

PART 1

Why work in groups?

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Placing yourself in a broader picture



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"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.

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



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

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.

- ➊ 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.
- ➋ 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.
- ➌ Ask participants to group these suggestions under the relevant headings on the 'problems' sheet. Ask them to suggest more if necessary.
- ➍ 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

1 Lack of knowledge

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

2 Lack of skills

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

3 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

4 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

5 Restrictive environment

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

Individual

Community

Society



Ways to make positive changes for people living with HIV

1 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

2 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

3 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

4 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

5 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