



HIV AND STIGMA: THE MEDIA CHALLENGE

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Methodology

The findings in this report are based on desk research, 22 telephone or face to face interviews and a field trip to Swaziland in April 2014 where 24 additional interviews were conducted and two informal focus groups were held. One focus group comprised of people living with HIV; the other comprised a group of young people from the general population. All interviews were transcribed. Relevant evaluation data of the impact of media initiatives has been included wherever possible.

Acknowledgements

Special thanks to all those who kindly agreed to be interviewed, and to Winnie Ssanyu Sseruma and Dr Martin Scott who reviewed and commented on a draft of the report.

Cover picture: Sven Torfinn/Panos. The picture shows Judith Atieno Basil, the secretary of Ulusi Youth Group. The group raises awareness within the community on a range of issues including HIV. When she lost her parents at the age of 12 from AIDS-related illness, she had to leave school, get married and raise her siblings.

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About IBT

The International Broadcasting Trust (IBT) is an educational and media charity working to promote high quality broadcast and online coverage of the wider world. Our aim is to further awareness and understanding of the lives of the majority of the world's population - and the issues which affect them.

IBT regularly publishes research and organises events to encourage a greater understanding of the role the media plays in engaging people in the UK with the wider world. We are a membership-based organisation. We organise briefings for our members so that they can work more closely with broadcasters and producers.

For a current membership list see the members' page of our website www.ibt.org.uk. For further information about membership contact us at mail@ibt.org.uk

About IPPF

The International Planned Parenthood Federation (IPPF) is a global service provider and a leading advocate of sexual and reproductive health and rights for all. We are a worldwide movement of national organizations working with and for communities and individuals.

We work towards a world where women, men and young people everywhere have control over their own bodies, and therefore their destinies. A world where they are free to choose parenthood or not; free to decide how many children they will have and when; free to pursue healthy sexual lives without fear of unwanted pregnancies and sexually transmitted infections, including HIV. A world where gender or sexuality are no longer a source of inequality or stigma. We will not retreat from doing everything we can to safeguard these important choices and rights for current and future generations.

FOREWORD

Huge progress is being made in tackling HIV, yet one fundamental obstacle remains: stigma. It's clear to all commentators that eradicating the shame related to HIV is a priority; what's less clear is how you go about achieving this change.

Stigma manifests itself in numerous ways and the result is that many people are reluctant to come forward for HIV counselling, testing and treatment and are much less likely to take the appropriate medication. The stark consequence of this is that incidence rates are far higher than they should be.

In this report, we look at the role of the media. There's a consensus that the media has an important contribution to make in challenging and changing societal attitudes. And there's also agreement that the media is not achieving its full potential.

It faces a number of challenges: there is fatigue with the HIV story both on the part of the public and of journalists; in many countries

there is a lack of training and resources; the media and NGOs using the media sometimes struggle to achieve the right tone and audiences turn away.

Our aim is to provide an overview of media initiatives which seek to reduce HIV related stigma, and to look at what works and what doesn't. Where something is effective, there is a strong case for replicating it. But the sector needs to work harder to measure the impact of media initiatives in order to make the case for scaling up more persuasive.

A crucial part of this report is the result of a field visit to Swaziland. This gave us the opportunity to examine in detail different types of media initiatives aimed at reducing HIV related stigma, to speak to people living with HIV and to explore public attitudes.

We hope this research will provide useful evidence and concrete suggestions that will be relevant to all who have an interest in this issue: funders, NGOs, policy makers and the media.

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EXECUTIVE SUMMARY

KEY FINDINGS

Despite the progress being made in the global response to HIV and AIDS, stigma remains a major obstacle to prevention and treatment. It is manifested in many different ways and fear of disgrace prevents people from coming forward for HIV testing and treatment. Key populations – sex workers and their clients, men who have sex with men, the transgender community and people who inject drugs – are particularly affected.

The role of the media in tackling HIV related stigma is crucial. It is seen as one of the drivers of HIV reduction, yet the media is far from reaching its full potential. Many governments and funders prefer to focus on service delivery, which has measurable results, whereas it's much harder to measure the impact of media initiatives that aim to bring about societal change.

Many of our interviewees believe there is fatigue with HIV in the mainstream media. While the tone of media coverage has improved in some countries, this is no longer a story that engages journalists - or the public. Newspapers were singled out for their tabloid and sensationalised coverage of people living with HIV.

In many countries, training of journalists has had a notable impact. Enabling journalists to hear the personal testimony of people living with HIV gives them a powerful insight into the human story. There are numerous models of media intervention: TV and radio drama; sponsored TV or radio talk shows; journalism training; the creation of journalist networks; public service announcements (PSAs); feeding storylines into existing dramas; multi-platform approaches; reactive campaigns, and comedy.

For NGOs working on HIV media campaigns, determining which model will lead to changes in norms and reducing HIV related stigma

is key. Newspapers are an important driver of public opinion; they influence decision makers and set the agenda for other media coverage. Television and radio drama has been effective at engaging audiences and making them more sympathetic towards people living with HIV, particularly when it can be done on the scale of African TV dramas like *Soul City* or *Shuga*. Drama attempts to engage the audience with a storyline, which works on a deeper, more emotional level than factual content.

RECOMMENDATIONS

- All media projects aiming to reduce HIV stigma should be evidence based, researched and targeted.
- Where projects can demonstrate an impact, they should be replicated.
- Greater focus on media for and about key populations at higher risk of HIV exposure.
- NGOs need to work together to scale up output rather than duplicate content.
- More effective use of media to engage decision makers and influencers.
- Journalists will benefit from any opportunities which help them to access more human interest stories.
- Prioritise drama because it engages audiences at a deeper level than factual content.
- More effort to improve the tone of factual content so it engages rather than lectures audiences.
- More role models should be featured in the media for people living with HIV to follow and aspire to.
- All approaches should be long-term and strategic rather than ad hoc.
- These recommendations are laid out in full on page 22 of the report

Introduction

For this report we interviewed people living with HIV, those working in media and on HIV related stigma projects, journalists, broadcasters and policy makers. We also interviewed media commentators and academics with an interest in media for social change. Contributors came from around the world: India, Malaysia, Nigeria, Zambia, South Africa, Uganda, Swaziland, Argentina, America and the UK.

We found that social disgrace related to living with HIV was pervasive in all these countries. Fear of being stigmatised prevents people from coming forward for HIV counselling, testing and treatment - and even from using condoms because people worry that their partner will suspect they have been unfaithful. Acknowledging the shame and fear related to HIV is central to any understanding of the virus. Its impacts go far beyond social exclusion.

Purpose of this report

The aim of this report is to explore the role of the media in reducing stigma related to HIV. It is not designed to be exhaustive or a piece of academic research. Rather, it has been produced as a practical guide for those working in this field, to inform them of the media models which have proved successful, encourage them to do more media work to reduce HIV related stigma and inspire them to try new approaches which are based on detailed research and the needs of the communities they seek to help. Additionally, we hope to encourage governments and funders to allocate more resources to media campaigns which are essential if the social and psychological impacts of HIV are to be tackled.

Why the media?

The role of the media is crucial. It is seen as one of the critical enablers in HIV reduction by UNAIDS¹ and many other agencies active in this field. All our interviewees agreed that, when done well, the power of the media to influence public opinion and social norms is huge. Yet it is far from reaching its potential.

Many of our interviewees asked whether the media follows or leads society. There is no easy answer to this, and in many ways there is a symbiotic relationship between the media and society, with each reflecting the other.

Garth Japhet set up the Soul City Institute for Health and Development Communications and the NGO, Heartlines, in South Africa. He believes

the media has a crucial role to play in influencing social norms:

"The most useful understanding of where media fits in is the concept of a social norm. The narratives we hear within society which are predominantly the media stories - news, articles, drama or whatever - are propagated by media of one form or another and that tells us what is normal and people tend to behave towards to what they think is normal, the social norm. Does media lead or does it follow? Clearly it does both but I am a big believer in the fact that it leads. So in terms of something like stigma if media is reflecting a norm where stigma is not acceptable then that is a norm which people will buy into and they will start behaving much more towards that norm."

What is stigma?

"When I was first diagnosed. I thought my friends and family would run away from me but everyone was ok. My family was supportive. They loved me and understood. I had no problem outside; it was my own fear. I was scared because I didn't know how was I going to tell my family."

"I haven't even told my mum or sister even though I was diagnosed years ago. I know if I tell them there would be a problem. I told my husband but he knows about HIV. He has tested. He is on treatment."

This testimony from two people in Swaziland who are living with HIV is a stark reminder that shame around HIV is very real and prevalent. Stigma - the shame or disgrace attached to something regarded as socially unacceptable - has many manifestations. There are two dominant types of stigma: self-stigma or internal stigma and external or enacted stigma. Self-stigma is characterised by negative feelings towards oneself, such as feeling ashamed, having low esteem or being depressed. It can lead to self-exclusion and fear of being abused verbally or physically. External stigma is when someone experiences discrimination or stigma by others, such as social exclusion, physical or psychological harm, discrimination at work etc. From the start of the AIDS epidemic, stigma and discrimination have made people living with HIV feel like they cannot admit to having the virus because they may face rejection. These fears of societal disgrace have fuelled the transmission of HIV.

While many of our interviewees said the success of treatment has reduced shame related to HIV, everyone we interviewed said stigma and discrimination continue to be manifested. In at least 58 countries around the world, people have been prosecuted and some imprisoned for transmitting HIV and/or exposing others to the virus. This criminalizes HIV. This trend is on the rise and is a driver of increased stigma.

“You don’t engage with something if you are afraid of the topic and there is a terror about HIV/AIDS here, which has never gone away.”

James Hall, Journalist, Swaziland

In 2008, a group of organisations came together to launch The People Living with HIV Stigma Index. The aim was to document the different types of stigma and how people respond to them. This global initiative was the result of a collaboration between The International Community of Women living with HIV (ICW), Global Network of People Living with HIV (GNP+), International Planned Parenthood Federation (IPPF) and UNAIDS. The index was developed for and by people who are living with HIV and is a practical country-specific, research-based tool to support those working in HIV prevention, counselling and treatment. The project documents how people have experienced HIV related stigma in a number of key areas, including access to work and services, HIV testing, treatment, having children, and the wider problems and challenges of living with HIV including self-stigma. The PLHIV Stigma Index has now been rolled out in more than 70 countries and 50,000 people living with HIV have been interviewed.

Manifestations of stigma

Stigma manifests itself in many ways – in the family, in relationships, at work, in education, in the community, in religion, among health workers and governments. It permeates every layer of life from deeply personal relationships to one’s professional world and, like racism, can also be institutional.

The fear around HIV originates from ignorance because of the high death rate due to AIDS in the early days of the epidemic. James Robertson from India HIV/AIDS Alliance observes that *“People are still nervous around this issue. It’s a conversation ender. The discomfort around HIV is ever present.”*

James Hall writes a newspaper column on HIV in Swaziland. He believes that because of fear there is a *“wilful turning away”* from the subject: *“We have to look at the nature of the disinterest. It’s mostly fear. You don’t engage with something if you are afraid of the topic and there is a terror about HIV/AIDS here, which has never gone away and it started with the initial doomsday approach in the 80’s. Mostly the problem is due to the fact that people don’t know their HIV status. There never has been a government initiative to get people to enrol in testing programmes. The NGO initiatives are insufficient. So I would guess that the primary reason why not everyone is on ARVs is that people just don’t want to know their HIV status. The stigma is very, very real.”*

Anu Mohammed, Head of Research for BBC Media Action in Nigeria, agrees that fear is a major barrier to HIV prevention: *“People say they don’t want to get tested because they are afraid of the outcome, what people will say, how they will get treated, what their lives will become once they have found out they are positive. So it does prevent people getting tested.”*

Often stigma is related to disapproval and taboos around sex. Leandro Cahn is Communication and Resource Development Director for the Huesped Foundation in Argentina. He sees how people respond to HIV: *“If I tell you I have cancer you will be sad, you will start thinking how much life do I have left, what a pity, so young and all this stuff. If I tell you I live with HIV you may think these things, but you also start asking what did you do, did you cheat on your wife or are you gay? So you paid for sex with a sex worker or do you use heroin or cocaine or did you forget to use a condom?”*

Winnie Ssanyu Sseruma, Senior Advocacy and Policy Officer for HIV at Christian Aid in the UK, says people living with HIV are still stigmatised: *“People living with HIV are not looked at in a good light. Many people think you are probably promiscuous.”*

This taboo around sex has been increased by morality preaching especially within faith communities. In an effort to stem the rise of AIDS, many faith leaders have preached the ABC approach – abstinence, be faithful, use a condom. But Winnie Ssanyu Sseruma believes that this approach has led to greater ostracism for those living with HIV because it reinforces assumptions that they are promiscuous and unfaithful: *“The ABC model had been around for a long time and it slips off the tongue very nicely but when you actually unpack it, especially with a changing epidemic and say abstinence – abstain for how long, who’s monitoring who is faithful, if you are faithful is the other person going to be faithful? The ABC model really stigmatised people because it meant that people living with HIV did not abstain, were not faithful or condomising.”*

Katie Harrison, Head of Media and Corporate Relations at Tearfund in the UK, says they have worked with faith leaders: *“One thing we have found is that the church or any faith community in many parts of the world is incredibly influential so if it says that something is right, everyone thinks it is right; if it says that something is wrong, everyone thinks that is wrong. Therefore some churches historically have specifically said something about HIV or the causes of HIV that*

have been immensely unhelpful and inaccurate. It has been very hard for people to come to them if they are HIV positive or using drugs or are men having sex with men. They haven't seen the church as a place which will welcome them."

In Malaysia, where there is a concentrated epidemic affecting key populations, discrimination is evident institutionally according to Fifi Rahman, Policy Manager at the Malaysian AIDS Council: *"You still have a lot of employment discrimination. We have had quite a few universities withholding degrees and diplomas because the individual had HIV. It got to the point where they were saying, tell us how you got HIV and we will release your diploma."*

Double stigma for key populations.

In most of the countries where we interviewed people, key populations suffer a double stigma. Key populations refer to sex workers and their clients, men who have sex with men, the lesbian, gay, bisexual and transgender community and people who use drugs. They are socially ostracised, because their behaviour is culturally not accepted, and then further persecuted because of their HIV status.

Discrimination is being compounded by governments around the world taking an increasingly anti-gay stance. In their *2013 AIDS Report: Tracking global progress toward the beginning of the end of AIDS*, ONE explored why in certain countries HIV rates were stagnant or rising and found this might relate to stigma. Erin Hohlfelder led on the report: *"We found that for many of these countries where they've either made stagnant progress or it's even gone backwards you will find that it often correlates anecdotally with government policies where there is persecution of the LGBT population. We profiled three countries - Cameroon, Nigeria and Togo - because all need urgent progress. In Cameroon and Nigeria since we published our research, anti-gay legislation has been passed and that only underscores the point we were making in our report. In Cameroon they already had instances where LGBT AIDS activists were murdered; the situation in Nigeria has only got worse."*

Ann Noon of the International HIV/AIDS Alliance views current trends which stigmatise key populations, as a real threat to the prevention and treatment of HIV in the long term: *"Increasing criminalisation and homophobia in India, Uganda, Ethiopia, Malawi, Tanzania and other countries is a huge issue for us and is ongoing and is set to get worse. That is just one structural societal barrier we face."*

In Uganda, the government's anti-gay stance with the passing of an Anti-Homosexuality Act this year has fuelled persecution of people living with HIV. Fionnuala Murphy, Campaign Coordinator for the International HIV/AIDS Alliance, says the media have used this as an opportunity to incite anti-gay hatred to sell newspapers: *"On 25th February Red Pepper ran a cover story called Uganda's top 200 Homos and they outed various people who are not out and some of them are not even gay. They also listed people who are working for sexual and reproductive health and HIV organisations, especially those who work with gay people. They incited people to go and attack these individuals. They called for them to be hanged. In theory people in Uganda are supposed to be able to get ART but there are lots of practical barriers to access. If you talk to people from key populations they are turned away from clinics all the time."*

Where governments do take a lead, discrimination can be reduced. Javier Hourcade Bellocq, Latin America and Caribbean Regional Representative for the International HIV/AIDS Alliance, cites the case of Argentina where recent legislation has reduced discrimination: *"You have the same sex marriage law and the gender identity law so the levels of stigma against gay and transgender people has been decreasing since those laws have been passed. It makes a huge difference if you have the President of the country signing in a new law or giving identity cards to transgender people. Leadership messages are really important to change stigma."*

From our interviews, it is clear that governments lead the way in either reducing or reinforcing HIV related stigma and therefore any efforts to reduce it need to engage policy makers at government level. The website www.hivtravel.org lists 24 countries in the world from which you will be deported if you are a foreign national and are found to be living with HIV. America and China only lifted their bans on people living with HIV entering their borders in 2010.

Reframing the debate

Another major challenge in treatment and reducing HIV related stigma is that many people's understanding of HIV is out of date and doesn't reflect the improved treatment available today, so the fear of a disease which could kill you is still very real.

Simon Collins coordinates information services for HIV i-Base, a treatment activist NGO in the UK. He believes this is an area where mainstream media could have a positive impact on attitudes but journalists often seem unaware of the latest research: *"Media stories*

“Increasing criminalisation and homophobia in India, Uganda, Ethiopia, Malawi, Tanzania and other countries is a huge issue for us and is ongoing and is set to get worse.”

Ann Noon, Media manager, International HIV/AIDS Alliance

are often based on information that is out of date. Firstly, treatment now lets people lead long and active lives. Secondly, it dramatically reduces any chance of further transmission. You would be hard pushed to catch HIV from having sex with someone on treatment, with or without a condom. The level of personal awareness also shows how difficult it is to change attitudes. Someone who finds out they are HIV positive has a gut reaction as if they are back in the 80s. If they react like this, their family and friends will be the same. Without accurate, clear and up-to-date information, this is a tough nut to crack.”

Some of our interviewees asked whether use of the word ‘stigma’ is itself a problem and raised the question as to whether the whole debate needs to be reframed. They suggested that people working in this field should not ask ‘Why is there stigma against HIV?’ but ‘Why is HIV not yet normalized?’.

Winnie Ssanu Sseruma of Christian Aid believes we need to bring about a paradigm shift: *“I think trying to change social norms is really, really critical. It is those social norms that people get their attitudes from. There are people who still don’t believe you can live long with HIV. There are people who don’t believe you can have a child who isn’t infected with HIV.”*

Treatment takes priority over prevention

It is clear from our research that organisations and governments working on HIV often see prevention and communications as less of a priority than treatment.

Although HIV related stigma is an issue which is often mentioned in the literature and in the work of NGOs, it has not received the same level of attention as treatment or prevention. This was acknowledged by UNAIDS when it set out its strategy, in 2011, to achieve an AIDS free generation. The *Getting to Zero* framework focuses on three key visions which include reducing HIV stigma as a priority: zero new infections, zero AIDS-related deaths and zero discrimination.

Most of our interviewees agreed that treatment is more straightforward than prevention: Erin Holthfelder is Policy Director of Global Health at ONE: *“On treatment it’s accepted that scaling up access to treatment is important and it’s really just a matter of getting the numbers right. It’s fairly straightforward in many ways. Whereas prevention - there are so many different ways of preventing*

HIV - it is less clear how to build a target that makes the most sense across the board.”

The complexity of the psychological and social aspects of HIV which relate to discrimination has led many governments to focus their efforts on treatment and leave NGOs to deal with the societal aspects of HIV.

In many instances, governments feel uncomfortable talking openly about HIV. James Robertson, Country Director of India HIV/AIDS Alliance, believes this is to do with the fact it is related to sex, drugs and key populations, none of which are vote winners: *“The government in India has taken significant control of the treatment side of HIV and AIDS with clinics and ART. But, when prevention is about using a condom... ‘Wait a sec, you are going to have sex, aren’t you?’... using a clean needle... ‘You are going to inject drugs?’... Then governments get a whole lot more nervous.”*

In our research, we found that the majority of the media projects aimed at reducing HIV related stigma are funded and run by NGOs rather than governments.

The media landscape: HIV is no longer a news story

All our interviewees believe there is fatigue with HIV in the mainstream media. While media coverage of HIV issues is now less stigmatising in some countries, this is no longer a story which engages journalists or the public. In broadcasting, there is a lack of innovation and often the quality is poor, comprising no more than studio discussions which are uninteresting and have little human interest. Newspapers were singled out for their tabloid and sensationalised coverage.

In Latin America, Javier Hourcade Bellocq has seen coverage improve in tone but getting HIV into the news is now proving more difficult: *“There is real fatigue with this subject. It is becoming more difficult to keep awareness up.”*

In India, according to James Robertson, the media has lost interest: *“We can’t make HIV the interesting story it was eight years ago when millions were dying of AIDS in Africa. Coverage needs to evolve to the more nuanced challenges of the AIDS response but it hasn’t.”*

For journalists who are interested in HIV, trying to find an angle which engages their editors is a struggle. Divya Arya, Social Affairs

Correspondent for the BBC World Service in Delhi, admits that she hasn't covered a single story on HIV in the past four and a half years: *"HIV is not something which is reported on so much now and I think it is because it is hard to make it sound like fresh news any more."*

According to Winnie Ssanyu Sseruma, there is a fundamental problem with media coverage: *"The challenge is that good news stories don't sell as much as the stories which arouse fear within people. It is the really grisly stories that sell. What has been happening is that journalists highlight stories that scare people and they have no idea what the impact is, not just on the people reading these stories but on the people who are highlighted in them."*

Why does media coverage matter?

In light of the apparent lack of appetite for HIV related content in the media, why would anyone suggest it is a useful means of engaging the public?

There is evidence that the media is a cost effective way of tackling HIV. In 2011, UNAIDS released an investment framework for reducing HIV. It looked both at biomedical interventions as well as what they called 'critical enablers' which are the softer interventions around education, stigma and engagement. These were considered to be important drivers to rates of progress and worth investing in. They viewed the mass media in concentrated epidemics as providing 'normalising treatment acceptance, encouraging adherence and notifying treatment advances.' In generalised epidemics mass media 'enables promotion of safer behaviour by challenging the norms, values and culture that fuel risky behaviour.' Additionally, a study was published in *The British Medical Journal* in 2005, by Daniel Hogan and others, which demonstrated that mass media combined with other interventions was the most cost effective way to halt and reverse the spread of HIV.

It is clear that there is a potential role for media organisations – whether they are platforms, producers, publishers or NGOs – to engage the public. The question is what works best?

Messaging or engagement?

There has been a lot of academic debate around development communication and media messaging, much of which has centred on whether direct messaging works – does it genuinely engage the public and lead to behaviour change or is a more nuanced approach required?

Garth Japhet, the founder of The Soul City Institute for Health and Development Communication in South Africa, believes that a more subtle approach is needed: *"The issues that we are dealing with are not slogan issues. You can say: 'Wear a condom; prevent HIV.' But it doesn't hit you the way a story can. There is this wonderful theory called Parasocial Interaction – where the gap between reality and fiction completely blurs and people begin to see themselves in the characters."*

Warren Feek, Executive Director of The Communication Initiative, goes further, calling for a radical change in the current approach: *"Part of my issue with the HIV and AIDS response at the moment is that it has become professionalised around technical experts. The model we should take for the communication strategy should be the civil rights movement or the anti-apartheid movement or the gay rights movement. Linked integrally to the communication process is social organisation. We are not going to get the type of change we want if we continually try to persuade people to do things based on expert opinion."*

Dr Martin Scott, Lecturer in Media and Development at the University of East Anglia, and author of several previous IBT reports, believes that message-based behaviour change communication is inherently flawed: *"It fails to take into account the structural factors around people's lives which shape their behaviour rather than simply their knowledge. One of the biggest problems is that simply knowing that you should change your behaviour or having a different attitude to something does not necessarily mean you will be able to change your behaviour."*

Erin Hohlfelder of ONE agrees that understanding the cultural, structural and social context in which you are working is essential: *"I think some folks are quite sceptical of messages around HIV - if condoms aren't available, or if they don't feel empowered socially to stand up to a partner and say no. One thing we heard time and time again is that increasingly you've got to look at gender and power dynamics as well as gender based violence issues to really understand the HIV epidemic as it stands now."*

Martin Scott argues for a more long term media strategy: *"Instead of thinking about the media as a tool for delivering messages, you need to think of it in broader terms – as agenda setting, or framing, normalising, or socialising or cultivating – which are longer term ways of making things more normal, or over time challenging things, or giving people role models, or questioning*

“Journalists highlight stories that scare people and they have no idea what the impact is, not just on the people reading these but on the people highlighted in them.”

Winnie Ssanyu Sseruma, Senior Advocacy and Policy officer, HIV, Christian Aid

things. It is a longer term cultural change which is required. Alongside this must be genuine changes on the ground – health provision, education, rate of migration and all the other things which affect HIV.”

Models of media intervention

There are numerous models of media intervention aimed at tackling HIV and HIV related stigma: TV and radio drama; sponsored TV or radio talk shows; journalism training; the creation of journalist networks; public service announcements (PSAs); feeding storylines into existing dramas; multi-platform approaches; reactive campaigns, and comedy.

For NGOs specialising in this field, determining which model will lead to a change in public opinion is key. Sophia Wilkinson, Senior Health Advisor for BBC Media Action, says their approach is evidence-based: *“It’s all about trying to determine what might drive change. That is what a lot of our research focuses on – so we can then design our projects based on that research.”*

Evaluating the impact of media projects to reduce HIV related discrimination and stigma is challenging. Many of the projects we looked at can cite evidence that they have produced a change in attitudes; what appears more challenging is to measure actual changes in behaviour.

TV dramas

Much research has been done to demonstrate the power of drama to engage an audience which may not be interested in news and current affairs. IBT’s own research in the UK clearly demonstrates this. The theory is that instead of pushing messages or facts out to an audience, drama attempts to engage people with a storyline, which works on a deeper, more emotional level than factual content.

Arvind Singhal, co-author of *Entertainment education: A communication Strategy for Social Change (1999)*, believes drama is more effective because of the way we respond to narratives: *“There is a lot of literature in social psychology even in brain science that looks at narrative as a way to make sense of the world. Narratives influence your heart and a bit of your mind but it is through emotion as you follow a character and you see the choices they are making and the consequences of those choices that we are moved.”*

Soul City

The South African drama series *Soul City* is one of the longest running public health media interventions in the world. While it is not focused specifically on HIV related stigma, this is an issue which has been addressed throughout its 20 history. *Soul City* is the longest-running primetime drama series currently airing on South African television, and there have been dozens of spin-offs, with the *Soul City* team producing radio and entertainment dramas which are shown throughout southern Africa and distributing millions of books based on the series.

A key to the success of the show is the time spent researching storylines, which are all based on real people. The *Soul City* project has been able to demonstrate measurable impact on HIV awareness. Recent findings show that 83% of those exposed to *Soul City* multi-media content professed willingness to help people on antiretroviral therapy, compared to 67% in a control group; and that there was a 6 - 8% increase in use of condoms specifically to prevent HIV.³

Garth Japhet founded the NGO which produces the series in 1992. He remains convinced of the power of drama to change behaviour: *“The only way that I know of that influences people’s attitudes and behaviour is through emotion. It is not through fact. There is a neuro-biological reason for that - it is that the neuro-biology of giving people facts is that you light up a tiny section of the brain. The neuro-biology of stories is that you essentially light up the whole brain and it becomes an emotive experience. One of the key things in *Soul City* is trying to build characters which people see themselves in. When there is resonance with the character there is resonance with what happens to them.”*

Shuga

A similar model to *Soul City* is the drama *Shuga*, which is targeted at young audiences. Funded by the MTV Staying Alive Foundation, it has been broadcast in Kenya and Nigeria since 2009. *Shuga* became a hit and has now been screened by more than 70 TV stations around the world. The producers and cast use social media extensively to engage with their audience.

Richard Warburton is the Project Director: *“What has been a fundamental for *Shuga* is trying to ensure it is grounded in*

popular culture and tells the truth about the experiences of young people. One of the things which became very apparent was the power of drama to facilitate conversations that wouldn't normally happen."

In both Kenya and Nigeria, it was assumed that the nature of the content around sexual health and HIV might be too explicit for a mainstream audience, but by working with local writers the team has been able to feature taboo topics in a sensitive way. There's one story in the current series of *Shuga* which has resonated with audiences - that of Sophie, based on a real story, who discovers that her sugar daddy is living with HIV: "One of the things we discovered in Nigeria is that there is a lot of denial in transactional sex which is not openly acknowledged. So that is an area we were very interested in trying to focus on and you could argue that potentially that means that Sophie as a character resonates with a lot of people. People see themselves in her."

There is evidence that *Shuga* has had an impact on its target audience. Among a sample of young people who had watched the show, 52% said they had talked with a close friend about the programme's characters or messages; 90% felt that the show had an effect on their thinking about stigma related to HIV.⁴

BBC Media Action

BBC Media Action is the BBC's international development charity, which works in 23 countries, producing a range of TV and radio content. Its ethos is similar to *Soul City* and *Shuga* - that drama, in particular, has the power to change behaviour. The organisation has grown rapidly in recent years and now has an annual income of over £40 million, with the UK Department for International Development as its largest donor.

One of its current projects, in Nigeria, focuses on HIV. It includes TV public service announcements, short films, and two radio talk shows *Flava* (broadcast in Pidgin English) and *Ya Take Ne* (in Hausa). There is evidence that the programmes impacted on knowledge and attitudes. 32% of *Flava* listeners said they would stop stigmatising people living with HIV; 27% had an increased awareness of the importance of faithfulness to one's partner and 23% an increased awareness of the need for consistent condom use.

BBC Media Action doesn't currently produce any drama for its HIV campaign but it has produced a number of dramas in the past aimed at tackling HIV related stigma. They had a long running series in India

from 2002 to 2007 which featured a detective and was called *Jasoos Vijay*. During its last 52 episodes, it was watched by 70 million viewers cumulatively, making it one of the 10 most-watched programmes on Indian television.

Huesped Foundation

In Latin America, where the tele-novella is the most popular form of media entertainment, there are many projects being run which address issues around sexual and reproductive health, some of which include content about HIV and stigma.

Notable TV series include *Sexto Sentido* in Nicaragua, *Revelados* in Colombia and the *Passion por la vida!* campaign which has distributed content across Latin America.

In Argentina, Huesped Foundation has been active since 1989 and works specifically on HIV issues, producing a range of drama content. It also works with other producers to feed storylines into existing dramas. Measuring the impact of these storylines is a key aspect of their work, according to the Foundation's Leandro Cahn: "Last year we worked with UNICEF in Argentina on an idea with one of the most popular tele-novellas. We did a phone survey before the episode was aired and after in order to assess if the story had had an impact. We found that resistance to the idea of young ladies proposing the use of condoms in their first sexual intercourse decreased after the episode and more respondents also agreed with the idea that a father can speak with his daughter and not just her mother about sexual and reproductive health information."

Newspapers

All our interviewees referred to newspaper coverage as a driver of public opinion. What is written impacts directly on the knowledge and understanding of the reader - but there's a wider impact too, as Garth Japhet notes: "It's a very good agenda setter because radio talk shows and television programmes pick up on print articles, so in terms of setting the tone for a debate or creating awareness that then gets picked up by other media, print is a leader."

Many of our interviewees were critical of newspaper coverage for presenting an out of date image of HIV treatment and the people who live with HIV in order to shock, scandalise or entertain.

As a result, much of the work carried out by NGOs with the print media to reduce HIV related stigma is focused on training staff.

“One of the things which became very apparent was the power of drama to facilitate conversations that wouldn't normally happen.”

Richard Warbarton, Project Director, Shuga

The goal of this work is to sensitise journalists to issues around HIV, help them to understand why certain language stigmatises people living with HIV and provide them with an up to date understanding of the virus.

This work has to take a light touch approach because many journalists don't like being told how to do their job. Some of the problems with newspaper coverage are structural: journalists don't have the opportunity to specialise in order to build up a knowledge-base in health or social issues; there's generally a high turnover of staff in newspapers, and a lack of money to enable journalists to travel and conduct their own research.

Journalist training cannot address structural issues but it can, at the very least, correct misconceptions. Fifi Rahman from the Malaysian AIDS Council organised a workshop for journalists and found that *“there were a lot of misconceptions – like you can get HIV from mosquitoes.”* She hopes that workshops such as these can inspire journalists to do more stories on HIV: *“What would be good would be to see the media playing a more active role. They are reactive. It's always us going to them and saying do this article.”*

Building networks of journalists

In addition to training journalists some organisations are creating global networks of journalists who write on these issues. The best known such initiative is the Key Correspondents programme, run by the International HIV/AIDS Alliance. The project trains journalists and publishes their work online as well as promoting it for inclusion in other media. Sarah Oughton is Editor and Coordinator of the programme: *“It's a network of citizen journalists who are either living with HIV or have been affected by HIV. It also includes people who are working in the sector as well. The point is to encourage them to find the issues and the stories which are most important to them and to give them an opportunity to get their voices heard on a wider platform.”*

Javier Hourcade Bellocq runs the Key Correspondents Programme in Latin America where they have 30 active correspondents and publish 200 articles a year in Spanish: *“There is not much information in the field for people who don't speak English so this is very valuable. One of the key aims of the articles is to impact on decision makers.”*

Public Service Announcements

Alongside other media content, many agencies use billboard advertising as well as Public Service Announcements (PSAs) or adverts on TV or radio. However, broadcasters are sometimes wary of inserting PSAs into popular slots and NGOs find it challenging to get the right tone, as Javier Hourcade Bellocq of the Alliance admits: *“With the World Cup in Brazil, UNAIDS are trying to push to have some AIDS messages during the coverage. I see them struggling with that because firstly, people don't perceive there is a huge crisis and secondly, we are still not finding the right balance to tap into people's entertainment without ruining the moment.”*

Targeting young people

As media usage habits change, many NGOs have adapted their models to include a greater online presence. One World has developed a project in a number of countries, which uses SMS messaging to answer young people's questions about sexual and reproductive health. Uju Ofomata is the Programme Director of Mobile4Good: *“We use platforms like Facebook, Twitter and Instagram to give out information as well as SMS messaging and try to make sure young people get information in school wherever possible. In Nigeria, for example, we get between 10 and 12,000 SMS queries a month.”*

Reactive campaigns

Sometimes when media coverage is stigmatising, NGOs take reactive measures in order to limit the damage done. In India and Latin America, NGOs we interviewed cited instances where they felt they had to respond to negative stories, especially in the print media.

In Uganda, the recent coverage by *Red Pepper* led the International HIV/AIDS Alliance to confront advertisers in the paper and ask them to withdraw funding. Fionnuala Murphy led the campaign: *“Red Pepper has a website and I realised that there were some multinationals advertising there. I saw that Orange had banners across the top of the website. So we got in touch with All Out, an online campaigning platform for LGBT issues, and within 24 hours they had 300,000 signatures on the petition and Orange agreed to withdraw. A couple of other companies have done so since. I don't know if it is enough to hit Red Pepper at their financial core but it will send a message.”*

SWAZILAND CASE STUDY

In this report, we present a case study of Swaziland, which has the highest prevalence of people living with HIV in the world – officially 26%⁵. We visited Swaziland to examine the media landscape and look at the media initiatives being carried out by local organisations. We met people living with HIV and discussed their view of media coverage and experience of stigma. We found that stigma has reduced in the past ten years since antiretroviral therapy (ART) has become more widely available but it is still a problem for many people living with HIV.

Why Swaziland?

We chose Swaziland because it is a small country and has limited media outlets which made it possible in the timeframe of this report to analyse the media output aimed at reducing discrimination and the wider context of HIV related stigma.

What we can conclude from this case study is useful because it has provided us with the opportunity to examine less high profile, small scale projects of which there are hundreds, if not thousands, around the world. These are an important aspect of the media campaign to counter HIV related stigma but they are not evident from desk research.

Background

Swaziland is an absolute monarchy, ruled over by King Mswati III, who has been on the throne for 25 years. Freedom of the press is severely limited. The country was badly affected by AIDS during the height of the epidemic, and there are officially 78,000 orphans out of a population of 1.2 million⁶. Swaziland is traditionally a polygamous society where men can have a number of wives and the King himself has 14 wives but this custom appears to be on the decline. Lack of rights for women is a major concern for NGOs.

Zelda Nhlabatsi, Executive Director of The Family Life Association of Swaziland (FLAS), one of the country's leading sexual and reproductive health NGOs, says this is a significant problem in responding to HIV: *"Unfortunately women are still dependent on men, including their choice of number of children, when to have sex and how to have sex."*

Traditional healers are still popular. From our research it appears that men are more likely to go to a traditional healer before visiting the clinic in rural areas.

The most influential voices in Swaziland are those of Parliamentarians (who are often community chiefs), government ministers, the King and church leaders.

HIV

Figures from the latest UNAIDS report, show that the incidence of new cases of HIV has decreased since 2011, but it is still relatively high. Women are disproportionately affected, with prevalence as high as 31% compared to 20% in men⁷ but this is likely to be because men do not come forward as readily for testing.

There is a high awareness of HIV in Swaziland (98%), as would be expected when so many died at the height of the epidemic, but there is a significant lack of comprehensive understanding (51%) about how it is transmitted and what treatment is available.⁸

HIV testing and ART are provided free of charge by the Ministry of Health to those who need them but travel costs to get to the clinic to collect ART medicines is cited by many interviewees as a barrier to treatment.

The role of the church

The church plays an influential role in Swaziland. We interviewed Babe Mkhwanazi, a pastor in the Church of Zion, one of the most popular churches in the country. He was trained in HIV awareness in 2012 and since then his attitude has changed dramatically, but he admitted that there is still discrimination in the church against people living with HIV: *"There are churches in Swaziland who feel HIV is still something you can't talk about. But I think we are now more aware of the truth about HIV. The training changed me because it changed the way I was thinking, so this changed the way I was preaching and then people started to tell me their status because I was accepting of them."*

Pastor Mkhwanazi promotes abstinence - he believes you should only have sex once you are married. The theory is that you get married and have one partner and you are faithful.

Attitudes to sex

The traditionally patriarchal structure of society in Swaziland, whereby a man might have a number of wives, all living with him in a single homestead has a pervasive impact on attitudes. Traditionally men believe they own their wives, but marriage appears to be in decline

“The impact of stigma is that people are not able to access the services because if someone wants to come for testing in their local health centre they are afraid people will know and talk about them.”

Lindiwe Simelane, Regional Coordinator, SWANNEPHA

with informal relationships and single mothers on the increase.

We spoke to a number of young men aged between 18 and 25 about their attitudes to relationships and sex:

“It is normal to have a few girlfriends. And women have a few boyfriends. The Swazis hide the fact they like a lot of sex.”

“I don’t mind my girlfriend having other boyfriends. But once she has a ring on her finger she has to behave. If I got married I would cut down on sleeping around too.”

“Guys here are more worried about getting their girlfriend pregnant than they are about HIV.”

Zelda Nhlabatsi from FLAS believes that because HIV doesn’t have any symptoms there is a lack of incentive to use condoms: *“We do not use condoms consistently. It is just an attitude. The nature of HIV promotes such behaviour because people won’t get sick immediately. If they got sick immediately it would stop them. But they want enjoyment now. People maybe use a condom in the first three encounters and after that they think trust will protect them. But most people don’t know their status and many of them have multiple concurrent sexual partners.”*

HIV related stigma

Bill Snaddon, Research and Communications Officer from the Media Institute of Southern Africa believes that attitudes to HIV are changing but that disgrace around HIV is due to its link with sex: *“The stigma often comes back to the fact that you don’t want to admit to it because it shows you have been having sex. There is a lot of innuendo in the language around sex but people don’t talk about sex publicly, however the younger generation is talking more in public. There is a clear generational divide.”*

We conducted a focus group with people who are living with HIV and they described their experiences of stigma:

“I was stigmatised. People were talking about me. Thinking I was like a prostitute.”

“When you disclose to a guy he pretends it is ok, but it changes things. That is why I don’t get into a relationship – I prefer to be alone with my kids.”

“I know lots of people who have died of AIDS. Most people are scared of getting the test. It is easier not to know.”

The PLHIV Stigma Index, which was researched in Swaziland, describes the different types of stigma people living with HIV experience – external stigma, internal stigma and anticipated stigma. Many of those working in the field have been surprised by the level of self-stigma.

Lindiwe Simelane, Regional Coordinator at the NGO Swaziland National Network for People Living with HIV (SWANNEPHA), worked on the PLHIV Stigma Index: *“Women are not sure how to tell their spouse. How do you tell someone you have just started going out with? It is not something you can easily talk about. The guy will leave you. You are then left with bad self-esteem. Sometimes you just want the relationship to flow to see how it goes but then if you disclose later the person will say you have deceived me because you didn’t tell me at the beginning.”*

Self-stigma is caused by a fear of being rejected or disapproved of by others and leads to people not getting tested, not wanting to visit their clinic to collect treatment in case they are seen by neighbours and not wanting to have ART medicines in the house in case their family see them. The fact that Swaziland is such a small country also means that privacy is an issue – there are few places where people can go to be tested anonymously and be sure of confidentiality. According to Lindiwe Simelane, *“The impact of stigma is that people are not able to access the services because if someone wants to come for testing in their local health centre they are afraid people will know and talk about them.”*

Key populations

As elsewhere in the world, key populations at a higher risk of HIV exposure are doubly stigmatised. There is no media aimed at them or about them, and many people do not accept they even exist. According to UNAIDS figures, HIV prevalence in Swaziland among men having sex with men (MSM) is 18% and among sex workers it is 70%.⁹

Homosexuality is not illegal in the country but it is not culturally accepted. According to Pastor Mkhwanazi of the Church of Zion, *“It is not acceptable for men to have sex with men. We don’t discuss it in the church. We cannot preach about it because the*

bible says we go to bed to have children and men going to bed with men doesn't lead to children, so how can we talk about this?"

Few NGOs work in this field. One openly gay man we spoke to said that gay people are regarded as paedophiles, although no one confronts him about this. He said that he is often approached by married men for sex, but they are terrified he will expose them. This suggests that homosexuality is more widespread than is publicly acknowledged.

Another gay man who hasn't publicly disclosed his sexuality, talked to us on a confidential basis. He works for an NGO which focuses on sexual and reproductive health issues: *"I am not able to talk openly about my sexuality. Even in my workplace people say bad things about gay people."* He says that the media doesn't report on health issues for these key populations but they need to because there is a lot of ignorance. But journalists told us that it is hard to write about these groups when people are unwilling to be identified.

Access to treatment

From our research it is clear that one of the key challenges the government and NGOs face in Swaziland is to engage more men in testing and treatment.

Thembisile Dlamini of UNAIDS believes there are cultural reasons for men's lack of engagement with HIV testing: *"Men do not come forward for testing as much. Service uptake by men is more difficult. They feel like it makes them less of a man if they are sick."*

One of the young men we interviewed explained why he thinks men don't go for testing: *"The clinic is not a place for men in Swaziland. You don't go unless you are actually ill. If I am negative I am good, if I am positive I am good if I don't get tested. I can just get on with my life. Maybe I have a limited time on this earth, but if I am going to die, I don't really want to know about it."*

There are currently no media initiatives aimed specifically at engaging men with testing although there are other NGO activities targeted at men. At a community meeting organised by the NGO SAfAIDS, which we attended, there were 18 men aged between 25 and 60. The goal of the meeting was to sensitise them to issues around HIV and encourage them to be tested. This was the first time they had attended such a meeting and they appeared

enthusiastic. Among the 18 men present there was 100% awareness of HIV but none of them had chosen to be tested. They all said they planned to take a test the day of the workshop.

The media landscape

The most popular form of media in Swaziland is radio which reaches 98%¹⁰ of the population. 80% of people live in rural areas¹¹ and radio is the most cost effective and practical media platform. Radio content has to be approved by the government before it is broadcast. The two main national radio stations are run by Swaziland Broadcasting and Information Services (SBIS). There is one privately owned radio station, Voice of the Church, however it has a limited reach and is only licensed to broadcast religious and health content.

Swazi TV, the national TV station, is 97%¹² funded by the government. It has no viewing data but estimates there are 200,000 TV sets in the country. Those with digital TV can receive South African channels, which are popular among more affluent urban audiences.

There are two daily newspapers in Swaziland: *The Observer* is viewed as state controlled and *The Times of Swaziland*, which is privately owned, is the most popular with a circulation of 25,000¹³. *The Nation* magazine is a privately owned monthly publication which has the reputation of publishing controversial stories but the editor, Bhekithemba Makhubu, has been in prison for contempt of court since March this year and his trial is ongoing. Newspapers often aren't available in rural areas.

Internet penetration is growing – it currently stands at 27%¹⁴ - but it is slow and relatively expensive.

While the majority of media content is controlled by the government, the most significant form of censorship is self-censorship. People who work in the media told us they follow a set of unwritten, unspoken boundaries in order to avoid censorship.

Media coverage of HIV

"I haven't seen the media play a very active role with positive stories. I have lived with HIV for a very long time. The media haven't caught up with the story that people live longer now. It's either journalists have not got enough information or they just

“The media haven’t caught up with the story that people live longer now. It’s either journalists have not got enough information or they just don’t want to flag up the positives about HIV.”

Person living with HIV, focus group

don’t want to flag up the positives about HIV.” Person living with HIV, focus group.

Most newspaper coverage of HIV in Swaziland falls into two categories: either sensationalist news stories about people who are living with HIV and commit a crime or more favourable coverage which appears in the health or community pages. NERCHA, the government agency responsible for HIV and AIDS, has published ethical guidelines on the reporting of stories about HIV but it acknowledges that they are not always followed.

Journalists we spoke to on the two national papers said that selling HIV stories to their editors was a major challenge. They said that these type of stories, unless they are sensationalist, don’t sell newspapers.

Bill Snaddon from the Media Institute of Southern Africa says the traditional style of journalism is a major problem: *“There is not a lot of human voice coming through, so even when it is positive it doesn’t impact. Most HIV and health reporting is event based. It is easier to go to an NGO launch and you have quite a boring article. Journalists here don’t get paid a lot, they don’t even have credit for their mobile phones, they don’t have money for transport so they are tied to their desks a lot of the time. So it is easy to say go and find the human interest story and do this or that but when it comes to the crunch they just have to write a story.”*

Nana Mdluli from NERCHA also highlights the problem of a high turnover of staff at newspapers, which means that even if one journalist has been sensitised to the issues of HIV, the next one may not be.

Bill Snaddon says that coverage of key populations is mostly disapproving: *“You see the whole gay thing reported a little but the media is mirroring society so it is reported in a negative light. There is a lot of stigma towards sex workers and they are sometimes seen as the enemy because they are spreading the virus. The discussion doesn’t really touch on the men who are paying for sex.”*

Television and radio frequently cover HIV, but according to our focus group of young people, the content is of little interest to them. They prefer to watch imported dramas.

“If you are watching TV and a show comes up about AIDS it’s time to change the channel. We’ve heard all this before.”

“Preaching head on doesn’t work. We don’t listen. We zone out.”

The role of NGOs

As is the case in many other countries, the government in Swaziland focuses on providing HIV treatment and leaves the psycho-social communications work to NGOs.

Chris Fleming, who is a Public Relations Officer at FLAS, believes that because the impacts of communications are less quantifiable than biomedical work, they are given less priority: *“People have a hard time spending money and not seeing a direct return for it. You can put up a billboard for 60,000 rand but no one comes back to FLAS and says that the billboard really got me and changed my ideas. It’s money you spend in faith. It gets pushed to the side and it is unfortunate because this is the time we really need communication the most because without health messaging how are we going to change things?”*

Media initiatives to combat stigma

While the media landscape is limited in Swaziland, there is a relatively large amount of output focussing on health issues, including HIV related stigma.

This is the result of a range of NGO projects running across all media outlets – print, television, radio and online. Often NGOs are expected to pay for the airtime or newspaper column inches.

Current projects include TV and radio talk shows, weekly newspaper columns, public service announcements, training for journalists and training for church leaders. These initiatives are seen as important both because they engage the public, but also because they reach and influence decision makers.

Nana Mdluli from NERCHA says the media were crucial in gaining government support for its roll out of ART across the country: *“They play a pivotal role in terms of advocacy. This assists the policy makers in understanding why it is important that they support the programmes. The people who are in parliament are the same community leaders. They need to be supportive if this is going to work.”*

Whilst it's possible to see the impact of media coverage on policy makers, what's less clear is its impact on the wider public, especially in terms of behaviour change.

Below are a number of examples of current or recent media initiatives.

TV adverts

In December 2013/January 2014 there was a joint television advertising campaign run by FLAS and UNFPA. It aimed to engage a male audience under 30 years old and used cartoons to tell stories. There were 40 slots and the NGOs were allowed to choose the slots they wanted to access the target audience. Chris Fleming from FLAS says it was important to keep the tone light: *"The concept was around two guys talking about sex and girls. One is educated and leads the other one into a clinic and asks him whether he knows about different family planning methods – condoms, the loop etc. They were 30 second adverts."*

Radio shows

FLAS currently sponsors a weekly show on SBIS1, the Siswati language radio station, which focuses on sexual and reproductive health issues including HIV. It runs for 30 minutes every Tuesday at 3.30pm and is a magazine format which includes a live phone in, music and studio discussion with one of FLAS's nurses. FLAS has to pay for the slot but SBIS provide the studio and production team.

NERCHA also coordinates a radio show called *Noma Kunje Lisekhona Litsemba* which runs at 7.15pm on a Tuesday evening and is repeated on Sundays. Any NGO working on HIV can contribute to the programme – providing content or expert guests. It aims to be engaging by putting a human angle to each story and connecting information to people's everyday lives, such as how to grow vegetables in your yard that will help your nutrition if you are taking ART.

In 2013 there was a 20 episode radio phone-in programme modelled on a South African show called *Beat It!* It was produced by people living with HIV and coordinated by SWANNEPHA.

Lusweti, the Soul City Institute's local NGO, works to engage young people aged 15-24 and its focus is on sexual and reproductive health. It operates across radio, TV, print and online and has had a radio show, *Wize Up*, which ran for 32 episodes in 2013. It is about to start another series. The show is a phone in with music. They, too, have to pay for the airtime.

Television

Lusweti has just completed a 13 episode run of its TV series *Wize Up* which complements the radio show. All the programmes covered sexual and reproductive health issues in a studio based chat show. They had to pay all the production costs and airtime for the series. As yet they have no evaluation for the impact of the series but intend to carry out an assessment.

In 2013, SAfAIDS, an NGO which works across southern Africa, sponsored *Your Health*, a pre-recorded TV show in Siswati which focussed on HIV issues and which ran for 26 episodes. The series was complemented by a live phone in on the Voice of the Church radio station, so that people could call in or send an SMS with their comments and questions in response to the TV show. SAfAIDS had to pay for the airtime on both radio and television.

An entertainment game show which aimed to reach a younger audience with sexual and reproductive health issues was produced by FLAS in 2013. *Battle of the Sexes* sought to help the audience understand which health services are available through a quiz show format.

Soul City, the South African series produced by the Soul City Institute was broadcast in Swaziland. Soaps are generally popular in the country but there is no locally produced drama.

Newspapers

There are a number of NGO sponsored health columns in Swazi newspapers but only one focuses on HIV. *AIDS Lifeline* appears weekly in *The Observer*, is sponsored by SAfAIDS and is significant because well written, engaging HIV stories are rare in newspapers in Swaziland. It's written by journalist James Hall:

“The training had an influence. I was emotionally engaged and I know what to write responsibly about HIV now. I didn’t know about this before.”

Sthembile Hlatshwayo, Reporter, *The Times of Swaziland*

“The column is a grab bag of local developments which are not that many, medical breakthroughs which otherwise would not be covered and the occasional international story. It is also frankly the only consistent source of HIV news in the country.”

Lusweti also produces a weekly *Wize Up* column about sexual and reproductive health issues which appears in *Swazi News* and complements its radio and television content. Unusually, they don’t pay to place the content but as a result they say the column inches they receive are limited.

Journalism workshops

A number of NGOs have run workshops to sensitise and inform journalists in Swaziland. This approach appears to have been productive and the feedback from journalists has been positive.

One of these workshops was run in 2013 as part of the Give Stigma the Index Finger project. It was organised jointly by IPPF’s partners in Swaziland and Panos Southern Africa.

Sthembile Hlatshwayo from *The Times of Swaziland* found it helpful: *“The training had an influence. I was emotionally engaged and I know what to write responsibly about HIV now. I didn’t know about this before. It made me realise how hard it is to live with HIV. As a result of the workshop I wrote an award winning article about a 15 year old boy who discovered he was HIV positive during health clubs at school when he tested. It was very tough because his mum hadn’t disclosed to him.”*

Winile Mavuso from *The Observer* also took part in the training: *“I think the workshops are useful because we get to understand how people feel. We don’t usually go out to find people who are living with HIV and say, ‘Tell us your story.’ They had a woman speak who is living with HIV. Her story was very moving. It involved her own sister sleeping with her husband in her house full time. They were denying they were living with HIV. She was at some point very sick but had got better through ARVs.”*

Swaziland - the way ahead

It can be seen from this research that there are a number of media initiatives to address issues around HIV being run by NGOs in Swaziland but there is little evaluation of their impact on public opinion and behaviour.

There are many challenges for both journalists and NGOs. The biggest challenge is a fatigue amongst the public with media content about HIV. Bill Snaddon believes the answer is more human stories: *“The media and NGOs could work better together disseminating the human stories which will touch people’s hearts on this and write more features about Swazis living with HIV, giving it a less patronising and more positive spin to say this person has HIV and has overcome certain challenges and is still living a pretty decent life.”*

James Hall says there is an urgent need for a radical rethinking of how the media is used by NGOs: *“The audience aren’t engaged. It’s not changing people’s behaviour and they resent the fact that their television time is being occupied with content that they don’t want to watch. Is there any thought to trying something else?”*

The lack of resources for journalists clearly limits what they can write or broadcast. Patience Magagula is a news reporter with Swazi TV: *“Health stories are interesting but we don’t have the time or resources to get them covered. You can just do 10 minutes recording and then you have to rush back.”*

Chris Fleming from FLAS believes the answer lies in a much lighter approach: *“We have tried one route which is dominated by fact and jargon or technical details and that hasn’t worked. Instead how about letting it be light-hearted? Don’t attack them head on by saying, ‘You should care about this as much as we do.’ We have done the ‘should’ approach and it isn’t working. We should get this out there via entertainment, music, poetry and drama.”*

Welile Simelane, Head of Production at Swazi TV, believes that drama is the way ahead - but there aren’t the resources to produce local drama: *“Drama is easier to engage with and you can get lost in the story and not realise you are being given a message like in Soul City.”*

CONCLUSION

From our research on the ground in Swaziland and based on interviewing many who are active in this field around the world, it's clear that a more concerted and strategic approach to media content aimed at reducing HIV related stigma is urgently needed.

The media has an important role to play in reducing the social and psychological impacts of HIV but achieving change is a slow process - and media alone is just one part of the solution. The task of reducing HIV related stigma remains important. A number of our interviewees suggested that we risk sliding backwards in responding to HIV because with the increased availability of ART there is a danger that complacency could set in.

NGOs have a vital role to play in promoting public awareness and they frequently collaborate with media on a range of initiatives, so they are in a strong position to influence coverage. But particular attention needs to be paid to quality and achieving the appropriate tone. When media content about HIV is at its best it has the potential to change public opinion. At its worst, it leads audiences to turn away, and reinforces discrimination.

HIV is no longer news

All our interviewees agreed that it is increasingly difficult to engage the public with issues around HIV. There is a perception that HIV is no longer the crisis it once was; there is fatigue with the subject, which has been covered, often not very well, for the past 25 years; and there is a perception in many societies that HIV is something that other people catch. This provides a very challenging environment in which to engage people with the issue of HIV related stigma because they feel they have heard it all before.

Media training

In most of the countries we talked to our interviewees about, training of journalists has had some impact on the output of media organisations. Training needs to be carefully devised as journalists do not respond well to being told what to write. However, enabling

them to hear the personal testimony of people living with HIV gives them a powerful insight into the human story, which is not usually reported.

Language is also an issue which many of our interviewees considered important because it can easily reinforce HIV related stigma and cultural norms. Any training needs to include sensitisation of producers and journalists to the type of language they use.

But training can only achieve a certain amount. Most of our interviewees said there is still too much sensational coverage of people living with HIV especially in the print media. Publishers appear to believe that extreme stories about people living with HIV, especially in key populations, sells newspapers. These publishers need to be challenged more forcibly, as such coverage reinforces discrimination and out of date perceptions about HIV.

Different genres

It is clear that there are many formats and genres, which have the potential to engage the public, but from our research it is evident that a multi-faceted approach is needed in order to reach different audiences. Young people may prefer music and celebrities while older people may be better served by factual programmes on the radio.

Our interviewees agreed that research is essential to the success of any media project aiming to reduce HIV related stigma. It needs to identify target audiences and measure impact so we can establish what works and what doesn't work so that the more effective models can be replicated.

Drama has been particularly effective at making audiences more sympathetic towards people living with HIV, especially when it can be done on the scale of *Soul City* or *Shuga*. In contrast, many of the more factual, diary stories in newspapers appear to bore readers and put them off the issue.

Lack of funding

It is apparent that there is a lack of funding in many countries for media projects which aim to reduce HIV related stigma, other than for those organisations of a size and profile which are well placed to fundraise and evaluate their projects. While some television dramas, for example, are distributed around the world, they are often not culturally or socially specific enough to resonate with local audiences.

Measuring impact

It is clear that there is a real challenge in quantifying the impact of media content aimed at reducing HIV related stigma. Most of the NGOs we spoke to indicated that they are working hard to devise evaluation models which provide accurate information to demonstrate the impact of their work. Some of the larger media NGOs have funding to conduct research, but smaller ones do not have the capacity for large scale evaluations. Many suggested that this deters funders from financing communications projects and instead they opt to fund biomedical activities the impacts of which are more easily quantifiable.

Norm changing

Many of our interviewees talked about the need to change social norms in order to normalise HIV as an illness. There is evidence to suggest that media can make an important contribution to this process but it is not realising its full potential. New approaches, such as country specific dramas, should be explored and to help facilitate this it would be useful to conduct research which investigates which media models work most effectively at changing norms.

Targeting key populations

With the rise in homophobic legislation to which many of our interviewees referred there is a risk that the pace in the reduction of HIV incidence will be slowed down. The portrayal of key

populations which are affected by HIV was not addressed in any of the content we encountered. This represents an important gap in provision, which needs to be filled.

Influencing decision makers

Many of the NGOs we spoke to regard the media as a powerful tool in influencing public policy, decision makers and key voices in society, whether they be in the faith sector, business or government. This indicates that funding needs to be maintained to engage these groups with the issue of HIV related stigma.

Role models

Many of the people we spoke to bemoaned the lack of high profile role models for people living with HIV to follow. The more people who disclose their status publicly via the media the faster HIV will be normalised. While hiding the identity of interviewees in the media can be seen as a sensitive approach to dealing with HIV, some of our contributors suggested it compounds the issue, implying that if someone is living with HIV, they need to hide their identity.

Silos of expertise

From our research it became clear that often silos of expertise exist in this area of work. This is perhaps inevitable because the issue of HIV related stigma and the role of the media cross over a number of disciplines – policy, campaigns, communications and media production. In many NGOs there are policy advisors who are experts in HIV but work separately from the communications teams who engage the media. Sometimes the priority of a communications team is to make the public aware of their agency's work, rather than tackle HIV related stigma. This is something which several of our interviewees suggested needs to be tackled if NGO campaigns to change public opinion are to be successful.

RECOMMENDATIONS

An evidence based approach

NGOs should be careful to ensure that any media work to reduce HIV related stigma is well researched, targeted and engages audiences. They should question these principles every time they embark on a project.

Measuring impact and scaling up

Where it is demonstrated that certain types of media content have an impact in reducing HIV related stigma, more resources need to be invested, especially at a local level, in such content. Currently resources are patchy and often ill-used.

Focus on key populations

More resources need to be devoted to addressing the representation and engagement of key populations, especially where they have been affected disproportionately in concentrated epidemics.

NGOs need to work together

Organisations working in the field of media which aims to reduce HIV related stigma need to coordinate their efforts to scale up their output to gain impact rather than duplicate each other's content.

Use the media to engage decision makers

A continuous effort needs to be made to use the media to target key decision makers, influencers and high profile celebrities with the issue of HIV related stigma.

Journalists need training and resources

Journalists benefit from training and resources, which mean they can leave their desks and cover stories in a humane way that is engaging. NGOs could provide greater access to stories or produce appropriate content for media outlets to use.

Prioritise drama

Drama has the benefit of engaging people emotionally and can lead to attitudinal change. More needs to be done to increase local capacity in countries, which are at high risk, such as Swaziland, to produce TV and radio dramas, which resonate because they are culturally and socially relevant.

Improve quality and tone of factual content

Factual content on television and radio needs to be of a high quality in order not to alienate audiences. Some of the content we encountered in this research was of very poor quality. The tone needs to engage rather than lecture.

Find role models

There is an urgent need for the media to find and feature high profile role models for people living with HIV to follow. The sooner this happens, the faster HIV will be normalised.

A long-term approach

All organisations working on changing attitudes to HIV related stigma need to adopt a long-term approach. Short running series on television or radio will not be effective.

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