



Addressing the Needs of Young People Living with HIV

A Guide for Professionals

**STOP
AIDS
NOW!**

Acknowledgements

This guide is developed by STOP AIDS NOW! partnership in Zimbabwe: African Regional Youth Initiative, Young Africa, Family Aids Caring Trust, Uzumba Orphan Care, Insiza Godlaywo Aids Council, Umzingawane Aids Network, Patsime Edutainment Trust, Bekezela Home Based Care. With technical support of Africaid, GNP+ and STOP AIDS NOW!

Colophon

Edition:

**STOP AIDS NOW!,
December 2011**

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Cover, p. 4, 12, 17, 18

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STOP AIDS NOW! is a partnership of Aids Fonds and four Dutch development organisations: Cordaid, Hivos, ICCO and Oxfam-Novib. Our mission is “working together towards a world without AIDS”. We work on expanding and enhancing the quality of the Dutch contribution to the AIDS response in developing countries. So far we have raised more than 90 million Euros. Besides we stimulate and support innovative initiatives. Our ‘Learning by Doing’ method, for instance, has resulted in several valuable new approaches and tools.

Our projects and programmes focus on children, youth, and women in countries hardest hit by the epidemic. Annually, we reach around 400,000 people who are affected by HIV and AIDS. We offer care, treatment and income opportunities, give AIDS orphans a new future, and slow down HIV and AIDS through prevention.

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3. Your Action Plan

Develop a Workable Set of Activities



‘What would she think of me?’

‘I always wondered how I would have to tell my future girlfriend that I am HIV positive. Sometimes, I practised in the mirror. But still whenever I saw a girl whom I liked, I just could not show my interest and talk to her. What would she think of me? Would she shout and run from me? I became very shy because of this and wondered if I would ever get married. Then I was introduced to a programme run by the local network of young people living with HIV. It organised training programmes for peer educators to counsel and work with other HIV positive young persons. I participated and learned a lot about disclosure and stigma from some experts. This stimulated me to educate other young people with HIV. Moreover, I stopped worrying about having a girlfriend. For if a girl does not want me because of my status, then this is her choice and I will find someone else. Now, I feel free to talk to different people and I hope that one day I will meet My One.’

HIV positive young man (24)
from Zimbabwe

Introduction

Why this Guide?

Life skills and sexuality education programmes usually only focus on HIV negative young people. And HIV prevention seems to be the main target of many of such programmes. However, HIV positive youth also need our attention and care. Fact is that worldwide 40% of all new HIV infections are among young boys and girls, while every day 2,500 other young people are infected. To address the specific needs of young people living with HIV (YPLHIV), this practical Guide has been developed. The Guide aims to motivate and support professionals who work with young people in life skills and sexuality education programmes and those who develop policies and design programmes in public and private institutions, for instance in schools. It explains how, with small adjustments, existing educational activities can provide HIV positive youth – without disclosing their status – with skills to cope with their status and lead a fulfilling life. Are you a teacher, educator or programme implementer? Then this Guide will assist you in finding ways to address the needs of HIV infected young people in your professional environment.

How to use this Guide?

We advise users of this Guide to go through it step by step. To address the needs of HIV positive young people, first of all you have to find out about the effectiveness of your programme. To this end, you can fill out the Checklist that is incorporated in this Guide (Chapter 1). The Checklist covers six items plus accompanying questions that are related to the needs of young people living with HIV. You can fill out the Checklist together with your staff and, of course, with the youths who participate in your programme. The completed Checklist will give you insight in what you do to meet the needs of HIV positive young persons and in what areas you could strengthen your programme. Then go through the recommendations and advice on how to improve your work (Chapter 2). Finally, design your own action plan (Chapter 3).

Why focus on young people living with HIV?

Nowadays, HIV infected people can lead happy and productive lives, provided that they receive timely treatment and take good care of themselves. Yet, HIV positive young people are faced with various challenges. Professionals who work with them, such as teachers and programme implementers, are in a position to detect these challenges and to find ways to meet the needs of HIV positive youths.

Challenges young people living with HIV meet:

- **Limited access to information regarding (sexual) relationships** Young people who are HIV positive have questions like: Can I have a sexual relation with my HIV positive or negative partner? How do I tell my girlfriend/boyfriend that I am HIV positive? How can I talk with my parents about my status? These questions are rarely addressed within programmes that traditionally focus on HIV negative youth. Often young people do not know whom to ask such questions.
- **Decision making about disclosure of status** HIV positive young people face a variety of challenging decisions related to revealing their status: If, when and how? First of all, laws and policies restrict them. And an environment which is not conducive is even more challenging for young people to feel comfortable with their HIV status. However, the decision of if, when and how to disclose one's status is an individual choice.
- **Unrecognised rights** Young people living with HIV have the same rights as every other young person, such as the right to education and the right to access to employment. HIV positive young people, however, often find it difficult to stay in school and to access employment opportunities. The education and employment sectors are often discouraging environments for young people living with HIV. Here, they can be confronted with stigma and discrimination.
- **Disrupted treatment** Treatment adherence is crucial for people living with HIV, but even more so for young people. Boys and girls continually go through changes in their young lives and move around, without having safe spaces (school, home or with friends) to take medication. This can lead to treatment disruptions. Treatment adherence is also often affected by lack of support in their dietary concerns. Failure to get a regular, adequate and nutritious diet often results in failing to take medicines as prescribed.



Definitions

Life skills programmes

'Life skills' refer to problem solving behaviours used to manage one's personal affairs. These skills are particularly relevant for young people living with HIV. Life skills programmes focus on teaching these behaviours, so that the target group members are able to handle problems and questions they encounter in daily life. Life skills include critical thinking, decision-making, self care, and social relationships. They can allow, for instance, young persons to make informed decisions and resist peer pressure. Life skills help young people living with HIV to:

- cope with their HIV positive status and to manage stress;
- face challenges related to stigma and discrimination;
- make healthy choices on safe sex, treatment adherence, nutrition, and family planning;
- get support from friends and family; and
- gain understanding of their (sexual and reproductive) rights.

Sexuality education

'Sexuality education' refers to instructing people on a wide range of topics related to human sexuality, including affection, intimacy, intercourse, reproductive health, contraception, and abstinence. Actually, this is a lifelong process of acquiring information and forming attitudes. Sexuality education is important for young people living with HIV to make them more aware of their sexual rights and how they can have healthy sexual lives.

1. Checklist

Analyse Your Organisation's Activities

To adequately address the needs of young people living with HIV, your organisation can start with finding out how effective the programme is. The Checklist in this Guide assists you to make a list of activities that are supportive to HIV positive youths as well as items that need improvement. Subsequently, you can look for suitable ways to support young people living with HIV. For instance, if the answer is 'No' to the question 'Does the organisation have a confidentiality policy?', then you know the development of such a policy is required. Sometimes, for example in case of information provision, only adaptations might be needed. Remember that even very small changes with little time and effort involved can make a big difference in the lives of young people.

The Checklist contains the following six categories, which are explained in Chapter 2:

- Youth participation
- Treatment literacy
- HIV and sexual rights
- Psychosocial support
- Stigma and discrimination
- Effective support system

■ **No** We do not, or hardly anything, on this issue. In the right column, you can give a striking example of an activity implemented within your organisation.

First fill out the Checklist individually, then compare the answers and discuss them as a team. During the discussion, the following questions are important: Do we agree? Where do we disagree? Also pay specific attention to questions that have the answers 'No' and 'Not really', because these are the areas that need improvement.

How to fill out the Checklist

We advise you to fill out the Checklist together with people within your organisation, from different departments and with different roles, such as a manager, a monitoring and evaluation officer, and an educator. Do not forget to ask young people, both HIV positive and HIV negative persons, to participate.

The Checklist is a way of analysing your organisation's work by indicating if and to what degree you address HIV positive young people's needs. The answers to the questions reflect the situation of your organisation, in the following way:

- **Yes** The item is incorporated in the work of our organisation.
- **A little** We work on this, but more can be done.
- **Not really** We have started to work on this, but much more can be done.

How to monitor and evaluate your work

In future, after six months and once more after twelve months, you can fill out the Checklist again and see if any changes have occurred. Thus, the Checklist can be used as a monitoring and evaluation tool, and you can gradually improve your organisation's methods to address the needs of young people living with HIV. It is advisable to integrate elements of the Checklist in the organisation's regular monitoring and evaluation system.

Checklist

What does your organisation do to address the needs of young people living with hiv?

Categories	Questions	YES	A LITTLE	NOT REALLY	NO	If 'Yes' or 'A little', provide an example
1. Youth Participation Read more on page 9	1.1. Are young people involved in development of the life skills and sexuality education programme(s)?					
	1.2 Are young people involved in the implementation phase of life skills and sexuality education programme(s)?					
2. Treatment literacy Read more on page 10	2.1 Is information provided on the existence of medicine (ARV) which can help someone with HIV to live a long and relatively healthy life?					
	2.2 Is information provided on the importance of treatment adherence and do participants understand what is meant by this?					
	2.3 Is information provided about the importance of eating healthy for HIV positive persons?					
	2.4 Do young people gain skills to seek for health services, such as counselling and testing services, support groups, clinics where you can go for a HIV and STI tests and where you can get ARV treatment?					
3. HIV and sexual rights Read more on page 11	3.1 Are myths and misconceptions regarding HIV discussed?					
	3.2 Are clear and frank messages provided as described on page 10?					
	3.3 Do participants receive training in communications skills and how to discuss disclosure with sexual partners?					
	3.4 Do participants of regular sexuality education programmes receive training in safe sex skills?					
	3.5 Do participants of regular sexuality education programmes receive training in reproductive health choices when being HIV positive?					
4. Psychosocial support Read more on page 11-12	4.1 Do participants of regular sexuality education programmes receive training in skills to manage stress and to cope with their situation?					
	4.2 Does the organisation support youth to start income generating projects or actively refer youth?					
5. Stigma and discrimination Read more on page 13	5.1 Does the organisation have a confidentiality policy?					
	5.2 Does the organisation engage in activities that aim to reduce HIV related stigma and discrimination?					
	5.3 Does the organisation make use of available policies and legislation that are friendly to (young) people living with HIV?					
6. Effective support system Read more on page 17	6.1 Does the organisation refer young people living with HIV to appropriate prevention, treatment, care, and support services?					
	6.2 Does the organisation facilitate linkages between HIV positive young people and their families and communities so as to create a support system for them?					

2. Recommendations and Practical Advice

Explore Possibilities to Strengthen Your Programme

Young people living with HIV are a diverse group who differ in age, gender, economic situation, educational, and cognitive abilities. Some have been infected from birth and others at a later stage through sexual transmission or sharing needles. HIV infection can affect young people in different ways, including various aspects of their physical, psychological and emotional development.

This chapter presents you with different ways of strengthening your organisation's current programme so as to meet the varying needs of HIV positive young people. It provides practical background information as well as suggestions for improvement related to six topics: youth participation, treatment literacy, HIV and sexual rights, psychosocial support, stigma and discrimination, and an effective support system.

2.1 Youth Participation Involve Young People

Our advice: Actively involve young people in the development and implementation of your life skills and sexuality education programmes



There is overwhelming evidence that the participation of young people in programmes leads to better outcomes for organisations. Young people know best what is good for them. Contact and dialogue with young people themselves ensures that the planned activities really suit their needs and that they appeal to them. Youth participation significantly increases that quality of programme activities.

Therefore, if you want to address the needs of young people living with HIV, the first step is to actively involve them, or to strengthen the current way of involvement. We recommend to use a practical manual, which can assist you in taking the necessary steps. Out of the numerous available manuals, we have selected two for you:

- **Making Sure Young People's Voices are Heard**, available on www.stopaidsnow.org/documents/HearOurVoices_UK.pdf. This manual shows how easy it can be to give young people a voice in an organisation. The manual explains the Youth Participation Model (YP Model). This model can assist organisations in a self-assessment of the inclusion of young people and in highlighting areas for further improvement of youth participation. The model can be used worldwide by all organisations that work for and with young people. It is not country-specific and not AIDS related.
- **The Flower of Participation**, available on www.choiceforyouth.org/en/information/meaningful-youth-participation. The Flower of Participation is developed by CHOICE, a youth-led organisation that strengthens the voice of young people worldwide on making choices concerning their sexuality and having children. The Flower aims to give a better understanding of youth participation.

2.2 Treatment Literacy

Inform Young People On HIV Treatment

Our advice: Explain treatment options and ways of accessing health systems to HIV positive young persons

We recommend to provide all young people who are HIV positive with basic information on treatment. It can be useful to ask an expert from a clinic or other health care worker to visit your organisation and provide practical information about where to get treatment, when to go, and what to expect.

HIV, health, and treatment

- **Testing** Before people can be treated they need to know they are infected. This requires not only HIV testing facilities but also widespread knowledge of the importance of testing and where it can be done. People may be more inclined to test if they are aware of the benefits of antiretroviral therapy and know they could be treated if they test positive.

What you can do

- Discuss the importance of HIV and sexually transmitted infection (STI) testing with your group.
- Explain where you can get a test and how the procedure works.
- Invite someone who knows how to talk with youth from a nearby test centre. Important questions are: How do they ensure confidentiality? And, of course, what happens when you are HIV positive?

- **ARV therapy** 'ARV' is the acronym of 'antiretroviral'. ARV therapy is the main type of treatment for HIV and AIDS. It is not a cure, but it can stop people from becoming ill for many years. The treatment consists of drugs that have to be taken every day for the rest of a person's life.
- **Treatment** When a person is diagnosed with HIV, she/he will not always need to start treatment immediately. To judge whether an HIV positive person requires treatment, a test is usually carried out.

What you can do

- Ask someone from outside your organisation to come and explain about HIV treatment.
- Show a video especially made for young people, such as www.webfoundation.nl/films/bobo1_english.html

- **Treatment adherence** It is extremely important for HIV positive persons to take drugs exactly as described, which is called 'treatment adherence'. This includes taking all of the medication at the right time and exactly as the directions state. Some people are resistant to a certain type of ARV, which means that the medication cannot work properly. Unfortunately, other treatment options become more difficult for them.

What you can do

- Invite someone from a support group of people living with HIV to share her/his experiences with taking a pill every day.
- Explain what is meant by 'treatment adherence'. Check if participants of your group can explain it too.
- Discuss in a group what could make it difficult to take a pill each day on exactly the same time.
- Especially friends and family can play an important role for young people to support treatment adherence. Discuss how they can support someone with taking her/his medication.

- **Nutrition** When taking ARVs it is very important to eat healthy. HIV positive people who suffer a loss of appetite may need to make an extra effort to ensure they eat enough, for instance with the help of a dietician.

What you can do

- Invite someone from a support group of people living with HIV to share her/his experiences and explain about nutrition and what food is especially good.
- Particularly friends and family members can play an important role for young people to support with nutrition. Discuss in your group how they think they could support someone.

2.3 HIV and Sexual Rights

Explain About Myths and Human Rights

Our advice: Provide clear and frank messages and discuss myths and misconceptions regarding HIV

If you want to address the needs of young people living with HIV, it is very important to provide them with correct and clear messages and discuss myths regarding HIV. Young people should receive sufficient and up-to-date information about the options of preventive behaviour, so that they are able to make their own decisions related to their sexual behaviour. Clear messages are, for example:

- Abstain from all sexual activities.
- Have consensual and safe sex.
- Delay your first sexual intercourse by practising other sexual activities.
- Use contraceptives.
- Use a condom each time you have sexual intercourse.
- Avoid having several partners or having sex with people who have several other partners.
- Go for HIV and sexually transmitted infection (STI) testing and treatment.

Programmes that only address the message of abstinence or delay among young people do not seem to have any effect on behaviour change. They only have an effect on the attitude to abstinence or delay) Comprehensive sexuality education programmes that address both delay and condom use have proved to be effective in delaying sexual intercourse and increasing contraceptive and condom use.^{1,2,3}

Our advice: Inform young people living with HIV about their sexual and reproductive rights

Always remember that young people living with HIV have the same rights as young people who are not infected. Below, we provide you with basic information regarding the sexual and reproductive rights of young people living with HIV. It is derived from the publication *Healthy, Happy and Hot* of the International Planned Parenthood Federation (IPPF). It is a guide written for young people living with HIV to help them understand their rights, and live healthy, happy and sexually fulfilling lives. We recommend you to read the full guide, as it provides very practical information and advice.

You can find the guide *Healthy, Happy and Hot* here: www.ippf.org/en/Resources/Guides-toolkits/Healthy+Happy+and+Hot.htm

Find out from youth participants in your programme what misconceptions are present amongst them. Example of myth: You can get HIV from deep kissing. But deep or open-mouthed kissing is a very low risk activity in terms of HIV transmission. HIV is only present in saliva in very minute amounts, insufficient to cause infection with HIV. If you or your partner have blood in your mouth, you should avoid kissing until the bleeding stops.

Some questions young boys and young girls living with HIV have:

- Do you disclose my status to all my previous partners?
- Where can I go for STI testing?
- How can I discuss condom use with my partner?
- If my partner is negative/positive and we want to have children, how do we avoid HIV transmission during conception and pregnancy?

International Planned Parenthood Federation (IPPF)

- 1 Kirby, D. (2002). The Impact of Schools and School Programs upon Adolescent Sexual Behavior. *Journal of S Sexual Research* 39, 27-33.
- 2 Thomas, M.H. (2000). Abstinence-Based Programs for Prevention of Adolescent Pregnancies: A Review. *Journal of Adolescent Health*, 26, 5-17.
- 3 Silva, M. (2002). The effectiveness of school based sex education programs in the promotion of abstinent behavior: A meta-analysis. *health Education Research*, 17, 471-481.



Facts

As there are quite some prejudices about sexuality and people living with HIV, we give you the following facts to pass on:

- HIV is a chronic disease. With the right medicines and a healthy life style, young people living with HIV have a long life ahead of them.
- People living with HIV can have a sexual life and sexual relationships.
- People living with HIV can have children.
- People living with HIV can have sex without transmitting HIV to their sexual partners.

Professionals, educators, teachers, managers, and all others who work with young people need to be role models and provide young people with correct information about HIV and human rights.

Advices for HIV positive young people

- **Enjoy sexuality** Many people think that sex is just about vaginal or anal intercourse. But there are lots of different ways to have sex and different kinds of sex.
- **Decide if, when, and how to disclose your HIV status** Young people know best if and when it is safe to disclose their status. There are many ways that can help to figure out how to tell your partner, such as visiting a counsellor or a local support group. People have different reasons for not sharing their HIV status, often related to fear of stigma and discrimination within their community. One of the hardest things about dating, sex and relationships is the possibility of being rejected by someone. But there are lots of people who do not mind whether their partner is HIV negative or positive.
- **Practise safer sex** Safer sex is a shared responsibility. When you share your HIV status, you and your partner

can work together to make your sex life pleasurable and safe. Sometimes, people who live with HIV think they do not need to practice safe sex if their partner is also positive. But you can still pick up a sexually transmitted infection (STI) that can affect your health.

- **Choose if, when, how many, and with whom to have children** People living with HIV can have healthy pregnancies and share a long life with their children. There is about 25–30% chance that your child will be infected during pregnancy, labour and delivery. The risk is reduced to almost zero when preventative measures are taken. Talk to your health care provider and/or child health service provider when you want more information. If they cannot help you or you have a bad experience, speak to someone else.

Advice for young people when they want to disclose their HIV status:

- Practice disclosing to people you trust.
- Speak to other young people living with HIV and learn from their experiences.
- Test how your partner might react like asking questions: **What do you think of HIV? and have you ever met someone with HIV?**

More tips: <http://www.ippf.org/en/Resources/Guides-toolkits/>

2.4 Psychosocial Support Help HIV Positive Youth to Cope

Our advice: Support HIV positive young persons to cope and manage stress

Young people living with HIV must learn to deal with their status and manage stress. Organisations can offer social support and teach them life skills. The first step is to realise that many young people are currently infected with HIV. In Sub Sahara Africa, 19% of all people with HIV are young people between 10 and 24 years and about 5.5 million young people worldwide are HIV positive. Moreover, millions of youths are affected because their family members have HIV. An HIV diagnosis can lead to a number of different emotions, such as stress, sadness, anger, and grief. To address needs of young people living with HIV, it is important to talk about coping skills within your programme.

Coping strategies for young people living with HIV

There are several coping strategies you can suggest to HIV positive young people you work with. You can inform all participants in your programme or focus on only a few. It can help them to reduce stress, deal more effectively with challenges, and promote their psychosocial well-being. Coping strategies you can suggest to HIV infected young people are, for instance:

- Talk about a personal problem with someone you trust, such as a friend, family member, counsellor, or peer educator.
- Seek assistance in resolving the problems that you are having with your family or caregiver.
- Join a support group.
- Change your environment and take a walk.
- Seek spiritual support.
- Join in recreational activities, like sports and youth clubs.
- Return to your daily routine, like cooking or going to school.
- Do something to make yourself feel useful, like helping a child with homework.
- Seek professional help from a clinic if you are sad, depressed, anxious, etc. for a long period of time.
- Develop confidence.
- Build self-esteem.
- Explore options and solutions to make better decisions.
- Maintain needed support from family members and other adults.

Actions for professionals⁴:

- Find out where young people can get professional help and invite people for an extra session to explain about their work.
- Invite someone from your youth support group to explain about their work and how they can be reached.
- Talk with all your staff members about how to increase confidence of the youth you work with.

Our advice: Financially support income generating activities

Increasing the income generating skills for young people living with HIV is very important. The need of good nutrition is greater for them, while job opportunities are often slimmer also because of stigma. There are many examples of income generating activities and a focus on income generating skills within organisations. Choose what suits your organisation best. One possibility is to link with other organisations that are experts in this area.

The organisation Junior Achievement (JA) empowers young people to own their economic success, and works towards the attainment of entrepreneurial skills for young people. It is a good organisation to partner with in ensuring that young people living with HIV acquire income generation skills. For more information on how you can start income generating projects with young people we advise you to contact the nearest Junior Achievement office in your area. You can find information here: www.ja.org



4 Colombia University – Medical Centre – Adolescent HIV Care and Treatment Zambia

2.5 Stigma and Discrimination

Reject Any Form of Exclusion of HIV Positive Young People

Our advice: Promote reduction of stigma and discrimination

Stigma and discrimination are some of the fuels of the HIV epidemic in the world. They prevent people from asking questions and going to services. If your organisation wants to address the needs of young people living with HIV, it needs to do something about stigma and discrimination. Or perhaps your organisation is already stigma free.

Definitions

- **Stigma** refers to the severe disapproval of a person on the basis of a particular attribute, such as HIV status.
- **To stigmatise someone** means to see a person as inferior because of something about her/him. Very often people stigmatise others because they do not have the right information or knowledge. People also stigmatise others because they are afraid.
- **Stigma towards others** refers to having a negative attitude about others because they are different or assumed to be different. For example, a girl with HIV feels isolated at school because of the stigmatising attitudes of her peers.
- **Self-stigma**, also called internal stigma, is used to describe the negative way a person, for instance a girl or boy living with HIV, feels about herself/himself, specifically if they feel shame about being HIV positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and depression. Internal stigma can also result in a person living with HIV withdrawing from social or intimate contact, or excluding herself/himself from accessing services and opportunities out of a fear of having their status revealed or being discriminated against because of their status.
- **Secondary stigma** is experienced by people, such as community health care workers, doctors and nurses at the HIV clinic, children of parents with HIV, caregivers and family members who associate with, for instance, young people living with HIV. For example, when a woman's male acquaintance finds out that she is seeing an HIV doctor, he can end their budding relationship.
- **Discrimination** is a manifestation of stigma. Discrimination is any form of arbitrary distinction, exclusion or restriction, whether by action or omission, based on a stigmatised attribute.

Strategies for young people living with HIV to deal with stigma and discrimination⁵:

- Stand up for yourself and talk back.
- Educate others.
- Be strong and prove yourself.
- Talk to people whom you feel comfortable with.
- Ignore people who stigmatise you.
- Join a support group.
- Try to explain the facts.
- Take and adhere to medicines and ART therapy. This reduces stigma around HIV, helps normalise HIV, and allows the community to see HIV as a chronic disease. People who openly taking ART therapy can reduce stigma around the disease.

Strategies for professionals to deal with stigma and discrimination:

- Make sure young people and young people living with HIV, such as peer educators, are part of the team. This includes making sure they attend regular staff meetings, training programmes and other events.
- Make sure young people are given opportunities to evaluate your services to see if they are stigma free and that feedback is formally reviewed by managers and staff.
- Ensure there are linkages with community-based youth groups and support groups for young people living with HIV.
- Talk openly with staff members about your own attitudes, feelings, fears, and behaviours.
- Challenge discrimination in your organisation. For example, if you see a colleague being rude to someone with HIV, talk to this colleague on a one-to-one basis. Tell her/him what you saw and how the situation could have been handled differently.
- Report to the manager discrimination in your organisation that is directed towards people living with HIV or their families.
- Listen to young people when they talk about their feelings and concerns related to stigma and discrimination, and report these back to other staff.
- Link with other staff members of other organisations you sometimes work with to identify where stigma and discrimination exist, and work together to make changes.

We advise you to order the toolkit Understanding and Challenging HIV Stigma via www.aidsalliance.org. This toolkit for action contains over 100 participatory exercises which can be adapted to fit different target groups and contexts. There are different sets of picture codes which help to identify stigma, discuss the rights of HIV positive people and help to stimulate discussions.

5 Colombia University – Medical Centre – Adolescent HIV Care and Treatment Zambia

Our advice: Ensure confidentiality

It is very important that you develop a system whereby you can ensure confidentiality of the HIV status of HIV positive young people within your organisation. This may be done by ensuring that the programme does not have components that clearly disclose the status of the young people, such as names, but having codes assigned. Publicity of your activities in a way that can lead to accidental disclosure must be prevented. However, it is important that you encourage young people to confide in the people that they trust, as this is important for getting support and treatment.

Our advice: Implement policies that are friendly for young people living with HIV

It can be helpful for your organisation to look at your current policies and identify what possible changes you can make in order to strengthen activities that address the needs of HIV positive young people and ensure a stigma free environment. You can take the following steps:

- Look at two good publications: Code of Good Practice for NGOs Responding to HIV/AIDS and Sexual Rights: An IPPF Declaration. (They are explained below.)
- Discuss the principles and rights presented in these publications with some of your staff members, managers, implementers, evaluators, and youth involved in your organisations.
- Develop or adapt your own guiding principles and make your own code of good practice: ten rules for a stigma free organisation.
- Inform all staff members of your organisations and all young people and their families about your guiding principles. Will every one sign? You can think of a ceremony to make sure everyone is aware and will act on these guiding principles.

Code of Good Practice for NGOs Responding to HIV/AIDS

See: <http://hivcode.org/search-the-code/guiding-principles/>

Human rights, public health and development provide the overarching framework for the Code of Good Practice for NGOs Responding to HIV/AIDS. Principles are given on how we do our work and what we do. Core values are:

- Valuing human life.
- Respecting the dignity of all people.
- Respecting diversity and promoting the equality of all people without distinction of any kind, such as sex, race, colour, age, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV), sexual orientation or civil, political, social or other status.
- Preventing and eliminating human suffering.

- Supporting community values that encourage respect for others and a willingness to work together to find solutions, in the spirit of compassion and mutual support.
- Addressing social and economic inequities and fostering social justice.

Sexual Rights: An IPPF Declaration

See: <http://ippf.org/en/Resources/Guides-toolkits>

Sexual rights underpin the approach and the contents of the publication Sexual Rights: An IPPF Declaration (2008). Sexual rights are constituted by a set of entitlements related to sexuality that emanate from the rights to freedom, equality, privacy, autonomy, integrity, and dignity of all people. The ten sexual rights are:

1. Right to equality, equal protection of the law and freedom from all forms of discrimination based on sex, sexuality or gender.
2. The right to participation for all persons, regardless of sex, sexuality or gender.
3. The right to life, liberty and security of the person and bodily integrity.
4. Right to privacy.
5. Right to personal autonomy and recognition before the law.
6. Right to freedom of thought, opinion and expression; right to association.
7. Right to health and the benefits of scientific progress.
8. Right to education and information.
9. Right to choose whether or not to marry and to found and plan a family, and to decide whether or not, how and when, to have children.
10. Right to accountability and redress.

What can you do

- Make guiding principle for your own organisations using the form below.

Guiding principles: Ten rules for a stigma free organisation

For (name organisation):

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Developed by (names):

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Recommendations

Signed by:

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2.6 Effective Support System Create a Caring Environment

Our advice: Create a high-quality support system for young people living with HIV

The support that a young person living with HIV needs is not just clinical. The role of family members, the community and friends in providing a conducive environment for a young person living with HIV to manage and lead a fulfilling life is crucial. Understanding the emotional and psychological stresses that HIV and HIV treatment can place on a young person is key to being able to provide appropriate support.

The benefit of peer support to young people living with HIV is unquestioned. HIV positive young people need opportunities to engage with, communicate and network either virtually or in person with their peers. This can happen via social networking structures like Facebook or informally via support groups and youth centres. One barrier that young people may face in joining such networks is the perceived risk of a lack of confidentiality and high levels of stigma.

Diagram of Support

A support system for young people living with HIV needs to ensure that a protective environment is available. The people that surround them should be able to provide support that will promote values of care, respect, non-

judgemental attitudes so as to build trusting and caring relationships with HIV positive youths. The Diagram of Support given below helps to discover what specific support different people can give to HIV positive young people. For instance, friends can form a buddy system, while health workers can provide nutritional support. Part of a good support system is a strong referral system.

You will need to draw on the experiences of the communities in order to involve HIV positive young persons as active participants in the community programmes so as to ensure a stronger referral system.

What you can do

- Discuss the Diagram of Support with staff of your organisation and young people and discuss how you can give support to young people living with HIV.
- A first step for a strong support system is to identify the available prevention, treatment, care and support services in your area. Identify the partners that you can work with from the non-governmental organisations, local government, private sector, government departments, professional bodies etc. that will enable you to create a strong referral system for the young people you work with.
- Contact these organisations, meet with them and see how you can link up. Perhaps they can come and inform youth of your organisation about their services.

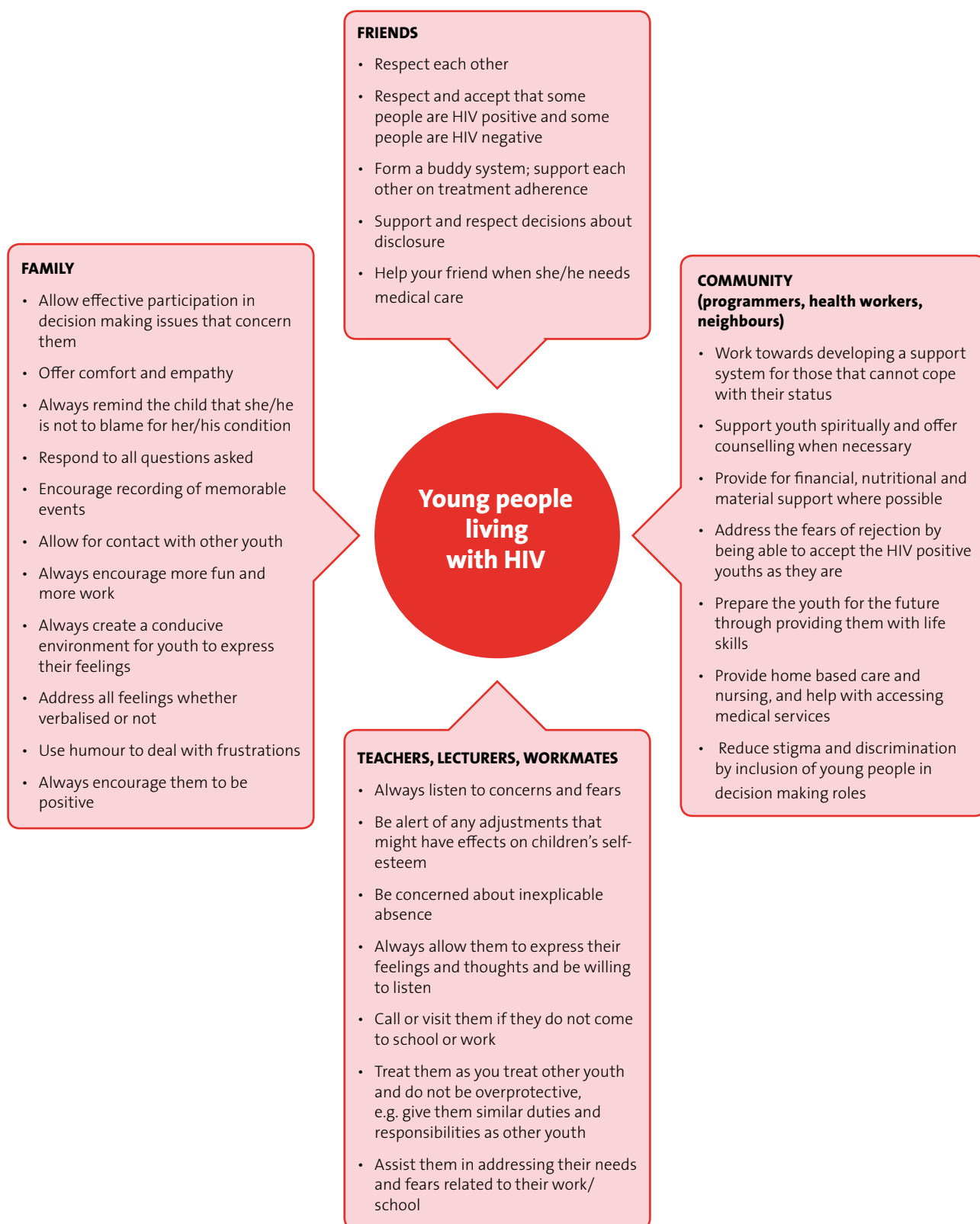




‘I know there is always hope as the people around me show me love every day’

‘My name is Amos and I have 17 years of age. I have been benefitting from the Uzumba Orphan Care programmes for two years now. The programme emphasises that youth remain in the community in their own households. Volunteer caregivers, many with families of their own, visit each such household, evaluate the youth’s living conditions, assess the availability of food, and look after the youth’s health, determining whether they are able to attend school or undertake income generating activities. The way these activities are conducted, this has allowed me to cope with my situation since both of my parents died whilst I was very young but because I have received so much support from my community I am living a fulfilling life and realising my dreams. Though things are not always rosy, I know there is always hope as the people around me show me love every day.’

Diagram of support



Recommendations

3. Your Action Plan

Develop a Workable Set of Activities

After you have completed the Checklist and studied the recommendations and advices, you are ready to design an action plan for your organisation. What activities will your organisation develop to adequately address the needs of young people living with HIV? The questions below will guide you.

1. Who within your organisation will you ask to fill out the Checklist?

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2. What would be a suitable date and time to discuss the completed Checklist? How much time would you need?

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3. Which of the items of your programme needs strengthening?

- Youth participation
- Treatment literacy
- HIV and sexual rights
- Psychosocial support
- Stigma and discrimination
- Effective support system

4. Indicate for each of the above six items what you currently do, what change you would like to bring and what activities you want to include.

Youth participation

What we currently do is:

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What we would like to change is:

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Activities include:

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Treatment literacy

What we currently do is:

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What we would like to change is:

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Activities include:

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HIV and sexual and reproductive rights

What we currently do is:

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What we would like to change is:

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Activities include:

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Psychosocial support

What we currently do is:

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What we would like to change is:

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Activities include:

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Stigma and discrimination

What we currently do is:

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What we would like to change is:

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Activities include:

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Effective support system

What we currently do is:

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What we would like to change is:

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Activities include:

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Annex 1

Overview specific needs and challenges of young people living with HIV

Rights literacy	Young people living with HIV need to know what their rights are, how to exercise them to the fullest and how to access support when their rights have been violated. In many cases young people living with HIV, are given misinformation about their rights and how to realise these rights. There is very little support given to young people living with HIV to identify and follow up on a human rights abuse.
Network	The benefit that peer support that be to young people living with HIV is unquestioned. Young people living with HIV need opportunities to engage with, communicate and network either virtually or in person with their peers. This can happen via social networking structures like Facebook or informally via support groups and youth centres. One barrier that young people may face in joining such networks is the perceived risk of a lack of confidentiality and high levels of stigma.
Care and support	The support that a young person living with HIV is not just clinical. The role of family, community and friends in providing a conducive environment for a young person living with HIV to manage and lead a fulfilling life is crucial. Understanding the emotional and psychological stresses that HIV and HIV treatment can place on a young person is key to being able to provide appropriate support.
Access to health services and facilities	Young people living with HIV require access to comprehensive prevention, treatment, care and support services that would include opportunistic infection detection, management and treatment and sexual and reproductive health services. Young people living with HIV in rural areas are even more acutely affected as there are often limited options in terms of health facilities. User fees and transport costs are also key barriers to accessing services.
Safe disclosure	Young people living with HIV face a variety of challenging decisions of if, when and how to disclose their status. Laws and policies restrict and make it even more challenging for young people living with HIV to feel comfortable with their HIV status, when the environment in which they live is not conducive. Parents of children born with HIV also face very difficult periods of time working out how best to disclose the status of their children to their children. The decision of if, when and how to disclose your status is an individual choice.
Treatment adherence	Treatment adherence is a crucial issue for all people living with HIV but even more so for young people who are continually going through changes in their young lives, moving around and not having safe spaces (school, home or with friends) to take medication can lead to disruptions to treatment regimens.
Education and employment opportunities	Young people living with HIV have the same right to education and access to employment as every other young person. Young people living with HIV can often find it difficult to stay in school and to access employment opportunities. The education and employment sectors must understand the need for creating conducive environments for young people living with HIV to learn and work, free from stigma.
Nutritional needs	Treatment adherence is often affected because of lack of support in their dietary concerns. Failure to get a regular adequate and nutritious diet often leads to the young people failing to take medicines as prescribed.
Stigma and discrimination	HIV related stigma and discrimination is still pervasive in many communities and settings. This remains the most significant barrier for young people living with HIV from accessing services, attending school, disclosing and realising their fullest rights. Self stigma that many young people living with HIV can experience, has a dramatic effect on their ability to realise these rights (see below). While a much more concerted effort needs to be made with whole communities to start breaking down stigma, the appropriate support must be available to young people living with HIV to address internalised stigma.
Internal stigma	Also called 'felt stigma' and 'self-stigma. Internal stigma is used to describe the negative way young persons living with HIV feel about themselves and specifically if they feel shame about being HIV positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and depression. Internal stigma can also result in a person living with HIV withdrawing from social or intimate contact, or excluding themselves from accessing services and opportunities out of a fear of having their status revealed or being discriminated against because of their status.