Child-Headed Households & Human Rights

A Capacity-Building Guide
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Published by
The Centre for the Study of Violence and Reconciliation (CSVR)
PO Box 30778, Braamfontein 2017, South Africa

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Acknowledgements

- Foundation for Human Rights (FHR) for funding this project. The Foundation is funded by the European Union under the European Programme for Reconstruction and Development in South Africa.
- Bread for the World for providing the Youth Violence Prevention Programme with the necessary funding in the preliminary stages of the project and for their continued support and belief in the work we do.
- Standard Bank of South Africa for also providing financial assistance.
- All the participants in the training workshops whose experiences and stories assisted in shaping the material contained in this book.
- The following organisations in Katlehong and Alexandra for their ongoing support, interest and involvement in the project: Khanya Family Centre; Katlehong Arts Centre; Katlehong Coaches Development Association; Banakekeleni; Friends for Life; Alexandra AIDS Orphans Project; Hope Worldwide; Association Francois-Xavier Bagnoud (AFXB); and Crisis Intervention and Cultural Centre.
- A special thanks to Dr. P Ndaba, specialising in youth issues in Alexandra.

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Printed and bound in The Republic of South Africa by: Colorpress
Date of publication: November 2006

This book is available on the internet at www.csvr.org.za
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Background

The Centre for the Study of Violence and Reconciliation (CSVR) identified the need to research the impact of HIV & AIDS on children orphaned by HIV & AIDS who become increasingly vulnerable to violence, abuse and exploitation. It is imperative to understand how these children manage their violent challenges and the interface with their circumstances.

Through the implementation of programmes among focus groups consisting of orphans and children who head households, the researchers were able to identify themes and trends that impact on the lives of children. These themes and trends were then developed within a human rights framework, and a three-day training workshop was held for members and leaders of civil society organisations (CSOs) and community-based organisations (CBOs) to test the material, which would be developed further into this book.

This project was piloted in Katlehong and Alexandra in Gauteng, and extracted experiences and lessons learned from civil society. These lessons can be applied to children in similar circumstances, who are heading households throughout the country.

It is the experiences that children orphaned by HIV & AIDS and civil society members shared with the researchers that have informed the content and the processes that led to the development of this book.

The objectives of the book are to:

- Strengthen the protection and care of vulnerable children through human rights education relating to social justice issues;
- Enable users of this book to develop an understanding and respect for vulnerable children’s rights and responsibilities as citizens;
- Enable CSOs and CBOs to challenge and develop action plans and to develop policies to advocate change locally; and
- Emphasise the holistic support of children within a rights-based model of support. This model focuses on the whole child and promotes the effective realisation of their rights.

The book is aimed at providing information and ideas to help build stronger more sustainable CSOs and CBOs, in order to tackle the issues related to child-headed households and violence.
Who should use this book?

This book has been compiled for members and leaders of CSOs and CBOs as well as youth development workers and concerned members of the community. These people engage actively with orphans and vulnerable children who are challenged on a daily basis, especially with those children who have the additional responsibility of being heads of families.

Outline of this book

The following is an outline of the contents of the book:

**Section 1** → Explores children’s rights within a human rights-based approach to working in the community, as well as the responsibilities and expectations of a community member.

**Section 2** → Unpacks stigma and disclosure, while the impact that these forces have on our communities, as well as the ways in which communities have traditionally dealt with stigma are explored.

**Section 3** → Discusses capacity-building strategies for CSOs and CBOs. It also provides information and basic strategies on mobilising communities and implementing a project plan.

How to use this book

The book has been designed to be read individually and/or to be discussed with members of your organisation. Each of the three sections contain questions and exercises that can be discussed in a group. The exercises provide an opportunity for people to reflect on their own experiences, as well as to learn from the experiences of others. The sections also contain tips and explanations that can be used to draw out or elaborate on key concepts and lessons. The CSO leader’s role is to facilitate a process whereby group members can meet to discuss the issues that they feel are important. This is a practical way to collectively approach and resolve problems.

However, it is important to bear in mind that each organisation is different and that group sessions with members of your organisation will need to be adapted to the needs and interests of the people concerned. Thus, sessions should be selected and changed where necessary to suit the group.

Abbreviations

- **CBO** community-based organisation
- **CSO** civil society organisation
- **PLWHA** person living with HIV and AIDS
- **PLWHAs** people living with HIV and AIDS
Children’s Rights and HIV & AIDS
- Children’s rights and the law
- The best interests of the child
- Reflection
- Why are children’s rights important to CSOs?
- Social Assistance Act of 2004
- What do you need to apply for a grant?
- Where do you apply for grants?

Responsibilities
- Role as a guardian or caregiver in the community
- Strategies for CSOs and caregivers/guardians dealing with orphans
- Developing solutions to new situations
- Points to remember
- What does your organisation and/or family expect from you as an active CSO member in your community?
- Reflection

Whenever a person does something that concerns and affects a child, this must be done in the best interest of the child.

WE HAVE RIGHTS TOO!
The HIV & AIDS pandemic has caused great hardship to millions of children, families and friends. Most of us know of someone who is either living with HIV or who has died of AIDS-related illnesses. Even if we are not infected by the virus we are still affected in many ways by the illness.

**Remember:** When we refer to children in this section, we mean people who are under the age of 18 years, who are living with HIV or AIDS, and/or who are affected by HIV & AIDS.

**Children's rights and the law**


Children also have these general rights for example:

- The right to equality and non-discrimination.
- The right to privacy and dignity.

The Constitution also specifically recognises that children need special protection. Section 28 of the Constitution sets out the special rights for children, which include the following:

- Every child has the right to family care, the care of parents or correct alternative care.
- A name and a nationality from birth.
- Basic food, shelter, health care and social services.
- Not to have their well-being, education, health or social and moral development put at risk.
- Be protected from bad treatment, neglect abuse or shame.
- Not to be detained except if there is no other way to deal with the situation and then they must be detained for the shortest time, kept away from people over 18 years of age, and have a lawyer at the state’s expense if it would be unfair not to do so.
- Not to be used directly in wars and to be protected during wars. If a child is taken away from his or her family, the child has a right to have other appropriate care.

**The best interests of the child**

An important principle that the Constitution and the UN Convention on the Rights of the Child emphasise, is the following:

> Whenever a person does something that concerns and affects a child, this must be done in the best interest of the child.

The ‘best interests of the child’ is a very important standard that we must use to measure everything that is done for a child. Sometimes it is difficult to decide what a child’s best interests are, as you often have to weigh up different issues carefully.

**Consider the following situations**

It is difficult to decide whether it is in the best interest of a child who has HIV or AIDS to:

- stay living in his over-crowded home, headed by his sister who is unemployed, but does occasional subsistence jobs, or
- be removed from the household to live with a family member in another community, who can assure him of three regular meals a day.

In deciding what is in a child’s best interests in these situations, you should consider all factors, including the child’s right to socialise (interact with other children), to live a ‘normal life’, to be healthy and to lead and develop with other children. It is also important to consider what the child wants or prefers.

**Reflection**

The HIV pandemic means that many thousands of children are in need of care.

- Do you think our courts can cope with the large number of children who will need to be placed in care? (The courts are actively involved in the placement of children in appropriate care. The courts draw on information and insight from relevant social workers and organisations in order to decide what is in the best interest of the child.)
- How can your organisation change our child and youth care systems to make sure that children in need of care are identified early, and are best taken care of?
Why are children’s rights important to CSOs?

CSOs need to ensure that children living with HIV or AIDS or who are affected by HIV & AIDS, are not discriminated against, are protected from harm and given the opportunity to develop and learn like all other children.

In South Africa children living with HIV or AIDS or who are affected by HIV & AIDS, face many forms of discrimination and human rights abuses.

* Children orphaned by AIDS struggle to find suitable caregivers.
* Children living with HIV or AIDS are sometimes denied access to schools.
* Children are often tested for HIV without their consent, or the consent of their parents or guardians.
* Young boys and girls are denied access to adequate sexuality education and sexual health care services.

Children are a vulnerable group in our society because they often cannot take care of themselves and usually do not have the financial means to do so. It is for these reasons they have been identified as a group in need of special protection.

It is important that as CSOs we know and understand the rights of children living with HIV or AIDS or affected by HIV & AIDS. It is vital for us to be enabled to engage with national policies, to share knowledge with other CSOs and to support and protect children who face the complex challenges of HIV & AIDS.

Suggested discussion questions:

* How does your organisation support and protect children in your community?
* In what way/s could your organisation be more involved in protecting these children?

Social Assistance Act of 2004

The Constitution says that everyone has the right to social assistance if they are unable to support themselves and their dependants.

Social Assistance means that the government provides assistance to people who have serious financial problems. Many PLWHAs will be able to work and support themselves. However, some PLWHAs become sick and are unable to support themselves and/or their families financially.

The Social Assistance Act of 2004 sets out who qualifies for government support and how to apply for such support. The aim of the Act is to:

* Protect people who cannot work because of old age, illness or physical or mental disability. When people living with HIV or AIDS become unable to support themselves and their families, the Act says that the government should provide support to them.

Types of social grants:

**Disability Grant**

There are two types:

1. A permanent disability grant. This is paid to people with a disability that is likely to last for more than twelve months.
2. A temporary disability grant. This grant is paid to people whose disability may exist continuously for a period of six months or less or in intervals for no more than twelve months.

Both grants were R820 per month in April 2006.

**Social Relief or Distress Grant**

This grant is given to people who are unable to meet their own or their family’s most basic needs. The grant is offered in the form of food parcels.

**Foster Care Grant**

This grant is paid to people who look after children that are not biologically related to them. The Foster Care Grant was R590 per month in April 2006.

**Care Dependency Grant**

This grant is aimed at children from birth to their eighteenth year who are either mentally or physically disabled and who require 24 hour care. It is paid to parents or caregivers responsible for the children. The Care Dependency Grant was R820 per month in April 2006.

**Child Support Grant**

This grant is paid to the primary caregiver of a child up to the age of fourteen. A primary caregiver is any person who takes the main responsibility for the daily needs of a child. The Child Support Grant was R190 per month in April 2006.
How do you qualify for a disability grant when you are a PLWHA?

- A PLWHA will only get a disability grant if s/he becomes too sick to work.
- If that person is unemployed but still fit to work, s/he will not get a grant.

Important: A disability grant for a PLWHA depends on that person’s CD4 count in some provinces. Different provinces apply different criteria, but all of them basically assess the person’s ability to work. A medical report confirming the CD4 count will be needed. A person may lose their grant if they become healthy enough to work.

What do you need to apply for a grant?

The Social Assistance Act (2004) says that you can apply for a disability grant if you:

- are a South African Citizen, or a permanent resident;
- are resident in South Africa at the time of application;
- are between 18-59 years of age if a female, and 18-64 years of age if a male;
- have submitted a medical/assessment report confirming disability;
- and your partner meet the requirements of the means test (a means test is a set of financial requirements that a person applying for the grant has to meet);
- are not kept or cared for in a state institution (like a prison or an orphanage);
- are not receiving another social grant (such as an old age grant. But as a parent/caregiver of a child, you can still access the Child Support Grant as well as a disability grant);
- have submitted a valid identity document.

Where do you apply for grants?

To apply for a grant, contact your nearest Department of Social Development office, or call these numbers for free from a public phone.

Social grants toll free: 0800 6 010 11
AIDS Help line: 0800 0 123 22
Child line: 0800 0 555 55

Important: For more information on identifying when children affected by HIV & AIDS may be in need of care and the different ways of placing children in need of care under the Child Care Act, contact the organisations below. New legislation is currently underway in the form of the Children’s Bill.

AIDS Law Project (ALP)
Tel: 011 356 4100
www.alp.org.za

Children’s Institute,
University of Cape Town
Tel: 021 689 5404/8343

Children’s Rights Centre
Tel: 031 307 6075
www.childrensrightscentre.co.za

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Responsibilities

We have all heard stories about the suffering that children experience due to the impact of HIV & AIDS. Often the person who is ignored or forgotten is the caregiver or the guardian. Society often expects the caregiver or guardian to offer support to a child they did not plan for or may not have the means to assist.

HIV & AIDS orphans often come to a new home with many mixed emotions. Orphans can suffer from behavioural changes such as depression, anxiety and decreased self-esteem, which may result in stealing, aggression and running away from home or school.

Supporting children in such situations to improve their emotional well-being is critical but also very stressful for older siblings who are dealing with these emotions themselves.

Role as a guardian or caregiver in the community

*Read the story of Thembi (on the right) and discuss the questions that follow.*

**Case Study**

This case study is not meant to isolate orphans but rather to gain a better understanding of the responsibilities and complex relationships that children who head households have to manage.

‘Thembi’ (not her real name) is 16 years of age and heads a household. She has a four year old sister and a 13 year old brother. Her mother died a year ago and she does not know who her father is.

Thembi wakes up early each morning, washes, dresses and then cooks soft porridge for her brother and sister. This will be their only meal for the day; perhaps there may be tea and a slice of bread in the evening if they can afford it. She walks her sister to crèche while her brother tidies and locks the house before heading for school.

Thembi sits exhausted in her grade 8 class, while her peers discuss television celebrities, the new music they are listening to and what they are planning for the weekend. Thembi hopes if only she could talk and joke with these girls. She also wants to have a seemingly carefree existence.

It is 09h00 and she had been up most of the night. This is because her ‘boyfriend’ of 32 years, as usual, came drunk to her house at a very late hour of the night and demanded sex from her. He is recently married, employed and believes that he owns ‘Thembi’. He has known her for several years and has always shown an interest in her. He gives her material possessions and sometimes money, assuring her that if she were older he would marry her. He enjoys the sex they have and demands it often. He is sometimes physically abusive towards her, which often results in her being absent from school.

Thembi receives a monthly food parcel from the nearby clinic, but she cannot rely on this as the food parcels are often not available. She needs her relationship with her ‘boyfriend’ to survive. This creates tension in her home because her brother is very protective over her and his younger sister. He has threatened to beat up her boyfriend with the help of his friends.

Thembi has an end of term test that she has been unable to prepare for due to the family pressures and responsibilities she has had over the past year.
Strategies for CSOs and caregivers/guardians dealing with orphans

As a caregiver, guardian or support person you need to encourage open dialogue with the orphan. Ask the child what exactly s/he would like and what s/he would like you to do for him/her. Don’t pretend to know all the answers – it may be a new challenge for you too.

- Set boundaries in the home or within the organisation so that everyone is aware of one another’s expectations and responsibilities.
- There is a need for youth to take responsibility for their attitude/s towards HIV & AIDS and PLWHAs. A useful strategy for increasing awareness and knowledge about the pandemic is to initiate discussions on the correct use of condoms, the meaning of abstinence, the importance of faithfulness to a partner and the stigma that is attached to HIV & AIDS.
- Guardians and caregivers must consider the traumatic experiences children have gone through and continue to live with, and should support them by being patient and tolerant of their emotions and the challenges they face in terms of their identity and values.
- Involve the orphans in home activities and treat them as your own children.
- Speak out against the stigmatisation of families affected by HIV & AIDS in your community.
- Contribute towards and support the needs of caregivers and guardians through the appropriate CBOs, CSOs, support groups and counselling services.

Suggested discussion questions:

- As a leader within your organisation, what responsibility should your organisation have towards people like Thembi?
- Is this story similar to ones you have come across in your community? Share those stories but remember to keep the names of the individuals anonymous.
- Draw up a task list of what could be done by either yourself or your organisation to address the many responsibilities/challenges that Thembi has, as a child heading a family?
- What support can you offer one another in your organisation so as to deal more effectively with these problems in your community?
Developing solutions to new situations

The table below outlines some key problems faced by children who head households or have moved to live with family members or neighbours in the same or new communities. In particular, these children often experience difficulties relating to their new families and fitting into new communities. When children are unable to deal with these problems they may run away or live on the streets, thus making themselves vulnerable to violence and crime.

Suggested discussion questions for each problem identified:

* What are the key issues in each problem?
* What possible solutions are there and how can they be implemented?
* How may a community worker or CBO contribute towards family discussions to assist them to deal with the difficulties they are facing?

### New Families

| **Treatment by foster family** | “When you go stay there [a relative’s home], you may find that your cousins are jealous of you and you may eat different foods as their parents favour them. If the parents are also bad they tend to favour their children.” *(girls’ focus group)* |
| **Rivalry between children** | “As an older person you might think you are taking good care of the children but among them there will also be fights and divisions. Because they are from two different families they fight saying ‘we came here first so it’s our home not yours’.” *(grandmother)* |
| **Learning new chores** | “When I first moved from my parent’s house...I was told to wash the clothes. I was tired from being at school all day and was unable to complete the task. I was beaten by my aunt. I swore at her and she locked me in my room and told me I was useless.” *(teenage girl)* |

### New communities

| **Making new social contacts** | “The children felt pity for themselves all the time after their parents died...I could see that they were different and had changed. They were sad and didn’t like going to play with friends.” *(neighbour)* |
| **Disrupted schooling** | “When they came to live with me, they had to change schools due to the distance they would have to travel. They don’t like the new school, as they have no friends, the classes are larger and the school does not offer the extra activities which they took part in at their old school.” *(aunt)* |
| **Moving between places** | “I moved to live with my cousins after my mother died. My little sister stays with my uncle as they thought my cousins wouldn’t be able to care for her. I found it difficult to be separated from her, because we were close and we had always lived together. Since my mum died I can only see her at my uncle’s on weekends.” *(girl’s drawing/storyboard)* |
**Points to remember**

- You are a facilitator who can assist families or children to identify specific problems and help them to develop their own solutions.
- The problems identified are not exhaustive and you may be able to recognise or prevent new problems through your knowledge and experience.
- The family and community solutions may require different approaches. One method would be to hold community discussions to sensitise them to the challenges children infected with or affected by HIV & AIDS face. Families may require specific interventions assisted by professional counsellors to discuss individual problems.
- If children are being mistreated in new families, community workers need to be aware of the appropriate channels of support.

**Did you know?** The responsibilities of children have been formally included in a children’s rights document for the first time. Article 31 in the African Charter on the Rights and Welfare of the Child says:

> "Children have certain responsibilities towards their families, state and government."

**Some of these responsibilities include:**

- Working for the unity of the family
- Respecting and assisting his/her parents
- Serving his/her community
- Strengthening national solidarity
- Strengthening cultural values in a spirit of dialogue, tolerance and consultation

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**What does your organisation and/or family expect from you as an active CSO member in your community?**

- Consider your organisation and/or family. What responsibilities do you have towards them?
- What are the reasons for these responsibilities?
- Are the expectations that your organisation and/or family have of you realistic? Explain.

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**Reflection**

- Do you think you have more power in a relationship because of the responsibilities you have? Discuss.
- What are some of the difficulties you face by carrying the responsibility of a caregiver or guardian?
- How can you manage your responsibilities better?
Section 2

Stigma and Discrimination
* What is HIV-related stigma and discrimination?
* Factors that increase HIV-related stigma and discrimination
* Ways of dealing with the impact of stigma
* Reflection
* Action on the way forward

HIV Status and Disclosure
* Important terms
* Reasons to consider disclosure
* Steps in disclosing your HIV status
* Possible consequences of disclosure
* Possible consequences of non-disclosure
Stigma and Discrimination

HIV & AIDS can inspire people to have feelings of compassion, solidarity and support. The disease however, is also associated with stigma, repression and discrimination. There are individuals affected by HIV & AIDS who have been rejected by their families, loved ones and their communities.

The HIV pandemic is accompanied by many social responses of fear and denial. Discrimination has resulted in anxiety and prejudice against groups of people who have been affected by or infected with HIV & AIDS. Stigma is used to marginalise, exclude and exercise power over individuals who have been affected by or infected with the virus. Communities often respond with blame and anger towards specific and identifiable people or groups as an excuse for not having to take the responsibility of caring and looking after members of their communities. This often happens in the context of HIV & AIDS.

What is HIV-related stigma and discrimination?

**HIV-related stigma** comes from fear and ignorance about the disease and/or hostility and existing prejudices about the groups most affected by it.

**HIV-related discrimination** is the unfair treatment of people on the basis of their actual or suspected HIV status.

Why is there stigma surrounding HIV & AIDS?

* In small groups discuss what factors you think contribute to HIV-related stigma in families, communities and organisations.

Factors that increase HIV-related stigma and discrimination

* HIV is a life-threatening condition and can be transmitted to others.
* Lack of understanding of the disease (e.g. myths, misconceptions and ignorance about how HIV is transmitted).
* Association of HIV with specific behaviours or lifestyles (e.g. homosexuality and sex work, which are already stigmatised in some communities).
* The disease is associated with risky sexual behaviour, which is already stigmatised within our communities.
* Religious or moral beliefs lead some people to think that a person living with HIV or AIDS has been morally weak (e.g. promiscuity or ‘deviant’ sexual behaviour) and deserves to be punished.

Read the following paragraph:

The family plays an important role in providing support and care for PLWHAs. However, not all family responses are positive. Infected members of the family often find themselves stigmatised and discriminated against within the home.

Suggested discussion questions:

* Do you think HIV-positive women are treated differently by the community to HIV-positive men and children? Share your views.
* How does this make them more vulnerable to HIV & AIDS and its effects?
* What is your organisation doing in preventing stigmatisation of people infected with and affected by HIV & AIDS in your community?
Ways of dealing with the impact of stigma

* Attitudes, misconceptions and fears related to HIV & AIDS can be challenged through preventive education, outreach and counselling. Presentations can be made at local primary and high schools, special interest groups, religious meetings and even at sport training sessions to brief players about these issues. Increasing knowledge and awareness is important to empower communities to diminish the stigma attached to HIV & AIDS.
* The impact of HIV-related stigma can be reduced by providing care, support, advocacy and consultation.
* Community mobilisation, advocacy and social change form an important basis for the development of responses aimed at dealing with stigma. While it is vital that stigma is dealt with both on an individual and collective level, community-based approaches are very effective.
* 'Breaking the silence' – disclosure of your HIV status can assist as a tool against HIV-related stigma, but positive response and social support are essential if disclosure is to be beneficial.

Action on the way forward

?? Suggested discussion questions:

* What values does your organisation uphold, which will assist to eradicate HIV-related stigma and discrimination in your community?
* How can your organisation, together with other organisations, assist in changing people's attitudes towards HIV & AIDS in your community and organisation?

A point to remember:

HIV-related stigma and discrimination remains a barrier to effectively fighting the HIV & AIDS pandemic. Fear of discrimination often prevents people from testing for HIV, seeking treatment for AIDS or from telling others about their HIV status. People with (or suspected of having) HIV may be turned away from health care services and employment even though this is against the law. In some cases individuals are evicted from their families and rejected by friends and colleagues.

Reflection

Read the following extract from a case study:

- How does it make you feel?
- Have you heard or know of similar stories within your family, organisation and community?

My peers used to share their lunch with me but now that they know that my mother died of AIDS. They don’t talk to me or invite me to share their lunch. They have pushed me away and I feel lonely. Sometimes when I have to stop at the shop to buy bread for my family, I can hear them talking about me, commenting on the way I dress and that my hair looks funny. I always went to the salon for my hair, but due to my additional responsibilities, I can’t anymore.

We are struggling to make ends meet and I often spend nights lying awake wishing I could have my ‘old life’ back. I wish nobody comes to be in my situation and I wish nobody does this to anybody. But what can I do? I feel everybody is against me and I continually feel excluded by my peers and now it seems by my neighbours too. (Sipho, age 16)

Silence and shame
Prejudices and fear
It’s all in a name that is always so painful to hear

- It is difficult to overcome
- Challenging to understand
- It continues to overpower
- As we fail to understand

- It is no mystery
- But simply, something called stigma
- That is enormously common
- In this process called life

(Anonymous woman living with HIV)
HIV Status and Disclosure

Take note: ‘Disclose’ means to make [secret or new information] known to others. There are many different forms of ‘disclosure’, these will be explored below.

There is still a lot of stigma attached to HIV & AIDS. This means that disclosure can sometimes have negative consequences.

In this chapter you will find information written for the person who wants to disclose her/his HIV status or who is unsure of whether s/he wants to disclose. As a member of a community organisation it is important that you are aware of the processes involved in order to assist and support members by referring them to professional counsellors and support groups.

Read and discuss the important terms:

Important terms

- **Voluntary disclosure**: refers to when you share information about your HIV status with other people. A counsellor can help you to identify possible ways in which this disclosure could impact on your life.

- **Full disclosure**: when you publicly reveal your HIV status (e.g. to family members, friends, support groups, organisations, etc).

- **Partial disclosure**: means that you tell only certain people about your HIV status (e.g. spouse, relative, counsellor friend, etc) and ask them to keep it confidential. You need to think carefully and prepare for the range of possible outcomes before disclosing your status. Once you have disclosed, you may not be able to control what happens. Most cases of involuntary disclosure arise from situations where PLWHAs decide to partially disclose their status and without their knowledge the information is made public by an individual or organisation.

- **Non-disclosure**: means you do not tell anyone about your HIV status.

- **Involuntary disclosure**: happens when a person reveals someone else’s HIV status without their approval or even without their knowledge.

- **Shared confidentiality**: disclosure is usually on the understanding that people will not tell others, unless they have been given permission to do so.

From the above you can see that there are many forms of disclosure. Respect and sensitivity are two of the most important values that you as a worker in a CBO need to uphold when building relationships with individuals who are infected and/or affected by HIV & AIDS.

* Make a list of other qualities you think are valuable and important when working in this context.
Reasons to consider disclosure

You need to understand the possible outcomes when you choose to disclose your HIV status to others. Counselling can help you make that decision.

**Disclosing your HIV status could have the following benefits:**

- Disclosure can help you to accept your HIV status and reduce the stress of coping on your own.
- Disclosure can help you access the medical services, care and support you need.
- Once you have disclosed your status, you may be able to influence others to avoid infection.
- As more people disclose their HIV status, it will help reduce the stigma, discrimination and denial that still surround HIV & AIDS.
- People may suspect your HIV status, particularly if you show symptoms of AIDS. Openness about your HIV status can stop rumours and suspicion and could encourage people to talk to you about it.
- Disclosure promotes responsibility – it can help your loved ones plan for the future.

**Steps in disclosing your HIV status**

Do not rush into disclosure – it is an important decision for you and others.

**These steps will assist you in the process of disclosure:**

- Take your time to think things through. Make sure it is what you want to do and plan how you are going to disclose.
- Identify sources of support, such as support groups for PLWHAs, members of your religious group and/or counselling organisations.
- A good counsellor can support and assist you and help you to accept your HIV status in a positive way.
- Once you decide to disclose, it may be easier to start with those closest to you (e.g. relatives, friends or someone you are close to and can trust).
- Think carefully about your sexual partner/s who you might need to tell.
- Be prepared for shocked or even hostile reactions. This often happens, but with time people close to you are likely to accept your HIV status and support you.
- When you have decided to disclose your HIV status to someone, think about his/her emotions and his/her level of knowledge about HIV & AIDS. This will help you decide what s/he needs to know and how to tell him/her, so that it is less traumatic for both of you.
- It is important to feel strong enough to allow others to express their feelings and concerns after your disclosure.

Read through the extract below:

You have recently been tested and are HIV positive. You are a volunteer leader for a life skills group for teenagers in a community organisation. You have shared your story with the learners when HIV & AIDS has been discussed. One afternoon at the end of the programme one of the participants discloses their status to you, but tells you not to share this with anyone, as not even her family is aware of this. She would like to tell them but does not know how to do this.
Role-play a situation in which someone discloses her/his HIV status to you but feels s/he is not ready to disclose to her family.

What advice and support would you give her/him?

Remember: You have to decide for yourself if disclosing your status is the right thing. It is helpful when you can be open, but you shouldn’t judge others who may not be ready to disclose their status.

Possible consequences of disclosure

Disclosure may cause problems in your relationships, whether with your sexual partner/s, your family and friends, community members, your employer or work colleagues. You may experience rejection or feel people are constantly judging you. Be prepared for this and be ready to make full use of the support that is available.

You too may decide not to accept support from family. Pushing loved ones away and justifying to yourself that you don’t want their sympathy may be some of your reactions.

Possible consequences of non-disclosure

Sometimes it seems there is too much to lose by disclosing your HIV status. You may also feel that you do not want your family to have to deal with your HIV status and therefore decide not to disclose. However, non-disclosure can also have major consequences for you and those around you.

Possible consequences of non-disclosure are:

- Lack of support – your family and friends will not give you the support you may need as they are unaware of your status.
- By pushing your family away – you will have to deal with everything on your own.
- Lack of care – you may be unable to access the right medical care, counselling or support groups.
- Suspicion – people may become suspicious of your actions because they are unaware of your status.

Disclosure or non-disclosure should not have an impact on the way you have sex. Everyone should practise safer sex all the time – whether they are HIV-negative or HIV-positive.

Whether you choose disclosure or non-disclosure or experience involuntary disclosure, it is important to try to adopt positive ways of coping with stress and anger. There are many options available to you (e.g. song, prayer, meditation, long walks, spending time with family and friends or joining a support group). A counsellor can help you to explore what works best for you.

Case Study

A voice on the feelings experienced through disclosure

I tested HIV-positive in July 1990. What made me disclose? I believe it was fear. Fear of illness. Fear of the unknown. I felt so alone and needed to talk to someone. I just could not handle it on my own.

Love and support from everyone around me made it easier. Their acceptance gave me strength and courage to keep telling more people. I wouldn’t have told so many if the first people had rejected me. If I had to do it again, I wouldn’t do it differently. My friends have always given me support, so I guess I’d still tell them first.
Section 3

Psycho Social Impact of HIV & AIDS
- Your definition of conflict
- Conflict, violence and HIV & AIDS
- Reflection
- Identifying trauma
- The needs of a conflict, violence and HIV & AIDS survivor
- Points (for the survivor) to remember
- Anger management
- What supportive role can you play?
- How can you help?
- Tips for managing conflict

Mobilising for Change
- Creating a vision
- Points to remember
- Understanding community behaviours and attitudes
- Identifying project goals
- Action planning
- Points to remember
- Monitoring and evaluation
- Reflection

Another word for VISION is an aim or a goal.
Psycho Social Impact of HIV & AIDS

In this chapter we will discuss three processes: 1. conflict, 2. violence, and 3. identifying trauma and anger that young people experience in heading a household. In unpacking these processes, you will be able to equip yourself with knowledge and understanding about the concerns orphans and vulnerable children experience.

Your definition of conflict

Suggested discussion questions:

- Drawing on your various experiences, briefly discuss the difference between violence and conflict.
- Each group is to come up with a definition of conflict and of violence. This can either be presented to the rest of the group as a drawing, diagram or written statement.

Conflict, violence and HIV & AIDS

Conflict and violence are different.

Conflict is a relationship between two or more parties (individuals or groups) who have, or think they have incompatible goals.

Violence consists of actions, words, attitudes, structures or symptoms that cause physical, psychological, social or environmental damage and/or prevent people from reaching their full human potential.

Conflicts are a fact of life, inevitable and often creative. Conflicts happen when people pursue goals which clash. Disagreements and conflicts are usually resolved without violence and often lead to an improved situation for most or all of those involved. From the micro, interpersonal level through to groups, organisations, communities and nations, all human relations – social relations, economic relations and relations of power – experience growth, change and conflict. Conflicts arise from imbalances in these relations – (e.g. unequal social status, unequal wealth and access to resources and unequal power) – leading to problems such as discrimination, unemployment, poverty, oppression and crime. Each level connects to the others, forming a potentially powerful chain of forces either for constructive change or for destructive violence.

Once a common definition is found, ask the group the following questions:

- Give a number of examples of conflict that you are aware of at this moment.
- Can you think of a situation from your own experience where conflict has made a positive contribution to all involved?
- How did conflict help to change the situation? Do you agree that conflict can help to stimulate necessary change?
- Do you agree that conflict can help to assist in positive or negative change?

Reflection

Share a conflict you have experienced, using the following questions to guide your thoughts and discussions.

- Was it difficult for you to resolve or understand where the conflict was coming from?
- How did you deal with the situation?
- Was the outcome of the conflict positive or negative?
- What feelings do you experience when talking about the conflict now?

Identifying trauma

Trauma is often the result of a conflict situation. A traumatic experience may not be part of our everyday life. It is generally sudden and unexpected and often threatens our life or the lives of those around us. A trauma often shatters our trust in people around us. This makes it difficult for us to carry on with our normal lives. Some examples of trauma include: rape, hijacking, losing a loved one or witnessing the death of a parent or sibling.
The needs of a conflict, violence and HIV & AIDS survivor

- Be able to speak and be heard in a ‘safe-space’.
- Know what s/he feels is important, and that it is okay for her/him to have these emotions.
- Experience reconciliation between life and death – both on the symbolic level and in one’s everyday life (e.g. rituals of mourning – “giving voice to anguish”, wearing black/green/blue/purple clothing for a certain period of time, or be given a chance to tell the truth in the form of story-telling).

Discuss how you would respond to these questions frequently asked by survivors of trauma:

- Why is this happening to me?
- What did I do to deserve this?
- What should I do differently now?
- How did God allow this to happen to me?

Points (for the survivor) to remember

- The person is often left feeling vulnerable, helpless and out of control.
- The person will find it difficult to trust others again.
- The person often feels guilty; as s/he thinks that s/he could have prevented the event or done something differently so that the event did not need to occur.
- The person may feel shame and might feel that s/he has done something to deserve this.

Anger management

Anger is often a result of trauma and emotions that often build up inside and which need to be released. During this phase a survivor may not act rationally but rather emotionally. Anger may be directed at inappropriate people or expressed destructively by using sexuality as a vehicle for aggression, or by physically or emotionally hurting others.

There are a number of short-term preventive steps that a survivor of trauma can use to control and manage his/her anger. These steps help us to create some ‘space’ – like a pause – between the angry feelings we have and acting impulsively on that anger.

- It is helpful to find a place away from others where it is okay to feel angry.
- It is almost always helpful to talk to a good listener about the anger you are feeling.
- Some people find it helpful to engage in physical activity that releases some of the pressure that has built up inside (e.g. jogging, chopping wood, cleaning the house, washing clothes, etc).
- Remember to avoid alcohol or drugs especially when you are feeling angry as this will make the situation worse.

The survivor needs to acknowledge, recognise and constructively express his/her anger, as it forms part of the healing process.

What supportive role can you play?

Remember you may not have the professional skills of a psychologist, but you have an extremely valuable role to play as a committed member of a CSO or CBO or a concerned friend.

- Draw up a list of what you, as a member of your community are able to offer to someone who has experienced trauma.

How can you help?

- Listen, comfort and support the person.
- Survivors should be encouraged to resume daily activities as far as they feel comfortable.
- Support with active listening, while keeping in mind the survivor’s need to re-tell the story or not tell it at all.
- Counselling is appropriate and a referral to an organisation that offers trauma counselling may be necessary.

Remember: Some community workers have counselling experience but everyone can be good listeners and supportive. If you do not have experience with counselling, please refer the person to an appropriate organisation that can assist the survivor in a professional manner. You are not a psychologist or a detective and under no circumstances should you assume these roles, as you might do more damage than good.
Tips for managing conflict

1. Use the response ‘I understand...’ or ‘I feel...’. This will support your goals when the tension is high and you need to find common ground to form compromises or agreements with the other person or group.
2. Take notice when you feel threatened by what someone is saying to you. Resist trying to defend yourself or to ‘shut down’ the other person’s communication. It will require this kind of discipline to become an open and trusting communicator.
3. Speak out sensitively when you are feeling angry. Do not keep these feelings bottled up inside of you.
4. Take responsibility for your feelings and avoid blaming others.
5. Learn to listen to the two sides of the conflict that you are in, as if you were the counsellor.
6. Wait a few days to cool down emotionally when a situation makes you feel wild with intense feelings, such as rage.
7. Speak with respect whenever you are angry or frustrated.

Creating a vision

In many organisations people have a vision of how things could be better for orphans and vulnerable children in the future. They want to work to make the vision real.

A vision is like a dream – it helps us to know what we are working towards. It gives us courage to work for the future, gives us some direction and it helps our organisation to decide what we should focus on, and what we should not.

Another word for “vision” is an aim or a goal.

Ask each person in your group to think about the following question: What is the aim of your movement/community platform?

1. Ask group members to discuss the following question: ‘What is your vision for the organisation or movement?’
2. Make a symbol, diagram or picture that represents your vision, either as an individual or as a group. Each person or group then puts up their poster and a spokesperson for the group explains it.
3. Each group is then asked to prepare a statement expressing the common vision in the light of all the posters. These statements are written on newsprint and put up around the room.
4. Each person goes around reading the statements, and underlining the phrases that they feel are particularly important.
5. A small committee is then asked to identify the statement that has received the most support, and use this as a basis for a common statement, including key points from other statements which may not have been included.
6. The common statement is then read to the whole group for affirmation.

Points to remember

* Your aim may often seem impossible to achieve right now. To make it more achievable you need to identify smaller goals, which are steps towards achieving your overall aim or vision.
* To set goals, you need to look at the current vulnerability of children and the HIV & AIDS situation in your community and see how different it is from your vision.
* You need to identify problems and issues and then set goals to overcome your problems.
* Identify what resources or contacts you will need to overcome the problems.
* Overcoming your problems will take you closer to achieving your vision.
Understanding community behaviours and attitudes

The first step in the process of designing a project is to determine what your organisation will focus on.

* Ask each member of your group to draw a picture on a piece of paper of what their community is like right now and the characteristics of their community. Then show your drawings to each other and discuss the following questions:

  * From looking at all the drawings – what are the three most important strengths of your community?
  * What are the three most important things that are holding back developing a responsible attitude and understanding of HIV & AIDS in your community?
  * What are the three most important problems or issues that your organisation can help to address in the community? Choose one of these issues. Write a sentence of up to 10 words to describe the issue in more detail.

The problems or issues that you see are often the result of other things that are happening in your communities. It is important for you to understand these problems more deeply and to find out what is causing them. This is to ensure that you take a preventative approach and deal with the root causes of the issue.

Use the problem tree to analyse the causes of your problem more deeply:

* Draw any shape of tree with the group, making sure it has the following:
* First – write your sentence, describing the issue/problem that you want to address, in the “branches” of the tree.
* Then identify the main causes of the problem – write these in the “trunk” of the tree.
* For each cause identify the two things that people do (behaviours) that lead to this cause. Write these on the “roots” of the tree.
* Finally identify two main attitudes or beliefs that lead to each cause. Write these on the “sub-roots” of the tree.

When you understand the causes of the problem and the attitudes related to it, it will become easier to decide how to deal with the problem more effectively. This is because you have a better sense of what they are. You are not just dealing with the symptoms of the problem but using a holistic solution-based approach.

Identifying project goals

Now that you have identified specific problems in the community, the next step in the process is to identify a goal for your project and to have a clear understanding of the activities you will have to embark upon in order to reach this goal.

* Look again at your “problem tree” diagram and discuss which attitudes and behaviours you think your organisation will be able to change or shift during the project.
* Discuss what you need to do as a group to make this change. The questions below will help you identify the best project activities.

Draw a diagram of a mountain and complete the following steps:

* Write your problem statement at the bottom of the mountain – the one you used on the “problem tree” diagram.
* Then write your goal statement at the top of the mountain. This will describe what people will be doing differently – or what the community will be like – at the end of the project.
* Then list all the activities that you and your group will have to embark upon to reach your goal at the top of the mountain. Think of these activities as steps that you will take to climb to the top of the mountain.

* Drawing of mountain (only provide the most useful steps you will need to take in order to achieve your final goal).

Action planning

Once you have identified your goal and the activities or steps that you need to take to reach your goal, you can start to plan activities in more detail. You need to discuss and decide what you will do, when you will do it and who will be involved.
This activity will assist you in writing up an action plan:

On flip chart paper, write the responses to the following questions. It is important to discuss these questions at the beginning of the project:

★ Who will be responsible for leading or coordinating the activities in this step? (This person does not have to do all the work him/herself – but s/he will need to take responsibility for making sure that the work gets done through delegation of tasks to others).
★ Identify a date by when each step will have to be completed. Usually one step has to be finished before the next one can start. Be realistic about the time required for each step.
★ List the resources (including human resources) that you will need to execute the activities involved in the steps and discuss where and how these resources can be procured.
★ List any outside help that you might need to execute the activities in the steps (e.g. help you may need from religious organisations, the clinic, the police station, other CBOs or community residents). Describe what help you will need and where to get this help from.

Points to remember

★ Try to involve everyone in the group when setting goals and deciding on action plans.
★ Keep goals achievable in a short time so that you and your group experience success often.
★ Check your work plan everyday and follow up on things that you need to do.
★ Make a real commitment to reach goals and be positive and enthusiastic.
★ When you reach one of your goals – celebrate it!
★ Compliment and encourage the group members when necessary.
★ Meet every month to evaluate the last month and to plan for the next one.
★ If an unforeseen problem comes up that makes it impossible to reach your goal – change the goal so that it is still reachable, but in a different way.
★ Make sure failures become positive learning experiences.
★ Meet regularly to check how the work is progressing. If things do not go according to plan, you can discuss a different approach.

Monitoring and evaluation

To make sure you have good structures that perform well; it is important to say how you think the organisation is doing at the moment – rather than how you think it should be.

Some suggested guiding questions:

★ What are the aims of your organisation? What do you want to do?
★ What activities are you already doing?
★ What structures do you have (e.g. committees or sub-committees)?
★ What does your committee do well?
★ What should your committee do differently?

Reflection

★ What is your own experience of mobilisation and advocacy? What special talents do you have in these areas? The causes could be very different and hence the talents.
★ In your organisation, your community and in our country what are the ways in which people are mobilising themselves and are being mobilised by others around the issue of orphans who head households?
★ Is this mobilisation effective in bringing about positive change?
★ What factors seem to help, or hinder these processes of mobilisation?

Conclusion: Working in the field of orphans and vulnerable children is challenging. It is also a learning process that never stops – no matter how much you think you know, or how long your organisation has been in existence.

We hope this guide has helped to answer some of your questions, and has also assisted your organisation to develop a deeper understanding of the issues that our communities face in the context of child-headed households and violence.
Organisations that can help you:

**Family issues**

* Family and Marriage Society of South Africa (FAMSA)

It is an organisation that provides support about family issues and concerns. They offer marriage and divorce counselling and support groups. Tel: 011 892 4272/3/6

Satellite offices:
- Benoni, Kempton Park,
- Germiston, Bedfordview, Kwa-Thema, Tsakane, Alberton,
- Duduza, Watville, Vosloorus,
- Katlehong, Etwatwa, Thokoza,
- Ratanda, Daveyton, Tembisa,
- Phomolong, and Devon

**Gender-based violence**

* Stop Gender Violence Helpline

This counselling service is specifically designed to assist with issues around gender based violence. You can call the number below from anywhere in the country and ask for the details of a service nearest you. The Helpline also provides free, confidential and multilingual telephone counselling.

Tel: 0800 150 150

**HIV & AIDS**

* Circles of Support Hotline

This is an information telephone line created to assist communities to address the problems of orphaned or vulnerable children. People can volunteer their time, donate goods or expertise and find out where to go to within their communities for help.

Tel: 0860 222 777

* LifeLine

Offers free 24 hour telephonic counselling.

Tel: 0861 322 322

* loveLife thethajunction

Provides support and advice for teenagers on issues of sexual health and HIV & AIDS.

Tel: 0800 121 900

* National AIDS Helpline

Offers multi-lingual 24-hour toll free assistance by trained counsellors. They will be able to refer you to your nearest health care facility that provides Voluntary Testing & Counselling, as well as anti-retrovirals.

Tel: 0800 012 322

* National Association of People living with AIDS (NAPWA)

Tel: 011 872 0975

* Treatment Action Campaign (TAC)

To make affordable anti-retroviral medication available to PLWHAs and to raise awareness about the human rights of PLWHAs.

Cape Town (National Office): 021 788 3507
- Durban: 031 304 3673
- Johannesburg: 011 403 2293
- Limpopo: 015 291 5448
- Mpumalanga: 013 755 2298
- Southernwood: 043 722 2645

www.tac.org.za
References


Human rights

- Centre For Human Rights
  Tel: 012 420 3034
- Centre for the Study of Violence and Reconciliation (CSVR)
  Johannesburg: 011 403 56 50
  Cape Town: 021 422 0258
- Lesbian and Gay Equality Project (LGEP)
  Tel: 011 487 3810/1
- National Youth Commission
  Tel: 012 309 7837
- South African Human Rights Commission (SAHRC)
  Tel: 011 484 8300

Legal advice

- AIDS Law Project (ALP)
  Provides free legal advice on issues of AIDS discrimination. If your rights have been violated, phone the ALP Paralegal team.
  Tel: 011 356 4100
- Lawyers for Human Rights
  Durban: 031 301 0531
  Johannesburg: 011 339 1960/2
  Pietermaritzburg: 033 342 1130
  Port Elizabeth: 041 487 0881/2
  Pretoria: 012 320 2943
  Stellenbosch: 021 887 1003
  Upington: 054 331 2200
- Legal Aid Board
  Legal Aid offers assistance with legal representation, access to justice and access to information and resources. They assist with divorce, maintenance and child custody problems.
  Tel: 0861 053 425
  Other Offices:
  Alexandra: 011 786 3603/8170
  Germiston: 011 842 7300
- Legal Resource Centre
  Cape Town: 021 423 8285
  Durban: 031 301 7572
  Grahamstown: 046 622 9230
  Johannesburg: 011 836 9831

School fees

- Centre for Applied Legal Studies (CALS) Education Rights Project
  Advice on the exemption of school fees. Foster care parents or places of safety are fully exempt from the payment of school fees.
  Tel: 011 717 8621
- Department of Education’s Bana Pele Programme
  Bana Pele (“Children First”)
  Call Centre
  Tel: 011 376 8007

Useful government offices

- Department of Home Affairs
  If you have any questions about identification documents and other important certificates such as birth, marriage, death etc.
  Tel: 0800 601 190
- Department of Social Development Hotline
  Tel: 0800 601 011
Provides information for civil society organisations, community-based organisations, development workers and concerned members of the community on how to engage actively with the challenges orphans and vulnerable children face on a daily basis, with the additional responsibilities of being heads of families.

For more information call:
The Centre for the Study of Violence and Reconciliation (CSVR)
Johannesburg: 011 403 5650
Cape Town: 021 422 0258
www.csvr.org.za