care

Ways to make positive changes for people living with HIV

❶ Increasing knowledge

- how to prevent infection and re-infection
- treatment options
- safe injecting drug use
- how to care for ourselves e.g. how our bodies work, eating healthily
- reproductive health e.g. healthy pregnancy, reducing risk of HIV transmission to babies, avoiding unwanted pregnancy

❷ More skills

- leadership
- counselling
- income generation
- communication skills
- negotiating condom use
- using condoms properly
- explaining HIV to our children
- public speaking, negotiating and advocacy skills

❸ Positive attitudes and beliefs

- believing men and women are equal
- wanting to make sex safer and enjoyable for people with HIV
- accepting people’s right to different ways of life and sexuality
- caring for others
- understanding personal risk
- accepting young people’s rights
- belief and confidence in yourself and your abilities
- feeling able to be different e.g. postponing sex or marrying someone else with HIV

❹ Helpful social and cultural influences

- challenging discrimination against same-sex relationships
- women have right to refuse sex or leave violent partners
- accepting abstinence, faithfulness, condom use as normal practice
- challenging traditions such as widow inheritance
- accepting rights of people living with HIV to sexual relationships
- include people living with HIV in making decisions
- less stigma about sex work etc.
- men and women sharing sexual responsibility
- challenging early sexual activity

❺ Supportive environment

Policy and laws/human rights

- legal access to condoms
- decriminalising sex work and same-sex relationships
- legal rights for women e.g. property and safety
- legal rights for people with HIV e.g. employment, housing

Access to materials and services

- access to health care for people with HIV
- safe blood supply
- health services for young people
- access to clean injecting equipment
- affordable condoms

Economic opportunities

- employment for people with HIV
- employment for women
- adequate income for men and women
- adequate social security for sick people

Open environment

- positive media images about people with HIV
- clear and frank messages about HIV
- condom advertising

PART

2

Getting groups going

© Petra Röhr-Rouendaal

Good planning and communication can go a long way towards helping a group to reach its full potential. When people are in a group in which they feel happy and fulfilled, they are also more confident and creative. They are likely to be more committed and to take more responsibility and will generally form a more effective group.

Before beginning

With or without another organisation?

Working with established AIDS organisations can have some advantages for new or small groups. There may already be an established local counselling organisation which can provide a ready-made source of people interested in joining a new group. Existing organisations may also have resources such as photocopiers, telephones and fax machines, which you may be able to use if your group is set up within the larger organisation.

The Friends' Club in Côte d'Ivoire is supported by a local NGO, which provides office space, a meeting room, the use of a telephone, and a monthly grant of about US$150. The grant is used for activities such as starting a roadside food stall employing club members.

© PROSA

The majority of PWA groups in developing countries are first set up by people who are not themselves HIV positive. This can work if people are treated equally and their needs are fully considered. However it can often lead to problems, for example, due to different expectations of what the group can offer, or conflict if people with HIV are not treated as equals.

> 'I was involved in a group that was being run by negative people with negative attitudes towards people with HIV. They looked down on us and took advantage because of our status. They exploited us for five years, forcing me to go public and sharing my testimony about how I was infected, in schools and factories. They received a lot of money for every session and used it for their own interest. My voice was never heard or listened to, and my needs were never met at all.'
>
> **Samantha, Zimbabwe**

Other groups are open to both HIV-positive and HIV-negative people. Some groups are open to both people with HIV and their HIV-negative partners. Some are primarily concerned with advocacy and campaigning and believe it is important to work together for human rights of people with HIV, gay rights or sex worker rights, for example. Other groups are not exclusively for people with HIV in order to protect the confidentiality of HIV-positive individuals in the group – groups that are open to both positive and negative people mean that individuals do not have to disclose their HIV status.

> 'The association recognises that, given the current high level of public prejudice towards people with HIV/AIDS, many people – especially those with families – do not feel able to declare their HIV status even to their friends, let alone to a wider public. To be active in the association, people with HIV do not have to make a public declaration of their seropositive status. Membership is open to both HIV-positive and HIV-negative people.'
>
> **Lumière Action, Côte d'Ivoire**

Working independently means that your group may be able to establish its own identity more easily and choose its own direction and activities.

> 'In our groups many people talk about issues relating to HIV/AIDS because they can't talk about it at home. They want to talk about their problems and to try to find solutions. Being able to talk makes people feel good about themselves. Our group has shown that it's more effective for one PWA to talk to another than to a psychiatrist – because we're in the same position and understand the situation better.'
>
> **Member of Amigos por la Vida, Guayaquil, Ecuador**

> 'INP+ is exclusively by and for people living with HIV/AIDS so that we can concentrate on our agenda without diversions, we know what our specific needs and goals are, we are more comfortable sharing experiences with people going through similar experiences, the group being positive can make decisions for itself.'
>
> **Indian Network of People Living with HIV/AIDS, India**

It is also important to recognise the needs of particular people with HIV, such as drug users, women, young people or particular ethnic or language groups.

> 'As Black gay men we have been invisible and under-represented in the services provided for people living with HIV. The often non-acceptance and denial of us in our own community makes it difficult for us to own our sexuality and makes coping or coming to terms with HIV testing, infection and illness that much harder. It is with this recognition that we have come together to offer this confidential service.'
>
> **Black Positive, Canada**

Double stigma

> 'There are limits on participation and openness for sex workers who are living with HIV. Most sex workers face stigma and persecution because of their work. They face additional problems if they test positive for HIV. They may be dismissed from a job, lose the registration that enables them to work or even face criminal prosecution. They may also face additional health problems related to their work, such as stress and exposure to opportunistic infections. Other HIV-positive people, counsellors and carers who are not sex workers sometimes believe that sex workers are 'to blame' for their HIV. They may also sometimes face disapproval from other sex workers.
>
> Often the best projects for HIV-positive sex workers are those that are run by or with involvement of other sex workers. These are often more acceptable to HIV-positive sex workers than other groups for people living with HIV. For example, a support group for HIV-positive women in Africa discovered that several members had worked as sex workers. These women were unable to discuss issues related to their sex work in the group, because it was not possible to be open about sex work.'
>
> **Cheryl Overs, Network of Sex Work Projects**

© Cal-Pep

Sex worker peer education, HIV testing and counselling combined in California, USA

POSITIVE
LIVING

KUMPULAN
SOKONGAN
BAGI MEREKA
YANG HIV+
DAN AIDS

What we offer women with HIV/AIDS

- **ONE-TO-ONE CONTACT** – women can talk to another positive woman either in person or by phone. Confidentiality is assured. Women don't have to give their name or phone number.
- **GROUP SUPPORT** – we currently offer evening and lunchtime support meetings for women to meet and share experiences.
- **MONTHLY NEWSLETTER** – this includes articles by positive women, notices of services and events, information and news about other Positive Women's groups in Australia and internationally. The newsletter is sent in a plain envelope to members only.
- **DROP-IN CENTRE** – we have an office staffed 5 days a week, between 10 am and 4 pm, to enable women to use our library, drop in for a chat or a cuppa, or get advice.
- **FREE MASSAGE** – we have a group of masseurs who offer regular free massages at the office.
- **INFORMATION AND REFERRALS** – we can refer women to other support services, counsellors, doctors and alternative

positive
women

VICTORIA is a peer support and advocacy group run by women with HIV/AIDS for women with HIV/AIDS. We are a statewide, independent service.

Positive Women offers confidential support and information to any woman who has been diagnosed with HIV. We can also provide advice to parents, friends and family members of women with HIV/AIDS.

Positive Women was established and is managed exclusively by women living with HIV/AIDS. In recognition of our special needs we provide a safe and comfortable environment that is completely confidential. We address the need for accurate information that is relevant to women's experience of living with HIV. We support women's rights to make their own decisions about their health and future.

Finding group members

How you contact potential group members will depend on how many people in your area have HIV and the levels of prejudice that exist. People who have discovered that they have HIV after going to a voluntary testing centre and having pre- and post-test counselling may already be receiving support from friends or counsellors. In other cases, especially where there is little or no access to voluntary testing and counselling, people are told that they have HIV only after getting sick. Where mandatory testing still occurs, for example as a condition of employment, immigration or insurance coverage, the person is unlikely to have received much counselling. Women at antenatal clinics and blood donors may have received some counselling but are unlikely to be fully prepared for the information.

All of these will affect how you choose to reach potential new members and what their initial expectations will be (see pages 24-25). Consider the following ways:

- talk to counsellors and health workers at HIV testing centres, blood transfusion centres, STD clinics and hospitals and give them your contact details to pass on to HIV-positive people
- put up posters and prepare brochures to place in waiting rooms where people may be tested for HIV, such as antenatal clinics or immigration centres

- contact local AIDS service organisations
- advertise the meeting in a local paper or put up posters in your area where people with HIV are likely to read them
- if you are willing, put your own story in the local newspaper or on the local radio for people to contact you
- talk to people one-to-one to interest them in joining
- visit people in their homes.

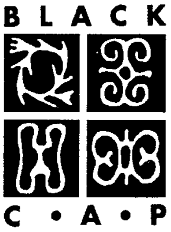
However you publicise your group, make sure that the following information is clear:

- who the meeting is for – only people who have tested positive? partners or families? men or women? gay men only? drug users?
- whether the meeting will be confidential (see page 27)
- where the meeting is and at what time
- contact details, if possible, for people who may be nervous about coming to the group for the first time.

Consider meeting people one-to-one first. They may be reluctant about visiting a group. Discuss how confidential your group will be and who is likely to attend – both men and women, mainly men, all sex workers, for example. If it is a new group they may be interested in knowing whether all the other potential members have been contacted in the same way as they have. They may want to know what is likely to happen at the group. If your group has a confidentiality agreement, it may be useful to describe this before the person visits the group.

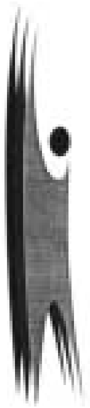
Group identity

You will most likely want to give a name to your group, and possibly even a logo (the image which identifies your organisation). Think about what kind of group you want when choosing your name. You may want to advertise that you are all HIV positive or all women or all young people, for example.



Our logo is comprised of Adinkra symbols from the Akan people of Ghana.

> **Philly Lutaaya Initiative, Uganda** chose its name in tribute to a musician who was the first Ugandan to give HIV a human face when he bravely declared publicly that he had HIV, in the face of much criticism.
>
> 'The LIME is an HIV/AIDS social support group targeting PHAs within the diverse Black communities... The word 'lime' is a slang word from the Caribbean for 'meeting and socialising with ones peers'. The LIME was established to do just that. It is an informal way for Black PHAs to come together, meet their peers and reduce isolation in their lives.'
>
> **The LIME, Canada**



Our logo shows an upraised arm, symbolising strength.

Red Mexicana de Personas que Viven con VIH-SIDA

In some places it may be necessary for the group's name to avoid showing that it is for people with HIV. In one country where HIV is still highly feared, people with HIV face physical danger.

> 'We have chosen a name which does not mention HIV. We do not say that we are only for HIV-positive women because this would expose group members to danger. It is only when the women come to the group that some choose to disclose their status.'

Some groups choose words such as 'Positive' or 'Plus' in their name to demonstrate that all members have HIV. For some this is to demonstrate that HIV is nothing to be ashamed of. For others, it may be necessary for group members to be confident that everyone else in the group has also been through the experience of testing positive.

Some groups make it clear to people who come along that they are not going to be asked about their HIV status. One group in Israel doesn't advertise the group as only for HIV-positive people and doesn't ask people their HIV status. It provides a friendly informal atmosphere – a cake shop donates free pastries and there is usually a music session, as well as regular information sessions, for example a talk on recent anti-HIV treatments. The group organisers feel that it is important that the group is open to everyone.

> 'One couple who came along to the group only disclosed their status (one was HIV-positive, the other was not) after many months of coming along to the group. It was the first place where they felt safe and ready to talk about it.'

HINTS & TIPS

If you are setting up a self-help group, keep it simple to begin with. You can always build up to bigger things in time.

◆

Start small, because smaller groups are easier to manage.

◆

Between 10 and 15 people can be a good size, and gives people plenty of opportunity to work in pairs or groups of three or four before they share ideas with the whole group.

◆

Begin with a group of people who are quite similar, for example the same sex, age and educational background. When people have gained confidence in these groups, it can be easier to develop more mixed groups.

◆

Try and make your group welcoming and friendly.

◆

Bear in mind how others may see your group in the community. For example, is it important to have the support of the elders, or of particular key people?

◆

Consider whether anyone is likely to feel threatened by the work of your group. Can you gain their support or challenge their opposition, if necessary?

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Holding successful meetings

Planning the first meeting

Think about the following:

Where – find a place that will feel welcoming and safe.

Arrange the room so that everyone feels an equal part of the group, can see each other's faces and can be heard easily. Usually this means sitting in a circle with everyone at the same height and without barriers such as desks. Seat people in a circle so they can all see each other.

What – make sure that any materials such as paper and pens that you might need are available. If possible, try and arrange for some drinks or snacks.

Be welcoming when people arrive. Start the meeting by making introductions and letting the group members get to know each other. It is a good idea to explain briefly what you suggest doing in the meeting, how the meeting will be run and when it will finish.

Expectations

Each group member will have his or her own expectations – what he or she wants to gain from being in the group. Expectations make a big difference to the success of a group. For example, people may be disappointed if they expect too much. In some cases, a self-help group is not what the person is looking for and their need is for an AIDS service organisation which can offer material benefits.

It is easy to take your own expectations for granted and not even be aware of them. Also, some people may assume that everyone else will share their particular expectations. For all these reasons, it is important to raise questions about members' expectations at the very beginning of the life of a new group, and if new members join later.

Finding out about a group's expectations can be done in several ways.

- Ask everyone in turn to speak briefly about their expectations for the group — both what they hope to gain and what they think they can contribute to the group.
- Ask each person to write down their expectations on a piece of paper (without signing a name), then collect all the papers together, read them out and discuss them with the whole group. This can help when some people are shy about speaking up, or afraid that others will laugh at their ideas. Alternatively, people could draw a picture of how what they see the group doing as a tree – with what they would like to get from the group drawn as fruits.
- Divide everyone in the group into twos or threes and ask them to discuss their expectations. Then ask one person from each small group to report back to the whole group.

> 'I think of a self-help group like a group of people in a bus. They are all heading to Kampala. There are a number of stops before Kampala. It is important for the driver to let the passengers know their destination, how many stops there will be and that they are on the right bus. If they do not want to go to Kampala or the bus looks like it is going in the wrong direction, they will get off the bus.'
>
> **Beatrice Were, Uganda**

If you find that everyone in the group has very different expectations, you may need to think again about what you can achieve together.

It can be useful to write down the expectations of the group. You can then look again at the original expectations when the group has been going for some time. This may give you a reason to celebrate, or perhaps suggest ways to make changes for the future.

CHECKLIST

Expectations of working with a group

* Why am I here?
* What do I want to get out of this?
* How am I going to participate?
* What am I going to contribute?
* How do I think I will feel and behave in this group (e.g. how comfortable, how serious)?
* How important is the group to me?
* What might prevent me from learning in this group (e.g. unresolved issues, tiredness, disinterest)?
* How am I going to learn (e.g. by listening or by doing)?

ACTIVITY
2.1

WHAT DOES THE GROUP WANT?

AIM To work out a programme of meetings or activities based on peoples' expectations.

It can be difficult for people to respond if there is no plan at all ('*What shall we do then?*'), but most people would not feel happy in a self-help group where they had no choice at all ('*This is what we are going to do*'). This activity is an attempt to steer between these two extremes.

The activity can be done by all group members. It does not need a facilitator to prepare it.

❶ Give everyone a piece of paper. Each person writes two headings on one side of the paper: '*In this group I want...*' and below '*In this group I don't want...*' .On the other side they write '*I wish I knew more about...*' and '*I wish I knew more about how to...*'.

❷ Allow five minutes for this, and aim for at least three points under each heading. Do not to worry about neatness or spelling — the ideas are more important.

❸ Then take turns to read out the list of 'wants'. Someone can note all the ideas on a large sheet of paper. Do this three more times for the other three headings.

❹ As a group, consider:

- Are there ideas that come up more than once?
- Which ideas come up most often?
- Are there more 'wants' than 'don't wants'? Why might this be?
- Is it possible to cover everything in the lists?

❺ Try grouping the items listed into categories. For example, a list of 'wants' might be grouped under the following headings: more information, more confidence, to talk and listen to others, company, a break from the usual routine, to know myself better, to find out what I can do.

> 'The current group that meets in the Corporación started out in response to a presentation by a doctor about the new treatment therapies... But we also took time to talk about what was happening in our lives. So it was always a combination of practical questions and personal sharing. Eventually, the more action-oriented people formed a separate political interest group which has been very successful, but they often come back because they like to set all the work aside and just say what is on their minds.'
>
> **Corporación Chilena de Prevención del SIDA, Chile**

Ground rules

Just as it is important for expectations within the group to be clear and understood by everyone involved, it is also important for rules of trust and behaviour to be established. In groups where people want to talk about personal feelings and sensitive topics, they must feel able to do so without being laughed at or silenced and without fear of other people finding out.

Ask group members what would make them feel safe and comfortable within the group. As members make a suggestion, the leader should make sure that the rest of the group is in agreement before it becomes one of the group rules. When agreed, write down the ground rules. These can be amended or added to as the group develops.

Confidentiality

HIV affects our most private emotions – our sexuality, our security and trust in relationships and in the future. Having HIV is nothing to be ashamed about, but many people may feel afraid to tell their friends, colleagues or even family. They may not feel emotionally prepared or they may fear the social consequences of others finding out. Sharing the fact of having HIV with others is usually a great relief, but it is essential that the individual chooses when and how this is done.

It is likely that new group members have not yet disclosed their status to family or friends or have very real fears of the consequences of their employers or community members finding out.

Group members have the right to expect that what they say will remain confidential, otherwise they will not feel that they can speak freely. They must know that their names will not be passed on to other people without their permission. It is important that your group has a common understanding of what confidentiality means for each of you. It is useful to write this up:

> *What you see here,*
> *what you hear here,*
> *please let it stay here!*
>
> **Positively Women, UK**

It is also important to discuss any fears that members have about confidentiality being broken – even by other group members and to see how to reduce the possibility of this happening (see 'Disclosure', page 93).

Possible ground rules:

- Confidentiality (see box).
- Respect: group members should listen to each other without interrupting and should only speak one at a time.
- Language: group members should agree to use a language understood by all and to not use words that might offend.
- Non-judgemental attitudes: group members should avoid being judgmental of other people's feelings, views and behaviour, unless these views lack respect.
- Group members should inform the group leader if they are unable to attend.
- Any money collected must be for the group's use.
- No one is to formally represent the group without its knowledge and consent.

Keeping a record

Some groups find it useful to have a plan for the meeting (an agenda). This can be organised or reviewed after first introductions. It can then be added to or changed if necessary.

AGENDA

1 Introduction: going around circle giving names

2 If new people have joined, ask a regular group member to say a bit about what we do

3 Check in: 10 minutes for anyone in the group who wants to, to share any news about themselves and how they are feeling

4 Introduce the nurse who will be talking about nutrition

5 After the talk, find out who we would like to come and talk to us at the next meeting

6 Organise New Year's party

7 Finish the meeting and check date of next meeting

Decisions

If you are making decisions, remember that it is important to record what you have decided and who is going to do the actions you have agreed. You might want to have a book where the decisions at each meeting are written down. Make sure that someone is responsible for recording these notes at each meeting

WE-CARE GROUP MEETING
21 OCTOBER

Agreed that Claudio will contact the local textile factory to see if we can have some spare cloth to make a World AIDS Day banner for our group

Agreed that Sandra will organise a cooking rota to run a food stall at World AIDS Day event

Decided to rehearse our short play next meeting

Next meeting 19 November at Neighbourhood Centre

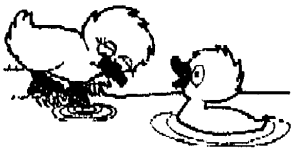
Welcoming new members

Some or all members may not have been part of a self-help group before and be anxious about joining. New group members may be uncomfortable about simply being in an HIV group, and may feel unsure about what is expected of them. They may feel that they could reveal things about themselves that they don't want to. They may have joined the group to acquire the necessary skills to make changes in their lives, but they may feel uncertain and unsure of all the possible consequences. These and many more issues can make joining the group seem risky.

Emphasising the following guidelines for working together as a group may make people feel more comfortable.

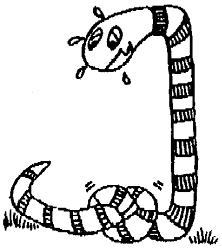
Share the time We are all important, we all have something to say. Take time to listen to one another.

Be patient – take one step at a time Different group members may have different needs. Be kind to yourself and to others. Respect views different from your own.

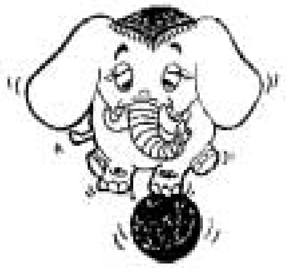


Encourage each other Think about the type of environment you work best in – one in which you feel welcome, accepted, and important. Others, too, need to feel this way.

Get involved You get out of a group only what you put into it. If you don't like what is happening, say so – become an involved group member.



Be responsible for yourself You are in charge of yourself. You can contribute only what you choose, and no one will make you do or say anything that you don't want to.



Stay on the topic Everyone needs direction and clear objectives. Stay on the topic agreed – the group can move on to other topics if everyone agrees this in advance.

HINTS & TIPS

'Two minutes' technique

Offer a space in each meeting for members to share everyday concerns. The 'two minutes' technique is a good example of this: each person in the room has two minutes in which to just state how things have gone for them that week, or whatever else they want to say, without interruption. This is an opportunity for every group member to say what is happening in their life without interruption and without others jumping in to offer solutions. It gives members the opportunity to clear their minds and to leave other thoughts or problems outside the group, so that they can participate fully at the meeting. It binds the group together because you all find out what is happening with each other.


© INP+

Keeping the group going

Groups are successful when they achieve their goals or tasks, while also meeting the needs of group members, whether these are emotional, mental or physical. Here are some ways of making a group successful or effective:

- aims and activities are set by the group
- there is open communication and discussion within the group
- everyone participates in discussion and exercises
- group activities are varied and different each time
- group members attend regularly
- there is a method of coping with new members and for what happens when people leave the group
- evaluation and feedback is encouraged in the group
- acceptance of all the group members is encouraged
- there is a high level of trust in the group
- conflict or disagreement is open and constructive

- there is learning in the group, for example on problem-solving skills
- all group members have equal status in the group
- no one dominates the group, and no one is left out
- group members are prepared for life outside and after the group.

A group does not need to have all the qualities in this list to be successful, but it does need to have most of them. You can use the list above to check how your own group is performing. Can you see areas for improvement?

Growth and change

No group stays the same forever. The number of regular attendees and the experience level may change as members come and go. You can plan for ways to adapt to these on-going changes.

Review group agreements and groundrules regularly so that new group members feel that they have been involved in agreeing them.

When new members join your group, make them feel welcome. Try pairing up a long-serving member with a new arrival, to give extra support and information.

When a topic is repeated for new members, keep the interest of other members by presenting the same material in new ways. Take turns in the group to lead sessions. Make sure that members are asked to share their knowledge.

Some members may eventually outgrow the group. Make them feel comfortable about moving on and show that their contribution has been appreciated.

If a group grows too big for everyone to be able to participate for much of the time, try splitting into two groups. Or split into two parts for just some of the time. You can divide the group in various ways: newer and longer-time members, older and younger members, or by common interest.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Problems in groups

There may be a drop in attendance after the first or second meeting of a new group. Sometimes this may occur because a member realises that their expectations are not going to be met, or that their expectations do not match those of the group leader or other members. Clarifying expectations as early as possible in the life of the group will help to reduce the 'dropout' rate.

Some people may need material support, such as money or food, rather than the opportunity to talk. Make sure that people know if your group cannot provide this and consider whether you or another organisation can respond to these needs with a different project. One women's group in Zimbabwe saw the need for economic support, and set up a successful tailoring business with a supportive working environment. It has decided that it cannot accept new members.

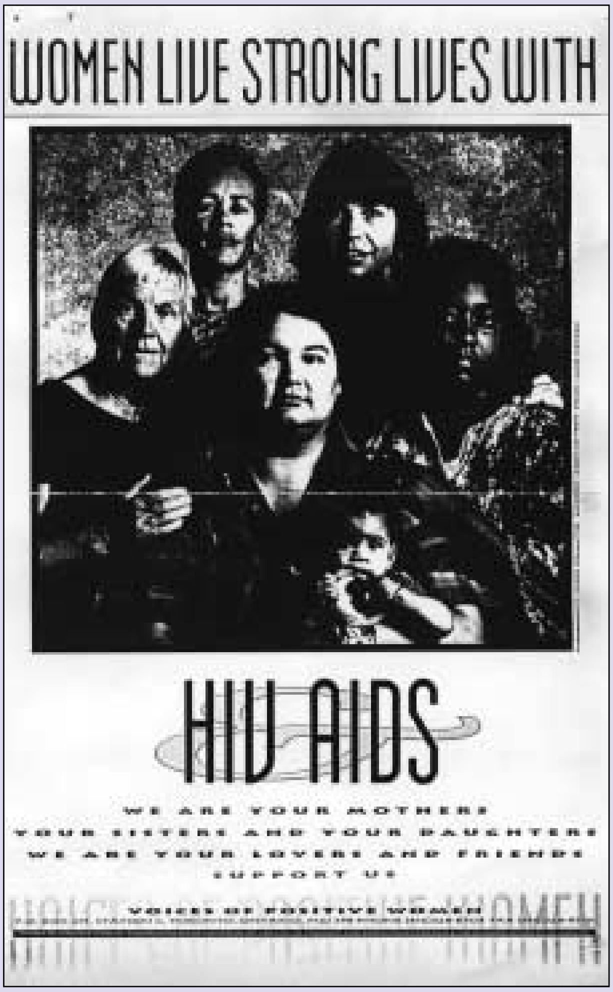
If people leave, try to find out the reasons. It may be that the group has supported someone when they needed it and they now no longer need support. Remember that this does not mean failure.

> 'It is easy to become discouraged if members leave but this does not always mean failure. Perhaps people join during a particular crisis, for example shortly after diagnosis. When the crisis passes they may prefer not to continue.'
>
> **Self-help group organiser, UK**

Part 4 suggests different activities that self-help groups often undertake, moving beyond support for group members to action for change.

PART
3

Working together



© Positive Women, Ontario, Canada

Understanding ourselves

Knowing the strengths and limitations of group members can make it easier for the group to function, and can help you to choose activities or topics that are most appropriate for your particular group.

ACTIVITY

3.1

HOW DO OTHERS SEE ME?

AIM For each group member to get a clearer picture of personal qualities within the group and for group members to recognise some of their own qualities which they may not have valued or even considered before.

❶ Each group member marks three columns on a piece of paper, with the headings ‘*People*’, ‘*Strengths*’, ‘*Weaknesses*’.

❷ Under ‘*People*’, each person writes a list of people who know them and have some view of them.

❸ Then everyone fills in the other two columns by naming what each person would say were their strengths and weaknesses.

For example:

PEOPLE	STRENGTHS	WEAKNESSES
	They think I am:	They think I am:
Mum	Helpful	Untidy
Brenda (best friend)	Good listener	Often late
Joni (husband)	Cheerful	Disorganised
Marcia (daughter)	Caring	Bossy
Wilson (neighbour)	Generous	Shouts too much

ACTIVITY

3.2

HOW DO I SEE MYSELF?

AIM To explore the differences between how others see us and how we see ourselves.

❶ Everyone makes a list of four people who know them well (e.g. mother, father, wife, colleague).

❷ Each person writes a few phrases or sentences about how each person on their own list would describe them. '*What words would they use to describe me?*', '*What are their expectations of me?*'

❸ Then each person writes a short description of themselves called 'Me, by me'.

❹ In the large group, pool everyone's ideas under each heading used (e.g. mother, father, child, friend).

❺ Discuss any common features, for instance, '*How are we seen by our fathers?*'

❻ If they wish, people can also read out their 'Me, by me' descriptions. Consider the differences between the views of each person. *'How easy or difficult is it to know how others see us? How do we know? Do people tell us directly?*'

© Petra Rohr-Rouendaal

Accepting differences

Everyone in your group will have some things in common – they are all affected by HIV or AIDS. However, it is important to remember that everyone is different, and to learn to respect the differences within your group and beyond.

Different needs and concerns within the group may sometimes cause disagreement or argument. If possible, try to see differences as something to celebrate and to learn from. The activities suggested below can help groups to explore the differences between people and also feelings about those differences.

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ACTIVITY

3.3

DIFFERENCES BETWEEN PEOPLE

AIM To recognise each group member's differences.

This activity is best led by a facilitator or group leader. It may raise some sensitive issues, which the group should be willing to discuss. Sometimes groups may try to avoid more contentious issues such as race, sexuality or class. It is up to the group leader to point out this and to facilitate a discussion about this in a safe way.

© PROSA

❶ Ask each group member to choose one way of describing themselves which is important to them (e.g. woman, Catholic, father, person with HIV, volunteer, black person, 40-year-old, farmer, grandparent).

❷ Ask participants to talk in pairs about how they are viewed in that role by friends, family, colleagues, peers and other community members.

❸ In the main group discuss the individual's life experience. Religion, culture, gender, sexuality, race, age and education often influence how we are expected to behave. Does everyone agree with and accept these expectations?

❹ In a circle ask everyone to spend three minutes looking at the others in the group.

❺ Ask the group to describe some of the differences between people in the group (for example, age, sex, colour of hair, eyes or skin, dress, hairstyle, sexuality, race, education, language spoken, height, weight, health status). List the differences on a sheet of paper or board.

❻ Ask each person in turn to say how they would describe themselves in terms of each difference (e.g. for age they might say *'33 years'*, *'44 years'*, *'that's private'*, *'29 years'*, *'old enough'*, and so on).

❼ Then discuss:

- How did it feel to define yourself in each way?
- Did you feel included or excluded?
- Did anyone feel that they did not fit exactly into one category?
- Was anyone alone in one category? How did this feel – good or bad?

ACTIVITY
3.4

HOW DO OTHER PEOPLE FEEL?

AIM To explore the ways in which prejudice and discrimination affect our options in everyday life.

The group leader will need to prepare this activity beforehand:

- Write down some 'roles' that people in your community play on separate pieces of card, for example: 50-year-old blind woman; sex worker; gay man with HIV; 35-year-old drug user; middle-class white heterosexual man; factory worker; married woman; 17-year-old girl with HIV.
- On a sheet of paper, write a list of activities, such as: run for a bus; tell someone what you do for a living; travel for work; buy a plot of land; be open about your sexuality; take your partner to meet your family; make long term plans for you and your family; get medical help when you need it; walk the streets late at night; have job security; have children; read a newspaper.

❶ Explain to the group that this is an exercise to look at how different people feel in everyday situations.

❷ Ask everyone to stand in a line, side-by-side, at one end of the room and not too close together.

❸ Give each person one of the role cards, and ask them to look at the role but not to tell anyone else what their card says.

❹ Ask everyone to imagine that they are the person described on their card, and to think for a minute about what their life is like as this person.

❺ Then explain that you are going to read out a list of activities, asking '*Can you do this?*' for each. Ask everyone to take one step forward if they (in their role) can answer yes. If the answer is no, the person stays where they are.

❻ Read out each statement in turn. When all the statements have been read out, everyone is likely to be standing at different distances from the starting point.

❼ Starting with the person who has moved farthest, ask each group member to reveal their role and make one statement about their experience of the exercise.

❽ Sit down again and discuss:

- What were the restrictions imposed on people by their roles?
- What factors influenced whether they stepped forward or not?
- Did assumptions or lack of knowledge of the role influence the decisions they made?
- What have they learnt about the effect of prejudice and discrimination on people they may be working with in the group?

HINTS & TIPS

Group leaders

Share only your own experience within the group; do not give away other people's confidences or personal business.

◆

Encourage group members to listen carefully to each other so that they really understand what people are saying and feeling.

◆

Encourage people to ask questions, either privately or in the group. No question is 'stupid' or not worth asking.

◆

Encourage everyone to join in, but remember that some people may not be used to speaking out or giving their opinions, whether by tradition or because they are shy. Avoid pressuring anyone to take part in an activity or share personal information if they do not want to.

◆

Try to put your own views to one side while listening to other people. When people feel judged or disapproved of they are likely to withdraw, or to become more closed to new ideas.

◆

Do not feel that you must have answers to every question.

◆

Build trust and respect in the group by encouraging everyone to respect each other's opinions and values.

© AHRTAG

The group leader

Most groups need someone to act as a leader or co-ordinator. The group leader could be the person who started the group or someone who the group elects. Depending on your group, this could be a different member each week, or it could be a regular leader who may also be a professional trainer or other expert.

A group leader explains group activities, guides the discussion and provides information where necessary. Being able to lead group discussions and use different activities to involve participants is a very useful skill. The ideas suggested here can be used for the different group members to practice and improve facilitation skills. These skills are very useful for developing confidence to participate in broader activities with others (see Part 6).

If you are a group leader, especially a permanent one, you have an important responsibility to the group. People will give extra weight to your views and opinions. Some leaders can have a big effect (good or bad) on members' lives. Even if the work you do is voluntary, you should be careful to act as professionally as possible.

Remember: as a leader you are responsible for the group running smoothly but each member has their own responsibility also. If you feel that people are placing too much responsibility on you, you may find it useful to refer to the list on page 29.

One of the group leader's main roles is to get people to contribute equally and to listen to one another. The following exercise may be a good starting point.

ACTIVITY

3.5

A GROUP EXERCISE TO GET EVERYONE TALKING

AIM To help to develop self-esteem and encourage people to talk in a group.

❶ Ask everyone to write down five qualities that they like about themselves.

❷ Going around the circle, ask each person to choose one of those qualities and say it to the group.

This technique encourages everyone to take part equally, and no one person is singled out for the answer. Each person also has plenty of answers to choose from. If everyone seems to be feeling comfortable with this, you can ask them to go around again, giving a second quality.

1. Generous
2. Good at making people laugh
3. Helpful
4. Loyal friend
5. Caring

© Petra Rohr-Rouendaal

Listening to each other

Listening is a skill that is often taken for granted because it is confused with hearing. Listening involves hearing, but also much more. Being a good listener is perhaps the most important skill for a group leader to have. Listening is necessary to give responses to what you hear and to check that information you have delivered has been understood.

Active listening

- Turn your whole body to face the person who is speaking.
- Try to be relaxed and lean slightly towards the speaker.
- Look at the speaker gently, offering plenty of eye contact but not staring.
- Let the speaker know that you are listening by occasionally nodding your head, making encouraging sounds, or saying something like *'really'*, *'yes'* or *'I see'*.
- Try not to interrupt the speaker.
- Take brief notes, perhaps jotting down key words, which you can use for asking questions later.
- Be aware of what is said and what is not said.
- Stay calm and neutral – try not to allow your emotions to stop you from listening.

© Petra Rohr-Rouendaal

Another technique for good listening is to reflect or offer back to the speaker what you understand that they are saying (reflective listening). Rather than repeating exactly what the person has said, reword something to show that you understand what they are expressing. For example, '*You are feeling nervous because you haven't done this before*', or '*You are feeling pleased because you have been able to talk with your father*'. If your understanding is not correct, this gives the speaker a chance to explain further.

Appropriate and sensitive questions can:

- encourage thinking
- find out what is already known, and what is not
- stress or highlight important points
- expand or share knowledge and information within the group and to hear a range of ideas
- encourage involvement and participation (an opportunity to draw out quieter members of a group)
- prevent disruptive behaviour, such as side conversations or domination by a few people
- keep the group interested and the discussion moving
- keep the meeting to its aims or to bring it back on track
- check what has been understood during the session (and to help people remember).

© International HIV/AIDS Alliance

Good listening and asking questions in the right way lead to lively discussions.

Asking questions

There are two types of questions:

- **closed** – invite a 'yes' or 'no' answer. For example, '*Do you agree?*', or '*When did you realise this?*' are closed questions.
- **open** – give people more choice in how to answer. They are questions like '*How do you feel?*' and '*What do you think?*'

If you do not want to always ask questions use statements which encourage more information ('door openers'). For example: '*I'd like to hear your opinion on that issue', 'I am interested in hearing what you have to say' 'It would be helpful if you could explain that a little more please.*'

Receiving replies

It is generally best not to repeat answers given by group members – this takes up time and can discourage people from listening to each other. If a reply is not loud enough, ask the person to repeat what they said: '*A little louder please*'. If an answer is incorrect, accept the reply but then rephrase your question to the same person, or to the group. There is generally something useful in any reply, if only as a starting point for further discussion.

- Give group members a moment to think about a question. A slight pause will not stop the flow of the meeting.
- Check that you don't offer value judgements after replies, such as '*That was a good answer*', or '*Well done Lucy, you've always got the right answers*'. This can make other people hesitant. If they think they don't have the 'right' answers they may not answer at all.
- Make sure that you listen carefully when someone answers.
- Always thank the person for their reply.


© ICW

Try to give everyone the opportunity to answer questions.

Encouraging group participation

- Stimulate discussion by putting a question to the group as a whole, to get everyone thinking about the answer. Then ask a specific member of the group to give you an answer.
- Try to give everyone the opportunity to answer questions. If you rely on the same few people all the time, the others will feel less involved. If you cannot remember who you have asked already then ask for 'someone who hasn't answered yet'.
- If the participants are very quiet you may need to use more direct questions. Make sure that the questions are not too difficult for the group to answer. When encouraging a shy group, or dealing with a sensitive issue, it can be useful to ask a question to everyone and then ask for one reply from each person (see Activity 3.1 for an example).
- Ask different people to start the answers and make your choices unpredictable. If you start always at the person to the left of you, for example, you may find that no one will want to sit there.

Helping everyone to take part equally

Two common problems in many groups are that some people may be very quiet, and others may dominate and take too much of the group's time and attention. There are many different reasons for under- or over-participation, and there may be underlying problems that you do not know about. Sometimes these problems just solve themselves with no intervention, and

© ICW

The group leader can make people feel at home and encourage participation.

sometimes the group members may take the responsibility on themselves. In some cases, a group leader may need to take action.

Under-participating members

Very quiet, or non-participating, group members may:

- avoid eye contact
- sit slumped or turned away from the group
- say very little or nothing at all
- talk to the person next to them, but not to the whole group
- arrive late and/or leave early
- miss meetings altogether
- not listen to the discussion
- not respond even when encouraged.

Some people may feel embarrassed or shy about the subjects discussed, or even that they are attending the group at all. It is very common for people to feel ashamed of being affected by HIV and AIDS, or for seeking help and support for any other problem. Some people may not be used to talking openly, and may find this hard when they do not know the other group members. Sometimes people join a group only to please someone else, and do not want to be there. Other people may feel that they deserve special attention.

Most people will understand that not everyone finds it easy to participate in a group, especially at first. However, very quiet or obviously unhappy members can be discouraging to everyone.

To encourage participation from someone very quiet or reluctant:

- try asking them very simple questions which are easy to answer
- ask rounds of questions that require everyone to answer
- encourage them to speak very near the start of the meeting (this can help to set a pattern for the rest of the session)
- be encouraging when they do participate
- involve them in work in pairs where they can share responsibility for reporting back to the group
- ask them privately about why they do not choose to speak in the group
- get to know them during breaks, or before and after meetings
- do a role-play and cast them in a dominant role
- try to sit them near people who are friendly and encouraging.

Over-participating members

Dominant or over-participating group members may:

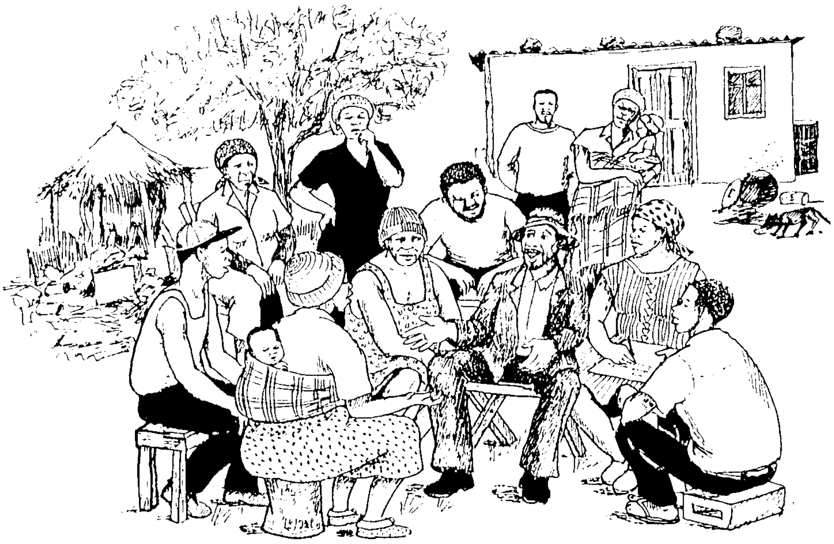
- talk often for a very long time
- always speak first, making it harder for others to contribute
- interrupt when other people are speaking
- get off the main point or topic
- dominate the smaller-group discussions
- reveal inappropriate personal information about themselves
- bring up their own personal problems all the time
- comment on everything, and ask a lot of trivial questions.

Sometimes groups are happy for one or a few dominant members to do most of the work. As group leader, you may have to point out that this is not in the best interest of everyone else. Alternatively and more commonly, the quieter members may feel discouraged about coming to the group if it is difficult for them to take part fully. The group may feel annoyed and resentful towards both the dominant member and you, the leader, for letting the situation continue.

It can help to understand why someone is over-participating. Possible reasons include: nervousness, insecurity, they do not know how to relate to others in a group, embarrassment about attending the group, wanting to be the centre of attention, they might usually be a leader themselves and find it difficult to be an equal member, or they may never have been told that their behaviour can be a problem.

Ways in which you can discourage over-participation include:

- give people a time limit for their contributions. If someone is speaking for too long, remind them of the time, ask them to conclude, or to finish in a specific time (e.g. *'two more minutes'*)
- make a point of asking others for their opinions
- state plainly that the work and attention of the group should be shared equally among group members
- speak privately to the dominant member about their behaviour
- have a skills session on listening techniques (for example, see page 40)
- sit any dominant person about two places away from you in the circle (where it is harder for them to get so much of your attention)
- say *'That sounds like an interesting point but we haven't the time to discuss that now'*
- give a dominant member a specific supporting role such as note-taking or tea-making.



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Assertiveness

One reason why people find it difficult to participate in groups is having the confidence to state clearly their wishes, values and decisions – being ‘assertive’ about what we think and feel in a clear and direct way which does not bully the other person. It is difficult, especially for women or people who are traditionally not respected, to assert themselves.

CHECKLIST

Reasons to be more assertive

* You will have increased self-confidence because there will be fewer situations in which you will feel threatened.
* You will have greater confidence in others because you will not look down upon them.
* You can take greater responsibility for your own wants, needs and decisions.
* You will have better working relationships because there will be a better chance that people will work with you rather than against you.
* You will save the time and energy (that you used to spend worrying, feeling angry or guilty).
* You will take more initiatives because you won’t be afraid to make mistakes.
* You will have more control over people and situations that used to control you.
* You are less likely to be personally or professionally exploited — and more likely to be taken seriously as a confident and competent person.

Practising assertiveness can be useful as a group activity for the group to develop confidence in working with others (see also Parts 5 and 6). It can also be useful to work with some members of the group who feel less confident than other members of the group – for example, traditionally women are expected to listen to men and may find it difficult to assert their views in a mixed group. The role play activity on page 50 can be used to practice assertiveness skills.

Techniques for successful group work

There are a number of different ways to get discussion going in groups. It is good to use different techniques in the group to keep everyone interested and participating.

BRAINSTORMING

AIM To bring out as many different ideas as possible — no matter how crazy — without worrying about how good or bad they might be until later.

A brainstorm is a technique to help a person or a group to think freely and creatively.

1. Choose one behaviour which everyone in the group might practise, and which they agree contributes to an important health problem (e.g. drinking alcohol, smoking, unsafe sexual activity, unhealthy eating habits).

2. Group everyone into teams of four people, and ask each team to agree on one person to take notes.

3. Ask each team to 'brainstorm', listing as many things as possible which influence their own behaviour on the chosen topic. Every idea should be written down without comment until the group has run out of ideas.

4. On a large piece of paper or flipchart, list all of the ideas from all of the groups.

5. Working in the whole group, take out repetitions or unhelpful ideas, and try sorting the remaining ideas into categories or priorities.

HINTS & TIPS

Brainstorming

Do not worry if you do not have perfect handwriting. When putting points up on a chart or board, make them just that — brief points.

◆

Don't try to repeat everything that is said in the discussion, but just note key words that will act as reminders.

◆

Sometimes it is helpful to have important points or charts written up in advance. These can be displayed easily and can help to make your presentation more efficient.

◆

If you use large sheets of paper to jot down these ideas they can be kept and displayed around the room. This helps to remind everyone of what has been done, and is a quick visual way to stress key points.

ROLE PLAY

AIM To help people practise communication skills and solve problems with others and to help people practise new skills.

During a role play, two or more people pretend they are in a certain situation and act out how those people might behave in that situation. Role play involves people in the group, not real actors, who have had little preparation other than real life.

Role play involves three steps:

❶ The group or facilitator describes an important problem or situation. Two or three people are asked to volunteer to 'act' out the situation. This should take 5-10 minutes.

❷ Participants discuss what happened during the role play.

- Is this a real problem?
- Can it be solved, and if so, how?
- How did the role players deal with it?

❸ Participants make suggestions for overcoming the problem.

The role play can then be acted again, perhaps by different members of the group, to show a possible solution.

© Petra Röhr-Rouendaal

ACTIVITY

3.6

NO THANKS!

AIM To learn how to be assertive about our personal belief and right with other people.

❶ Ask two people to role plays some situations (you will need to adapt the examples below to your own situation). In each role play person B should try to convince person A of his or her view. Person A should be assertive – firm but polite – about their right to hold their view.

Example 1:

Person A: *You believe that the DJ of the local radio would be the best person to invite to your support group fundraising disco. Be assertive about inviting the DJ.*

Person B: *You know that the local DJ is not as good as the local bank manager at giving speeches. Try to pressurise person A into agreeing to invite the bank manager to your fundraising disco.*

Example 2:

Person A: *You have been nominated as the treasurer for your club. You know that you do not have time to do the work this year because of family commitments. Be assertive about not accepting the nomination.*

Person B: *You want person A to be the group's treasurer. Try to pressurise them into agreeing to do this.*

❷ Discuss in the group.

- Is it easy to be assertive?
- What did person B feel while trying to pressurise person A?
- What did person A feel while trying to be assertive?

© Commuicating about AIDS,
ZAN/Sue Laver, Zimabwe

PICTURE CODES

AIM To focus people's attention on a difficult situation at the beginning of a problem-solving session.

A 'picture code' is a poster-sized illustration without words, which shows a situation about which people may have strong feelings. The illustration should clearly describe the situation (e.g. a woman buying condoms, a young man visiting an STD clinic).

❶ Place the picture code in a position where it can be seen clearly – on the ground or fixed to the wall.

❷ Guide the group through a series of questions to stimulate discussion:

- What is happening in the picture?
- Does this happen in real life?
- Why is this happening? What does the picture make you feel?
- Do any problems or benefits arise from this situation?
- What are the root causes?
- What can be done about it (to make it happen more or less)?

At the end of the discussion, summarise what has been said.

This technique may be useful for starting discussions with other people, for example during public education sessions at schools.

OPEN-ENDED STORIES

AIM To present a real life situation and raise issues which people can easily understand.

An open-ended story is short and stops at a point where decisions are needed.

Tell a short story, which reflects a situation, which your group members are facing. The following example highlights the need to consider the needs of HIV-positive sex workers:

'Mary works in a brothel in town. She sends money that she earns to her mother who is looking after her two small children. She is sick now and her young children are unable to care for her. Her elderly mother depends on Mary for food and is getting too old to care for the children. Mary's relatives live in the neighbouring country. Other women in the brothel are starting to talk about Mary and saying that she should leave.'

- What could the other women do to assist Mary?
- What could people do about the children who will shortly be without a mother?
- What could the community do for the grandmother?

PART

4

Planning your action

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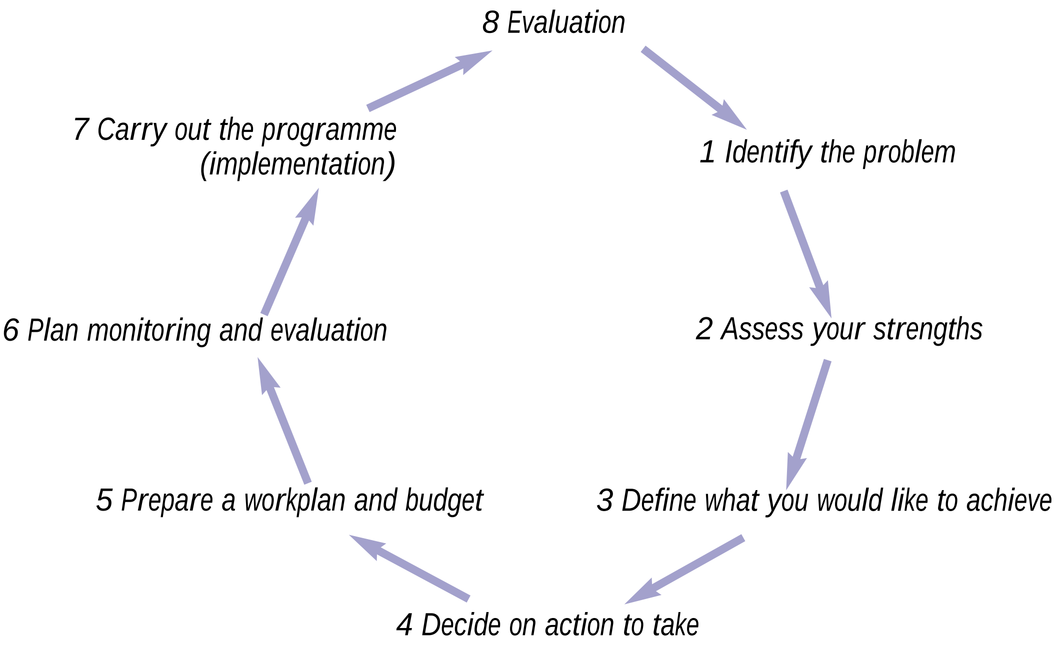
The planning cycle

Careful planning is essential for the success of any project, whatever its size. This means planning work before you begin, continuing to think about your actions, changing plans when necessary, and seeing how effective your work is. This on-going approach is sometimes known as the ‘cycle of project planning’

A project is a set of activities which are carried out within a specific time period to a achieve a particular aim.

Many groups do not plan because they are worried that it is too complicated. Do not be afraid. Planning what you do is very important! If you discuss it before you start, it can be make your work easier to do.

THE CYCLE OF PROJECT PLANNING



❶ IDENTIFY THE PROBLEM

Living with HIV may raise many new issues in your personal life, and you may want to change the world! However, this is not always possible straight away.

A group which is planning to try and make changes needs to be clear about what it is planning to do now and what it is not going to do now. If the group does not decide this before it begins a new project, there is a danger of being pulled in so many directions at once that it does not move at all.

ACTIVITY

4.1

PROBLEM TREE

❶ In the group, brainstorm the main problems that you face (see page 49 for an explanation of this technique). Ask everyone to think about problems that you would like to change. It can be useful to have done Activity 1.1 (on page 13) before this.

❷ Decide on the main problem that you have identified. On a sheet of paper, write this down in large letters. For example: *'We do not know enough about possible treatments for our illnesses.'*

❸ Then ask everyone to write down on separate pieces of paper the problems that they think this results in, or ask people to call out their ideas one by one and write them down on separate sheets of paper. For example: '*Doctors prescribe the wrong treatment' 'We do not go to hospital early enough' 'Feeling sick keeps us from farming or working'.*

❹ Read out these suggestions one by one and, as a group, decide whether they are caused by the original problem or if they lead to the original problem. Place the problems on the sheet of paper with the original problem written on it, either above the original problem (if you think they are caused by it) or below the original problem (if you decide that they lead to it).

For example:

3 *We do not go to hospital early enough* (branch)

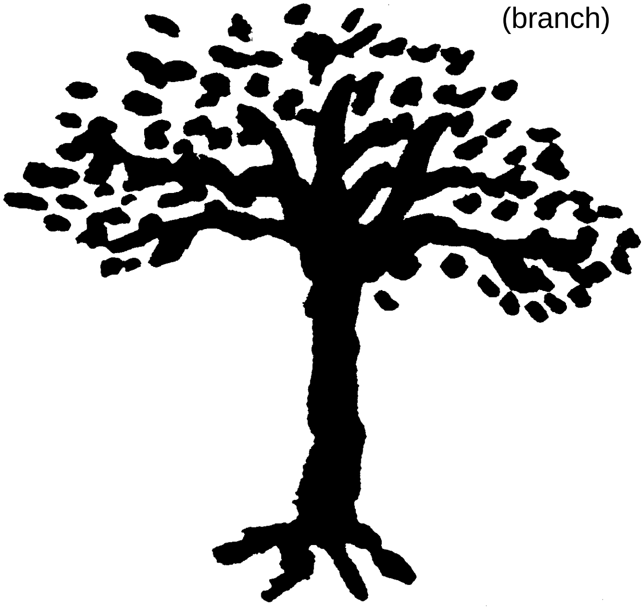
3 *Doctors prescribe us the wrong treatment* (branch)

2 *We do not know enough about treatments for our illnesses* (trunk)

which will lead to:

1 *Health workers and NGOs only see us as ' victims' and do not want to give us information* (root)

might lead to the problem that:



HINTS & TIPS

Before you start

What do you need to know? Is there anywhere where this information already exists? Find out what groups are already doing in your area and discuss with them what you hope to do and what they are planning to do (see Part 7, page 112)

◆

Whose views and experiences are most necessary when planning your project or making it more effective? The more directly affected a person is the more important their opinion is. It is important to involve those who often have less influence, such as people who are sick, young, or who are discriminated against by their community, such as injecting drug users or sex workers.

◆

Whose active support is essential for the success of the project, such as funders, managers or leaders in the community? Try to include them in the process as much as possible.

◆

Who is likely to feel threatened by the possibility of changes to the project? Think about how you can gain their support or challenge their opposition if necessary.

◆

Who takes decisions about the activities and who will be expected to act on the decisions? They need to be involved, especially in planning new activities that will need more resources or training to implement.

◆

Set up a working group to plan your project so that everyone knows who is doing what

◆

Hold regular meetings to keep group members informed and to check that everyone is happy with the progress

© International HIV/AIDS Alliance

Members of Pinoy Plus, Philippines, planning their action.

❺ After trying this exercise, you can decide whether the original problem you identified is the main cause or 'root issue'. If it is not, you may decide to change your proposed activity.

Looking at a 'problem tree' does not mean that you will definitely end up with the ideal project. You may start and then realise that in fact there are other more serious problems to tackle first — or that there are barriers that need removing before you can tackle the problem that you identified. You can always go back to a problem tree at any stage of a project and re-think.

If your group is planning a project you will probably already have a good idea of what the problem is and what the group would like to do. This means that you will not need to spend much time on the problem tree.

Needs assessment

If you are planning a project that reaches or involves people not already in your group, you should collect information first about what is needed (a 'needs assessment'). A needs assessment consists of gathering information (baseline data) before planning the project, so that you can be confident your project is based on people's concerns and priorities, and on what is actually happening in the community.

> 'We looked at existing government data to see where the government and NGOs had projects on HIV. We found that there was a poor – sometimes non-existent – response in many districts. We have prioritised the communities where there is currently no response. We go to these areas first to run workshops for PWAs in capacity building and other activities.'
>
> **Red Mexicana de Personas que Viven con VIH-SIDA, Mexico**

Gathering existing information

Information about HIV/STDs or existing services may be collected from:

- records from local health services
- articles about experiences of people living with HIV in local newspapers and magazines
- personal accounts by PLHAs
- studies carried out by researchers, available from local resource centres or universities.

© Jeremy Hartley/Panos Pictures

Useful information can be collected from discussions with the local community.

ACTIVITY

4.2

FOCUS GROUP DISCUSSION

AIM To find out what people think about a specific topic.

The person leading the discussion (the facilitator) does not participate in the discussion except to introduce the group members, ask them key questions and record the main points.

❶ Select a group of 8 to 10 people who share similar backgrounds, ages and experiences. People are more likely to talk freely and feel less threatened if they have a lot in common. For example, it is usually better to run separate groups for women and men. A joint session could be organised if they wish.

❷ Arrange a comfortable meeting place, where people can sit in a circle. Consult the group about a convenient place and time, and arrange transport or child care if necessary

❸ Prepare a topic guide as a reminder of the main issues to be discussed. For example, some introductory questions to introduce the subject, some general questions about participants' experiences, then specific questions which ask for concrete suggestions and proposals that will provide you with the information that you are looking for.

❹ Explain the aim of the discussion, for example that the main points will help in designing a income generation project for people affected by HIV.

❺ Use the topic guide to help focus the discussion. Try not to ask personal questions because people are unlikely to talk about private things in public. Instead ask about what friends and others in the community do.

❻ Encourage group members to respond to questions, and to talk as openly as possible. This is especially important in mixed groups when men and women are present and women may feel uneasy about making a point. Try to ensure that everyone is given the opportunity to speak. Listen to and note down what people say. Don't become involved in the discussion, except to remind people of the questions. The discussion should last no longer than two hours.

❼ Summarise the discussion at the end but try not to pass judgement or give an opinion. Explain any misunderstandings and challenge prejudices only after the discussion has finished.

❽ Finally, ask the group about their suggestions for project activities.

❷ ASSESS YOUR STRENGTHS

When you have defined a problem, the next step in planning your action is to identify the group's strengths. It can be useful to identify weaknesses as well, and consider factors which may work for and against you in this action (opportunities and threats or barriers). This is sometimes called a SWOT analysis. For example:

Problem statement:
Health workers and NGOs do not want to give us information

S The group's strengths

- *We are people with HIV so we know what it feels like to live with HIV.*
- *Many of us are young and so other young people will identify with us.*
- *One of our members is a nurse.*
- *Many of us have experience of talking to family and friends and successfully changing people's attitudes*

W The group's weaknesses

- *We are mainly men and we would like to involve more women in the group.*
- *We would like to be able to reach more women who are not getting treatment.*
- *Some of us depend on local doctors for medical care and are afraid of losing this if local health workers feel threatened by us.*

O Opportunities

- *A local traditional healer and nurse have offered to teach us about HIV-related illnesses.*
- *One of the group members can teach us about nutrition at our monthly meeting.*
- *A local NGO-run home care programme has invited us to be represented on their planning board.*

T Threats (or barriers)

- *It is difficult for some of us to challenge health workers and doctors.*
- *Only a few of us are open about our status. Some group members haven't yet told their families they are HIV positive and are unwilling to disclose their status to health workers.*
- *Lack of money*
- *There are only a few of us and we are afraid of 'burn out'.*

❸ DEFINE WHAT YOU WOULD LIKE TO ACHIEVE

It is important for the group to agree on am overall aim for the project. The aim (or goal) is a statement of what you would like to see changed or introduced to improve the problem you have identified (sometimes called a mission statement).

It is important to have only one aim that the project is addressing. If you have more than one aim, you will need more than one project.

❹ DECIDE ON ACTION TO TAKE

Objectives explain how the aim will be achieved. They describe what you hope will happen in the short term. They describe the 'outcome' (the end result) of activities. They need to be specific and measurable, stating:

- what will be accomplished
- who will do it
- who will benefit
- how much or for how many people it will be done
- how long it will take.

For example, if your objective is to run a training course for group members, the objective must state what the course will achieve, who will run it, who and how many people will attend and how long the course will be.

This approach is sometimes known as using SMART objectives:

S Specific – *training group members in chicken rearing*

M Measurable – *25 members will be trained*

A Appropriate – *your needs assessment shows that chicken rearing is financially sustainable*

R Realistic – *25 members trained in 6 months is manageable*

T Time-bound – *training will take place in 6 sessions over 6 months.*

© D Gibson/WHO

25 members will be trained in chicken rearing.

Below are examples of possible aims and objectives:

AIM

is to improve the quality of care of people with HIV who are sick

OBJECTIVE

is to train group members and family members in first aid and care through a 6-month training course, run by local nurse and Red Cross volunteers

AIM

is to promote acceptance of people with HIV

OBJECTIVE

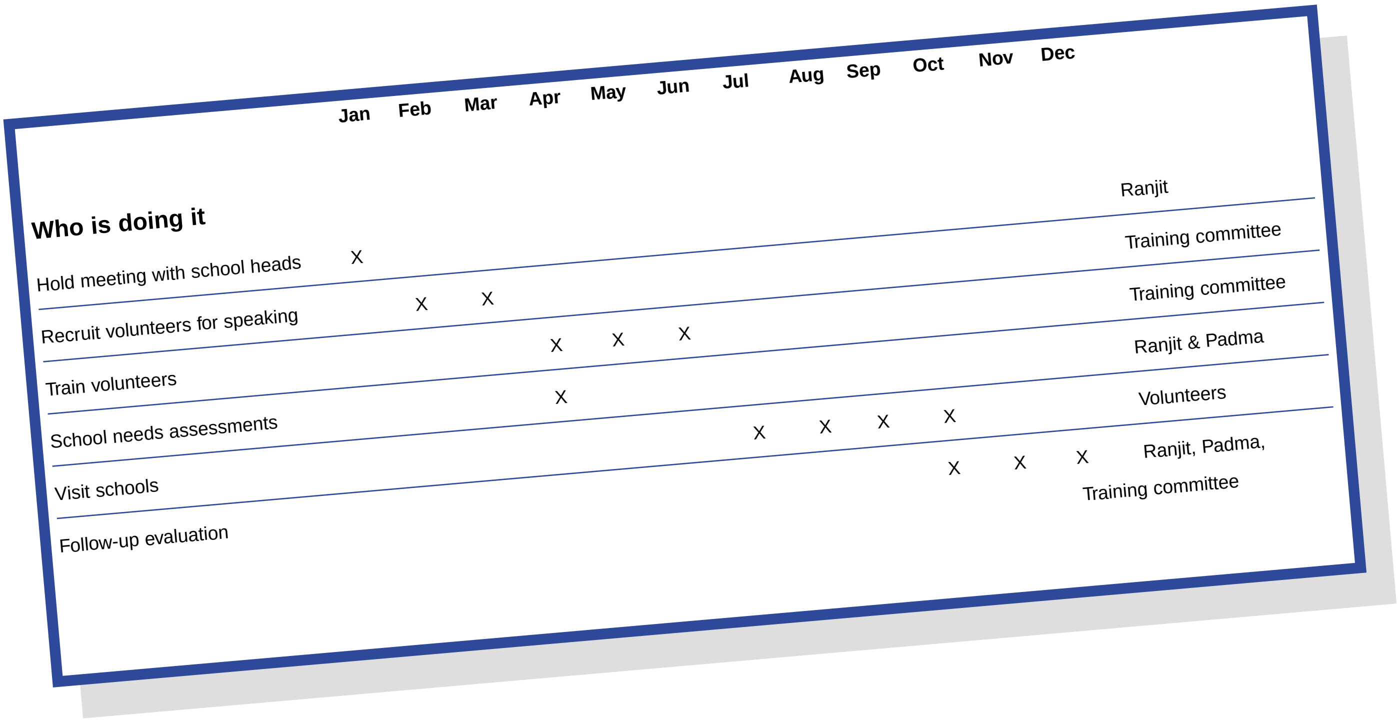
is to train group members for speaking in local schools and (visit 30 local schools in next 12 months)

Once you have decided what you would like to change, the next step is to plan specific activities, which will achieve your objectives and overall aim. Each activity planned should relate to an objective and overall aim. Write down the activity and decide what you will need to have to be able to do the work (inputs), such as people, materials, time and money.

❺ PREPARE A WORKPLAN AND BUDGET

A workplan records who will be doing what and when, for each activity. It is a good way of keeping a record of what everyone in the group is doing.

Here is an example of a workplan for a project taking speakers into schools.



	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Who is doing it
Hold meeting with school heads	X												Ranjit
Recruit volunteers for speaking		X	X										Training committee
Train volunteers				X	X	X							Training committee
School needs assessments				X									Ranjit & Padma
Visit schools							X	X	X	X			Volunteers
Follow-up evaluation										X	X	X	Ranjit, Padma, Training committee

For each project you will need to consider each activity and see what resources are needed and the cost (budget). Make sure that all resources are included – not all of these are financial – time spent by volunteers, for example, is a resource. It might be useful to divide the resources that are needed into two columns – one for financial inputs and one for inputs which do not cost money but which (e.g. volunteers' time or use of a hall which someone has lent you at no charge). See Part 5 for more information on preparing a budget.

© Caroline Firenza

❻ PLAN MONITORING AND EVALUATION

Monitoring

Monitoring means keeping an on-going record of an activity as it happens. It can tell you if the project activities have been implemented according to your plan.

To measure progress you need to develop indicators (markers which will indicate how far the activity is achieving the objective). For example, if you plan to distribute condoms in local nightclubs you will need to measure whether the number of condoms that you planned to distribute has in fact been distributed.

It is important to monitor your work because regular checking gives you the information to manage things. For example, if there is a problem, you are more likely to be able to minimise it if you can find out about it as soon as possible. Monitoring also provides information for reporting back and accounting to other group members, donors, partners, and anyone affected by the activity.

Evaluation

Evaluation is judging the value or effectiveness of your project. This usually happens at the end of a particular project or process. It is a way of assessing whether the activities have achieved their objectives and how far the objectives have achieved your aim.

Many projects fail to evaluate. This is often because:

- evaluation is felt to be too difficult
- it is left until too late, when the project is nearly finished
- changes in attitudes or behaviour can take a long time and are difficult to measure
- evaluation can feel threatening when it is carried out by ‘experts’ outside the project, who may expose problems in the work.

Evaluation is very important. If your project is successful, you will find it easier to do more. If it is less successful, you will need to make changes and measure whether new activities are achieving your aim. There are always lessons to be learned from any activity, successful or not. It is important to record and understand these to avoid making the same mistakes again. Some donors will require any project they fund to involve some evaluation of its activities.

Evaluation and monitoring should ideally be carried out at all stages of the project:

Before the project starts (the needs assessment): What is the situation like? What are people's priorities and what needs to be done?

During the project (project monitoring or process evaluation): Are the activities being carried out as planned?

After the project has ended (endpoint or impact evaluation): Did it make a real difference in people's lives and what changes have occurred? Results from this evaluation are used to plan the next phase of the project or any new activities.

Collecting information for monitoring and evaluation

Quantitative methods are used to collect data that can be measured in numbers. They answer the questions: who? what? when? how much? how many? how often? For example, finding out how many condoms were distributed in a nightclub, when, and how much time and money was needed.

Qualitative methods find out about questions in more detail. They normally answer the questions: why? and how? For example, finding out whether people in nightclubs used the extra condoms or not and why (talking to people).

Most groups are already collecting information about their activities and often collecting more information than can be used! Whatever methods you decide to use, think about how to make the information that you collect:

- **systematic** record sheets and checklists are only useful if they are filled in regularly
- **specific** only collect information that refers specifically to what you want to measure
- **easy to use** and that the person using the recording system understands what it is for.

When you want to measure more qualitative aspects of your project aim – such as changes in attitude or behaviour – you may have to carry out a more detailed evaluation. The following activities suggest some techniques for doing this.

ACTIVITY 4.3

STRUCTURED GROUP DISCUSSION

AIM To assess whether the project activities are being carried out as planned with the people you are working with.

❶ Prepare a few questions for the discussion: *What are the main successes and problems that have been experienced during the project? What changes in attitudes or behaviour have been observed in the people involved in the project since the project started? What are the possible barriers to change? How should the project develop?*

❷ Ask the participants to form groups of six to eight people.

❸ Give each group a pen and a large sheet of paper.

❹ Ask each group to discuss the questions and write their answers in order of importance.

❺ Regroup with the other workshop participants, and display all the response sheets.

❻ Discuss the similarities and differences in the large group.

❼ Reach agreement about the project priorities in either small groups or as the large group.

❽ Make a final list, which will be displayed in the project offices as a reminder of the discussion.

ACTIVITY

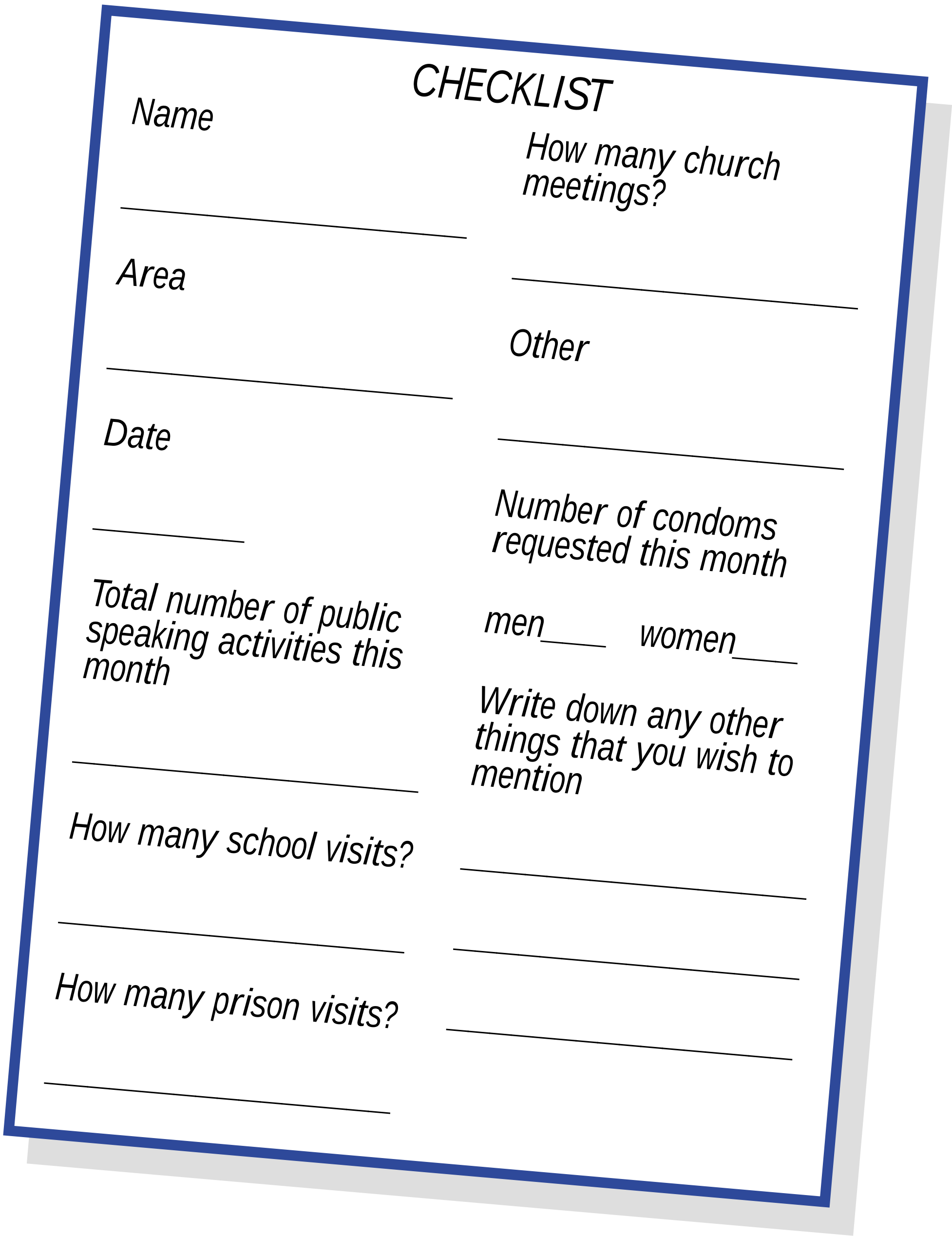
4.4

USING CHECKLISTS

AIM To keep simple records about project activities.

Checklists are completed regularly by people working with the project. They can provide information about a wide range of things, for example:

- who is attending activities
- what methods are used, such as group activities, drama sessions, picture code sessions
- numbers, for example of condoms distributed, where and by whom
- other interesting observations about the project.



CHECKLIST

Name ______

Area ______

Date ______

Total number of public speaking activities this month ______

How many school visits? ______

How many prison visits? ______

How many church meetings? ______

Other ______

Number of condoms requested this month

men____ women____

Write down any other things that you wish to mention

______

______

______

ACTIVITY
4.5

USING QUESTIONNAIRES FOR A SURVEY

AIM To collect information for an end of project evaluation.

Questionnaires are often used in surveys to collect information from a large number of people. If people are literate, then they can complete the questionnaire themselves. In nonliterate communities, researchers will use the questionnaire to collect information through a personal interview. Whichever method is used, everyone must be asked the same questions in the same way so that the results can be analysed and compared.

Designing a questionnaire

Decide what you want to find out, who will collect the information, from whom and how many people, when you need to collect the information, how the information will be collected (personal interviews or written questionnaires), how the information will be analysed and what will be done with the information you have collected.

Then, think carefully about what information is needed. The information should relate to the project aim and objectives.

- Keep questions brief and use simple language.
- A question is easiest to understand when it addresses one idea at a time.
- Use exact words which cannot be misunderstood to obtain precise answers and accurate information ask '*How many times have you had diarrhoea in the last week?* rather than *How many times recently?*'
- Use closed questions if a 'yes' or 'no' answer or a number is needed. For example '*Have you received any AIDS education at work?*'
- Open ended questions require the respondent to give a longer answer in their own words. For example: '*What have you learnt at work about HIV* and *AIDS?*' Open ended questions help to gather opinions that you may not have expected. Ask straightforward questions rather than ones which threaten or make a person feel uncomfortable, such as: '*In your opinion, how do you feel about the treatment which you receive from health workers at this clinic?*' rather than '*Do you think that the health worker at this clinic is polite and caring?*'
- Most importantly, keep the questionnaire short by avoiding unnecessary questions.

HINTS & TIPS

Planning your activities

What do you want to achieve (your aim), and why?

◆

What do you know about the situation now?

◆

How do you plan to do it (your objectives and activities)?

◆

How long do you think that your objectives will take to achieve?

◆

What resources will you need?

◆

How will you measure your achievement?

◆

How will you share your information with others and report back to the group? How often?

Before finalising the questions go through the questions (pretest) with a small group of people who are similar to the people who will be interviewed. This ensures that the questions are easily understood and that people are willing to answer them and that the interviewers know how to complete the questionnaires. The pretest will also show whether the information collected is useful and can be easily analysed.

Choose interviewers who are trusted and with whom people can easily talk. Go through the questionnaire in a place where people feel comfortable and have privacy.

Interviewers must be sure to explain why the survey is being conducted and what the findings will be used for. Ensure that respondents have time to answer questions. Invite further comments at the end of the interview.

CHECKLIST

Evaluations

* Have you helped things to change?
* Is the situation better than before?
* By how much?
* Have you accomplished your objectives?
* How have your efforts changed the big picture?
* If you have accomplished what you set out to do, did it go as you anticipated?
* If you did not accomplish what you had intended, why not?
* What made you re-plan your strategy?
* What would you do differently another time?
* Did you do even more than you expected?
* What does this mean for any future plans?
* What have you learned about the issue?
* Are the people and organisations involved in your group happy with the results of their actions?
* Are they happy with the process?
* Are they satisfied with their participation in the process?

What project?

What your group decides to do depends on the members' expectations and on what you feel you need to do. The main activities usually run by self-help and support groups for people with HIV are:

- emotional and social support for other people with HIV
- sharing ideas and practical information about HIV-related issues with others
- training in group skills, or personal or professional development skills
- running education programmes or speaking in public about HIV, such as at local schools or workplaces
- financial support through running loan or credit schemes, or income generation activities
- advocacy and campaigning, for example on workplace issues, confidentiality, access to treatment or 'gaining a seat at the decision-making table'.

Each group will have different priorities for action and most do a number of different activities. Here are some of the key issues that your group might like to consider before planning your own project.

© Crispin Hughes/Panos Pictures

Namirembe Post-Test Club make handicrafts for sale and have formed a drumming and singing group.

© Hjalte-Tin/Still Pictures

Groups can work with others in the community to support children who care for sick parents.

Support for other people with HIV

Possible activities:

- visit sick people to provide support and care for them and their families
- find out about locally appropriate and recommended medicines for illness and see if local health services or NGOs can provide 'home care kits', including condoms
- learn nursing and care issues to teach the family and others
- fundraise to support local HIV-positive people, for example, to enable purchase of medical treatments or farming equipment
- ask local lawyers to offer legal advice, for example on making wills, employment, housing, benefit or land rights
- work with religious groups to offer spiritual support to members and families at home
- contact traditional healers and talk to them about HIV. In some areas there are traditional remedies which are useful for illnesses such as skin rashes, diarrhoea and fever
- arrange for group members and other community members to help families during sickness, such as help with harvesting, supporting children who are caring for sick parents
- make links with doctors, dentists, lawyers etc. who you know are sympathetic and develop a 'referrals' list of useful local contacts
- become involved in local planning meetings for HIV care and suggest that people who are diagnosed HIV positive or develop illnesses are referred to your support group.

HINTS & TIPS

Be clear what you can do yourself and what it would be better to encourage and advise others (for example, health workers or church groups) to do.

◆

Do a needs assessment to find out what health and other services are available locally – home care, health centre, hospital and other sources of care such as traditional healers, complementary therapists, counsellors, legal advice, benefits advice etc.

◆

Care for yourself too! Avoid visits to places where your own health may be at risk, especially visiting people with TB.

◆

Make sure that there are people to talk to and an opportunity to rest and take 'time out' to avoid becoming over-stressed.

◆

Be aware that women are often under more pressure than men. They are usually the main carers when other family members are sick and are responsible for childcare. They are often poorer than men and have less legal rights.

◆

Consider whether there are other groups of people with HIV who have particular needs and are rejected from their community and cannot rely on family or community support.

◆

Poverty is the greatest problem that people with HIV face. Be aware of the limits of the support work that you can do and do not try to do too much!

◆

If you are providing support with donated medicines, make sure that you have access to health workers who can provide accurate and up-to-date medical advice.

'When I discovered that my husband and I had HIV, I enrolled in a home care training programme offered by the Red Cross Society. Most of the work I have done is home visits, giving moral support, providing education on self care and coordinating with hospitals when people become ill. Through making home visits, I have come to realise that people with HIV have an important role to play. If they make home visits or give talks, the people who are sick begin to confide in them. Now the ones who do home care visits are able to understand more about the problems faced by people with AIDS. If families work together with determination and sincerity, then people with HIV will have fewer illnesses and live for longer.'

Phimchai Inthamun, Chiang Mai, Thailand

' I have chosen to tell other people (that I have HIV) because I want to be honest with them. I did so because I wanted to talk to people about the dangers of AIDS and having many sexual partners. I feel very strongly about some of our customs which make life more difficult for women, such as wife inheritance and the fact that a husband's family inherits the widow's possessions even after a legal marriage. Women need to know there are laws which govern a divorce. I help women write their last testaments and help them provide for their children. I believe that each of us can live positively with AIDS and that we don't have to give in to unjust practices.'

Anna Kitwala, Tanzania

HINTS & TIPS

Make sure that people with HIV are involved in planning the centre so that the services offered and the atmosphere reflect their needs.

◆

Make the centre feel warm, friendly and welcoming – for example, put pictures of the staff and volunteers on the wall

◆

Make the centre easy to reach – for example, if you would like it to be accessible for street-based sex workers, make sure that they can call in easily while they are at work or on their way to or from work.

◆

Make the centre accessible for all users, if possible, for example, by making it accessible to wheelchairs, to deaf people, for people who cannot read.

◆

Provide childcare if necessary and possible.

◆

Make the atmosphere informal – avoid covering all the walls with AIDS information so that people can 'get away' from AIDS for a a while.

◆

Make drinks or snacks available, if possible.

Drop in centres

Drop-in centres are 'safe spaces' for people living with HIV. They may be:

- an informal meeting space where people meet and talk
- offer services such as counselling, therapies such as massage, laundry facilities, food, condom distribution
- provide hospice and respite care for people who cannot be cared for at home but do not need to go to hospital (or are excluded from hospital).

Some drop-in centres are for other groups of people, for example, centres for sex workers or drug users, which provide a 'positive space' for people with HIV.

© Where there is no woman doctor

HINTS & TIPS

Find out what employment opportunities are available locally before planning training – make sure that there will be a demand for people's new skills.

◆

Prepare external speakers and trainers so that the group and the trainers know what to expect.

◆

Make sure that any outside trainers respect your group's ground rules.

◆

Consider setting up a small 'resource centre' for your group, where you can keep up-to-date information (see Resources, page 123).

◆

Make sure that you have some information that is available in pictures or posters for people who cannot read and, if appropriate, translated into local languages.

◆

Do not assume that just because group members have HIV, they know about other health issues – consider planning some information sessions on reproductive health care, for example, and make links with the local clinics to provide contraceptive or ante-natal support to HIV-positive women and couples.

◆

Try turning some training sessions into activities – for example, after a training session on low-cost healthy cooking, see if people would like to try out and cook new recipes at regular support meetings.

Self-learning

Possible activities:

- one-off or longer courses for group members on self-care and HIV-related issues, for example, nutrition, new HIV treatments, massage, legal information, caring for our children
- 'capacity building' training for groups to strengthen their activities
- training for group members in new skills to improve economic opportunities, for example in vegetable gardening, money management, computer training.

'We set up a school run by ourselves called the HIV University for women to learn together about HIV, support one another and learn to advocate for better health care.

First we planned a curriculum. We focussed our 16 classes on: how the body works; what is HIV and HIV disease and how we can protect ourselves; reproductive health and STDs; safer sex; nutrition; treatments and side effects; alternative & complementary therapies; clinical trials; how to talk to your doctor; addiction; spiritual and mental support; and sharing what we have learned with others.

Once we had decided on these topics we contacted people in the community to help us. Some were living with HIV. Others were from service agencies, which was helpful in improving communications and access. We drew up guidelines for resource people, which included explaining complicated words, using objects and pictures such as samples of medicines or pictures of body parts, allowing time for questions and making lessons relevant to our lives.'

Sandi Luna, WORLD, USA

Public education

Many groups are asked to talk to the public about HIV. This can be a useful way of providing information about HIV to the general public, reducing fear and stigma against people with HIV and making contact with other people with HIV.

Possible activities:

- offer speakers to the local media. For example, have a regular ‘slot’ on local radio or TV programmes or in the local newspaper where group members offer advice or information to the audience
- arrange speaker meetings at local schools, workplaces, prisons etc.
- enable group members to participate in other organisations’ training sessions, to ensure that HIV-positive people have an input in training and education.

Commonly asked questions

How were you infected?
How did your family or friends react?
Are you gay?
How have you benefited from going public?
Have you informed your children?
What is the difference between HIV and AIDS?
Do you have sex? Would you marry again?
How do you feel about death?
What have you planned for your children?
Do you believe in God?
What about women choosing to have babies if they are HIV positive?
How did you get the courage to take an HIV test?
Where do I get tested?

Philly Lutaaya Initiative, Uganda &
Toronto People with AIDS Foundation, Canada

‘Our aim is to give AIDS a human face by giving education sessions on request to groups in the community. This encourages others to think more personally about HIV, support those who are trying to remain free of HIV and take away the stigma for people with HIV/AIDS. We try and answer questions as honestly and openly as possible. Each of us has a different story – some of us have children and others do not, some have chosen to abstain from sex and others have a healthy sexual life using condoms. When people listen to someone else’s story they understand much more. We have discovered that it is very important to be open about sex and sexuality with young people. They are interested in learning different ways of saying ‘No’ to unprotected sex and of having safer sex rather than being told simply to abstain. Many people after our sessions decide to make some change in their own behaviour or to seek further counselling and a test.’

Public educators, Philly Lutaaya Initiative, Uganda

© Philly Lutaaya Initiative

Members of Philly Lutaaya Initiative speaking in a local market.

HINTS & TIPS

Know your audience – make sure that you know what you are being expected to speak about before you arrive – be clear whether they are asking for you to provide a personal testimony or to talk about your group's activities, for example. Most people identify closest with speakers who are similar to them, such as young people listening to other young people.

◆

Don't be used! Consider charging organisations for your time and expenses, either a fixed fee paid to the group or volunteers' expenses.

◆

Train volunteer speakers and provide support and expenses for trained volunteers, covering food expenses, travel and childcare. Some groups prepare guidelines that public educators have to follow, such as being clear when a speaker is representing their group and when they are giving a personal opinion, providing receipts for expenses, informing the group if the person cannot turn up for a talk.

◆

Appoint someone in the group to coordinate speaking events.

◆

Prepare a 'speaker's pack' for volunteer speakers, containing basic facts about HIV and other useful information

Prepare a list of key questions that you might be asked and practice your answers. Some organisations collect a list of the 'commonly asked questions' (see page 74).

◆

When you go to give your talk for the first time, prepare your talk before you go – make notes that say: why you are there, what you will talk about (see pages 97-100).

◆

Take along a video or other information material to support your talk.

◆

Leave contact information with the audience after your presentation so that the audience knows where they can go for more information or for someone to talk to. Leave a phone number of the local telephone hotline or address of the local confidential drop-in centre if there is one.

◆

Provide support and 'debriefing' for the speaker after the talk – it may be useful for two people to go together.

HINTS & TIPS

Consider the social or cultural barriers to improving income. For example, are men expected to take control of family money?

◆

Decide if your activity will be a viable business enterprise or mainly aims to provide social support to people. If so, make this clear so that people do not have unrealistic expectations.

◆

Consider the extra administrative work and for how long you will continue to need extra financial support before you start an income generation activity.

◆

Consider all the costs of setting up a credit scheme, including salaries and office rent. Make sure that beneficiaries understand the need for repaying money with interest. Give adequate support to beneficiaries, such as literacy and basic financial skills and child care.

◆

Find out if there is a market demand for your product. Talk to local, sympathetic entrepreneurs or business development projects.

◆

Consider the particular needs of people who may be sick at times and what support they will require to run a successful project.

© International HIV/AIDS Alliance

This woman has used a small grant to set up a small shop outside the hospital, Senegal.

Financial support

The most serious problems faced by people with HIV is usually poverty.

Possible activities:

- provide advice about existing sources of support, such as church or welfare groups, or government benefits
- find out about existing employment options, such as arranging temporary work with local employers
- provide training for people who already run small businesses in production or business management
- set up a ‘savings club’ (where members put in a fixed sum of money each week and take it in turns to use the money)
- set up a welfare fund for small oneoff payments from a local donation or from fund-raising
- provide training, support and a ‘starter loan’ for individuals to start small businesses, such as petty trading
- start a group income generation activity, such as setting up a mill, printing and selling T-shirts or tailoring.

> 'The AIDS Service Organisation (TASO), Uganda, set up day centres for PLHAs. When TASO first started they wanted to meet all the needs of their clients and distributed food, such as eggs, rice and sugar, to clients and gave financial assistance for school fees... They also provided income generating training. However, material assistance still remains one of clients' key needs. Few of the income-generating activities set up were successful in supporting financial independence. People felt that they had not achieved self-reliance mainly as a result of lack of start-up capital, lack of adequate supervision and a lack of a clear policy in funding projects.
>
> **'TASO Uganda: the inside story', 1995, TASO, Uganda**

PART

5

Accessing resources

Ingrid Emsden/AHRTAG

‘We are our own best resource!’

Self-help and support groups around the world rely most importantly on the skills, enthusiasm and hard work of members. However, we also rely on other resources (things which we use to achieve our aims). Resources can be:

- human (time and contributions from people in terms of their skills and knowledge)
- material (office space, equipment, free food)
- financial.

Much can be done without resources. However, your group will probably need some external support and funds to carry out activities – even if this is simply a small amount of money to cover small expenses for a regular meeting.

CHECKLIST

Organising a fundraising event

- Set a date.
- Choose a venue or route – safe and accessible, with toilets, medical facilities and child care, if this is possible and necessary.
- Consult and get permission from the local authority and police if necessary.
- Consider involving other organisations, such as local schools, youth clubs, sports clubs.
- Organise publicity for the event and about your organisation.
- Ask for sponsorship or gifts from a local firm to pay for costs in return for publicity for the firm.
- Contact local press and radio.
- Invite a local or national celebrity to start the event or take part.
- Arrange all the necessary equipment.
- Tidy up afterwards, and thank everyone who took part.
- Publicise the total amount of money made among members and the community.

Looking for funds

Fundraising events

A good way for small groups to begin fundraising is to organise local events and activities, such as:

- fetes and carnivals or community festivals
- bingo games or lotteries, sports events, sponsored walks
- sales of produce or donated goods, auctions
- dances, discos, karaoke nights or concerts.

Businesses

Local businesses can support your group with:

- money, through grants, employee contributions, or donating a percentage of their profits to the group
- 'in kind' support, for example, access to equipment or offering to post mail
- technical support and expertise, for example, free services or advice, 'lending' a member of staff, for example an accountant to help you look at budgeting, or engineers and sound equipment for a World AIDS Day concert. Some businesses may also help to run free or low-cost training sessions, for example in book-keeping or public relations skills.

Businesses can reach many people that may be interested in your work. Employees may want to join or support your group. Businesses have contacts in the wider community who you may want to reach in awareness raising activities. Businesses can also play an important role as advocates, by providing examples of good practice in their workplace or using their economic strength or social standing in the area to lend support (see Part 7, page 112).

A word of caution – there are many reasons why a company may want to support your group. It may be concerned about the impact of HIV on its productivity, office morale and health costs. It may hope to create good relations with the local community. A company may want to be associated with your group to promote its own commercial interests. Before you contact local businesses, ask yourselves what the pros and cons of working with businesses will be. Will you be seen as 'selling out'? Be sure that group members and people who you work with do not feel that a company's commercial interests conflict with your aims and objectives.

© TAP NEWS

HINTS & TIPS

Use personal contacts and relationsips. Does someone in your family have business contacts?

◆

Find out which local businesses are interested in supporting your group's aims.

◆

Be clear what you are requesting and present it in business language.

◆

Find out what the business will expect in return? Can you meet these expectations?

◆

Find out what other support the company could offer as well as, or instead of, money.

◆

Know their motive and persuade them of the benefits of working with, or supporting, you. Remember that businesses exist primarily to make money.

© International HIV/AIDS Alliance

By developing links with local businesses OCAFI can do outreach work in local casinos.

Companies generally prefer to support local organisations, issues that are relevant to their business, of interest to their customers or in which a member of staff is involved. It is therefore worth contacting businesses most likely to be interested in your group.

Your request will have a better chance of success if it is clear and well-presented. Find out about the organisation and see if your expectations are appropriate. Try to give the company all of the information it needs to make the decision to support your group. A good way to do this can be to contact someone at the company first to find out what sort of information they want. Then you can write a brief appeal letter, addressed to the right person, highlighting the potential benefits to the company of involvement with your group or project.

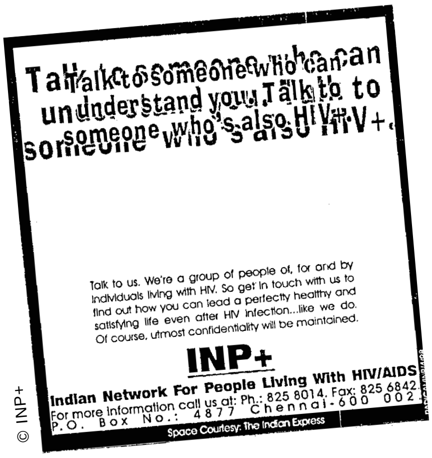
> OCAFI provides prevention and care services, including a support group for people living with HIV/AIDS, in Olangapo City, Philippines. They have built strong partnerships with local businesses, for example, working together with the local casino for World AIDS Day.
>
> 'We've learned about treating business as partners rather than enemies. We realised that we could reach out to our community through many different ways. We've learned that we had to sell ourselves not in an artificial way, just by showing our strengths and our links with the community. We interested local businesses and talked to them about why they should care about AIDS and what they'd gain. After that, they were keen to help.
>
> Business partnerships have led to benefits such as: a higher profile and respect among a variety of local businesses; financial and inkind support, for example, local businesses donating banners and materials for promotional work; increased access to entertainment workers in casinos. It takes time. In 1995 we got a small amount of funding for World AIDS Day but by 1996 companies were offering full financial support. We are now being by other businesses who are impressed by our reputation and want to become involved.'
>
> **Jude Asunción, Olongapo City AIDS Foundation (OCAFI), Philippines**

Sponsorship is where a business pays to have its product advertised by your organisation. Sponsorship ideas include:

- paid-for advertising in your annual report, brochures or newsletters
- displaying the name of the sponsor, for example at events or on equipment.

> 'One of the leading advertising agencies in Chennai produced a set of four advertisements free of cost for us. Space for these advertisements is being sponsored by a leading national newspaper. The advertisement advises people that we are all HIV positive and living positively and provides information on how to contact us.'
>
> **Indian Network of People Living with HIV/AIDS, India**

If you are looking for sponsorship you will need to be able to say how many people are likely to see the company's name or how many areas you can cover with a sponsored product.



Talk to someone who can understand you. Talk to someone who's also HIV+.

Talk to us. We're a group of people of, for and by individuals living with HIV. So get in touch with us to find out how you can lead a perfecty healthy and satisfying life even after HIV infection...like we do. Of course, utmost confidentiality will be maintained.

INP+

Indian Network For People Living With HIV/AIDS

For more information call us at: Ph.: 825 8014. Fax: 825 6842.
P.O. Box No.: 4877 Chennai-600 002.

Space Courtesy: The Indian Express

© INP+

Subscriptions

You can ask people to become a 'friend' or supporter of your organisation, for example by offering membership, a newsletter, reserved tickets for events, or other benefits, in return for a subscription fee. A subscription scheme can be an easy way of raising small amounts of money, but remember that you will have to provide the subscription benefits, collect the money, send out reminders, and keep an up-to-date list. All of this may not be possible for small groups.

However, an important advantage is that it gets people involved in your group over time. Supporters can also contribute to your group in other ways, such as skills or links with local businesses.

It is useful to have different subscription rates, for example, for HIV-positive people, family and friends and others.

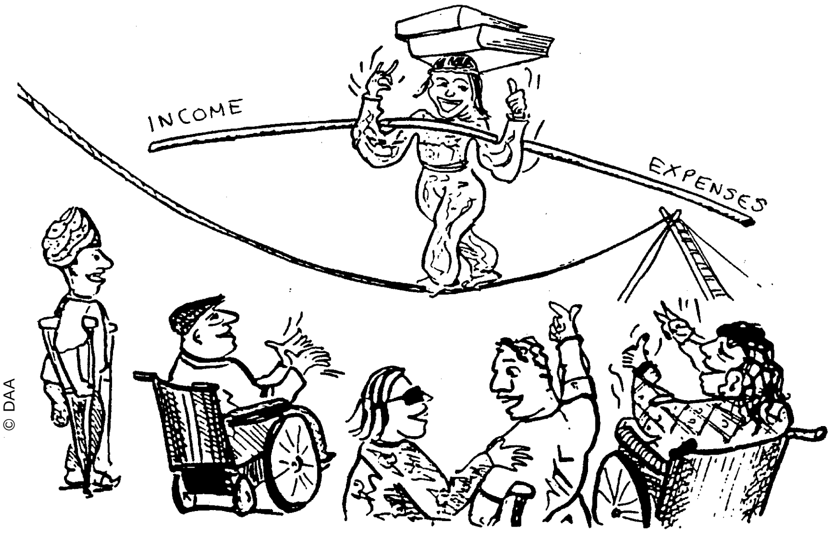
Self-financing

Self-financing means raising money through your own activities. People with HIV have acquired knowledge and experience that can benefit others. For some time, many groups have given their knowledge and experience for free, but some organisations are now charging others for:

- advising funded organisations or the media
- participating in research programmes, when the research has been approved by ethical committees and your members do not feel that they are being used as 'guinea pigs' (this is especially the case in medical research)
- providing training in HIV awareness work
- providing technical support to other groups, such as in organisational development.

'We used to do a lot of training for other AIDS service organisations. This led to some concerns – we sometimes felt our involvement in other organisations' activities were tokenistic. Now we make sure that if our name is put on a proposal we are involved from the planning through to the evaluation stage. We will do workshops for other organisations, but we will not go and do just anything anywhere as we did at the beginning. Now we prioritise certain workshops, those which we can do well. Now that we have had training in capability building the government has seen that we can handle projects ourselves and we are funded. '

Pinoy Plus, Philippines



© DAA

Good fundraising practice

For all fundraising, however small-scale, the following general principles are important.

- Collect good information and present it in a way that is easy to use. For example, one-page fact sheets, simple charts or leaflets are a good way to communicate facts and figures.
- Provide evidence of the value of your group for its members or benefits of its activities. This is useful for both general publicity and for showing to potential donors or partner organisations.
- Show any cost-savings that your services or project can provide.
- Be proud of what you have done and tell people about it. Publicise your activities and achievements. See page 103 for more information on dealing with the press.

HINTS & TIPS

Form a finance group with at least three members so that the responsibility for looking after the money is shared.

◆

Develop clear, written guidelines for how money can be spent, and by whom.

◆

Meet regularly, and keep up-to-date about how much money there is. Check the book-keeping system regularly, at least once a month.

◆

Make sure that the finance group has all the items necessary to look after money well.

◆

Keep a record in a book of all money coming in and going out (see example below). You can record all cash and cheques in the same book.

◆

Keep the finance records in a safe place.

◆

Keep as little cash in your cash box as possible.

◆

Give a receipt (and keep a copy) to anyone who gives money to the group for any reason, including donations.

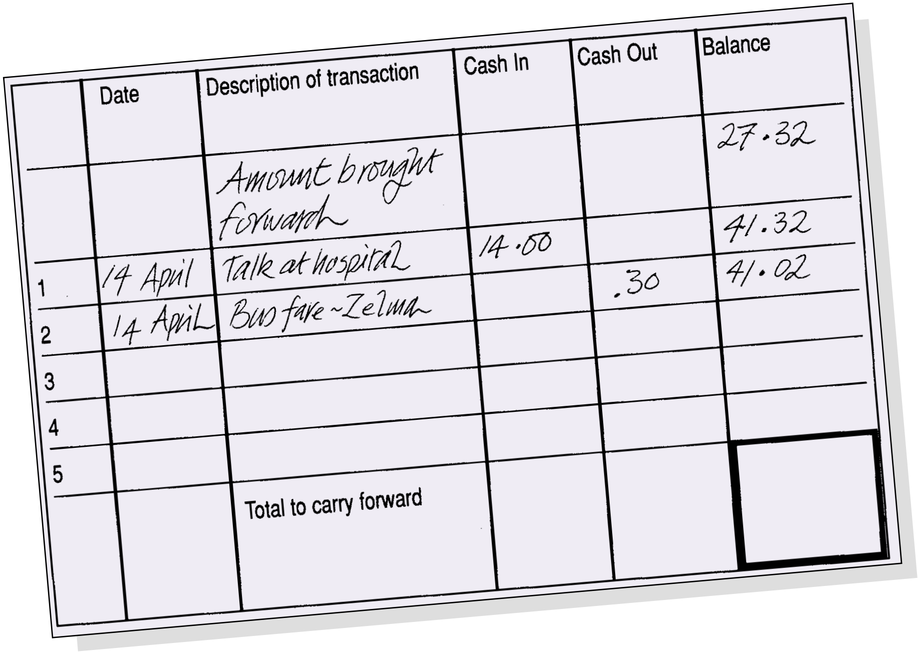
◆

For larger amounts, open a group bank account so that deposits and withdrawals are recorded by the bank.

Managing your money

Managing your finances is important, however small your group's budget. Serious problems can develop if you do not keep track of all your funds and expenses and if it is not clear who is responsible for monitoring the money.

Example of a cash book record

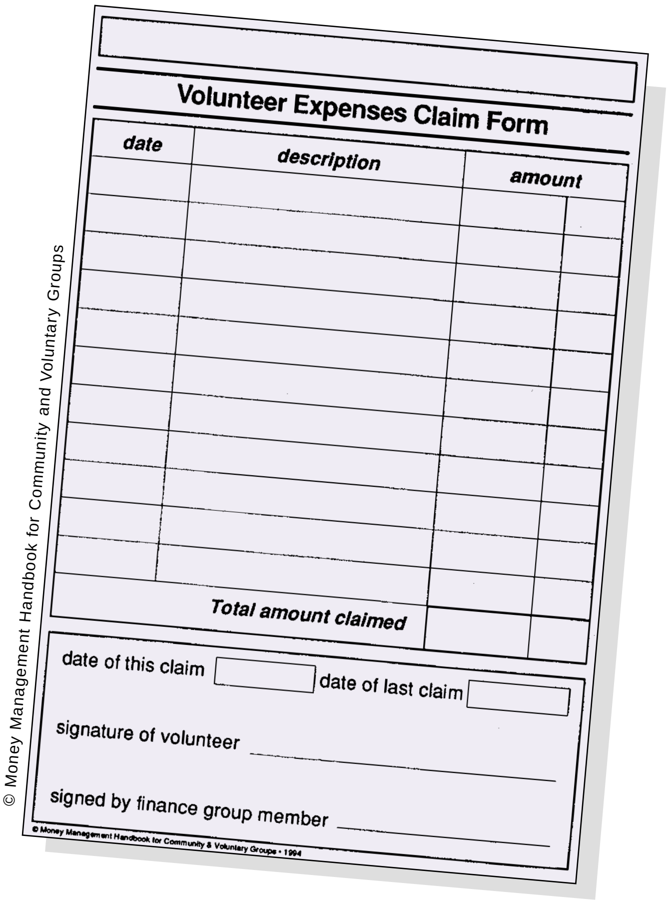


	Date	Description of transaction	Cash In	Cash Out	Balance
		Amount brought forward			27.32
1	14 April	Talk at hospital	14.00		41.32
2	14 April	Bus fare ~ Zelma		.30	41.02
3					
4					
5					
		Total to carry forward			

Dealing with cash

It is important to have some rules about the small amounts of money which are not kept in a bank account (petty cash). These should be written down and everyone should know and understand the rules. For example:

- Be clear about who is responsible for handling petty cash – ideally this should be the finance group.
- Have a sensible place to keep small amounts of cash. This doesn't have to be a lockable cash box but should be kept somewhere secure.
- Always get a receipt for anything that your group spends money on.
- If you can't get a receipt, or have lost it, get a petty cash voucher signed.
- Keep receipts and petty cash vouchers in a secure file – a ring binder is ideal.
- Always give receipts to people who give your group money.



Volunteer Expenses Claim Form

date	description	amount	
	Total amount claimed		

date of this claim ☐ date of last claim ☐

signature of volunteer ____________________

signed by finance group member ____________________

If you are paying out small amounts of cash on a regular basis, such as travelling expenses, you might want to use claim forms for writing down the amount of money requested, what for is clearly written, the date. These forms can then be signed by another group member (the person who is responsible for coordinating public speaking events, for example).

Book-keeping kit

In order to manage money well, it is helpful to have the following items to make the job easier:

- account book – this is the book in which every transaction is recorded
- large, strong ring binder file to keep receipts
- ring binder file for important documents, such as letters, bank statements and finance reports
- glue and scrap paper for sticking small receipts onto
- receipt book, with carbon copies, to people who give money to your group
- petty cash claim forms
- somewhere safe to keep cash, for example a tin
- somewhere safe to keep financial records – a lockable cupboard is probably the best place.

© Caroline Firenza

Fundraising for larger amounts

Research

Talk to other people and groups who have experience of fundraising. Your local library may be able to help with contact numbers and addresses. Large international and regional donor agencies may have branches near you. (See also the fundraising resources listed on page 123).

Learn as much as possible about each funding agency you approach. What interests them most? What size and type of grants do they give and to what kind of organisations?

Target

Choose the funding agencies whose interests best match your project and its needs. Highlight any connections between the funder's interests and your work.

Do not send copies of your proposal to agencies which you have not researched, to which your proposal is clearly not appropriate, or which do not fund your type of organisation.

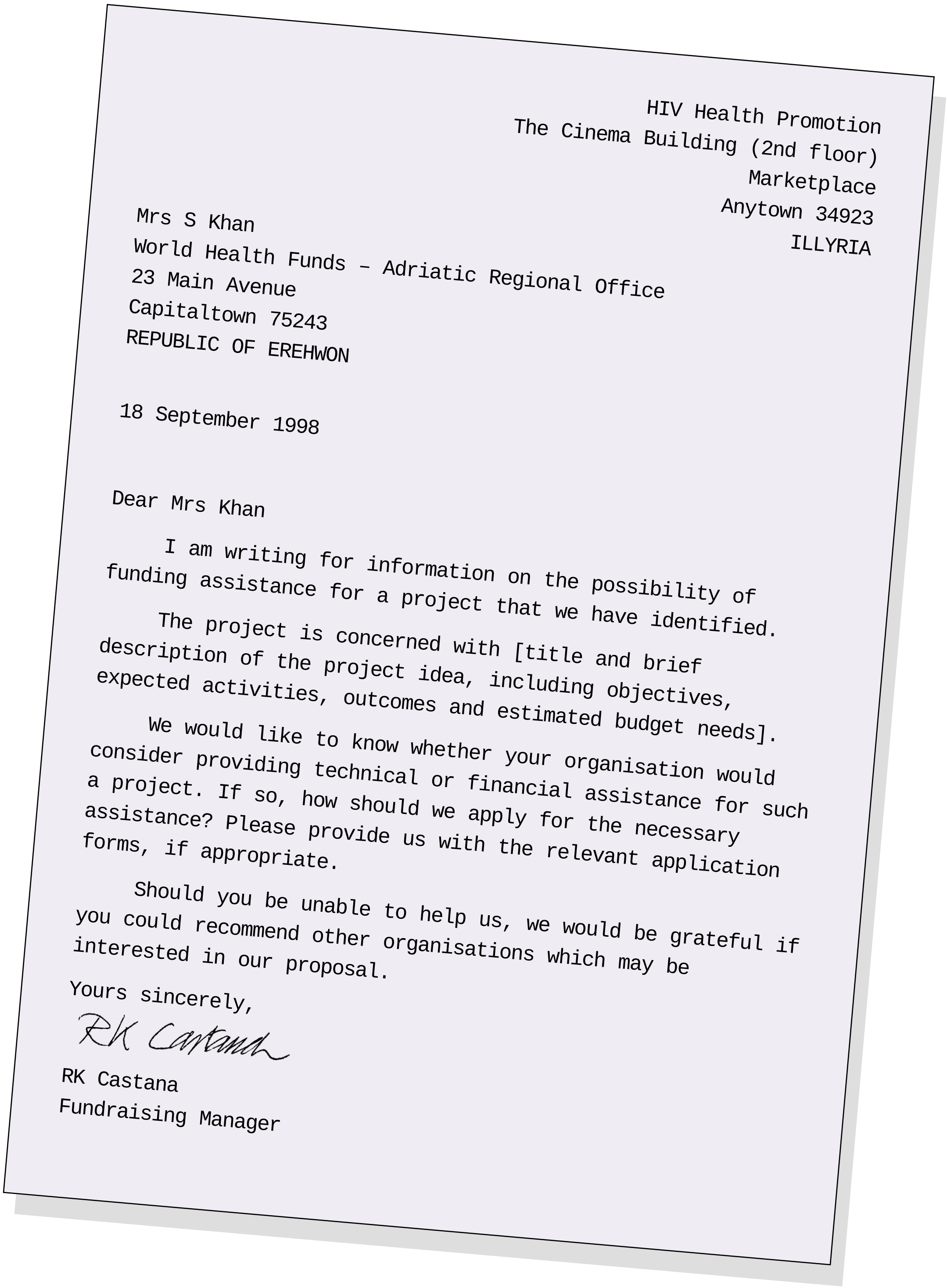
Funding agencies are likely to want to know:

- Who are you, where do you work and who do you work with?
- What is the problem, need or want?
- What action are you proposing and why have you chosen it?
- What are the expected benefits, and who for?
- How much will it cost?
- How will you evaluate what you have done and how will the lessons be used?

Letter of enquiry

It is a good idea to send an initial letter of enquiry before you prepare a full proposal. Address it to a named person if possible, asking whether their organisation is willing to consider a proposal for your project and, if so, whether they have any particular requirements.

Sample letter of enquiry



HIV Health Promotion
The Cinema Building (2nd floor)
Marketplace
Anytown 34923
ILLYRIA

Mrs S Khan
World Health Funds – Adriatic Regional Office
23 Main Avenue
Capitaltown 75243
REPUBLIC OF EREHWON

18 September 1998

Dear Mrs Khan

I am writing for information on the possibility of funding assistance for a project that we have identified.

The project is concerned with [title and brief description of the project idea, including objectives, expected activities, outcomes and estimated budget needs].

We would like to know whether your organisation would consider providing technical or financial assistance for such a project. If so, how should we apply for the necessary assistance? Please provide us with the relevant application forms, if appropriate.

Should you be unable to help us, we would be grateful if you could recommend other organisations which may be interested in our proposal.

Yours sincerely,

RK Castana

RK Castana
Fundraising Manager

HINTS & TIPS

Fundraising proposals

Follow the donor's guidelines and address its special interests.

◆

Be brief. A standard proposal should be no more than ten double-spaced pages, plus a title page and a list of contents.

◆

Keep it simple. Avoid complicated words, slang or jargon. Explain any special terms, abbreviations (shortened words) and acronyms (words made from initial letters, such as PWA).

◆

Focus on one message. Explain the importance of what you propose to do.

◆

Talk about specific activities and concrete results. Avoid general statements other than perhaps in describing the long-term aims and philosophy of your group.

◆

Emphasise the impact that your project will have. Explain who will benefit, and how.

◆

Emphasise your skills and knowledge. Show that your group and project is unique, and explain why.

◆

Make your proposal attractive — it should be clear and easy to read. Use double line-spacing.

◆

Be prepared for the funder to suggest changes to the proposed project design.

◆

Keep copies of the proposal and any correspondence.

© Marie-Thérèse Feuerstein

Get to know your funder. If possible, arrange a meeting with the person who is dealing with your application. If they cannot spare the time for a meeting, see if they will talk to you on the phone for ten minutes. Talk about your ideas before sending in a final proposal. Some funders may tell you about what they would like to see in a particular programme.

Your appeal has more chance of success if you start by asking for smaller grants. You can then gradually increase the amount as your organisation builds up a record of successful projects and experience in financial management. Be realistic and 'transparent' (open and honest) about your needs. If you overestimate figures this will cause suspicion and they will be unlikely to fund you.

Consider asking an established organisation to host the account and provide financial backup if you have not done this before. Keep careful records of how all your money is used.

Show how the project will be funded in the future. Funders like to support projects which have the potential to become self-sufficient over time, so their contribution can reduce as a project gains increased local support. Show that this is being considered in your proposal, for example by including a 'start up' year followed by less costly 'scaling up' activities in the second year.

Read the funder's guidelines carefully. Make sure that you send in your proposal within any time limit and that your proposal follows their specified format.

Stages of fundraising

1. An agency officer looks at your appeal or letter of enquiry, along with many others. This person then decides if your project is within the agency's funding guidelines.
2. If your project fits the donor's requirements, your group is then asked to send in a full proposal. You may also be given a particular outline to follow
3. You send in your full proposal.
4. The agency officer reads the proposal, along with many others. The officer may contact you to ask for further information or explanation of certain points in the proposal.
5. The officer than writes a report assessing each funding proposal.
6. Copies of all proposals are given to members of the agency's board of directors or grants committee, along with the officer's report.
7. At the next meeting of the board or committee, the members decide whether or not to fund each proposal.
8. You are informed of this decision.

This process can take a year to complete, and sometimes longer.

Elements of the proposal

❶ Summary (not more than one page)

The summary must be short but should highlight all the key points of your proposal, including:

- a brief description of your organisation
- a few sentences on the problem or need for the proposed project
- a description of the project (including where it will be carried out, long-term aims and one-year objectives)
- the expected results or outcomes of the project, specifying who will benefit
- the planned length of time of the project
- how it will be monitored and evaluated
- the total funds needed for the project (include any funds from other sources, and the amount requested from the funding agency).

❷ Information about your organisation and its track record (about one page)

This section should include: the name of the organisation, who started it and why; overall philosophy (or ‘mission statement’); the members and who benefits from your group; how the group is organised (number of paid or volunteer staff, any governing body or advisory groups, your legal status as a charity, if appropriate); recent activities and achievements; awards or honours your group has received; quotations about your group from community leaders or experts, or any past evaluations which demonstrate success.

❸ The need for the project (about one page)

Briefly explain the problem or need that your project is proposing to meet. Explain why and how you know that this need is important, and back this up with information, such as quotes from authorities or people who will benefit. Do not assume that the reader will know about HIV. Explain why your work is significant, for example, that you work in the region with the highest prevalence of HIV in your country. Point out what is special or unique about your project.

❹ Project description and plan of action (not more than three pages)

List the project’s overall aim and the shorter-term objectives, for example objectives to be achieved in the first year of the project. There should be no more than five of these for a large project.

Describe the stages you will go through to reach your objectives and explain why those particular stages are important. This section will say what your project will do, how, why, where and when it will do it. Show any significance of your plan for the future, for example any cost savings or improvements in quality of life resulting from your project.

Explain future plans including an outline workplan or timetable of activities, showing the months when different stages of the project will be carried out. Show when you will be making major financial expenditures.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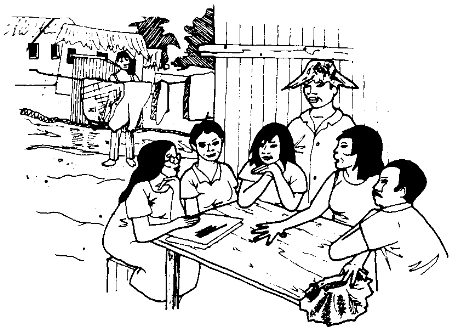
Explain who has overall responsibility for directing the project, who else will be involved and what each person or group’s responsibilities will be. Use job titles rather than individuals’ names. State whether each person will be paid or is volunteering their services. This information will explain what you have budgeted for in salary costs.

If any special advisory committee will be set up for the project, describe this and what it will do.



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❺ Expected outcomes (up to two pages)

In this section, describe what you expect the results of the project to be. Explain who will benefit from this project (and give any details such as their age, sex and HIV status). Emphasise that people with HIV and AIDS will be directly involved in the project design, planning and implementation. Show how this is done and explain why it is important.

Describe your monitoring and evaluation methods and how you will use this information for any future plans. Mention:

- any regular monitoring arrangements to identify and correct problems as you go along
- who is responsible for carrying out and for directing the evaluation process
- how often evaluation will be carried out, when the results will be reported and who to
- exactly what you will examine to measure the success of the project (these indicators should be related to the project objectives and there should be at least one for each objective)
- what data or facts you will collect for your evaluation, how you will collect these, and how they will be analysed
- how you will share the lessons learned from the evaluation with the community and with others, including the funder
- how the evaluation will be used to improve the project.

❻ Budget (one page plus notes)

A proper budget must be based on amounts that you know are correct, because funders will want to know how you arrived at your figures. Check that every item in the budget clearly relates to your planned activities.

It is good practice to put notes into the budget to explain any expenses that may seem high. For example, if appropriate, you could explain that travel estimates are based on the lowest available costs, or that translation costs include sign-language interpretation.

Include in the budget a list and explanation of all non-money elements which will contribute to the project (‘in-kind’ contributions). These might be volunteers’ time, loaned vehicles, office space or any donations of services, supplies or equipment.

Mention other funding that you have and who else you are approaching for future funding. In particular, explain how you will raise any additional money for this project which is not being requested in this application.

Outline any plans you have for how you will support an on-going project when this proposed funding ends. Some of your budget costs may be for once-only expenses such as buying equipment. But have you included costs for maintenance and repairs? Are there any plans for the project to generate income without outside funding?

Explain briefly the financial management system for the project including where the funds will be deposited. How is spending controlled and who by? Who does financial reports and how often? Are your accounts audited? If so, who by?

(See example budget worksheet on next page)

❼ Supporting materials

With your proposal, you can include support materials such as: your organisation's latest annual report; any policies on equal opportunities or human rights commitments that your organisation has made; copies of any newspaper reports about your activities; a list of member groups (if you are a coalition); the curriculum vitae (CV) of the person leading the project.

Follow-up

Even when you have submitted your proposal, remember that there is a lot of competition for funds. It is advisable to check that your proposal has been received at the funder's office, but do not pester them for an immediate reply. If you have not heard from the funder after a month of submitting your proposal, you could follow up with a polite letter. Ask for confirmation that your proposal has been received and about when you are likely to receive a response. (It may be in six months or a year.)

Keep a record and copies of all applications, with dates of each, and notes of any connected phone calls or meetings.

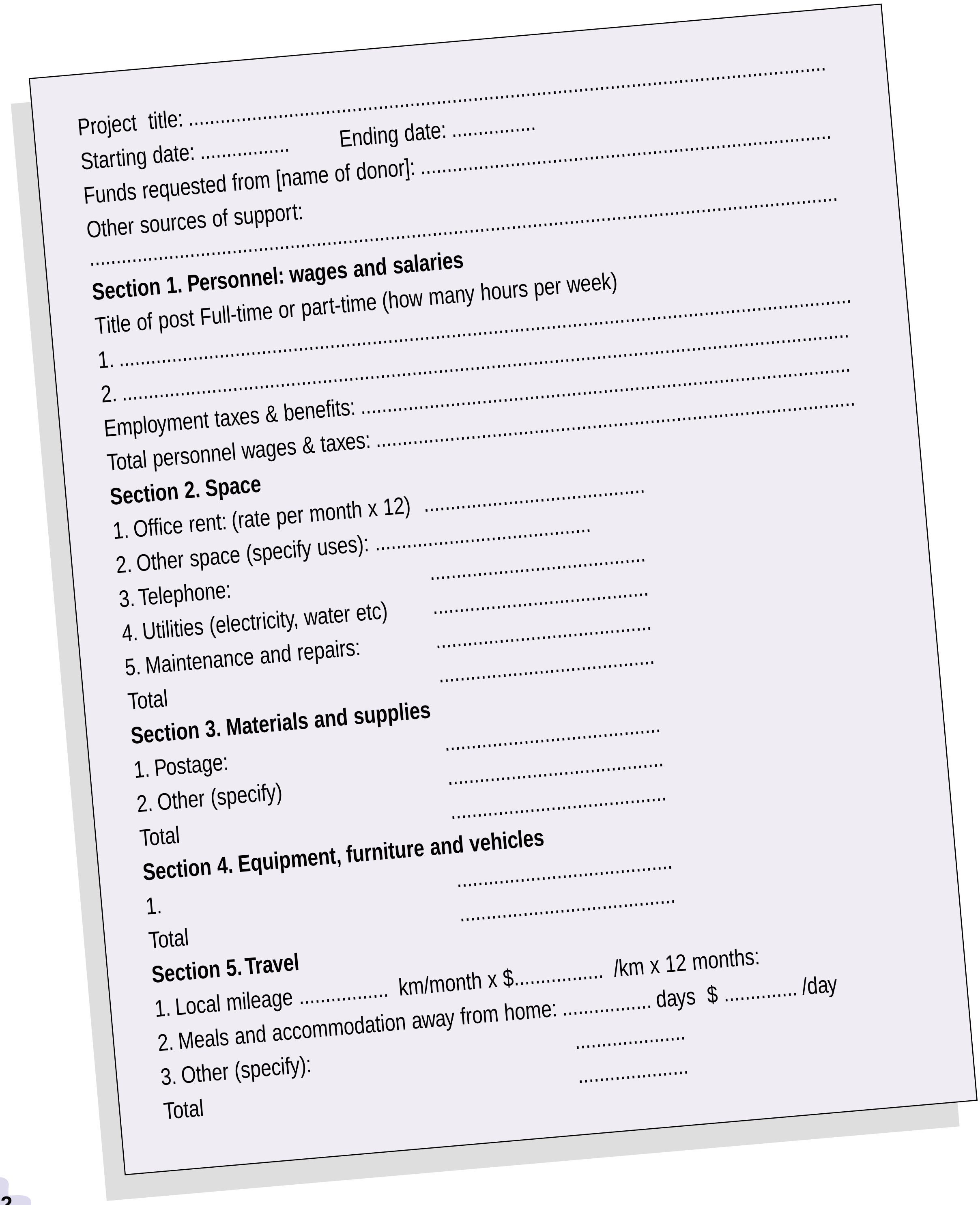
Use every opportunity to build relationships and increase the funder's knowledge and confidence about your organisation

If your proposal is not successful don't give up. Any proposal can be rejected – even those from very experienced and successful fundraisers. Try to find out the specific reasons why your proposal was rejected. You may be able to submit your proposal again with some additional information or by putting your case in a different way.

If your proposal is successful, it is very important to thank the funding agency for their help. Make sure you meet reporting requirements, for example by providing them with quarterly reports. You may want to apply again for something else in future. They will be more willing to fund you next time if they feel that they know you well. Invite them to visit you or the project they are supporting, invite them to attend activities and encourage them to feel appreciated and ‘part of the family’. Ask them for feedback during the project. Do not forget to acknowledge your donors at meetings or in publications and reports.

Example budget worksheet

This will need to be adapted to relate to your proposed activities.



Project title: ....

Starting date: .... Ending date: ....

Funds requested from [name of donor]: ....

Other sources of support: ....

....

Section 1. Personnel: wages and salaries

Title of post Full-time or part-time (how many hours per week)

1. ....

2. ....

Employment taxes & benefits: ....

Total personnel wages & taxes: ....

Section 2. Space

1. Office rent: (rate per month x 12) ....

2. Other space (specify uses): ....

3. Telephone: ....

4. Utilities (electricity, water etc) ....

5. Maintenance and repairs: ....

Total ....

Section 3. Materials and supplies

1. Postage: ....

2. Other (specify) ....

Total ....

Section 4. Equipment, furniture and vehicles

1. ....

Total ....

Section 5. Travel

1. Local mileage .... km/month x $................. /km x 12 months:

2. Meals and accommodation away from home: .... days $ .... /day

3. Other (specify): ....

Total ....

PART

6

Communication skills

Source: Oxfam

© Gideon Mendel/Network

"Telling people makes me feel stronger." Positive educators, Hlabisa, South Africa

Making presentations to your own group, and also speaking at larger meetings and events, can be a valuable way of increasing awareness and understanding about HIV and AIDS. At some stage some group members will want to speak in public or to their family and friends. This section provides practical advice for developing public communication skills – speaking to larger groups and the media.

Disclosure

When you work as part of a group concerned with HIV and AIDS, people may assume that you are HIV positive. This is not always the case. Some groups include people who are not themselves HIV positive. However, because of this assumption it is important that anyone who is prepared to speak up in the name of your group considers the impact of disclosing their HIV status.

As individuals and as a group, you may want to consider the issue of disclosure – revealing your HIV status – before beginning activities that raise your public profile or talking to other people outside the group.

- How would you feel about people assuming that you are HIV positive because of your work with the group?
- Who do you want to know about your HIV status – everyone? Only family and close friends? Only the people you work with? Only people outside your own home area or country?
- If you appear in public, speaking to a group for example, or on television talking about living with HIV, do you want to be open about your own HIV status?

Being open about your HIV status can affect your life greatly. People can react to your disclosure in many different ways. Some people may be hostile or angry, while others may accept and respect you for being open.

Advantages and disadvantages

There is no simple answer as to whether or not it is best to disclose your HIV status, and your feelings about this may well change over time.

It can be very difficult to tell people that you are HIV positive. Some people may find it hard to take in the news that you are giving them. This can be upsetting for everyone concerned. It may be useful to consider the advantages and disadvantages of being open about your HIV status in your own particular situation.

Some possible advantages

- You may be relieved to stop keeping your HIV status secret. You will be able to speak more freely and openly.
- You may be better able to help other people who are learning about HIV and the issues and concerns around it.
- Other people may be encouraged if they see you as an example of someone who can be open about your HIV status.

'After speaking publicly about having HIV, what has happened is that – curiously – I have become someone who is listened to more than before. When I talk to people at meetings or my friends, they listen to me as if I were a wise elder. I welcome being seen as an older person because in Africa they are the most respected.'

Group leader, Lumiére Action, Côte d'Ivoire

`It is important for people living with HIV to have visibility in training workshops. We've created a consciousness in people through these types of workshops. People think AIDS isn't a problem in Ecuador, but when we're in a workshop and I tell people that I'm positive, it's a surprise for them because they thought noone here has AIDS. They can see that we're here and that AIDS is real."

Member of Amigos por la Vida, Guayaquil, Ecuador

'When I came out, the Department of Health helped by providing me with work. I'm also asked by NGOs to talk to their communities about HIV/AIDS. It's more effective for me as a person living with HIV/AIDS to do this work because I can talk about and share my experiences. I can tell people why I have this disease and what I'm doing now – and that, although I have this hard trial, I'm still here and productive. People want to see people living with HIV/AIDS – it's an experience for them. I tell people that HIV is not the end of your life. After you're diagnosed, another life begins.'

Archie Rivera, Pinoy Plus, Philippines

Some possible disadvantages

- Telling people that you are HIV positive may make you feel worse than when you alone knew about it.
- You may feel that everyone is talking about you as a person with HIV, not just the same person that you always have been.
- You may find that people cannot accept you in the same way as they did before they knew that you were HIV positive.

`I live in a society where it is not acceptable to talk about HIV. If my neighbours and work colleagues knew that I was HIV positive my life would not be worth living. I have told my family and they are very supportive, and I go along to a small group of other HIV-positive women, but I make sure that noone else knows.'

`I go abroad and talk about the needs of people with HIV. But I cannot be open in my own country. My children would suffer.'

ACTIVITY
6.1

PRACTISING DISCLOSURE

AIM To consider what might happen as a result of letting other people know your HIV status.

This can be done as a group brainstorm or individually.

Make a list as in the example below. Add other people who may find out that you have HIV if you disclose your status.

	Advantages	Disadvantages
Partner		
Mother/father		
Children		
Work colleagues		
Boss		
Football team members		

Going public

Everyone has worries when they are asked to speak before a group for the first time, and very few people are `natural speakers'. With practice, however, we can all learn to improve our self-confidence and presentation skills. It can help to watch how public figures present an issue successfully.

Preparing your presentation carefully will help you to communicate your ideas clearly and simply. It can also help you to present your message with clarity and conviction.

CHECKLIST

Planning your presentation

1 WHY are you making this presentation?

* Is it to persuade, teach, inform, entertain or all of these?

* What actions, if any, do you want your audience to take as a result of your presentation?

* What other objectives do you have?

2 WHAT do you have to say?

* Make a list of all the ideas, information and issues which you could present on your subject.

* Choose the best of these that you would like to link to your objectives. Which are the most important?

* Make only a few important points – not more than three, for example. This helps to leave your audience with a very clear picture of your presentation.

3 WHO are you saying it to?

* How many people may be attending your presentation?

* Why are they coming, and what do they have in common?

* Do they have any knowledge of the subject that you will be presenting?

4 HOW will you be saying it?

* Will you be alone?

* Do you need any visual aids or hand-outs?

* Can you include any humour or drama to add impact?

* Will you ask the audience to contribute?

5 WHEN will you be saying it?

* At what time of day? (Will this affect who can come, and how they might be feeling?)

* How long will the presentation last?

6 WHERE will you be saying it?

* How big is the room?

* How near will the audience be to you?

* Try to visit the room before you speak there.

HINTS & TIPS

Making presentations

Do not forget to breathe, especially before you speak. Whenever you feel that you may be in trouble: stop – breathe – breathe again – and then re-start.

◆

Avoid leaning against the furniture, and try not to sway or rock.

◆

Avoid distractions such as jangling money or keys, playing with your hair, clothes or spectacles, or distracting jewellery which will reflect the lights.

◆

Have a glass of water at hand, if possible, but not so close that you may spill it.

◆

Try not to become rigid and stay free of tension in your head, neck, shoulders and arms (some of the activities below can help with this).

◆

Smile with your audience, as this helps to relax your face and to give a warm and relaxing quality to your voice.

◆

When you have finished your presentation, pause (do not run away).

It is often useful to brainstorm ideas and think about your presentation with friends or colleagues first. Think about the messages that you want to put across and how to emphasise them.

Everyone – even a very experienced speaker – benefits from practising. If possible, rehearse enough so that you only need to glance at your text and not read it word for word – practice in front of your friends, your baby, a mirror! Ask friends or colleagues to be your `audience' and give you feedback. Time yourself and, if necessary, make your text shorter or longer to fit.

Delivering your presentation

To help you cope with nervousness, arrive well in advance and get to know the venue where you are doing your presentation. Try to be in control of the occasion, and remember that you know more than anyone else in the room about what you are going to say.

Your presentation begins before you start to speak: it starts as soon as you stand or come into view. Make a confident entry and take control of your space. Stand square and upright, facing your audience, and with your feet comfortably balanced.

Be seen, and try not to give the impression of sheltering behind a table. Avoid creating any barriers between you and your audience: these can obstruct the flow of communication between you and your listeners.

Body language When delivering your presentation, be aware of how your body language and behaviour can have an impact on your audience. Look at your audience and make eye contact as soon as possible. This is very important as it can give you an idea of how people are receiving your message.

Appearance `Look the part' and dress appropriately. If you wear a business suit to a group of young people, this will probably not help the young people to feel relaxed, but rather intimidated. On the other hand, wearing jeans to a presentation for local business leaders would probably not be well received either. Appropriate clothing can help to build trust and give people confidence in you. If you are unsure about what to wear to a particular meeting, you can always ask what form of dress is usual.

Gestures Physical gestures can add great impact to your presentation. Try to gesture from the shoulder, and not just the elbow or wrist. For greatest impact, make a gesture before you speak the words to go with it.

Talking out loud

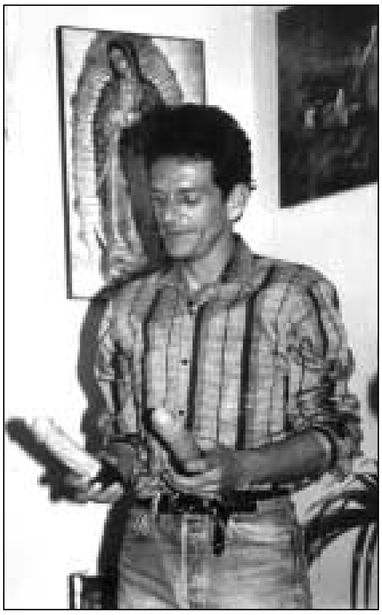
Are your words clear? Try to make sure that your words do not run into each other. If you have tongue-twisting things to say, or difficult words, rehearse them before until you can say them easily and clearly. (Alternatively, avoid the difficult words altogether, by using other words.)

Is your voice interesting? Show enthusiasm for your message by being expressive in what you are saying. If you sound bored, your audience will probably feel the same way. Your voice should move up and down as it does in everyday conversational speech. This is much more interesting to listen to.

How fast are you talking? Are you racing – too much to say in too little time? Make your speech shorter. Is it too slow? If you do not have enough to say, make your presentation shorter rather than slower. Pause occasionally – people need time to think about what is being said or what might be happening. It might be useful to mark certain places in your text to remind yourself to emphasise certain words or to take a breath.

Do you sound nervous? Take three deep breaths, or simply say you are feeling a little nervous. The audience will probably feel relieved: maybe they are feeling that way too.

Is your voice loud enough? If people have to strain to hear you they will quickly give up trying. Ask people to let you know if you get too quiet by saying *‘Put your hand up if you can hear me’*. Even presentations to a small group require more volume than your normal voice. Speak to the people at the back of the room.



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‘Use real objects like condoms, where possible,’ Eudes, Ecuador

Visual aids

People usually remember images more easily than words. Visual aids can add impact to your message. Try to make them communicate something which words cannot. Use your visual aids sparingly for maximum impact – to emphasise a key point, add drama or mark a change of pace or focus. Visual aids must be relevant, and should support your message.

- Slides and photographs – use strong, active images that clearly communicate your message. Always make sure that the people in the slides are happy for their images to be used.
- Use real objects rather than models where possible. For example, pass real condoms and bananas or cucumbers around the audience, for people to practice using condoms.
- Avoid complicated diagrams, tables and charts. Try to keep them as simple as possible
- **Remember** that you are your own number-one visual aid.

Answering questions

- Don't feel you have to know everything. It is fine to say "I don't know" and where possible, offer to find the information later.
- Speak from your own real life experiences, rather than giving theoretical answers.
- Where appropriate, encourage discussion, rather than simply question and answer.
- Prepare some answers to possible questions beforehand. Decide which questions you will not answer, if you feel the questions are too personal and be prepared to explain why.

After your presentation

Speaking to a large audience, especially when you are not very experienced, can be difficult and tiring.

- Make sure that you can talk to someone after the presentation, if you need to.
- Consider taking someone with you to your presentation so that you have someone there who knows you.
- Get feedback — the audience can help you by their response sometimes. Also tell the people in the audience that they have been supportive by listening to you.

Relaxation and breathing exercises

A good way to relax is to do some stretching exercises. For example, lift and then relax your shoulders, then gently shake your whole body and keep breathing. Just before you speak, check that your posture is free and relaxed, with no tension in your neck. Breathe deeply and from the bottom of your ribs. Look at your audience and remember what you want from them. Breathe in, then start to speak only when you breathe out. This means that you start off as relaxed as possible and with plenty of breath.

Note: always stop doing any exercise which hurts, and stretch only as far as feels comfortable. Try and stay relaxed and in control all the time. Keep your breathing and movements as smooth as possible.

ACTIVITY

6.2

RELAXING YOUR UPPER BODY

Head

❶ Stand or sit as straight as you can, with your arms relaxed.

❷ Drop your head forward and then lift it slowly, feeling the muscles in your neck pulling up.

❸ Drop your head gently back and then lift it up.

❹ Drop your head to one side (ear to shoulder), then stretch and lift it back. Repeat on the other side.

❺ Gently roll your head around as fully as possible.

❻ Nod gently and feel the muscles at the back of your neck tense and then relax.

❼ Roll your head very slightly, just to free and centre it. Your head should now be still.

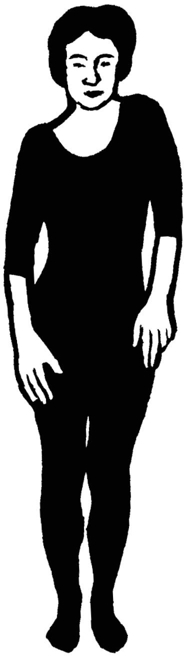
Shoulders

❶ Stand or sit as straight as you can, with your arms relaxed.

❷ Lift one shoulder and then gently let it drop. Repeat with the other shoulder and then both shoulders together.

❸ Feel the sensation when your shoulders are dropped.

❹ Gently move one shoulder around in a circle, and then the other. Repeat for each shoulder in the other direction.



Upper body

❶ From standing with legs slightly apart, reach your arms up high and let the movement take you on to your toes.

❷ Hold your balance, and stretch out your fingers to reach as high as you can. Hold while counting to five.

❸ Drop gently down onto your heels and bend forward and down from the waist, letting your arms swing easily between your legs. Let your own weight take you down as far as is comfortable.

❹ Stand upright again.

Chest

❶ From sitting or standing, put your hands behind your head – as comfortably as you can.

❷ Breathe in through your nose, and sigh out.

❸ Wait until you feel that your ribs need to fill again, then let them widen and fill.

❹ Repeat this cycle two or three times. (This exercise widens the chest). Try to make sure that you feel the different muscles tense and free as you use them.

ACTIVITY

6.3

PREPARATION FOR USING YOUR VOICE

First, lie down and relax:

❶ Lie down with your arms loosely by your sides and feet slightly apart.

❷ Spread your back as much as possible – the shoulders far apart and your back and neck becoming wider. Think of spreading across the floor, not into it.

❸ Feel your shoulders, neck and arms free and relaxed. Gently shake them out as necessary.

Second, focus on your breathing and voice:

❹ Put your hands on your ribs where they are widest and breathe in through your nose. Hold the breath for a few seconds and then sigh out through your mouth to release all the air. Wait until you feel that the muscles between your ribs need to move, then slowly breathe in again feeling your ribs widen at the back and sides. Repeat this sequence several times.

❺ Now, breathe in through your nose, and then breathe out through your nose while counting to 10. Try to be aware of the muscles between your ribs. Repeat this cycle, increasing the count to 15, and then to 20.

❻ Breathe in through your nose, feeling the muscles between your ribs expanding. Then sigh out through your mouth, gently, several times on the one breath. Put your hand at the bottom of your ribs to feel where the air is being produced from (your diaphragm).

❼ Repeat this cycle making a small sound: `er, er, er’. Repeat using the sound, `ah, ah, ah’. Make sure that you breath out completely before breathing in each time.

❽ Breathe in and feel your ribs open and expand. Sigh out. Inhale again and breathe out while counting slowly aloud to six. Inhale again and speak aloud a few words. Make sure that your lungs fill each time you breathe in, and that the sound starts when you breathe out. Keep checking that your neck and shoulders are free and not tense.

Third, standing:

❾ Stand upright with your back as wide as possible, legs slightly apart, well-balanced and with your neck feeling long. Let your arms hang loosely at your sides.

Try to be aware of how you feel different now, compared with before you started this exercise.

ACTIVITY

6.4

VOCAL WARM-UP

❶ Walk around talking to yourself to get used to hearing your voice projected louder than usual.

❷ Listen for the different sounds of your voice – high, low, fast, laughing.

❸ Try saying parts of your presentation in exaggerated and different ways – without worrying about how silly they sound.

❹ Say your opening and closing remarks with as much as possible of the following feelings: pleading, angry, demanding, tempting, calmly.

❺ Sing! Try singing where you will be relaxed, for example as in the bathroom.

❻ Try singing part of your presentation in different styles, such as: a love song, a rap song, a children's song, operatic.

Just before your presentation, try a few breathing exercises and then add some sound.

❶ Hum on one note (pick the middle of your range first).

❷ To open your throat, drop your jaw and make a gentle `aaaaahh'.

❸ To warm up the muscles needed for clear speaking, try a short poem or read a piece of text fast (or repeat one you know).

❹ Have a big yawn, and then check that you are breathing from the bottom of your ribs and not from the chest only.

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Working with the media

There are two reasons to work with the media:

- they are an essential means of communicating your information to a wide audience
- the media do much to shape the social and cultural environment in which you work.

Using the media to communicate

Newspapers or radio or television programmes are a good way to get your information across. The disadvantage may be that you will not have complete control over what is printed or broadcast. The following points offer suggestions for how to make the media work for your group:

The media can be used:

- before an event for promotion or awareness raising
- to respond to recent events after they have happened
- to communicate prevention and care messages
- to alert them to things about to happen.

It is useful to understand how journalists work if you are going to work with them:

All journalists – whether radio, television or publishing – work to tight deadlines. Find out before you send them information when their deadlines are.

If you are contacted by the press and you feel unprepared, say you will get back to them in a few hours. As a rule, do not say anything to the press which you would not want to put your name to. Always check that your name, and the name of your group, has been spelled correctly. Ask to see a copy of the finished report beforehand but this will not always be possibly.

Try to develop a trusting relationship with individual journalists. Many journalists are personally affected by HIV and may actively want to work with you to combat discrimination and stereotypes. Get to know your local newspaper journalist and people who work in radio and television. These people are often looking for new stories, and you may be able to suggest approaches or aspects of your work which is suitable. Journalists may be interested in interviewing someone from your group or in reporting events or activities in which you are involved.

HINTS & TIPS

Working with journalists

Provide the press with information they need in forms that they can use.

◆

Develop good relationships and be as helpful as possible.

◆

Understand the constraints and pressures under which journalists work

◆

Work with rather than against journalists whenever possible.

◆

Avoid dictating terms - any good journalist will resent being told what to think or write.

◆

Try not to be defensive, even if challenged, just state your position clearly.

Press interviews

If you are being interviewed on the radio or television:

- Be prepared – know your facts and figures. Having notes with you can help you stay on the issues and avoid you repeating yourself or becoming boring.
- Be clear and concise. Keep to the point.
- It may be useful to add some examples – human stories. But remember not to mention names and keeping confidentiality.
- Keep it simple and avoid jargon or long words that listeners may not be familiar with.

You only have to talk about things that you feel confident about. If you are asked about personal issues that do not relate to the interview, you can either bring the interviewer back to the issue or gently refuse to answer.

You may be able to help journalists in their coverage of HIV issues. For example, few journalists have the time or resources to travel outside their own town. If you have projects in a rural area, you could offer to take a journalist you trust to visit.

Writing a press release

A press release is a short `news bulletin' which describes a forthcoming event or significant issue. It is written in a style which makes it easily usable directly by the press, without having to make changes.

A press release can be used to advertise:

- formation of a new self-help group
- a forthcoming meeting or publicity event
- publication of a new book or leaflet
- a speaker on a special topic.

You may find it useful in your group to develop a `press kit'. This could include:

- a standard style for press release
- fact sheet on HIV/AIDS (See Information Factsheet 1 on page 131)
- speeches or statements on the issue by group members or local famous people
- copies of public testimony, if appropriate
- one page description of your organisation

- background piece on who will be your spokesperson, if appropriate.

Media are often treated with suspicion by groups of HIV-positive people and AIDS organisations. Inaccurate, prejudiced and sensational media coverage of HIV is common and can be very damaging. Much can be done to improve such coverage by forming longer term relationships with journalists and media organisations. Journalists are often (though not always) eager to listen and respond to calls for them to play a positive role in media coverage of HIV.

CHECKLIST

Preparing a press release

Before you issue a press release, consider the following:

* Are you allowed to make contact with the press or radio (if you are employed by the government, for example)?
* Are you sure that the information is accurate and is in line with the policies of your group?
* Is what you have to say genuinely newsworthy? If not, the release will go straight to the bin.

Make sure that you have included the following information:

* What will be happening – the event, names of important people who may be attending
* Why the event is taking place
* Where is the event or activities taking place, giving details of how to get there
* When it will be taking place – give time and date.
* Give an address and telephone number of someone to contact if they need further information.

Use newspaper style writing: that is, short, fact-filled sentences and paragraphs.

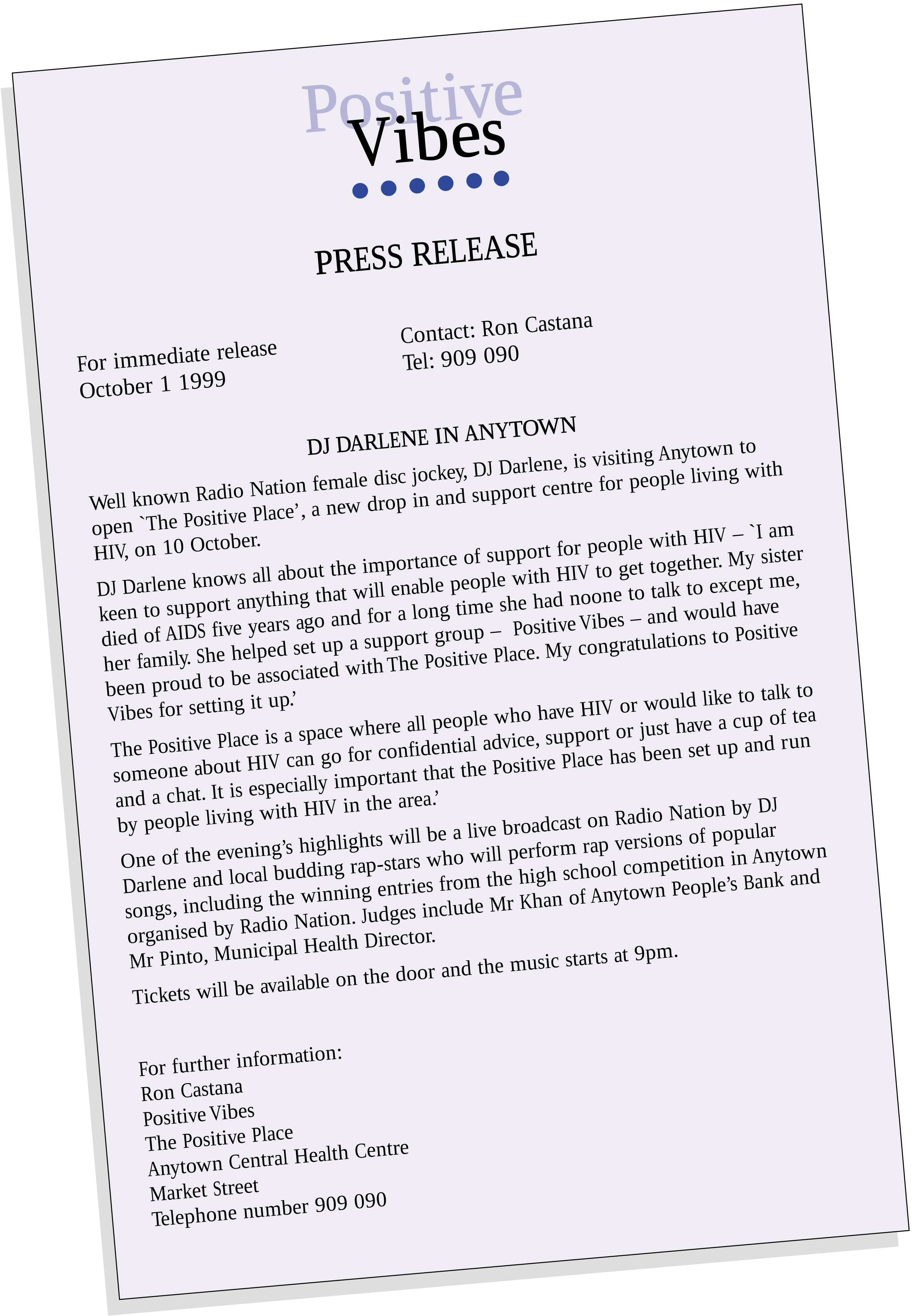
Have the five `W's (Who, When, What, Where, Why) in your first sentence or first paragraph. Make sure that this explains the reason for the press release – is it linked to a forthcoming event? Does it relate to current news events?

If you include quotes, always give the name of the person speaking (respecting their confidentiality if this is required).

Keep your press release to one page.

Include a good photo or line drawing, if possible.

Be prepared for a reporter to want to interview. Discuss possible questions that you may be asked in advance in your group.



Positive Vibes

PRESS RELEASE

For immediate release
October 1 1999

Contact: Ron Castana
Tel: 909 090

DJ DARLENE IN ANYTOWN

Well known Radio Nation female disc jockey, DJ Darlene, is visiting Anytown to open `The Positive Place', a new drop in and support centre for people living with HIV, on 10 October.

DJ Darlene knows all about the importance of support for people with HIV – `I am keen to support anything that will enable people with HIV to get together. My sister died of AIDS five years ago and for a long time she had noone to talk to except me, her family. She helped set up a support group – Positive Vibes – and would have been proud to be associated with The Positive Place. My congratulations to Positive Vibes for setting it up.'

The Positive Place is a space where all people who have HIV or would like to talk to someone about HIV can go for confidential advice, support or just have a cup of tea and a chat. It is especially important that the Positive Place has been set up and run by people living with HIV in the area.'

One of the evening's highlights will be a live broadcast on Radio Nation by DJ Darlene and local budding rap-stars who will perform rap versions of popular songs, including the winning entries from the high school competition in Anytown organised by Radio Nation. Judges include Mr Khan of Anytown People's Bank and Mr Pinto, Municipal Health Director.

Tickets will be available on the door and the music starts at 9pm.

For further information:
Ron Castana
Positive Vibes
The Positive Place
Anytown Central Health Centre
Market Street
Telephone number 909 090

PART

7

Making an impact

© Strategies for Hope

Volunteers in Ahmedabad, India, campaign against stigmatisation of people with HIV.

All of us, as individuals and in our groups, are affected by our community and wider society. This can be valuable – especially if we are supported by other individuals and organisations. But more often, HIV-positive people are discriminated against – others ignore, blame or fear us, and policies actively discriminate against us. It is essential that we can participate in the process of making decisions and changing attitudes which affect our lives and the lives of other people living with HIV or vulnerable to HIV.

There are several different approaches to change:

- influencing individuals and institutions to change their practice, by providing information, negotiating and discussion
- using laws and policies to create a change in practice, for example, in workplaces and hospitals
- including people with HIV in decision-making processes, for example by becoming members of local committees, district health care committees or national advisory bodies
- overcoming resistance to changes in attitude or practice by drawing attention to the issues through campaigns and media coverage.

Supporting individuals

Self-help and support groups can play an important role in helping individuals to solve a problem. For example, they mistrust advice that their doctor is giving them or their child is being bullied at school.

Help the individual to improve their own negotiation skills or suggest asking a friend or colleague to support them. Successful negotiation happens when arguments are put across convincingly and without aggression. Negotiation involves making a decision with someone else, where both people consider their different opinions together, without one simply deciding for both. Negotiation involves each person being able to express herself or himself and listening to the other. Both need to be respectful and willing to compromise.

It may be useful to practice negotiation skills within your group, in order to be better prepared for raising difficult issues with others.


© Women Fighting AIDS in Kenya

Be glad; together we can overcome

> ‘Women Fighting AIDS in Kenya (WOFAK) is a self-help group of women living with HIV. An HIV positive woman asked us for support – she wanted to find a health worker to assist at the delivery of her baby. This had been refused because of her HIV status. We met local health workers and one doctor agreed to assist at the birth. Following this successful action, we are providing information and training to health workers to reduce their fears about infection.’
>
> **WOFAK, Kenya**

ACTIVITY

7.1

NEGOTIATING SKILLS

AIM For group members to practice individual negotiating skills.

❶ In the group, consider the situation that you want to challenge or change. Two volunteers role play the situation for 3-5 minutes.

Example role play – Negotiating treatment options with a doctor

A person with HIV wants to understand more about the drugs that are being offered to him. The doctor suggests a particular treatment for his skin problem, but the man does not want this. Role play the conversation that takes place between the doctor and the man.

❷ One other person, or the rest of the group, observes the role play and writes down observations to the following questions:

- *What might be the factors that are causing the doctor to suggest this treatment?*
- *Why does the man not want this particular treatment?*

❸ After the role play has finished, discuss the situation:

Did they take time to listen to each other's opinions? Did the man listen to why the doctor thought that this treatment was useful? Did the doctor listen to why the man was questioning her advice?

What might the doctor feel when her advice is questioned? What might the man feel when his own opinion about his health is not taken into consideration?

How could both of them think about coming up with a solution that suits them both?

❹ Discuss the observations noted by the observer and use this as a starting point to plan how to raise the issue with the doctor on the man's next visit.

Negotiating with individuals can sometimes (though not always) improve a particular situation. If this situation is not resolved or if a similar situation is likely to occur again, it may be necessary to think about negotiating change at a broader level.

© International HIV/AIDS Alliance

Groups role-play convincing the local bishop to support them, Ecuador

Positive networking

Working with other people strengthens our own work and can lead to a wider impact on society by `pooling our resources'. Building links with others can:

- influence other people and make them aware of the existence and needs of people with HIV
- increase the effectiveness of our own work, for example by benefiting from the skills and experiences of other groups
- widen the impact of our work, for example, by enabling our successes to be adapted or replicated by government services and other NGOs
- overcoming barriers to our work, for example by helping to change laws which allow private companies to dismiss HIV-positive employees.

It can be useful to form local partnerships with other NGOs, local government departments and community groups.

Meeting regularly with other organisations and individuals who work in similar areas helps to share ideas and to cooperate on work. Networks of organisations or individuals can offer:

- the opportunity to compare ideas and experiences
- a forum for sharing information
- a forum for collaborating on a specific activity
- a collective voice to challenge people in decision-making or powerful positions.

These networks may be groups working on HIV and AIDS but may also be groups of people working on other issues which affect your members – groups of gay men or sex workers, for example.

> `REVS+ (a French name which is short for Responsibility, Hope, Life, Solidarity) is a self-help group of people living with HIV/AIDS. At first we were full of ideas but found it difficult to prepare project proposals to be submitted to funding organisations. We took part in a training session on the subject of community support run by a local group (Initiative Privèe et Comunautaire de Lutte contre le SIDA au Burkina Faso). Two of us attended and we had the opportunity to meet people from other groups all working, in their own way, in the support and care of people with HIV. It was useful to make this personal contact and now we participate in a network of associations supporting people living with HIV. We are receiving technical support to develop our self-help projects now.'
>
> **REVS+, Burkina Faso**

ACTIVITY

7.2

© International HIV/AIDS Alliance

WHO SHOULD WE WORK WITH?

AIM To explore useful local partnerships.

❶ Put a large sheet of paper on the wall.

❷ Write your group's name in the middle and draw a circle round it. Draw two wider circles around the circle, labelled 'our community' and `wider society'.

❸ Ask the group to brainstorm which groups they should be working with (such as mothers, local shopkeepers, national AIDS programme staff, donors and religious organisations).

❹ Write them in the appropriate circles, in order of importance.

You can then think about who you already have good links with, who you have no links with and who is hostile to your group or your work. See the advocacy checklist on page 115 and decide who you will need to work with.

> `We hold a partner's meeting once a year. `Partners' are those NGOs who provide services to people with HIV. The purpose of the meeting is to we explore where we (Pinoy Plus) fit into their activities. At the meeting NGOs present their needs and see who will give support to us, who we will work with, and where NGOs are duplicating our own work (in this case they are discouraged from trying to take on this role). We identify support which we need, for example, office equipment and fax machine.
>
> We still have some concerns. We often feel that we are being used and our involvement is only tokenistic. So if our name is put on a project proposal, then we have to make sure that we are involved from the planning through to the evaluation stage. We will do workshops for other organisations, but now we will not go and do just anything anywhere as we did at the beginning. We realised that we were not getting anything out of it that would benefit Pinoy Plus so now we prioritise certain workshops, those which we can do well.'
>
> **Archie Rivera, Pinoy Plus, Philippines**

Advocacy

`Advocacy' means putting across your message to other people to bring about:

- wider public understanding about HIV and other issues
- changes in policies, laws and services.

Advocacy work can involve action at all levels, locally and through representation national decision-making bodies.

© International HIV/AIDS Alliance

Providing care and support at a community care centre in Ecuador.

`Fundación EUDES is an NGO which provides care for people with HIV and includes HIV-positive staff and volunteers. It set up a community hostel where people with HIV could stay on the outskirts of the capital city, Quito. When local residents discovered that it was for people with HIV, they were very hostile. Rumours started spreading and staff, volunteers and people visiting the centre were threatened.

They decided to call for help to resolve the situation. They thought about who would be in a good position to help them and persuaded them to support their work. A local priest acted as a `go-between' and facilitated community meetings and talked about the project in his sermons. Because of his standing in the local community, local people were less able to challenge him than the EUDES staff and so they listened more. The group rang up the local press and worked with individual journalists to persuade them to provide supportive media coverage. They also began an awareness raising and education campaign in the area – this resolved some of the misconceptions and fear that local people had previously had.

Changes did not happen overnight. However, over time the situation has altered from nearly having to shut down the centre to an acceptance of the centre.'

EUDES, Ecuador

`From 1986 to 1990 Cuba's national AIDS policy included compulsory isolation for people with HIV in special sanatoriums, which included family visits and, shortly afterwards, weekend passes. A group of HIV workers and people living with HIV began questioning these policies. In 1990, people living with HIV, resident in Cuba's main care and prevention centre, the Sanatorium Santiago de las Vegas, formed the AIDS Prevention Group (GPSIDA). Our aim was for their voices of people living with HIV to be heard, do AIDS education in the community and campaign for the right to be treated with respect.

After training ourselves as prevention educators we began working with the National AIDS Programme to ensure that their information was accurate and challenged the prejudices that people have about HIV. We targeted teacher training colleges and workplaces and used TV and radio to reach families and young people

Partly as a result of our work, in 1993 sanatorium residents were given the choice of continuing to stay in the sanatorium or returning home and receiving outpatient or home care provided by a network of family doctors based in the community. This was a decisive step towards integration of people with HIV into Cuban society. GPSIDA educated and prepared people for the changes. These sanatoria have now been closed.'

Juan Carlos de la Concepción, GPSIDA, Cuba

HINTS & TIPS

Four steps to becoming an effective advocate

1 Work in coalition

* involve a broad range of community groups

* set realistic goals and objectives

* `formalise' your coalition with a name, stationery, membership lists

* make sure your members understand and agree the aims and objectives

* set short-term tasks and long-term objectives

2 Conduct research

* what are the needs in the community

* what is the community situation – who can you involve?

* what is the political situation – how can you succeed?

* what criticism do you expect and how can you address it?

3 Prepare

* materials that are appropriate to the audience, answer their concerns, explain the need for your programme and can be left behind after meetings

* responses that make your case, respond to criticism, help keep the discussion calm

4 Educate

* the public

* policy makers

* the media.

CHECKLIST

Before starting an advocacy project

- Why do you want to challenge the existing situation and what do you hope to achieve?
- What precise issues will you focus on, and what changes do you want? Choose a few key messages, and explain clearly how you propose to make these changes and show that they are possible.
- Who do you want to work with during the campaign? Who needs to be involved and who will strengthen your message? (Could you work with groups for people with HIV, health workers, human rights groups, lawyers, celebrities, religious leaders, politicians, unions, NGOs?)
- Who do you need to influence: media, policy makers, local NGOs or the hospital, church or mosque?
- What information will best explain your arguments and back up your demands? (Aim to ensure that you have all the facts about the situation and that your arguments are persuasive and appeal to people's self-interest.)
- How and when you will get your message across (e.g. through letters, meetings, rallies, press releases, interviews, information updates or fact sheets)?

Source: Rau, B., Ten steps for HIV/AIDS advocacy, AIDScaptions, July 1995


© International HIV/AIDS Alliance

OCAFI hold monthly meetings with the city mayor, Olangapo City, Philippines.

Taking a seat at the table

One of the most important steps for influencing change is to become involved in decision-making bodies. Increasingly groups have become involved at local, national and international level as representatives of people living with HIV.

> `It is important for any organisation working in the field of HIV/AIDS to include people living with the virus because it is we who have first hand experiences of the problems that we face... In 1995, the Zimbabwe AIDS Network (ZAN) introduced a system whereby the Chairperson of Zimbabwe National Network of People Living with HIV/AIDS (ZNPP+) became a member of the ZAN National Executive. This has led to better relationships between various NGOs and PWA support groups. Some NGOs have employed people living with HIV/AIDS on their staff. ZAN itself provides office accommodation for the ZNPP+ secretariats.'
>
> **Emily Chigidwe, ZNPP+**

This can be a very valuable experience. However, it is important to consider the disadvantages and potential problems. Sometimes the HIV-positive representative is often just a `token' on the board. Often the people who are chosen as representatives lack the necessary skills or knowledge to participate. The representatives may not `represent' the community and only speak on behalf of their own group. This may mean that decision makers can say that they consulted with HIV-positive people and yet make few changes.

You may be able to reduce these problems by:

- as a group, agreeing key points for your representative to make, and providing debriefing sessions after meetings
- ensuring that representatives are chosen by the groups or networks of people with HIV in your area, and are accountable

to other people with HIV, for example, by reporting back to their group

- ensuring that representatives on committees and decision making boards are treated on an equal basis as others, for example, financially or in terms of decision making power
- training in assertiveness and negotiation, and ensuring that they feel confident with the subject area, for example by providing basic legal training before becoming involved in a campaign to fight discrimination at work or in prisons
- encouraging the involvement of people with HIV who already have such skills, knowledge or training, for example, HIV-positive lawyers, doctors and others.

`I was doing work for nothing, sitting on diverse boards. Everyone expects that I should go on doing it for nothing. And I thought, here I was sitting in conferences and speaking with consultants – consultants who knew nothing – and they were paying them $900 and giving me two bus tickets, thank you. I had to scream at them, `I can't do this for nothing. I want to do this because I believe in it and it has to be done. But you have to take care of me'.'

Winston, Canada

`The Leadership Training Initiative aims to train and support PWA/HIV community leaders to 'maximize their unique and essential contributions to policy formation, program development, service delivery and program evaluation.' People living with HIV in New York State realised that many of our experienced `leaders' were becoming burnt out, ill or dying. There was no structured way of transferring skills to future leaders and very few of us had expertise in planning programs.

The LTI identifies people who are interested in becoming trained through an application process. The LTI covers topics such as the history of PWA leadership in New York State; effective leadership; identity, difference and HIV; community organizing; government process; presentation skills and presenting public testimony. Graduates are then encouraged to join local HIV decision-making bodies and government boards in organizations where they can develop their skills in a supportive environment. We hope that eventually some of these graduates will be able to take up the paid jobs that PWAs currently do not have access to.'

Jairo Pedraza, LTI Steering Committee

See Information Fact Sheet 3 on page 135 which is a declaration from countries who have signed the `Paris Declaration' committing themselves to the `Greater Involvement of People Living with HIV and AIDS'.

Human rights and HIV

Some NGOs and individuals are using human rights approaches to challenge the discrimination that directly affects people living with HIV or makes some groups of people more vulnerable to infection.

Human rights means that all people have a right to be treated as equal in human worth and dignity, whoever they are. A Universal Declaration of Human Rights was drawn up in 1948 and is now signed by almost all nations. There are more recent international agreements on rights which are legally binding for nations who have signed them.

Of course, human rights are not only relevant to HIV – many people do not have access to minimum basic needs. But there are some forms of discrimination that directly affect people living with HIV or make some groups of people more vulnerable to infection.

The `framework of action' aims to make it easier to document, monitor and successfully challenge human rights abuses in the region. The framework has six elements:

1 Understanding and adoption of a **common vision** by all people involved in the region
2 Agreement on **common standards** for human rights and availability of situation analyses
3 **Capacity building** training of individuals and groups to be advocates
4 **Empowerment** of vulnerable groups to enable them to organise, take action and solve problems
5 Development of **advocacy tools** which are easy to understand and use in the local context
6 Existence of a **critical mass** of individuals and organisations from NGOs, the media and the private sector, who are committed to human rights.'

Source: Human Rights Working Groups of APN+ and APCASO (See Information Factsheet 2 for a list of human rights standards)

Using legislation

Legislation can establish standards in society, deter people from going against them, and encourage others to claim their rights. In many countries, laws have been changed, or new laws have been introduced in response to AIDS. Unfortunately, some of these laws limit the human rights of people with HIV. For example, isolation of people with HIV, compulsory screening of prisoners and immigrants, compulsory HIV testing of sex workers, imprisonment or detention of HIV-positive sex workers or of injecting drug users.

Laws, however, can also protect people with HIV – for example, prohibiting discrimination against HIV-positive people at work or HIV testing as a requirement for insurance or employment. By making links with legal and human rights organisations, groups of people with HIV can start to challenge this discrimination.

> In the Philippines a woman living with HIV faced criminal charges when it was discovered she had become pregnant from a relationship with a 17-year old boy. An NGO working on legal rights worked with groups of people with HIV, other NGOs and the media to convince the courts to drop charges against the woman and make arrangements to support the woman and her baby. This was done through discussion and persuasion.
>
> In Chile, prisoners were being forced to have compulsory HIV tests using contaminated needles. In this case, a gay and lesbian NGO, Centre Lambda Chile, worked with others to publicise the incident through a press conference. They are taking legal action against the prisons to stop degrading and dangerous procedures.
>
> **Source: An advocates guide to the international guidelines on HIV/AIDS and human rights**

Some governments have policies that prohibit discrimination, for example against people with HIV infection or AIDS in government workplaces. Adopting such policies sets a good example for businesses, organisations, institutions and individuals outside government.

> In South Africa, the government has banned pre-employment testing in the public sector. This and other laws are monitored and developed through a committee including HIV-positive representatives that reports to the South Africa Law Commission.

Members of CChPS, Chile, campaign for condoms.

Governments can also work to correct the reasons for human rights abuses and to reduce the vulnerability of people whose rights are abused. For example, social and welfare assistance programmes for vulnerable communities or providing appropriate resources for programmes concerning HIV and AIDS.

International bodies, such as the United Nations, World Health Organization, the International Federation of Red Cross and Red Crescent Societies, Amnesty International, and many others also produce useful recommendations and information (see addresses on page 121).

Public campaigning

Sometimes it is necessary to back up the advocacy work you are doing with a public campaign to draw attention to the issue or to yourselves.

Developing a key message

First think about what you want to say. Who do you want to target? What will appeal to them?

Make sure that the message is

- true
- suitable for your audience
- short, specific and strong
- in clear, simple language
- positive and inspiring
- known and agreed by everyone in your organisation.

Getting your message across

Think about:

- badges and buttons, pens, flags
- fliers and posters
- banners
- newspaper and radio advertisements.

These can be backed up with fact sheets, articles, presentations at community meetings.

Displays can attract attention. The Names Project is a successful example of drawing attention to HIV, involving people in HIV awareness raising and focussing minds on HIV. Quilts (embroidered squares of cloth made by lovers, friends and family of people with HIV who have died) can be made together in groups – your own groups, community groups etc. – but can then also be used as an awareness raising and campaigning tool. They are hung up in public places or laid out in parks. This makes people stop and think.

© Township AIDS Project

Public demonstrations are most useful when they show that people with HIV are angry and upset, but offer positive messages too. For example, at a recent regional conference on HIV, participants who were HIV postive were angered that a work of art was funded and displayed which represented `pain and death'. People with HIV staged a demonstration on the final day in front of the sculpture and draped it with quilts. They organised spokespeople who explained why they were angry and showed that many works of art – such as the quilts – better express the sadness but more importantly the hope and positive approach that people with HIV have.

© CCHPS

Display quilts on World AIDS Day, Chile.

© CChPS

"Solidarity is dignity".