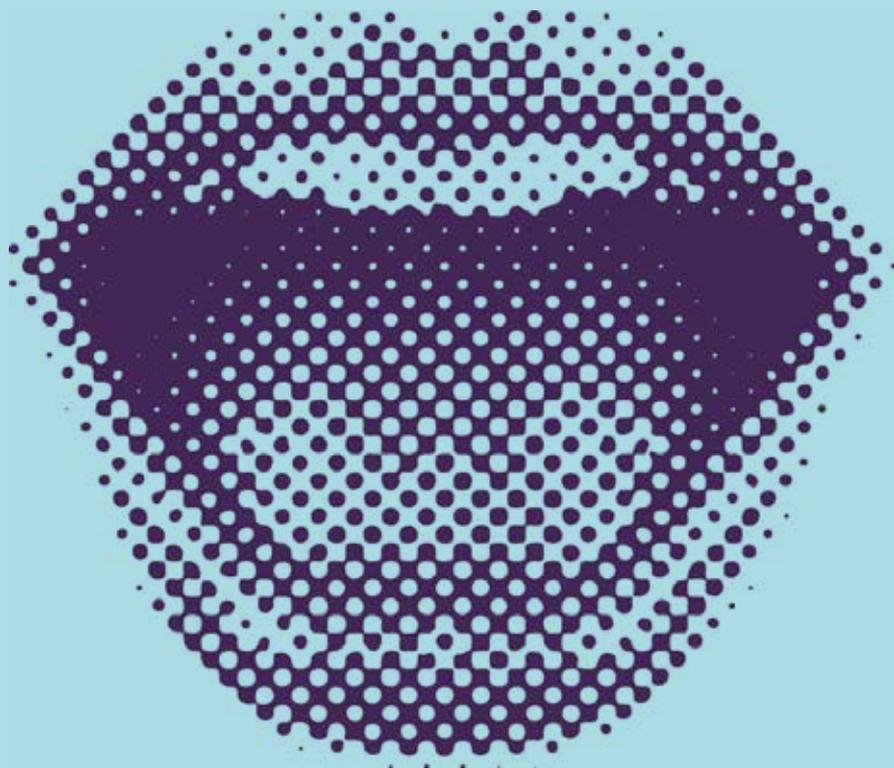


LIFTING THE BURDEN OF SECRECY

POSITIVE SPEAKERS' GUIDE



For people living with HIV who want to speak out and change attitudes to HIV, and who want to advocate for appropriate HIV laws, policies and practices

BY SUSAN PAXTON, PH.D

FOREWORD

The first two chapters of this Positive Speakers' Guide are based on the manual, *Lifting the Burden of Secrecy*, first published by the Asia Pacific Network of People living with HIV in 1999. At that time there were no resources for people living with HIV who were thrust into public speaking without any training or background. I wrote the manual to help people who chose to speak out about living with HIV decide on what to say and how to say it. The manual was reprinted in 2001 and subsequently translated into over a dozen languages.

This update, almost twenty years later, enabled me to expand the original work and include steps to a successful advocacy campaign. It highlights examples of how people living with HIV around the world have specifically advocated for policy change, and some of their success stories.

Thank you to Daniel Cordner, who freely offered to take my text and design it into an accessible format. Please feel free to use and reproduce this manual... There is no copyright.

I hope that this Positive Speakers' Guide will inspire many more people living with HIV who have appropriate support, to speak out and dispel the stigma of HIV, encourage others to get tested and treated, and help create public policies that respect the rights of all people living with HIV.

Susan Paxton, Ph.D.

Living with HIV for three decades

World AIDS Day, 2018

Graphic Design: Daniel Cordner
www.cargocollective.com/danielcordnerdesign

Lifting the Burden of Secrecy
POSITIVE SPEAKERS' GUIDE

CONTENTS

04 Introduction

06 CHAPTER ONE: The power of positive speakers

- 08 1.1 Who openly discloses their HIV status
- 09 1.2 Why speak out
- 11 1.3 Negative consequences of speaking out
- 13 1.4 Personal benefits of speaking out
- 15 1.5 Support needed before you begin
- 17 1.6 Legal issues

18 CHAPTER TWO: What to say and how to say it

- 21 2.1 Telling your story
- 22 2.2 Structuring your presentation
- 24 2.3 Preparing for your talk
- 26 2.4 Delivering your presentation
- 28 2.5 Soliciting questions
- 29 2.6 Common questions and sample answers
- 32 2.7 Dealing with emotions and debriefing

34 CHAPTER THREE: HIV advocates

- 35 3.1 Advocacy issues
- 39 3.2 Steps to a successful advocacy campaign
- 40 3.3 Influencing policy change
- 42 3.4 Language matters
- 43 3.5 Using the media
- 45 3.6 Avoiding burnout

INTRODUCTION

This Positive Speakers' Guide is aimed at people living with HIV who are considering speaking out in person, to any group of people, about their experience of living with HIV in order to change attitudes or policies related to HIV.

Since early in the HIV epidemic, people have spoken out about living with the virus. The primary aim of publicly disclosing is not to give medical information, but to share the reality of living with HIV, challenge perceptions about who can and cannot contract HIV, reduce the stigma towards people living with the virus, and inform progressive HIV policies which respect people's rights.

The vast majority of positive speakers find that speaking out and giving a face to HIV is an extremely rewarding experience. Most say that the benefits, including increased self-esteem and the relief of lifting the burden of secrecy, outweigh any negative responses.

Encouraging more people living with HIV to speak out in public and put a human face to HIV will contribute greatly to better public health messages. Positive speakers break down discrimination and prejudice against people living with HIV, help prevent the spread of HIV, and inform government policy. However, NO person should go public unless they are ready. You need support before taking this step.

You should always start by talking to a small, safe, closed group of people. Bigger does not mean better. The larger a group, the harder you have to work to make yourself heard and keep attention.

A person living with HIV should NOT go public in the media unless they have a great deal of emotional support, and their financial position will not be negatively impacted (e.g. by losing their job). The possible consequences of media exposure are far greater than speaking personally, face-to-face, with an audience, and once you have gone public in the media, you cannot reverse it.

I dedicate this Speakers' Guide to all the courageous people who have chosen to speak out about living with HIV despite possible discrimination.



**THE POWER
OF POSITIVE
SPEAKERS**

CHAPTER 1

Almost universally, our earliest messages about HIV imply that people who are diagnosed as HIV-positive are morally blameful, and some people still believe HIV leads to early death. After diagnosis, people living with HIV generally live in fear and isolation. Many live a double life, unable to disclose their secret to most people for fear of discrimination.

People who speak out about living with HIV challenge societal attitudes. They show their communities that anybody is vulnerable to HIV and that people living with HIV can lead positive and productive lives. They show policy makers that respect for the rights of people living with HIV is essential for a successful response to HIV.

1.1

Who openly discloses their HIV status

People who choose to speak out about living with HIV come from all backgrounds. Some did not finish primary education whilst others have university degrees. Some work as teachers, nurses, artists, farmers, sex workers, government officers. Some have no source of income. Some contracted HIV from sharing needles, some were born with HIV, and most contracted HIV from their sexual partner who invariably did not know he was HIV-positive.

As a result of speaking openly I can see that the public has become aware of the epidemic as a problem that also affects women. It opens up a place for others to follow. Before, HIV was seen as a gay-only problem. Throughout Latin America the epidemic continues to be concentrated among gay groups. This is real but it is not the total picture.

(GRACIA VIOLETA, BOLIVIA)

I am proud that I can come out and do what many people cannot do and say I am HIV-positive, without hesitating and with the conviction that it's not wrong for me to be positive. It's an accident and that's the way I take it. I've challenged a lot of misconceptions in my country. People have come to accept that there is no danger in associating physically with people with HIV.

(JOE, KENYA)

Some people have experience in public speaking before their diagnosis, perhaps in school, but most people have no previous experience. Some people are inspired to speak out after listening to other positive people doing so. A few have never heard another positive speaker before they go public.

Meeting people living with HIV face-to-face is the most powerful way to educate people about HIV and change attitudes, and to advocate to governments and other agencies on behalf of people living with HIV. Very few people disclose their HIV status on national television, radio or newspapers, and you do not need to in order to be effective. Most speakers talk to small groups in classrooms, or to health care workers. Increasingly, young people born HIV-positive are speaking out.

I speak out because if I don't do it, no one will. It isn't an obligation, but a duty that I have chosen to take on. Many times, I'm not sure if I will have any impact, or if it is important what I say or do, but then a young person comes to me to talk about her or his experience, and that's how I confirm the value of my work.

(L'ORANGELIS, PUERTO RICO)

I was forced to undergo sterilisation, my babies died, and my belongings were taken away from me after their father died. I had to start all over again to build my life. Before I first came out, I was scared. When I talked of my experiences, I could see that my story was powerful. It touched all the mothers, who cried, and hugged me afterwards. Realising that I could change people's attitudes gave me a new inner strength. It's been a long walk for me. Now I have risen above my pain and struggles and I am a leader.

(MAURA, PAPUA NEW GUINEA)

1.2

Why speak out

The only unifying character of people who disclose their HIV status publicly is that they are all strong people who chose to respond to their life situation rather than become victims. They are people who, in the face of adversity, decide to challenge the status quo. Only a small percentage of people diagnosed with HIV take this brave step.

People who speak out publicly about living with HIV are passionately motivated to stop the HIV-related discrimination and rights violations, prevent the spread of HIV, or change policies and practices in relation to people living with HIV.

Years ago, the situation was very, very bad regarding acceptance and misunderstanding and since that time our efforts have made a big difference to improve the acceptance of people living with HIV in northern Thailand.

(KUNG, THAILAND)

Challenging discrimination and violations of rights

People living with HIV often face discrimination because of the fear and stigma still surrounding the virus. Many have experienced physical violence. People have lost their jobs, been expelled from school, evicted from their homes, lost custody of their children, or faced rejection from their health care providers and/or communities. Many people speak out to challenge discrimination against people living with HIV.

When community members of the school where I was head teacher learnt of my HIV status, they locked up my office saying they could not tolerate an HIV-positive person leading their school. From one school to another I was rejected. Rather than wallow in self-pity, I decided to take on activism and advocate against stigma and discrimination of people living with HIV. As a teacher, I used my communication skills to enable me to go through the process of going public about my HIV status. After speaking publicly, curiously, I have become someone who is listened to more than before. When I talk at meetings, people listen to me as if I were a wise elder. I welcome being seen as an older person because in Africa they are the most respected.

(AYOO, UGANDA)

Society has changed, and only because people have been prepared to put their faces to stories. If HIV is talked about in a depersonalised way it becomes dehumanised, which it was in the 80s when hospital workers left people's meals outside their rooms. That is real fear. And the only way you can challenge it is to say "I'm here. I'm talking to you. I am not an insidious, evil person, and you haven't caught AIDS". Issues of discrimination are a lot to do with the way you approach them. If you say, head on, "I've got HIV", it disarms people. I feel I've made a real contribution in terms of changing some people's attitudes. If you were to compare Australia in the 90s, we had to have people come out and show that people with HIV were no different from anybody else with a serious illness.

(DAVID, AUSTRALIA)

After my husband learnt he was HIV-positive, he could not face the stigma of HIV and committed suicide. My husband was shamed even after his death. One night soon afterwards, neighbours set fire to my house where my two daughters and I were asleep. Had my children been HIV-positive I would have taken them and jumped into the river. They tested negative and that gave me hope. No one should have to live or die like that. I drew strength from that. That is when I decided to fight for those living with HIV.

(PRINCY¹, SRI LANKA)

Many people who speak out to about HIV-related discrimination dispel the myths surrounding HIV, which leads to greater acceptance and improved health outcomes.

I come with an open face because not all people are willing to talk openly about their HIV status. I voice our needs and problems to the people who live next to us so they know about HIV and are able to hear about us. I want to convey to all the people that HIV does not prevent me from living a full life, with children, family, friends and favorite work. I do my best to stop discrimination.

(OLENA², UKRAINE)

Every time I've done a talk with health care professionals, they say that the best part of their education is when they actually talk to a person with the virus. We should be out in the schools and the community. Train us. Accredite us. Give us resources and get us out there talking. We are possibly going to prevent someone being infected. That's the idea of it. It's health promotion. And that's valuable and worthwhile in itself.

(JOE, AUSTRALIA)

Many people speak out to show that they have the same rights to housing, employment, health care, access to treatment, contraception, privacy, freedom of movement and freedom from violence, as everybody else in society.

The voices of women who use drugs was not there in the response to HIV. We face double discrimination, as HIV-positive and as drug users. It is not acceptable to be a female drug user in society, and we face more violence because of this.

(NARO, INDIA)

It wasn't an easy journey to go public and speak about my status. Being a sex worker does not make you ineligible to being treated with dignity. I had to face my fears and fight for the rights of my community of sex workers to access legal services, sexual, reproductive and other health service. I advocate for their human rights and I help them to face their fears, change their perceptions that HIV is a death sentence, and move on with their life.

(JOYCE, KENYA)

1 In 2012 Princy Mangelika and the Positive Women's Network of Sri Lanka received the UNAIDS Red Ribbon Award (Celebrating Community Leadership and Action On AIDS).

2 In 2014 Olena Stryzhak and the Cherkassy Branch of the All-Ukrainian Network of People living with HIV received the UNAIDS Red Ribbon Award (Celebrating Community Leadership and Action On AIDS).

1.3

Negative consequences of speaking out

As well as educating communities, people living with HIV advocate for changes in policies. Within government health services in many countries people living with HIV have successfully challenged access to treatment and care, breaches of confidentiality, degrading treatment, coerced sterilisation, and have created programmes that are more sensitive to the needs and respectful of the rights of people living with HIV.

HIV prevention

HIV is still shrouded in secrecy and people do not like to talk about it. The fear and stigma connected with HIV makes most people convince themselves that HIV only affects particular groups in society, “other” people, not them. People diagnosed with HIV invariably hide their status, for fear of negative repercussions of shame and stigma, and live with a carefully guarded secret. This masks the face of HIV. The power of people living with HIV speaking out publicly is in lifting this secrecy.

Some people go public because they were married and did not see themselves at risk of HIV. They break the silence. Meeting people with HIV reduces people’s fears and creates an atmosphere for people to discuss HIV openly and change perceptions about their vulnerability to HIV and responsibility for HIV prevention.

Globally, the highest rate of HIV infections occurs in young women under twenty-five years old. Many speakers focus on getting their message across to young people in particular. Young people are curious and it is easier for them to discuss sexual behaviour with an anonymous person who they are unlikely to meet again, than with their teachers or parents. Sometimes their straight questions may seem impolite, but research shows that talking about safer, protective sexual behaviour with young people before they become sexually active is the most effective time to carry out HIV education. Young people who learn about safer sexual practices before they become sexually active tend to delay the age of first intercourse, use condoms and have fewer sexual partners.

Most people who come out publicly do not face negative consequences. Occasionally speakers face hostility from an audience, but most people quickly warm to the speaker and relate to them as their story unfolds. For many people, discrimination is reduced after disclosure.

Some people face some social discrimination if they are in the public eye. This can come from their immediate family, who may be opposed to sharing sensitive personal information publicly. In most cases, family members become more sympathetic and supportive over time, particularly after they see the beneficial consequences of their work on their loved one’s personal health or in the community.

Speaking out builds resilience. HIV caused violence in my marriage but that did not deter me from advocating to stop violence against women. This attracted various critics, like, “She has become useless and hopeless, that is why she is disclosing”. Others said I wasn’t infected but just doing it for money. Now people compliment me for work well done. People went to counselling and testing and started accessing treatment. Others, after losing their spouses, got

into new relationships and settled. Communication skills improved in households. Many children of positive parents are negative. Widowers' and orphans' property is no longer grabbed. Support groups started. Standards of living of women with HIV improved. Sustainable livelihoods were initiated. Now HIV is no longer a threat.

(SOPHIE, UGANDA)

Some speakers faced rejection from friends or members of the community. Some have lost their jobs because people in the workplace have found out that they are HIV-positive. Some women are concerned about the impact going public may have on their children.

Overall, positive speakers generally have no regrets about going public. In fact, participation in the HIV response enriches the lives of most speakers, and the benefits of disclosure usually outweigh any disadvantages they may face. It is important for you to reflect on what you are intending to do, because once you have “gone public”, it is impossible to retract it.

Extract from a discussion with school students 15-16 years old, following a talk by a woman living with HIV in Australia

How did the talk make you feel?

Vulnerable.

Surprised that anyone can get it.

It was very relevant because she went to a private school just like us, and she got HIV.

It was weird how she had AIDS. They don't look different from anyone else.

I used to be worried about being around them but now it feels better.

Do you discuss safer sex in school?

The teachers drum into us, 'Don't do this. Don't do that'. They never tell us why. They just say 'You'll get AIDS'. That's it.

It's hard to talk to teachers, but with the positive speaker you can ask anything. You're not worried about what they'll think or judge. You don't have to see them again.

She wasn't preaching. She just sat down and talked to us.

If you ask teachers questions, they'll wonder why. And they know your parents.

The speaker wasn't going to leave and then go and write your report.

That's a major difference.

We found out more in that talk than we have in the last three years.

Did you learn more factually?

No, but it pushes you to use it more. The reality that if you don't, that's what you end up having.

We have to accept it now because it's around. We have to accept it.

1.4

Personal benefits of speaking out

Often a positive diagnosis shatters one's self esteem. Most people face issues of loss, disempowerment, stigma and social isolation. Coming out openly and discussing one's status is rewarded by an enormous feeling of relief; a feeling that one is lifting the burden of secrecy that has weighed heavily since diagnosis. Releasing this stress has a positive impact on the speaker's health and well-being.

After going public about my HIV-positive status, my confidence increased. I became assertive, standing up for my rights, improving relations with others and gaining more control over my life. Stigma was rampant but as I inform the audiences of the rights of people living with HIV, the community stigma reduces. Understanding and awareness of HIV spreads and people diagnosed as HIV-positive can plan for their future and become useful again in the community.

(LEAH, KENYA)

I have increased confidence. Disclosing has been an extremely profitable experience. Previously I was very quiet and I couldn't bear to say anything. Now here I am a completely different person who dares to present to an audience. It's been a wonderful thing.

(KUNG, THAILAND)

Positive speakers feel they are doing something worthwhile and contributing to their community. They have a valuable role to play. Encouraging responses from audience members instils self-respect, increases self-esteem, and motivates them to continue speaking out.

I never looked back. I am providing leadership in communities and at national level through advocacy for integrated sexual and reproductive health and HIV services for adolescents and young mothers in government health facilities. We are reinvigorating support groups for positive adolescents and youth to demand sexual health services for all.

(TENDAYI, ZIMBABWE)

The overall impact of speaking out on a personal level is that it enables many people to take back control over their lives, re-establish their personal dignity, build self-confidence. Greater visibility is also inspiring for other people living with HIV and helps them to develop an optimistic outlook. They realise that it is possible to live a long, healthy and fulfilling life with HIV; that there is life after diagnosis. These messages can be a lifeline for people who are newly diagnosed.

The most difficult thing about living with HIV is putting on a mask. Now, I no longer have to live in a shell, with a split personality. I'm no longer afraid. I can be myself whenever I want, wherever I want. I don't have to put on a mask when I leave. It makes me feel good and enhances confidence in myself. It empowers me in many areas. It gives me peace in general, because in the past, before I could speak publicly, I felt so scared, so abnormal. At times we are our own barrier. We are our own enemy.

(PAUL, SINGAPORE)

I feel better. I feel I have opened the door because everything was tight inside me. When I spoke out I feel I opened the door to my health. Everything is helped. Life is better from the day that I was open about my status. I am happy I have come out. I am happy. I am training more and more staff to go out to the public.

(JOSEPH, TANZANIA)

I feel very good. I feel relief. When you are HIV-positive, you cannot accept it because of the fear. Talking out has helped me to understand myself, understand people, understand life. It develops my feelings and emotions, and this connects to the physical. In all these years I've never been sick, never admitted to hospital.

(PAISAN, THAILAND)

Hope of Living

(Maura Elaripe, Papua New Guinea)

Sitting on my platform;
in front of my house
I tend to question myself . . .
Where am I heading to?
Do I have a hope of living?
All sorts of negative thoughts
crowd my mind
giving my eyes a hazy view.
But down within me, there seems to be a
little flame burning
encouraging me, and urging me
to carry on with my life.
I strive and persevere,
struggling to be recognised and accepted
as a productive citizen,
I look at this life as an opportunity,
an opportunity to leave the world
a better place than when I came into it.
AIDS is not going to steal that opportunity
away from me.
That's what gives me the courage to go on.
I am living my life positively,
and I will continue to contribute my bit
in this struggle against AIDS
that is my hope of living.

1.5

Support needed before you begin

Disclosing one's HIV status is confronting. Taking the first step and speaking out to a group of strangers about your experiences of living with HIV can be terrifying. This is so even if you are very strongly motivated. Most people need time to come to terms with their status after diagnosis. Usually it is necessary to talk through issues that arise after diagnosis with other people living with HIV, or with a counsellor.

Before you go public about living with HIV, you must have good support. You need trustworthy people with whom you can discuss any issues that arise when you do a talk and any negative consequences you may face from disclosing your status to others. It is important to feel safe in your home, your work and your community.

While I was preparing for public disclosure, it was important that I remained financially independent if I lost my business. I retrained myself and acquired new skills I would need to survive. Even though I had a college degree, I learnt various crafts I could do with my hands so I would not be at the mercy of an employer.

(ROLAKE, NIGERIA)

It may be years before you feel ready and safe enough to come out about living with HIV to people you have not met before, and that is okay. Do it only when you are ready. Your first experience of speaking out should be in a safe environment such as a small supportive group of health workers, to decide how public you want to go. Most speakers are afraid before their first talk, but provided they have good support, they overcome their fears early on and continue to speak out again and again.

Positive peers

For the majority of speakers, their greatest support is others living with HIV. Your peers know what it is like to face the fear of HIV disclosure. Meeting and listening to other positive speakers can be a great source of inspiration. If there are people who do HIV talks in your area ask if you can come to one of them. If it is okay with your “buddy”, try to answer some questions at the end of the talk, to give you experience of speaking to a group without taking on the responsibility of a session. When you are ready to give your first talk, this buddy may support you by accompanying you to your first talk and discussing it with you afterwards.

Family

Family members are often more supportive than people expect. It may be frightening to talk to your family about your status but do consider it. Most people believe that if they tell their family about their status they will cause excessive emotional pain. In most situations, few negative repercussions come about because of telling family members, and the outcome is invariably more supportive family relationships.

When disclosing to your family, start with a family member with whom you can share your thoughts and feelings, perhaps a sibling. This person may be able to help you to disclose to other family members, including your parents. A common response from parents, on hearing of their child's status, is anger. This anger is generated by the grief that parents experience on first hearing of your diagnosis. From your viewpoint, it may

seem an unreasonable response, but if you are willing to give them time, they will probably become increasingly supportive.

I was fortunate to have parents who respect me and understand that my actions will result in my own freedom and happiness. Ultimately, they began to accept it. And they will defend me. If someone was to discriminate against me, my mum would say “I have a positive son, so what? It’s just another disease”.

(PAUL, SINGAPORE)

In the beginning my brothers and sisters asked “Why do you want to do this?” But today I don’t have any problems. All my relatives support me. I got back trust and confidence from my family, especially my mother. She has really taken care of me. Now it’s time for me to give it back.

(JAFAR, MALAYSIA)

Many women face the threat of violence if they are diagnosed during pregnancy. Many women who tell their partner are blamed for being the first to bring HIV into the family. For these women, although they may wish to be more active in the response to HIV, they may have to live in secrecy to protect the safety of themselves and their children.

Some people talk publicly about living with HIV without telling their family and without revealing their status to their local community. It is possible to do this by carefully selecting your audience. You may choose to talk to small, closed groups, or groups of people who live in other areas. Some people who do public HIV education take on a pseudonym, a name they adopt when disclosing their HIV status, to protect their identity.

Counsellors and others

If you are not able to disclose to your family, seek the support of a counsellor if possible. A good counsellor is a trained, independent person who can help you to overcome your fears. Find out from your local health service if counselling is available.

If you go public, you will need some way of discussing your feelings with another sympathetic, supportive, trustworthy person; somebody who is there to listen to you and, if asked, to give you feedback. Health care workers and workers in non-government organisations can be important avenues for support. Some people say their religion is a great support but none rely solely on this. Talking to other people is necessary.

1.6

Legal Issues

Every person has the right to personal security. Nobody should ever harm you physically or mentally because you are HIV-positive. Before you speak out publicly, talk to a legal advisor and find out how the law can protect you. Consider ALL possible consequences of going public, and how you would deal with them.

- What would be the consequences if somebody breaches your confidentiality?
- If people threaten you because of your HIV status, what recourse do you have?
- What is the likelihood that your partner or his family may become violent?
- If this happens, where can you go? What protection is available to you?
- How sympathetic are police towards people living with HIV?
- What would happen if you lost your housing or your job because you went public? Would you have the right to challenge this in court?
- Would you be willing to challenge discrimination in court?
- If your child(ren)'s education is threatened, what recourse is there?

CHAPTER 2

WHAT TO SAY AND HOW TO SAY IT





One of the most difficult questions you will face is how much of your personal story to share with your audience. The golden rule is, only disclose as much as you feel comfortable to share with strangers.

Only tell as much of your personal story as feels comfortable for you.

The value of going out and speaking face-to-face with an audience is that it challenges people's perceptions about who gets HIV. It is important that any talk has a personal perspective, your story. If you are advocating to government officers for policy change (see Chapter Three), rather than carrying out community HIV education, it is still important to share something of your personal experience of living with HIV, so they can relate to the issues you raise.

2.1

Telling your story

The art of good public speaking is to speak from the heart. No matter what the purpose of your talk, it is important to personalise it. If you are passionate, people listen.

If you can communicate passion about something, if it's something you really want to say, they will listen. No matter how much training or how much strategy or technique you use, it's the passion that's there that says what I am saying is worth hearing. If you don't have that passion you're not worth listening to.

(DAVID, AUSTRALIA)

Parts of your story may make people feel sad; other parts may make them laugh. Human experience is composed of a range of emotions. If you are true to yourself you will allow the audience to empathise with your story. They will relate to you on a human level, and they will realise that people living with HIV are not very different from them.

You are not there to reveal everything about yourself. It is okay not to tell parts of your story, for whatever reason. For example, there is no need to tell the audience how you contracted HIV. Do not tell people anything that makes you feel uncomfortable.

I've recognised the boundaries that I'm prepared to go to. When I first started, I hadn't thought about how much of my personal story I would divulge. A few times I found myself in uncomfortable situations where I was asked a question that led to me giving away more information than I actually wanted to, that is still too emotional and painful to discuss. Over time I've learned what my limits are. I've become more confident.

(MICHELLE, AUSTRALIA)

Speaking out in public is NOT giving a “testimonial”. You are not there to tell people that you did anything wrong. There is nothing wrong with having contracted HIV. You are there to describe how HIV affects your life. Do not apologise for anything in your talk. Most listeners will feel humbled by your story.

Telling your personal story is not about giving a lecture. Unless specifically asked, you are not there to provide medical information. The strength of it being you is that you enable people to see that people living with HIV are a cross-section of society; you break down prejudicial attitudes and get people talking about HIV. Of course, it is important to go out with accurate and up-to-date knowledge and information, because people will ask you for it. If you have a good relationship with an HIV organisation, non-governmental organisation, or government department, investigate ways to ensure that the training you need is provided to you.

It is also important not to share your whole life story. You need to select the parts that are relevant to the audience you are addressing. And, because your life is constantly changing, so also will your story change, depending on who you are talking to and why. Adapt your story to each new audience - workplace employees, healthcare workers, youth, policy makers.

2.2

Structuring your presentation

Every talk needs structure: a beginning, a middle and an end.

Before you speak to a specific audience, ask why you are talking to that particular group of people and what you hope to achieve. This helps you to structure what you are going to say. If you know why you are doing it, you will know what parts of your story are relevant to get across your message.

I consider the following questions as I prepare a presentation:

Why am I making this presentation? Is it to persuade, teach, inform?

What actions do I want to take?

I try to be in control of the occasion. I make a confident entry into the room and take full control of my space. I stand square and upright facing my audience. I take care of my body language, appearance, gestures.

At an appropriate moment I encourage discussion rather than simply take questions and answer. This gives an opportunity for others to share their personal experiences. I also prepare some answers to questions in advance. I decide which questions I will not answer, if I feel some questions are too personal, and I explain why. I do relaxation and breathing exercises.

(AYOO, UGANDA)

Introduction

People remember beginnings. Your introduction must be positive and powerful, so you create interest and a desire to hear your story. Begin by introducing yourself and stating your purpose in talking to them.

Example introduction for school talk: “Hello everybody. My name is I am here today to help you think about the choices you make in your sexual relations... I am HIV-positive. I was diagnosed with HIV [number] years ago....”

Example introduction for health workers: “Good afternoon. My name is I am here today to talk about the treatment faced by people living with HIV in government hospitals. I am HIV-positive and was diagnosed with HIV in [year]....”

Focus on the common points between you and the audience. If it is a group of young people you may say you went to a similar school, if it is a group of mothers and you have children, mention that.

Body of talk

For the body of your talk, select three major points to focus on for any particular audience and write them down. These may include:

- disclosing to family, partners, friends
- the impact HIV has on your social life
- discrimination you have faced

- attitudes within the health sector
- access to health monitoring and treatment
- how you maintain your emotional well-being in the face of a life-threatening condition that is surrounded by stigma
- support available

To make sure that what you say comes from the heart, DO NOT write out your presentation as a speech. If you do, it will sound monotonous and the audience will switch off. Instead, make prompt cards. These are small pieces of paper with the key points you plan to cover written in large bold print. Highlight the most important points, and note those you can omit if you run out of time.

During your talk, glance at your prompt cards from time to time, to remember what issue you want to cover next. You can hold the prompt cards in one hand. If during a talk you forget what you are saying, that is only human. It is okay to check your prompt cards.

Make sure you pace your talk so that you cover your major points within the allocated time, and still have time for questions. Keep a check on the time as you deliver your talk.

Some speakers like to write out a “running sheet”, with the timing of each section of their talk. This can help you avoid getting half-way through your presentation and running out of time before you get to the most important message.

Conclusion

End your talk with a powerful statement that reinforces your message, why you are there. Perhaps you may decide to end your talk with a slogan, examples: get tested and stay safe; we are human too; there is life after diagnosis; all people living with HIV have the right to non-discriminatory health care; nothing about us without us.

Sample running order for 60-minute talk	
Introduction	
00 mins	Say your name, explain <i>why</i> you are there
Body of talk	
05 mins	Diagnosis and disclosure to family
15 mins	Discrimination faced; response
25 mins	Health and access to treatments
Conclusion	
30 mins	Reiterate message
35 mins	Organisational contact information
40 mins	Questions from audience
60 mins	End

2.3

Preparing for your talk

One thing you will need to speak out about your experiences is a strong voice. The quality of one's voice depends on lung capacity, projection and articulation. Like anything, exercise improves ability. Regular breathing exercises lead to increased lung capacity. Voice exercises reduce stress on your vocal chords and improve the clarity of your speech. Try these exercises on a regular basis to focus your mind, strengthen your voice, and improve your articulation.

VOICE EXERCISES

Alternate Nostril Breathing

Sit comfortably. Using one hand, place your thumb on one nostril and a finger on the other. Press the right nostril closed and inhale a full deep breath through the left nostril. Close the left nostril and release the right. Breathe out through the right nostril. Inhale a full deep breath through the right nostril. Close it with your finger. Release the left nostril and breathe out. Repeat six times. The effect on controlling emotions and focussing the mind is instant.

Releasing the Voice

Stand up straight with your feet placed evenly apart and shoulders relaxed. Drop the chin towards the chest. Hum softly and deeply with your lips gently closed. See how deeply you can hum. Relax your throat. Repeat several times. Start with lips gently closed, then open the lips and make a "Mmmaaaaaa" sound. Repeat several times. Imagine the sound travelling far across a great hall.

Loosening the Lips and Tongue

Squeeze and stretch the lips into every possible strange shape. Write your name with the tip of your tongue on the roof of your mouth. Repeat. You can do this exercise in front of people and they will not know you are doing it.

Improving Articulation

Say a tongue twister, such as: "red leather, yellow leather", or "dibbity tiddity, dibbity tiddity". Repeat it over and over. Start very slowly and increase your speed without "twisting" your tongue.

If you have access to an audio recorder, overcome your natural shyness and speak into it alone at home and try out your talk. Play it back and listen to yourself. Don't be put off. Everybody hates listening to their own voice at first. The exercise will help you to speak clearly and with expression. It will also help you to hear when you are speaking too quickly, a common problem with many speakers.

Keep powerpoint presentations to a minimum and only use if there is a very good reason. And be prepared for broken equipment or power failures. If you use a powerpoint, make sure you have only a few major dot points on each slide, and no more than six lines of text in large type. Switch off the projector when you are not using it as it is distracting.

CHECKLIST - DAY BEFORE THE TALK

- Prepare prompt cards indicating major points to address.
- Try your presentation on an audio recorder.
- Check time and place of the talk.
- Have contact details for any support services audience may want.
- Prepare smart, comfortable clothes.
- Arrange to do something relaxing afterwards and meet somebody to debrief.

The day before you go to a speaking engagement, select the most appropriate clothing to wear for that particular audience. Check that everything you need is ready for the following day. Before you go to sleep that night, visualise yourself giving a successful talk, calmly and smoothly.

Creative Visualisation

We all create our own reality. If you can visualize yourself doing a successful talk, you will get positive results. As you go to sleep, try this exercise.

Go through the body, part by part, relaxing with every outward breath. Imagine you are walking towards where you are to give your talk. Your path takes you along a beautiful garden to a body of crystal clear water. You have plenty of time so you decide to have a swim in the water. Nobody is around and the sun is shining so you take off your clothes and step into the water. Imagine yourself swimming under the water, even if you are unable to swim in reality. When you have finished, come back and dress.

Picture yourself walking to the speaking venue and being warmly greeted by the audience. See yourself delivering a successful talk. Imagine yourself delivering your words calmly and clearly. Look at your body language and check that you are relaxed. See yourself smile. As you fall asleep, check where you are holding tension in your body. Every time you breathe out, release the tension.

On the day of the talk, give yourself at least an hour to wash, eat and calm your mind before you leave home.

When you arrive at the venue, go to reception and ask for the person responsible for the booking. Refresh yourself, and then ask to look at the room where you will be speaking. Consider where people will sit. The layout of the room will determine where you will stand in relation to the audience. Avoid standing in front of a window, as this will put you in silhouette and will be a strain on the audience's eyes. If possible, place yourself in the lightest part of the room, and the audience with their backs to any windows.

If the audience is large, stand up in front of them. If it is a small group, you can sit with them in a semi-circle. An effective place to stand is with a

2.4

Delivering your talk

desk or table behind you. This gives you support if you need to lean against it, provides you with a place to put your glass of water, your watch, and any handouts you may want to distribute at the end. If the chairs are moveable, avoid rows of people. If it is a small audience (say less than forty) do not feel shy to ask the organiser to rearrange the seating. Try to seat people in a semi-circle and close to you. The more intimate you make the environment, the more engrossed the audience will be and the more easily they will listen to you. Make sure that from where you intend to stand, you will be able to see the face of every person in the audience, and that there is no furniture immediately in front of you, such as a table or bench, as this will act as a psychological barrier between you and the audience.

Ask for a glass of water before you begin, and place it nearby in case you dry up during the talk. Stop from time to time during your talk and take a sip of water. Make sure you have a clock or watch nearby so you can check your pacing occasionally, and put your phone on silent.

Before the audience comes in, spend at least five minutes alone, doing some exercises to focus your mind, relax your breathing, and loosen your tongue and lips.

CHECKLIST - ON ARRIVAL AT VENUE

- Give yourself time to eat and rest before you depart.
- Arrive at the venue with plenty of time to locate the organiser.
- Check that any equipment you want to use is working.
- Consider the layout of the room and decide where you will stand.
- If possible, do not stand in front of a window but in the lightest part of the room.
- If the chairs are moveable, rearrange the seats to your best advantage.
- Focus your mind and loosen up your voice and tongue.
- Have a glass of water and place it on a table nearby with your watch.
- Ensure everybody can see you and there is no barrier between you and the audience.

Before you start talking, make sure your hands are free (other than your prompt cards), and both feet are placed evenly on the ground. Do not hold anything in your hand such as a pen, as you will fiddle with it during the talk and distract attention. As you face the audience, think of somebody you love or somebody who would be proud of what you are doing, and you will naturally smile. As you begin your presentation, imagine that this is the first time you have told anybody your story. This way, you will approach each talk with a fresh perspective.

I start my sessions in a gentle way by introducing myself and sharing my HIV-positive status. Every time I imagine that this is the first time I am talking about myself, maintaining eye contact so as to involve everybody, carefully watching my language both verbal and non-verbal. I share the impact of HIV in my life and introduce the planned topic. I get the audience's views about the topic then I follow up with how I have dealt with it. I mention the support systems available and discuss the strategies that can work in the HIV response at individual, family and community levels.

(LEAH, KENYA)

Be mindful of your audience – language, education, culture and social location. All people are not the same age, sexual orientation, dis/ability, geographical location, education, etc. Your experience might be different from others; acknowledge that if possible. Read as much as you can related to the advocacy issue – do your own research or work with others who have the expertise. Involve all people affected by the issue, including those at the grassroots.

(MARVELOUS, ZIMBABWE)

Volume

When delivering a talk, it is important to make sure, first and foremost, that the audience can hear you. When you begin, no matter how big the group, ask: “Can the people in the back raise your hand if you can hear what I am saying?”.

Tone

The rhythm and tone of your voice is important in capturing the audience’s attention. Aim to vary your delivery so that it has changes of pace, volume, and intonation.

Speed

A very common problem is speaking far too quickly. The quicker you speak, the higher your voice rises and the greater strain you place on it. Do not rush anything. Start off gently. Before you talk, take a sip of water, breathe in and out calmly, and smile. The audience is not only becoming used to your voice and what you are saying, they are also adjusting to the idea of somebody telling them that they are living with HIV. Many thoughts might be going through their minds.

Eye Contact

Make eye contact with each and every person you are addressing. Do not focus for long on any one person as it will make them feel uncomfortable. Move your eyes around the audience at various levels, and catch the eyes of different individuals in different parts of the room for a second each. Keep scanning the audience throughout the talk. This way everybody will feel involved.

Appropriate Language

In the same way that you dress appropriately for the audience, use language that is appropriate. How you educate school girls about HIV and how you advocate to government officials about discrimination within services are very different approaches. Some people may not understand the terms you use. Avoid complex words and acronyms people may not know.

Be aware of your body language. Holding one’s arms across one’s body closes you in and creates a barrier between you and the audience. Nervous fidgeting or feet shifting is annoying and distracting. Try to appear relaxed and in control and the audience will feel at ease and want to listen to you.

2.5

Soliciting questions

CHECKLIST - DURING THE TALK

- Hold only prompt cards in your hands.
- Before you begin your story, imagine it is the first time you have ever told it.
- Check the audience can hear you. Ask if the people at the back can hear you.
- Use appropriate language.
- Make eye contact with people in the audience.
- Vary your rhythm and tone to capture the audience's attention.
- Keep a check on the time, and pace yourself so you cover your major points
- Allow time for questions.
- If you become overwhelmed by emotion, take a deep breath.
- Always speak from the heart AND REMEMBER TO SMILE

The most successful talks are those that involve the audience and get them asking questions. With time you will become more comfortable answering questions.

Speaking for the purpose of filling in time will turn off the audience's interest. As you gain confidence in encouraging and handling questions, reduce the length of your presentation and leave more time for questions. If you cover areas that interest the audience, they will gain much more from the talk.

Always leave at least ten minutes, preferably much longer, for questions at the end. Tell people before you begin the talk that you will speak for approximately however many minutes and then you will open it up and welcome questions. Encourage the audience by saying something like, "At the end of my talk I will leave an opportunity for anybody who wants to ask questions. Please feel free to ask whatever you wish and I will answer as much as I am able."

People will appreciate it if you give them the chance to ask questions on any topic. They want to know about your life with HIV, your feelings, how you cope with HIV every day, what makes you happy and what makes you sad. This might be the only opportunity they will have to meet a person with HIV. An honest answer based on your experience always helps in reducing the stigma among people with HIV. You don't need to perform and act, just tell them the truth of your feelings and life. The more transparent you are, the more people will feel attracted to you. I always received positive feedback that made me realise how desperate for information people continue to be.

(GRACIA VIOLETA, BOLIVIA)

Do not feel pressured to answer a question you are not comfortable answering. Ask yourself, who else does the answer I am going to give impact? Am I ready to answer the question I am being asked? Do I have support available, in case my emotions are triggered? On whose behalf am I answering the question? Is it personal or am I being the voice for others?

(MARVELOUS, ZIMBABWE)

2.6

Common questions and sample answers

Sometimes you may not know the answer to a question. It is okay to say, “I do not know the answer to that”. People respect you for being truthful. If you can tell them the answer later, do so. If not, find out anyway for the next time somebody might ask.

If a question touches a sensitive area, take a deep breath, relax and tell them you don’t want to talk about that issue. People will respect your right not to answer anything too personal.

You do not have to answer anything you do not want to

If you decline to answer, do so in a way that makes people feel welcome to ask more questions. For example, “I prefer not to discuss that, as it is a sensitive issue for me at the moment, but perhaps you would like to know how my family have reacted to my status, or how my children have coped...”

Have contact details of any support services that the audience may find useful, such as testing sites, support groups, access to female condoms, treatment information.

How did you get it?

Most people contract HIV through intimately trusting a person who often does not know that they have HIV themselves. It is therefore important, particularly for young people, to examine the basis on which they trust their partners, and their ability to be assertive about the sexual choices they make.

Whether you disclose how you contracted HIV depends on your audience. If they have a similar background to you, it is helpful to tell them so that they identify with you and understand how vulnerable they may also be.

You may choose not to state how you got the virus, and that is fine. Simply state the fact that most people get HIV from unprotected sex - the same way their mum and dad created them! Be sensitive about not shaming others who get HIV in other ways, for example, using drugs, casual sex. The way one contracts HIV is no protection against the stigma people living with HIV face.

What is the difference between HIV and AIDS?

HIV stands for the Human Immunodeficiency Virus. When a person contracts HIV, the virus attacks their immune system (measured in CD-4 cell count) which fights disease. Over several years, without treatment, HIV depletes the immune system. At this point, a person may contract opportunistic infections such as pneumonia, meningitis, tuberculosis. Once opportunistic infections begin to occur, the person is then said to have AIDS. AIDS stands for Acquired Immune Deficiency Syndrome. AIDS is not a disease itself, but is a state or condition indicating an inability to fight infection. People do not die of AIDS. They may die of an AIDS-related illness if they do not get access to treatment.

Is there a cure for HIV?

No, however triple combination anti-retroviral drugs (ARVs) stop HIV replicating and have greatly reduced the incidence of HIV-related deaths. With appropriate ARV treatment, HIV is now a chronic manageable condition. Although there is no cure for HIV, people who take ARVs consistently and have an undetectable viral load CANNOT transmit the virus to others and can live a long and healthy life. Undetectable = Untransmissible

Can you get HIV from mosquitoes?

No. When a mosquito bites, it sucks a person's blood into one part of its stomach, and then injects saliva (which may contain malaria) from another part of its stomach into the skin, causing it to itch. If people were able to contract HIV from mosquitoes, HIV-infection rates would be evenly distributed across all age groups in society, which is not the case.

Can I get HIV from touching people?

No. HIV cannot be contracted by casual contact. HIV is not transmitted by air, skin, or saliva. If a person is HIV-positive and not on ARVs, his or her body fluids contain the virus, but it is only in blood, semen, vaginal secretions, breast milk, and anal mucus that the virus is found in enough quantity to cause infection in another person. For an adult to contract HIV, there must be blood-to-blood contact (from injecting or tattooing equipment, a blood transfusion, or blood products), or sexual contact with a person who is HIV-positive and has a detectable viral load.

HIV transmission via injecting or tattooing can be prevented by using sterile needles only. Blood screening and adoption of infection control guidelines has greatly reduced the possibility of acquiring HIV through blood transfusions. Sexual transmission of HIV is greatly reduced by correct and consistent use of good quality condoms and treatment of sexually transmitted infections (STIs). People living with HIV who are on ARVs and have an undetectable viral load cannot pass on HIV through sex.

Are men and women at equal risk of contracting HIV from sex?

No. Globally, most people contract HIV through sexual intercourse. In countries where the epidemic is most prevalent, more than 50% of people diagnosed as HIV-positive are women. This is due to a number of factors: women have least socio-economic power within society and least negotiating power within sexual relationships; older men generally choose younger women as sexual partners; young women are physiologically more vulnerable to infection because their vaginal wall is thinner and more susceptible to microscopic ruptures from trauma or friction during intercourse; most women are tested for HIV during pregnancy.

During sexual transmission, the virus passes from the semen or vaginal fluid, through the mucous membrane, and into the blood stream of the sexual partner via the vaginal wall, the penis, the anus, or the mouth. The virus passes most easily if there are breaks in the skin lining of the vagina, anus or mouth. Forced sex therefore leads to increased risk of HIV transmission. This is particularly disturbing considering the high

incidence of rape of children and young women in many countries.

Can a woman who is HIV-positive have a healthy baby?

Yes. About one in four babies born to mothers who are living with HIV and are NOT on ARVs are born with HIV. The probability of a mother who is HIV-positive giving birth to an HIV-positive baby is greatly reduced to less than one in ten if the mother takes a course of ARVs before delivery. If the woman is already on ARVs and has an undetectable viral load before she becomes pregnant, the likelihood of her giving birth to a child who contracts HIV from her is close to zero.

Can a woman with living with HIV breastfeed her infant?

Yes. In fact, the World Health Organization recommends exclusive breastfeeding as the best option for all infants, including those with HIV-positive mothers, for the first six months of life.³ A baby who is not breastfed is at increased risk of death from diarrhoeal disease or pneumonia. Breastfeeding is a significant way to improve infant survival rates. In some countries however, laws forbid breastfeeding by women living with HIV and a woman who does so may risk having her child taken away.

Giving ARVs to mothers who have HIV significantly reduces the risk of transmission through breastfeeding. WHO recommends that mothers who are HIV-positive take ARVs and exclusively breastfeed their babies for 6 months, then introduce appropriate complementary foods and continue breastfeeding up to the child's first birthday. Even when ARVs are not available, mothers should exclusively breastfeed for 6 months and continue breastfeeding thereafter unless environmental and social circumstances are safe for, and supportive of, feeding with infant formula. Breastfeeding should only stop once a nutritionally adequate and safe diet without breast milk can be provided. When a mother who is HIV-positive decides to stop breastfeeding, she should stop gradually within one month. ARV prophylaxis for the baby should continue for one week after breastfeeding has fully stopped.

Why focus on HIV when other diseases kill many more people?

In low-income countries, HIV-related illness is a leading cause of mortality, after lower respiratory infection, heart disease and diarrhoea. Unlike other leading causes of mortality, HIV selectively affects young adults, the most productive members of society. The effects of illness and death amongst these individuals are amplified because of their dependants. HIV has had a significant impact on average life expectancy in many countries. Unlike other infectious diseases, such as malaria and diarrhoea, it is possible to arrest HIV infection through attitudinal and behavioural change of individuals and adoption of appropriate government policies.

Does sex education make young people more sexually active?

Evidence around the world indicates that most young people become sexually active in their mid-teens, irrespective of culture or religion. Studies show that providing sex education to young people, before they become sexually active, delays the onset of first intercourse,

³ <http://www.who.int/mediacentre/factsheets/fs342/en/>

2.7

Dealing with emotions and debriefing

and encourages safer sexual practices, such as condom use and/or monogamy. In countries where HIV rates have decreased, significant reductions have occurred in young people. This indicates that it is easier to bring about change in adolescents before they become sexually active, rather than change people's sexual behaviour patterns once they are established. The most successful HIV education programs use a variety of interactive teaching methods, including opportunities to practice negotiation skills and to talk about sexuality with trusted others.

At first it may be difficult to control your emotions when speaking about HIV. This will change. As you become more experienced, you will acquire techniques to deal with them. You will feel a mixture of emotions after delivering your first talk. Some speakers find the experience emotionally draining. Take heart that it will become less so as you speak out more. There may be some parts of the talk you want to change for next time. The overall response to your talk is likely to be very positive. You will improve with time and gain more confidence.

The first experience I had I was shaking all over because it was not easy for me to come out. I had to take time. Now, I can speak out very clearly.

(JAFAR, MALAYSIA)

When I started speaking, I cried. I could not talk. But I saw that other speakers can cry when they speak in the public. Now I don't cry, I just laugh. People don't believe that I am HIV-positive. They say "It's good you can still laugh and enjoy yourself. I cannot think that you are sick because you are always laughing. It's as if you don't have a problem". I reply, "Should I sit in the corner and cry about my HIV status?"

(GINA, PHILIPPINES)

The first time I did it, I can still remember. I was driving home and I was singing like a canary. I loved it. It was fantastic because of the response I had from the audience. I had a big impact and I was on a high. It still happens now. They ask so many questions, they come up and hold you, and shake your hand, and thank you at the end of the talk. It's terrific. It is the best reward you can get.

(JOE, AUSTRALIA)

I have learned skills through repeated exposure. I have developed different strategies of approach. Now, I rarely talk about myself. I talk about issues. I mention I am HIV-positive, I have a family, and all that and then I leave people to ask questions. Previously, I would talk about how I was infected, my age, strictly personal matters. Now, there are more important issues, like discrimination, which I want to see change. That's what I focus on.

(JOE, KENYA)

If you become overwhelmed by emotions, relax and take a deep breath, and don't worry. The audience will understand. As you do more talks, you will gain more control over such moments, but do make sure you have an opportunity to debrief after a talk. Part of preparing for a talk is planning what you will do after the talk. Make sure you have an opportunity to meet with somebody soon after. This may be another positive person or a counsellor. Certainly, if there are any negative feelings that arise from your talk, it is important to have somebody with whom you can discuss these.

Why it is important (and at times invaluable) to debrief after a talk:

- to discuss one's emotional response to the talk
- to work out how to deal with any difficult situations
- to increase confidence
- to evaluate and acknowledge one's accomplishments.

CHAPTER 3



HIV
ADVOCATES

Educating communities about HIV is very different to advocating to government to change policies. Yet many of the changes that have happened within the HIV sector have come about primarily because of the efforts of advocates who are living with HIV over many years. People living with HIV who have spoken out have managed to create changes in laws, policies and practices in many countries across the globe.

Successful advocacy campaigns:

- **address urgent issues**
- **are well-planned**
- **have feasible outcomes**

3.1

Advocacy issues

Sexual and Reproductive Health and Rights

Many people living with HIV across the globe are deprived of their sexual and/or reproductive rights, including inability to prevent unwanted pregnancies, particularly for young women and adolescents; inability to choose when and with whom to have sex; coerced abortions and sterilisations; refusal of safe abortions; refusal of appropriate, non-discriminatory treatment and care during labour.

All people living with HIV need to make informed decisions on matters related to their sexual and reproductive health and rights, including the right to have fulfilling sexual lives and express their sexual identities, the right to make autonomous decisions about whether they will marry and whether they will have children, freedom from all forms of violence and the right to make those decisions with access to comprehensive information about their bodies, sexuality, and the full range of reproductive choices.

Women living with HIV must have access to appropriate and safe contraceptives to avoid unwanted pregnancies, access to abortion and pregnancy support services; reduction of maternal mortality; an end to forced and coerced sterilisation or abortion.

NAMIBIAN GOVERNMENT FORCIBLY STERILISED HIV-POSITIVE WOMEN

In 2008, the Namibia Women's Health Network discovered that 40 women living with HIV had been subjected to coerced sterilisation. In all cases, medical personnel in public hospitals failed to obtain the woman's informed consent prior to performing the sterilisation. In some cases, women were asked to sign papers while they were in labour and on their way to the operating room. In other cases, women learned of the sterilisation only after their delivery. Some women believe they were misled or coercively sterilised because of their HIV status.

Three of the cases were heard in the High Court of Namibia in July 2012. In its ruling, the High Court found that the women did not give their informed consent for the sterilisation operations. The Government of Namibia appealed this ruling. In November 2014 the Supreme Court gave its final ruling on the cases stating that the women were indeed sterilised without their informed consent and that coerced sterilisation violated women's rights under Namibian law, and that these women should be compensated. The Namibian case has been adopted as best practice to inform the advocacy and litigation processes of sterilisation cases in other countries in Africa.

This decision by the country's highest court is a victory for all HIV-positive women as it makes clear that public hospitals in Namibia have been coercively sterilising women without their consent. However, these three women are only the tip of the iceberg. We have documented dozens of cases of other women who have been forcibly sterilised. The government needs to take active steps to ensure all women subjected to this unlawful practice get redress.

(JENNIFER GATSI MALLET, DIRECTOR, NAMIBIA WOMEN'S HEALTH NETWORK)

Many women living with HIV in Namibia and other countries have come forward describing similar experiences at public hospitals.

In spite of the advocacy efforts, the Namibia Government has not put in place policy measures to ensure forced sterilisation is halted in Namibia, nor has the government begun to review laws impacting on informed consent and sterilisation.

Recommendations to the Government of Namibia:

- Take adequate measures to prevent the practice of forced, coercive and otherwise involuntary sterilisation, including adopting clear policies and directives that are compliant with the state's international human rights obligations under CEDAW¹.
- Provide ongoing training of medical personnel, social workers, and community health workers on the rights of patients, including the right to full and accurate information and to personal medical records.
- Launch a comprehensive and independent investigation of all claims of coercive/involuntary sterilisation of women living with HIV and publicise the findings of such investigation(s).
- Take appropriate action against medical personnel in cases where forced, coercive or involuntary sterilisation is found to have occurred.
- Provide effective remedies in cases where there is forced, coercive or otherwise involuntary sterilisation, including providing adequate compensation to victims.

Criminalisation

Laws that criminalise HIV transmission, same-sex relationships, drug use and sex work all contribute to increasing vulnerability to HIV. When people are afraid to be open about their HIV status or sexuality, they tend to have poorer access to health information and services, and thus poorer health outcomes. Criminalisation discourages people living with HIV from accessing care, undermines the goals of counselling and the service provider relationship to their patients, increases the risk of violence against people living with HIV and discourages people who know they have HIV from disclosing that fact to sexual partners. Criminal laws should only be used in extraordinary cases of intentional exposure or transmission. Overly broad use of criminal law results in unjust prosecutions and incarceration of people living with HIV.

I started to speak up because of my own experience of being criminalised under the Islamic laws in Malaysia because of my gender identity. I was denied my right to live my life as I wanted to. At first it was a personal fight but when I started to speak up, I realised that such discrimination happens not only to me but to other people in the transgender community. Shariah law on cross-dressing is not standardised throughout Malaysia and many transgender women face violence. I started to advocate in regards to transgender issues. Since I have been speaking out, I see that the issues of trans are becoming more visible and most of the time I get very positive feedback.

(NISHA, MALAYSIA)

Access to Treatment, Care and Support

People living with HIV in many countries do not have access to appropriate treatment and care. A huge issue in many countries is lack of monitoring of viral load.

People living with HIV must have access to reliable, comprehensive and sustainable care, treatment, and support, and must be able to make informed decisions about their own treatment and care. Stigma, discrimination and other barriers to treatment and care must be eliminated in order to ensure that people living with HIV, especially young people, can receive the care they need and are entitled to.

[When I was ten years old] I attended a National Consultation for children living with HIV. In front of the National AIDS Council, I presented on the need for pediatric medicine. I said it was difficult for us to swallow these big tablets. After that we got pediatric ARV formulations. They are liquid so they are much easier to take. I feel very happy because I suffered having to take such big tablets, and I don't want other children to suffer like me.

(SARANYA, INDIA)

Violence Against Women

Institutional, systemic and intimate partner violence against women living with HIV is endemic and largely underreported. Violence, including sexual assault, increases women's risk of contracting HIV. Once women are diagnosed as HIV-positive, many experience increased violence from their partners.

Violence against women is not always recognised as violence by those who experience it. For years I represented the community of women living with HIV in the review and drafting of CEDAW Shadow Reports and mobilised women to participate in research. In 2012, I received a certificate of recognition for my work in ending violence against women from the Jamaican Prime Minister.

(OLIVE, JAMAICA)

All people living with HIV should lead lives free from violence including sex workers, gay, lesbian, bisexual, transgender and queer people, people who use drugs, people who are displaced and/or living in conflict zones, people in prison, migrants, and people living with disabilities. Violence must be addressed in all efforts to respond to HIV.

LEVERAGING POSITIVE ACTION TOWARDS REDUCING VIOLENCE AGAINST WOMEN LIVING WITH HIV, Coalition of Women living with HIV (COWLHA), Malawi

The objective of this three-year project was to reduce intimate partner violence towards women living with HIV and create an enabling environment for the promotion of women's rights.

The project made use of community "Stepping Stones" facilitators and paralegals as part of the community structures that proved effective in promoting local ownership of the project and maximising its impact.

Collaboration among community facilitators, police victim support unit, courts, social welfare officers and local leaders significantly contributed to the success of the project.

Approaches were geared towards addressing a high prevalence of intimate partner violence. With improved communication among couples through the Stepping Stones approach, there is a drastic reduction in intimate partner violence because violence resulting from improper communication, no communication and miscommunication is being prevented.

(ANNIE BANDA, NATIONAL COORDINATOR, COWLHA, MALAWI)

3.2

Steps to a successful advocacy campaign

Before you start any advocacy campaign, you need to be very clear about why you are doing it and what you want to achieve. You need to be realistic in your goals, and develop a plan from the outset. Below are clear steps in planning an advocacy campaign.

Identify the issue

What do you want to change?

Research the issue

Gather as much information about the issue as you are able.

Develop SMART objectives

Your objectives should describe your desired outcome and be SMART:

Specific

Measurable

Agreed

Realistic

Time-framed

Identify major target

Who has the greatest power to respond effectively to the problem?

Identify resources needed

What financial and human resources will be required to carry out the advocacy?

Identify allies

Who else can you work with in government or other agencies to help you achieve your objective?

Develop action plan

What activities need to be carried out for the advocacy campaign to succeed?

List each step required.

How will the activities be carried out?

Is this sufficient to achieve the desired outcome?

When will each activity happen?

Who will take responsibility for each step?

Develop budget

What will it cost to carry out your campaign?

Include time, effort, discipline, commitment.

Implement plan

Role play meetings with key stakeholders.

Explain why you are there, what you want to change and how it can be done.

Monitor and evaluate

Develop a system of performance indicators to review what change happens.

3.3

Influencing policy change

ADVOCACY SUCCESS BY WOMEN IN INDONESIA

A successful advocacy campaign by the Indonesian Network of Women living with HIV (IPPI) followed this formula. They identified an issue of concern – pregnant women who were HIV-positive, were routinely coerced into sterilization after giving birth in public hospitals. They realised that this practice had continued from the era before ARVs, and was a violation of women’s rights to reproductive health. IPPI researched the issue and gathered data about the extent of the practice. Of 109 women interviewed for one study, 44 had been asked to consider sterilization after giving birth.

They developed a SMART objective with an identified target - to change the government policy and practice of coercing HIV-positive women into sterilization. The research was completed a year before Indonesia was due to present its periodic report to the UN on how it was advancing the Convention for the Elimination of Discrimination against Women. IPPI recognised that they could add a section to the UN Country Shadow Report, to be presented by NGOs, which they did.

As a result, the policy of coercive sterilization of HIV-positive pregnant women was stopped throughout much of Indonesia in 2014.

Meeting decision makers face-to-face is a very effective form of advocacy. Before you organise a meeting with officials, you must be clear on why you want to meet, what message you want to get across, and what change you expect. Structure your message clearly and simply. Use assertive behaviour and language.

Always go to a high-level meeting in pairs, never alone. That way you appear strong and you can share discussion points. Do not criticise the person or organisation and never be apologetic. Keep in mind the objectives of the meeting and how much time is available to get your point across. Keep control of and direct the discussion and be aware of your body language. Avoid crossing your arms and remember to smile.

It is important to make sure the right people are chosen to do advocacy work. Often donors, policy makers, government and agencies “cherry pick” people to come to their meetings. These people may not be fully briefed on the issues to be discussed and may be just excited to attend an important meeting and stay in a hotel. They may not gather ideas of what to say from others and may not report back on what happened. It is important to mentor people into advocacy roles, and to value and respect the mentors who pave the way for new activists.

We always had women living with HIV alongside high-profile speakers on the speakers' platform. Women living with HIV who were part of the audience could also share their experiences with other guests afterwards over refreshments, in an informal way. This was a powerful process because it meant that loads of women could take part and share their stories - and the fact that many guests from many different walks of life were knowingly meeting a woman with HIV for the first time was huge, given that no one could tell in advance who was who.

(ALICE, BRITAIN)

It is also important to know when it is time to step aside and guide new people into advocacy roles.

You are where you are today because some people built platforms for you and created stages for you to act and shine. Never forget that. Leave when the ovation is loudest, look for ways to use your present experiences to transition to new unconquered territories.

(ROLAKE, NIGERIA)

ROLE PLAYING

Before you go out and meet face-to-face with key stakeholders, try out what you are going to say. Role play the situation with your fellow advocates to make sure you know who is going to say what and to build your confidence. When you meet with government or other agencies, do not go alone. Ensure there are at least two of you so you can share the presentation and provide a strong, united voice.

When you meet potential decision makers:

- Introduce yourselves
- State why you are there - what is the issue/problem that needs to be addressed?
- Make a personal statement about how you are impacted by the issue
- Expand this to its impact on other people living with HIV
- Explain the outcome you hope for - only deliver information relevant to the issue
- Explain how this will benefit public health outcomes
- Offer a way to address the situation with mutual cooperation from all players
- Reiterate your message
- Keep focused and be aware of any questions that take you off track
- Leave written material for their reference
- Thank them for their time
- Do not leave without a commitment to further follow-up.

⁴ From: Dilmitis S et al. *Journal of the International AIDS Society* 2012, 15(Suppl 2):17990
<http://www.jiasociety.org/index.php/jias/article/view/17990>

3.4

Language matters⁴

Language impacts on how we think about ourselves, as individuals within our families and within society. As advocates and activists, we constantly use language as a tool to affect change. People living with HIV have been critical in shaping language over the last thirty years and still play a central role in ensuring that discourse in the HIV field does not stigmatise but catalyses empowerment for our community members.

It is important to shift the language used in relation to ourselves, our medical condition, our bodies, our identities and the events we face, towards something more life-enhancing, self-affirming and positive in outlook.

People living with HIV, instead of HIV-infected or HIV-positive person

When we use language that puts people first, we acknowledge ourselves and others as fellow human beings. For example, “people living with HIV” puts the individual first rather than “infected people”, which puts the virus first. Similarly, when we say people who are, or have been in prison, or people who engage in sex work, or people who use drugs, we are making a distinction between “being” and “doing”.

People living with HIV, instead of PLHIV

Spelling out people living with HIV highlights that actual persons are being referred to. Using acronyms when referring to people can dull awareness of the person or people and adds to a sense of being labelled and the loss of our identity as human beings. Using the whole phrase puts people at the centre of the issue being outlined.

HIV or AIDS, instead of HIV/AIDS

In our efforts to raise awareness of HIV and to change public perceptions, we encourage the use of the term that is most specific and appropriate in the context to avoid confusion between HIV (the virus) and AIDS (a clinical syndrome).

Avoiding the use of the word “infection” and its derivatives

Unless “infection” is an essential word, use more neutral words, for example, “One in seven people who acquire HIV globally do so perinatally”. The word “infection” is associated with “corrupt, dirty, tainted”. More neutral words such as “acquire” and “transmit” can be substituted without any change in meaning.

Prevention of vertical transmission, instead of MTCT

Mother-to-child transmission (MTCT) is perceived to have an accusatory tone, blaming the mother for “transmitting” the virus to her child, which can have a negative impact on the mother (such as, criminalisation, forced sterilisation, abuse by family members). Focusing on the event, rather than the person removes blame and guilt for transmission of HIV.

Stopping or ending vertical transmission, instead of eliminating

The term “elimination” can be seen as threatening and, if taken out of context, can evoke fear and be disempowering. It may be misunderstood to mean eliminating women living with HIV or infants living with HIV in order to eliminate “mother-to-child” transmission. For those who do not support the sexual and reproductive rights of women living with HIV, the term may justify the use of any means to achieve “elimination”, including sterilisation or the criminalisation of all HIV exposure or transmission.

¹ Convention for the Elimination of all forms of Discrimination Against Women (CEDAW). This UN Declaration has been signed by more UN member states than any other.

² http://www.steppingstonesfeed-back.org/resources/7/COWLHA%20END%20OF%20PROJECT%20EVALUATION%20REPORT_2015.pdf

3.5

Using the media

Engaging the media to respond to government statements or practices can be a very effective form of advocacy. The media can be an important advocacy tool if we understand how to use it wisely. If we do not have the right supports to handle the media, it can be emotionally stressful.

Nobody should go public in the media unless they have a great deal of support. Do not let anybody talk you into doing a media interview if you are not absolutely sure you are ready for it. It must be your decision to take that step. An interview with the media is very different to speaking live to people. The live experience gives people an opportunity to relate intimately to you on a personal level. Once you go public in the media, you lose that element of live interaction and the negative consequences are potentially far greater than speaking face-to-face with an audience.

When I started to feel more comfortable about my status - mind you I don't think that you ever feel completely okay with it - I went public on national TV. I didn't prepare at all for my first media interview - which was a mistake. It was more emotionally draining than I expected, and I did not have the support I needed to process what happened afterwards. I got a phone call from a friend of a friend who was "devastated" when she saw me on TV and realised that we were both having sex with the same guy. It was horrible. I felt my sexuality was being policed by ignorant people. The media is not your friend, just a tool to share information and change public opinion. As a young woman I was "discovered" by the media as being open about my HIV status - they called me a "goldmine", and it became so intrusive. One reporter insisted on calling me for weeks to ask questions. It was a breach of privacy and personal space. She made me feel as though I was letting down the HIV movement by not allowing her to film an important event in my life. It was confusing for me. I didn't have any support to debrief or work through the feelings I was having.

(JESSICA, CANADA)

Before deciding to speak openly about my HIV status on TV I had to do a lot of thinking to be really sure about the implications of disclosing. In an environment that does not have information about HIV, stigma prevails, therefore the decision has to be well thought out. This preparation involved talking to my family because they come from a conservative religious background. Analyze the advantages and disadvantages if you disclose. It is a good thing to save the world but not for the sake of your identity, dreams, image. The one who discloses her HIV-positive status will always lose something. I find it important to ask myself, before, "What do I want to accomplish as a result of disclosing?". The media is looking for sensationalist news. It is possible they will ask how you got HIV. The way I curve this question is by declaring upfront: I want to begin by telling you I have HIV as a result of unprotected sex. The media want to catch you unprepared but when you respond first to that type of question, then you can move on to the issues you really care about.

(GRACIA VIOLETA, BOLIVIA)

I granted an interview in a national newspaper giving permission to use my name and photograph. I expected negative responses and loss of family and friends but I was amazed at how my closest friends and family rallied round. My cousins called me to express their love and tell me how proud of me they were of me. Most of my friends were awkward initially because they didn't know what to say, but I have never felt more loved than I did after my disclosure in the media.

(ROLAKE, NIGERIA)

Although there are many serious and trustworthy journalists, it is important to carefully consider both the potential benefits and drawbacks of each and every media opportunity. Some people have given interviews under the assumption that their names will not be used and then later seen their name published. Others have asked that their faces be blacked out or camouflaged and this has not happened, causing problems within the family. Be very clear about whether you are going to use your real name or a pseudonym, and whether you will to be photographed or filmed.

Be very clear on the conditions under which you will do a media interview and choose interviews carefully. Do not give an interview unless you are confident that the interviewer is sympathetic towards what you say, and the style of the publication will allow the interviewer to present what you have to say accurately. Do not give interviews to media that sensationalise HIV or portray people living with HIV as “victims” or “blameful”, unless you are confident that you can cope with any distortions to your story that may appear in the final product.

Some journalists will ask difficult questions. If that happens, simply say: “I prefer not to discuss that”. Immediately move on and talk about issues that are important to you. Keep bringing the conversation back to the major issues YOU believe are important. Otherwise you waste the opportunity and the media coverage may backfire. Watching politicians answer questions on television is a great learning opportunity. If they do not want to respond to a question they steer the listener back to issues they want to address. When you first discuss an interview, find out what questions you will be asked. This will give you an idea of the tone and trend of the interview, but it will not guarantee against surprise questions being inserted by an unscrupulous reporter.

Before the interview write down a maximum of three major points you want to discuss. Take control of the interview from the start. It is your choice to do the interview, so decide what you want to say. If you wish to stop the interview at any point, do so.

CHECKLIST - MEDIA INTERVIEWS

- Choose your medium (radio, television, print) carefully.
- Be very clear on your conditions.
- Decide immediately if you are going to use your real name or a pseudonym.
- Decide whether you are willing to be filmed.
- Only give an interview if you are confident the interviewer has sympathetic views.
- Check that the style of the media will allow an accurate

3.6

Avoiding burnout

presentation of you.

- Do not give an interview to media that sensationalise HIV, depict people living with HIV as “victims” or “sufferers”, or place blame on them.
- When you first discuss the interview, ask what questions to expect.
- Beforehand, write down a maximum of three issues you wish to address.
- If the journalist asks you surprise questions, say, “I prefer not to discuss that” and immediately move on and talk about an issue that is important to you.

Do not trust a journalist out of hand. If there is sensitive material that you do not want published, do not tell them, and ask if you can see the product before it goes to press or air. Even if an interviewer promises that you can see the final draft, you cannot demand changes other than correcting factual errors, and there is always somebody higher up in the organisation, a senior reporter or sub-editor, who can change anything at the last minute, without concern for the feelings of the reporter or any assurances you were given. You have every right to refuse to give an interview if you are not 100% comfortable with the possible outcome. Seek legal advice if you are unsure of your rights.

Most people start off speaking informally to small groups of people, then requests for further talks follow. As you become more engaged you may face difficulties finding a balance between the competing demands of responding to more requests for your expertise, maintaining your own health, and catering to the demands of your family.

It is really hard to do this sort of work - very demanding, very exhausting.... and it requires oceans of courage and energy that many of us find challenging to our health. I think our families also feel very stressed by the time it takes out of our lives - and sometimes by the knock-on impact it can have on their lives.

(ALICE, BRITAIN)

Our work is very stressful and can be lonely sometimes as one feels isolated with no one to share the burden. We are always there for others but we do not have opportunities for psychosocial support for ourselves and we face a heavy workload with lack of funds. Donors do not acknowledge the work we do.

(JENNIFER, NAMIBIA)

Burnout is a real issue for many positive leaders, particularly if they are the only advocates speaking out in their region. Be very careful not to overdo it. It benefits nobody if your work exhausts you to the point that you become ill. Do not over commit yourself. Make sure you allow some time each day when you can be alone, looking after your own needs of rest, relaxation, and eating well. Ask, who is taking care of you? Sometimes it is important to take time out to do what you have always wanted to do. Many people have returned to study after breaks that span over twenty years, and are happy they have done so.

Sometimes being an advocate, you feel you have the weight of the movement on your shoulders and you need to always be “on” and “educating” people. You cannot do this alone as it will eat you inside. You are part of a network - a family of amazing people living with HIV from all over the world. Build a nest around you of other advocates and link into the network to help support you. In recent years, I have made a commitment to spend more time doing other things that I love and nurturing the relationships with my friends and chosen family.

(JESSICA, CANADA)

Debrief with others when needed. Find professional support or talk to peers. Learn to identify when you are burnt out and take some time off to take care of yourself.

(MARVELOUS, ZIMBABWE)

Sometimes we experience frustration at the slow pace of change within society and we work passionately to accelerate change. If you are the only person who can do the job, then realise that you cannot do everything at once. It is okay to say no to a request. The opportunity will arise again. Learn to take time out for yourself regularly to reflect and congratulate yourself on what you have achieved.

Further references about the author and her work

- Talking about Sigma – Susan’s Story: www.youtube.com/watch?v=L8Qqr-Rbk_o
- UNAIDS. Women living with HIV speak out against violence. A collection of essays and reflections of women living with and affected by HIV. Paxton S, Health-sector violence and women living with HIV (2014) http://www.unaids.org/sites/default/files/media_asset/womenlivingwithhivsspeakout_en.pdf
- UNAIDS. Women Out Loud - How women living with HIV will help the world end AIDS. Paxton S, et al: Chapter 8: Eliminate Stigma and Discrimination against People living with HIV (2013) http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/20121211_Women_Out_Loud_en.pdf
- Dilmitis S, Edwards O, Hull, B, Paxton S, et al. Language, Identity and HIV: Why do we keep talking about the responsible and responsive use of language? Language matters JIAS 15(2) (2012) <https://onlinelibrary.wiley.com/doi/10.7448/IAS.15.4.17990>
- Paxton S. Positive and Pregnant in Asia - How dare you. Open Democracy (July 2012) <http://www.opendemocracy.net/5050/susan-paxton/positive-and-pregnant-in-asia-how-dare-you>
- APN+. Positive and pregnant - How dare you. A study on access to reproductive and maternal health care for women living with HIV in Asia - Findings from six countries: Bangladesh, Cambodia, India, Indonesia, Nepal, Viet Nam (2012) file:///C:/Users/SUSANP~1/AppData/Local/Temp/APN%252b+Reproductive+and+Maternal+Health+Report+A4+13+April.pdf
- Namiba A, Welbourn A, Foote C, Paxton S, Ross V, Dilmitis S. In HIV Prevention, Protect the Mothers: A Message to the World Health Assembly 2012. RH Reality Check (May 2012) <http://rhrealitycheck.org/article/2012/05/22/let-them-eat-cake-enabling-mothers-to-protect-their-babies-from-hiv/>
- UN Women. CEDAW Advocacy Training Module for Positive Women (2011) <https://trainingcentre.unwomen.org/mod/data/view.php?id=1&rid=17>
- APN+. Diamonds – Stories of women from the Asia Pacific Network of people living with HIV; book and dvd (2009) <http://www.apnplus.org/wp-content/uploads/2016/01/Diamonds-Stories-of-Women-from-the-Asia-Pacific-Network-of-People-Living-with-HIV.pdf>
- APN+. A long walk – Challenges to women’s access to HIV services in Asia (2009) <http://www.apnplus.org/wp-content/uploads/2016/01/A-Long-Walk-Challenges-Woman-HIVAccess.pdf>
- Paxton S. Steps to Empowerment: Challenges to the greater involvement of people with HIV in the response to AIDS in Cambodia. The Policy Project, Cambodia (2005) www.policyproject.com/pubs/countryreports/CAM_StepsToEmpower_en.pdf

