

PART
2

Getting groups going

- 18 Before beginning
- 24 Holding successful meetings
- 26 **ACTIVITY 2.1**
What does the group want?
- 30 Keeping the group going



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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.



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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



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 masseuses 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 state-wide, 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.

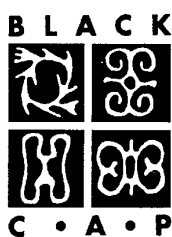
Group identity

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.

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



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

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)?

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.

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.

- 1 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...'*.
- 2 Allow five minutes for this, and aim for at least three points under each heading. Do not worry about neatness or spelling — the ideas are more important.
- 3 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.
- 4 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?
- 5 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.

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*

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.

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.



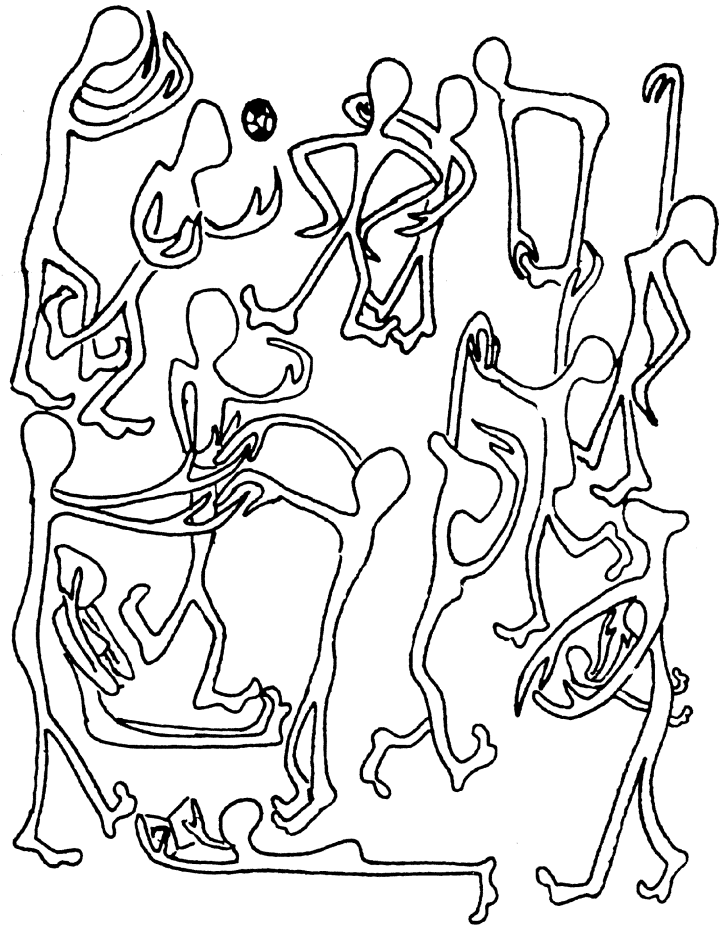
Stay on the topic Everyone needs direction and clear objectives. Stay on the topic agreed – the group can move on to other topics if everyone agrees this in advance.

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.

© INF+



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.