Lifting the veil

Shedding light on HIV stigma and discrimination

A report from the XVI International AIDS Conference,
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Foreword

HIV-related stigma is exceptional in its scale, its context, and its causes. It is encouraging that we are now seeing more programmes designed to reduce stigma, practical toolkits, and ways of measuring the phenomenon. However, we have a long way to go and there is much to be done.

It is vital that we don’t let our approach to stigma and discrimination become too technical, losing sight of the personal impact of loss of self and feelings of isolation felt by HIV-affected people. Many eventually come through the experience stronger, but we must empower positive people in the context of addressing stigma. By doing this we can ensure the individual is always the focus.

Strong community responses against stigma and discrimination are absolutely crucial, and we must be aware of new processes and initiatives that could exacerbate stigma within communities, particularly in relation to gender. The current debate around opt-out HIV testing, for example, must include due consideration that testing can lead to increased levels of stigma, especially for women, who risk having the critical element of choice denied to them, and who may suffer extreme consequences of being found HIV positive.

In addition, issues around funding can lead to aid being given to groups headed by men, who then bring in other men as experts and consultants. Women at the forefront of community responses to stigma, and other care and support needs of affected people, are consequently denied proper resources.

Leadership is a key element in the fight against stigma. Leaders at all levels, have a clear responsibility to create a more open society that is free from stigma, silence or denial about HIV and AIDS.

Finally, health is a human right. HIV-related stigma cannot be tackled until health systems are strengthened at the local level so that everyone has access to basic health care, no matter what their position. Adopting this approach with those affected by HIV and AIDS must be central to all our endeavours.

This publication, written by a small team of dedicated Key Correspondents from a range of developed and developing countries, provides an overview of presentations and discussions around HIV-related stigma at the International AIDS Conference in 2006. It provides a unique snapshot of the current state of HIV stigma, and forms part of what must be a robust, committed and tireless fight against the most damaging phenomenon of the HIV epidemic.

Mary Robinson

Preface

This publication is a compilation of articles on HIV-related stigma written during the XVI International AIDS Conference (IAC) held in Toronto, Canada in 2006. A gifted team of Key Correspondents (KCs) from India, Ireland, Namibia, Thailand, Uganda, the United Kingdom, Zambia and Zimbabwe[1] tracked the theme throughout the IAC, so in addition to reporting on HIV stigma, they maintained a country-specific focus. The result is an intense series of short essays and reports describing various aspects and insights into HIV-related stigma that surfaced during the week-long conference. The essays consider the contextual antecedents of HIV stigma, as well as more generic and universal features.

Organising this material into a coherent framework, and condensing the issues raised into a set of concise conclusions has been challenging. The essays speak for themselves, and reflect the individual perspectives of the KCs in so many ways that condensing them inevitably denies their true richness and credence. But we also appreciate that some readers will need an abridged version. So we have attempted to condense their overall message in a brief summary and conclusion, as well as reproducing them in full.

HDN firmly believes that the overall availability and quality of information and reporting must be improved if we are to see an invigorated response to HIV, TB and other health- and development-related issues. Discussion must expand beyond those who are typically in control, and national and international policy-makers must be prepared to be more accountable for their decisions and actions. Multistakeholder dialogue must be strengthened at all levels.

In response to this need, HDN supports a team of country-based writers (or Key Correspondents). KCs help to document local experiences, provide independent reporting on HIV- and TB-related issues and events, and monitor some of the commitments, declarations and other plans issued at international and country levels. KCs bring local and national views into their essays and articles – examining and documenting the views of those dealing and living with the epidemics on a daily basis.

In this way, the KC Team generates high-quality articles and information, providing a continuous barometer of what is making a difference, what is not, and why.

Earlier in 2006, HDN published key findings and recommendations on the nature and impact of HIV-related stigma[2], based on several years operation of the Stigma-AIDS eForum, a discussion space for interested people and communities to share their views and experiences. The current publication builds on those findings and recommendations,

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[1] Countries in which Health and Development Networks (HDN) is also helping to facilitate National Partnership Platforms on HIV and tuberculosis

[2] Living on the outside – Key findings and recommendations on the nature and impact of HIV/AIDS related stigma, Health and Development Networks 2006

and moves us further towards a better understanding of HIV-related stigma, as well as practical approaches to reducing it.

We hope the report provides a window into both the personal and social impact of HIV-related stigma, and that the contents are informative, thought-provoking, challenging and ultimately inspiring for – though the picture is bleak – the benefits of fully confronting HIV stigma will ultimately have a greater impact on the epidemic than perhaps any other step we can take today.

Health and Development Networks
October 2006

Summary and conclusions

It has been previously argued[3] that significant issues relating to HIV stigma cluster around three specific features:

- Stigma and the person: the lived experience of HIV-related stigma;
- Stigma and place: specific contexts in which stigma occurs;
- Stigma and society: the representation of HIV at the societal and cultural level.

At the Toronto IAC, these elements were clearly apparent, reconfirming the multi-layered nature of stigma. We saw evidence that the personal experience of people living with HIV (PLHIV) continues to be characterised by trauma, outrage and personal cost. The Toronto IAC and the essays in this publication, however, provide an opportunity for taking a more wide-ranging and in-depth look at the current state of HIV stigma. In particular, we will focus on four areas:

- Understanding the origins and causes of HIV-related stigma;
- Personal experiences of HIV-related stigma;
- Evidence that HIV-related stigma and discrimination are significant barriers to prevention, care, treatment and support efforts, and to international efforts to scale-up towards universal access to such services;
- Approaches to addressing HIV-related stigma.

The origins of stigma lie in the shame, fear and silence that dominate negative perceptions of people living with HIV and of the behaviours thought to be associated with HIV transmission. Several essays in the series refer to a conspiracy of silence surrounding the disease that is both entrenched and pervasive.

Such perceptions of HIV, and of people living with the virus, are partly fuelled by the inadequate health care infrastructure and services in many settings. This means that there are few incentives for HIV testing and for disclosure of HIV status. Completing the vicious cycle, HIV-related stigma discourages infected and affected people from seeking counselling and testing, as well as other related prevention, care and support services that are available.

As highlighted in the main body of the publication, HIV-related stigma is influenced by factors as diverse as food insecurity; the low status of women in many societies; other cultural and traditional dogmas and norms; the way in which the ‘exceptionality’ of HIV seems to be continuously emphasised; prevalent ignorance and misconceptions about HIV – often driven by fear-based messaging; the lack of coherent policies and programmes to address HIV-related sensitivities and stigma in schools and other settings;

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[3] Living on the outside – Key findings and recommendations on the nature and impact of HIV/AIDS related stigma, Health and Development Networks 2006

the existing stigmatisation of marginalised groups often heavily affected or vulnerable to HIV, including sex workers and drug users; and finally, difficulties in stimulating sustained interest in the subject of HIV among the media and the public at large.

Personal experiences of HIV stigma were much in evidence during the conference, and in one article, for example, we see the uncertainty faced by affected children in Thailand as they make complex decisions about HIV disclosure. One child was worried that she would never be employed if people knew her status: “her secret must never be disclosed”. Another was prevented from playing with other children at school: Other parents told their children to stay away from her.

The reported widespread prevalence of HIV-related stigma in health care settings continues to be a significant and confounding issue. If people with HIV are separated, humiliated and scolded, they will be reluctant to subject themselves to the ‘ordeal of services.’

Voluntary counselling and testing (VCT) for HIV is a crucial entry point for people accessing prevention, care, treatment and support services. VCT offers the opportunity for many people to: (1) find out their HIV status, (2) normalise HIV and reduce stigma, and (3) access other essential prevention, care, treatment and support services. Unfortunately it is also one of the contexts in which people experience their first exposure to stigma, as this is their first point of contact with the health system and with possible feelings of hopelessness and shame which often result in self-stigmatisation.

In order to reduce stigma, specific attention must be urgently given to the quality of voluntary counselling and testing services, in order to ensure that they are as receptive and supportive as they can be towards people coming forward for testing. In this regard, VCT centres and services are unique among the HIV-related services in their potential to help decrease stigma. The current opportunity and drive to expand antiretroviral (ARV) drug access is not an excuse for health care services to compromise the standards of VCT, including the vital elements of informed consent and confidentiality.

There is also evidence that the social stigma towards traditionally marginalised groups, such as sex workers, drug users, men who have sex with men and mobile populations, acts as an additional barrier to their accessing health services. Such attitudes are often deeply rooted in religion and traditional beliefs, and are frequently buttressed by outmoded national legislation. In many countries legislation actually perpetuates discrimination experienced by typically marginalised groups, thus driving them further away from essential prevention, treatment, care and support services. In some settings, laws exist to prevent discrimination but they are not enforced or enacted by people living with HIV. Often such laws are not accompanied by the necessary legal education and sensitisation and thus it can take many years to see the impact of anti-discrimination legislation and to achieve acceptance by society. Nevertheless, the essays also include encouraging descriptions of how some grassroots organisations have been able to gradually gather support for anti-stigma initiatives from government and international organisations.

The conference heard clear calls for further examination of the relationship between stigma reduction and health-seeking behaviour, an important area where little research has been undertaken to date. This will be particularly critical in future considerations regarding the scale up of provider-initiated HIV testing and counselling.

Stigma as a barrier to accessing essential services has been well documented in the past, and this highlights one of the confounding questions raised by the conference and a major cause of concern: Why, after 25 years of responding to HIV, is stigma still a problem? Perhaps it is for the same reason that after 25 years of the epidemic, it still challenging for so many leaders to acknowledge sex workers, men who have sex with men, transgender and drug using populations and their specific vulnerability. It is abundantly clear that there has been insufficient investment in concrete programmatic interventions to reduce stigma and discrimination. Moreover, the wilful neglect in addressing the cultural, social and structural factors which perpetuate stigma has effectively undermined the global response.

It is also important to note that the reverse relationship – inadequate HIV services being a factor intensifying stigma – is also possible. The dearth of appropriate and adequate prevention, treatment and care services feeds the perception that HIV infection is a hopeless situation, which in turn provokes harmful social attitudes towards typically marginalised populations and people living with HIV, including their personal sense of self. It was interesting to note that there was little evidence presented on the relationship between antiretroviral treatment and levels of stigma.

Of course, some progress in measuring and concretely redressing HIV-related stigma is being made and there are many examples in the report of such projects and initiatives.

For example, breaking the silence surrounding HIV and promoting open discussion is key to addressing stigma and discrimination. Sport can play a significant role in identifying and changing harmful attitudes that promote stigma. It can increase the confidence of children infected and affected by the disease, and in the process help to minimise the fear, silence and denial associated with HIV.

The most frequently cited antidote to stigma is education and awareness: Essentially putting HIV back in the public arena and talking about the epidemic. There is a clear need to build awareness and capacity among leaders, involve groups experiencing stigma, and target the media, police and health workers, in drafting plans for universal access that would fight stigma, ensure appropriate prevention and treatment access for people infected and affected by HIV. The reports also make some direct appeals to the media to be more consistently and constructively engaged with HIV, presenting a more balanced view of people living with HIV, as opposed to dying of AIDS.

The pervasive and systematic stigma experienced in health care settings by people living with HIV – and by vulnerable groups – is a disgrace, and underscores the need for a comprehensive plan to strengthen the health systems of all countries so that health workers have enough knowledge and basic equipment to protect themselves while caring for people with HIV. In addition, education for health care workers must include a component which addresses attitudes.

The contributions identify specific interventions and areas for research to help decrease HIV-related stigma in the health care setting:

- To help reduce health care workers' fear of infection, universal precautions should be promoted, as well as availability of supplies (gloves, etc);
- Provision of PLHIV-friendly health services, including voluntary counselling and testing, and care and support services must be scaled up;
- PLHIV must be involved in development, implementation/management and evaluation of such services;
- Social openness about HIV should be encouraged, while maintaining individual confidentiality.

It is interesting to note that the need to address stigma experienced by health care workers living with or affected by HIV is seldom discussed.

Understanding the process of disclosure of HIV status is an important element in achieving acceptance and reducing stigma. The visibility of the epidemic is one of the most important inhibitors of stigma, and yet paradoxically, disclosure itself can result in immediate and acute stigma. Development and provision of effective tools to help people living with HIV navigate through the choices and processes associated with HIV disclosure, and minimise the likelihood of negative responses and consequences, is an important priority and a neglected area.

This report recognises that the nature of HIV-related stigma is not static. This is because new solutions to HIV are being found, tested and applied that in themselves can bring new forms of stigma, but also because diseases such as TB and XDR-TB (extremely drug-resistant tuberculosis) are providing complex challenges that will affect the stigma experienced by people living with HIV. Vigilance in understanding new forms of stigma remains key, together with the need to continue designing new stigma reduction programmes.

The descriptions of the ground-breaking Movement of Men Against AIDS and the Network of Positive Teachers, both from Kenya, are illustrations of what can be achieved through lateral thinking about how to address stigma, and how to engage specific groups in particular.

The enduring 'PLHIV-friendly checklist' developed for hospitals by the Population Council several years ago surfaces once again as an extremely useful tool to help planners and service providers undertake a self-assessment to highlight where their services might be inadvertently stigmatising their clients. In addition, a toolkit for stigma reduction developed by the International Center for Research on Women (ICRW) now exists and is being used in many settings. Tools for measuring stigma are also now available.

Finally, the essays highlight the need for the HIV policies and programmes of many countries to be reviewed in light of persistent HIV-related stigma and discrimination.

Conclusions

“Fear and ignorance are the causes of stigma, which lead to prejudice”
IAC Delegate, Toronto 2006

HIV is different in many respects to the bulk of other diseases faced by humankind. Successful interventions in the past that have reduced the stigmatisation of disease and increased awareness and understanding – such as education, social support mechanisms, developments in medical science and robust epidemiological models – are often absent, ineffective or simply undeveloped in the case of HIV. HIV stigma is also reinforced by significant social, cultural, legal and economic factors, demanding a multi-dimensional, comprehensive and sustained solution, rather then one that relies, for example, on education or awareness alone. As is the case with effective prevention, which demands a combination of actions, effective stigma reduction demands a set of interventions which simultaneously address law and policy, education and awareness, political and social mobilisation and the meaningful involvement of people living with and most vulnerable to HIV.

In the meantime, HIV stigma continues to dominate the epidemic, and will not be mitigated by half-hearted solutions: it is too robust. This report, sadly, illustrates how a lack of focused and aggressive action against HIV stigma over the years has led to its continuing ascendancy. It is a significant, and largely preventable failure by governments, agencies, NGOs and civil society that has instead allowed the prevalence of mechanistic and (at times) partisan solutions to the ‘problem’ of HIV: antiretroviral (ARV) drug scale-up; vaccine development; and lengthy debates on morality and sexuality. It seems little has been invested in understanding some of the fundamental social and structural problems underpinning stigma – despite the knowledge of the negative affect stigma has on the uptake of HIV prevention, treatment, testing and care services.

It is also essential to mention some of the progress made by projects tackling stigma. We have seen that these initiatives are usually characterised by rigorous research evidence, used to predict and measure stigma in specific areas, to shape, deliver and evaluate anti-stigma interventions. This progress must be applauded. But, the limited global reach, and stigma’s ever-changing nature (similar to virus itself), mean that high quality anti-stigma programmes, tailored to context, need to be rapidly scaled up and continually adapted. They must be driven by an equivalent level of funding, passion and commitment as that which has resulted in the successes in ARV roll-out. Without sufficient attention to and investment in stigma reduction interventions, the battle against HIV will fail.

This report recognises that new forms of stigma are emerging as new solutions to HIV are been found, tested and applied but also because factors such as the resurgence of TB in heavily-affected countries – and the emergence of extremely drug-resistant TB (XDR-TB) among people living with HIV in particular – are creating complex challenges that potentially inflame stigma. Understanding, anticipating and immediately counteracting these new forms of stigma is vital, and modifying anti-stigma programmes in this light will be an ongoing need.

This report has provided a snapshot of the current state of HIV stigma, and we can conclude that:

- The continuing presence of stigma represents a catastrophic failure in HIV policy-making and programme design;
- Medical science alone – often the most influential of disciplines – is limited in its affect on HIV stigma; but HIV stigma can block the benefits of medical advances by simply preventing affected people from engaging with testing or treatment services;
- HIV stigma forms a significant barrier to advances in repairing the personal, social and cultural damage inflicted by the HIV epidemic.

In light of this Toronto ‘window’ on HIV-related stigma, we recommend that all HIV policies and programmes should include a specific component that addresses the impact of HIV stigma. Adequate funding must be available to scale up concrete and comprehensive stigma reduction interventions, and to monitor and evaluate the impact of HIV stigma and the effectiveness of stigma reduction strategies and programmes.

HIV stigma will continue to prevent the scale up of effective solutions for prevention, treatment and care, rendering them ineffective and wasteful, until such actions are taken.

As we decide what action to take, millions of people across the world face significant stigma, rejection and prejudice. They cannot wait: we have an imperative to act.

Causes of stigma

In Africa stigma lives off silence

Masimba Biriwasha, Zimbabwe

Pull Quote

Millions of people living with HIV are at risk of infecting their partners because stigma forces them to choose silence

"HIV is just like any other disease and until people accept and tackle it, we will continue to be reduced in numbers like animals drinking from a poisoned well" – Sazini Ndlovu, a sex worker and member of the Hwange AIDS Project, The Daily News [Zimbabwe], 15 August 2001

Harare, Zimbabwe – HIV stigma is a social construction founded on a mixture of myths, misinformation, fear and ignorance, as well as some real life experiences of the disease. In spite of the bio-medical and social work that has been done to fight HIV, stigma and discrimination remain like two towers blocking progress. The fight against HIV will not be won on the medical front if the social phenomena that propagate the disease are not addressed.

In Africa, a continent where HIV is predominantly transmitted through heterosexual sex, being HIV positive is seen as a sign of promiscuity. Being infected is seen as a curse and in such a context naturally carries shame with it.

Lack of access to antiretroviral (ARV) drugs and other therapies that prolong life for people living with HIV (PLHIV) has only worsened levels of stigma within society. HIV is perceived as a death sentence. Many people are afraid of the disease, and they turn their fear into disdain and discrimination of anything associated with HIV, including people living with the disease.

In many instances, people who are open about their status are poor and impoverished. This has a major impact on the negative perception of PLHIV, who are stigmatised not only for carrying the virus but also for their poverty. As a result, most prefer silence.

People's experiential knowledge of HIV in Africa often consists of the pain that they have seen their loved ones experience as they die of the disease, and this undoubtedly influences their attitude. Many people prefer to live without knowing their HIV status. The majority of infected people in Africa do not live with HIV, instead, they die of the disease, intensifying the belief that to have HIV equals death. The conspiracy of silence surrounding the disease is so entrenched and pervasive that burials often happen without a single mention of the disease.

Due to the nature of the illness, people with AIDS may need a great deal of intensive care and support. If these people are to receive the expert and compassionate care that they undoubtedly deserve, one paramount issue that has to be addressed is that of stigmatisation and coping behaviours among health care workers. When caring for the chronically ill, unprejudiced, sympathetic and comprehensive care is essential as it helps maintain psychological health, and prevents pain and suffering.

In most African countries, the health care infrastructure has inadequate facilities, inadequate manpower and poor logistics such as drug supplies and other equipment. Low quality of services has further worsened the levels of stigma within society. High levels of poverty also prevent the infected and affected from accessing services. In many local settings throughout Africa, HIV is frequently still equated with hopelessness and death.

Such perceptions of HIV have fuelled prejudice towards people living with the virus. Where there is stigma against PLHIV, they retreat, driven by both internal and external stigma. As a result, millions of people living with HIV are at risk of infecting their partners because stigma forces them to choose silence.

Stigma discourages infected and affected people, and their partners and families, from seeking counselling and other services that may prolong their lives. According to UNAIDS executive director Dr Peter Piot, “It is unfortunate that we are still hampered by our old enemy: stigma. Eliminating stigma must be central. It is about breaking silence, and breaking silence means breaking secrecy, not confidentiality, about AIDS.”

Breaking the culture of secrecy about HIV is essential in combating stigma. An intensive and appropriate communication campaign could go a long way to reducing stigma in Africa. The media is central to such an initiative. Such a programme would have to utilise all the channels available to encourage a positive change in the perception of HIV. Otherwise, HIV stigma will remain the biggest hidden killer in African today.

Until people in Africa accept and tackle HIV just like any other disease, they will continue to be reduced in numbers like animals drinking from a poisoned well.

Realities of stigma in health care settings

David S Mukasa, Uganda

Pull Quote
There are still cases where health workers express sentiments like: “treatment of opportunistic infections in PLHIV is waste of valuable resources.”

While the majority of health care professionals comply with ethical guidelines and do not deny care, treatment or support to people living with HIV (PLHIV), a disturbing number of health care professionals engage in stigmatising and discriminatory behaviour, according to studies presented at the recent XVI International AIDS Conference in Toronto.

Health care workers are also reported to engage in practices that contravene codes of professional ethics, including HIV testing without consent and disclosure of confidential medical information without prior permission. Examples of this reality were revealed by Takawira Moses, who works with Medicin Sans Frontiers (MSF) in rural Zambia.

The health sector is clearly not immune to HIV-related stigma or discrimination, and stigmatizing attitudes are reported to be ‘rampant’ in communities where HIV is still regarded as a taboo. This is a serious impediment to many PLHIVs disclosing their status and fully facing HIV, and coming forward to receive much needed treatment, care and support services.

According to research findings presented by JS Oruko, conducted in four district hospitals and eight rural health units in Kenya, the lack of adequate knowledge and lack of universal precautions to protect health workers from HIV, such as gloves, adequate needle disposal and post-exposure prophylaxis (PEP), contributes to the formation of stigmatising attitudes among health workers, who themselves fear infection.

“The fear they face affects the kind of treatment given to the PLHIV”, said Oruko.

This underscores the need for a comprehensive plan to develop the health systems of resource-limited countries so that health workers have enough knowledge and basic equipment to protect themselves while caring for their patients.

The uneven distribution of knowledge, care competence and basic resources between urban and rural settings also means that stigmatising attitudes tend to be highest in rural health care settings. This suggests that poverty is also one of the underlying factors in creating HIV-related stigma.

According to Dr Katende from Uganda, who has provided technical expertise in developing tools to measure stigma, a considerable number of health workers admit to having refused to care for, or admit, people with HIV. According to Dr Katende, there are still cases where health workers express sentiments like: “Treatment of opportunistic infections in PLHIV is waste of valuable resources.”

It is appalling that among health workers, the three most important concerns about treating HIV-positive patients appear to be: fear of becoming infected, contamination of the health facility and lack of availability of materials and instruments needed for treatment, as revealed through a report on the situation in Nigeria published by Physicians for Human Rights.

One way to reassure health workers working with PLHIVs is provision of PEP to treat possible cases of ‘nosocomial’ infection through, for example, needle stick injuries to doctors and other health workers when they are treating people. By administering a post-exposure course of ARV drugs, PEP is an effective way to reduce HIV acquisition under such circumstances, but to some health workers, particularly those working in rural settings, PEP is still a mystery. But where PEP is available it has been shown to provide health care workers with the reassurance that in the case of accidental exposure – which is rare – then something can nevertheless be done.

If we are to reduce and eventually eradicate HIV-related stigma and discrimination in health care settings, we must look very honestly at the realities that health workers face, and to try to imagine the epidemic from their personal perspective. Provision of support and information for health workers is essential to fight the fear that breeds stigma.

Nursing students may facilitate stigma

David S Mukasa, Uganda

Pull Quote

Some establishments don’t allow student nurse placements because people have expressed concern about ‘gazing’ visitors

Nursing students can be a vital resource in responding to the HIV pandemic. Unfortunately, the themes and patterns of students’ experiences are yet to be explored by research. Studies on nursing students’ expectations of providing care to people living with HIV (PLHIV) are mostly absent from nursing literature according to Shannon Quinn and her colleagues Carroll Iwasin and Carol McWilliam of the University of Western Ontario, who have experience in providing nursing training in both developed and resource-limited countries.

As nurse trainers, the trio began work on trying to understand and document nursing students’ expectations in caring for PLHIV. The attitudes, beliefs and comfort levels of nursing students and registered nurses (RN) working with PLHIV have not been well researched – nonetheless, it is clear that HIV interventions such as training courses, systemised education and persuasive strategies have a significant impact on HIV-related knowledge, attitudes and beliefs among nursing students.

The perceptions and attitudes of the community and families where nursing students come from will also influence the type of care and support they give to PLHIV. Societal values and any tendency for individuals to be judgemental about HIV will interface in the initial relationship between student nurses and PLHIV.

Some student nurses have confessed to consciously hiding or suppressing negative feelings within themselves so that PLHIV wouldn't feel they are being treated differently. Because of the increased self awareness of many PLHIV, as an automatic defence mechanism to anxieties resulting from real or perceived feelings of stigma, they tend to sense something is not completely authentic, thus detecting this superficial expression of warmth as truly 'artificial'.

On the other hand, when informed about their role, nursing students anticipate their own potential to be caring and compassionate. They also hope that the experience will be both exciting and rewarding – but does it prove so in reality? One student said, "I suppose it will be a positive experience, just for me personally. I think I will be able to appreciate life a little bit more, you know, having to deal with a chronic and terminal illness." If this is the attitude she comes with to the care arena, she may be in for a surprise to see people live year after year, possibly even outliving her.

Just as in the general health care service, nursing students expect their own protection to be 'a priority'. "I would really be careful and obviously that would go beyond the first time. Be careful every time but particularly conscious of it the first time", said another student.

Sometimes it seems student nurses see HIV as not really happening in 'their world'. That's where the biggest problem lies because to have empathy, one has to 'own' the challenge of HIV. If this detachment persists, and indeed it may if students are not supported more adequately, it may breed a kind of permanent indifference to PLHIV among health workers, leading to the quality of care being sub-optimal.

This may explain why most PLHIV support organisations and specialised treatment centres take on mature and experienced nurses. In Uganda for example, some of these establishments do not allow student nurse placements because people have expressed concern about 'gazing' visitors.

Nursing students who have not been provided with adequate information, knowledge and exposure, often understand HIV care and treatment as 'end of life care'. They have not gained sufficient experience to understand that PLHIV may require holistic support and care long before the onset of the visible signs of AIDS. One student said, "I'd just prepare myself . . . to possibly be working with someone dying".

Strategies should and be put in place to more actively and constructively engage nursing students. We can look at the curriculum being used in nursing colleges and such institutions to include the aspect of stigma and HIV care. Field visits to home care activities are essential but the understanding must start in the classroom if the attitudes are to be changed.

Fighting HIV stigma with food

Henry Kabwe, Zambia

Pull Quote

Food security among people living with HIV and their families is not only essential to maintaining good health, but is also a vital tool in addressing stigma

In many African settings poor food security negatively impacts on the lives of the most vulnerable groups – including women and children. As HIV strikes such populations, lack of proper nutrition creates a devastating synergy with progression of HIV infection. As they weaken, their bodies grow thinner and they are exposed to further stigma and discrimination as their physical condition betrays their HIV infection.

People in many African settings do not consider identifying a person living with HIV (PLHIV) through shared clinical or diagnostic results. They tend to make judgements based on physical appearance. A number of information, education and communication materials designed to raise awareness about the epidemic have illustrated the progression of the impact of HIV through misleading 'before' and 'after' images. A man or woman is shown as a 'huge' person before getting infected and 'thin and weak' after.

Such messages are so crude that PLHIV start to feel not just the impact of stigma from their community but also from themselves. Self-stigma can incorporate feelings of shame, dejection, self-doubt and sometimes feelings of guilt, self-blame and inferiority. The impact of self-stigma can be just as debilitating as that from the community.

Because so many people in sub-Saharan Africa, including those affected by HIV, depend on agriculture for food and income, agricultural policies and practices loom large in determining how well households cope with the disease. According to the International Food Policy Research Institute (IFPRI) the links between the HIV pandemic and hunger are particularly acute in rural communities, where households are often dependent on agriculture for their livelihoods, both as a source of income and food. Consequently, agricultural policies and programmes that are blind to HIV fail to help households cope with its effects and impact.

"This disease is having disastrous consequences for agriculture by affecting adults at the height of their productive years, reducing labour power and other resources, and making it difficult for poor people to provide food for their families," said Joseph Tumushabe, consultant to the UN Commission on HIV/AIDS and Governance in Africa, who attended the International AIDS Conference in Toronto. "Though not visible with the macro-level data that economists frequently use, the pandemic is clearly worsening inequalities. For that reason, ensuring rural livelihoods, including those dependent on agriculture, and mainstreaming AIDS work into all rural development projects, is critically important for mitigating impacts."

People living with HIV have heightened nutritional needs and less labour capacity, while others in their households require significant amounts of time for care-giving. If agricultural policies and programmes fail to account for these realities, they are unlikely to meet their objectives and they can even inadvertently magnify the impact of HIV.

"Policy-makers need to rethink agriculture in the face of AIDS," said Stuart Gillespie, an IFPRI senior research fellow at a press briefing in Toronto, adding, "The art is to think across sectoral lines."

An IFPRI publication entitled 'Women: Still the Key to Food and Nutrition Security', states that upon the death of an HIV-positive spouse, women are often stigmatised and driven from their communities, losing all property and other assets, a condition which drives them further into poverty and vulnerability to contracting HIV.

"Research and experience have confirmed that HIV/AIDS and food insecurity are increasingly entwined in a vicious cycle. Malnutrition and food insecurity heightens susceptibility to HIV exposure and infection, while AIDS in turn exacerbates hunger and malnutrition," explained Gillespie.

Good nutrition among PLHIV is vital to maintaining health and extending lives. Before antiretroviral treatment can be considered, food security must be established.

"The Western world needs to know that African countries operate differently because they are family oriented. They should not focus on the sick person alone but the whole family in order to sustain the system because if the families do not have food on the table, they will stigmatise and discriminate the person being helped through donor programmes," said Joesph Oruko, a trainer of pupils and teachers in Kenya under the Joint Peer Counselling Training (JOPECOTRA).

Food security among PLHIV and their families is not only essential to maintaining good health, but is also a vital tool in addressing stigma. If people are healthy and are seen to be thriving, it is possible for them to live longer lives but also be free of stigma and discrimination.

HIV stigma in Southern Africa

Chilombo Mwondela-Katukula, Namibia

HIV carries a terrible stigma in Southern Africa. It is possibly the worst stigma in African society: that of having 'illicit sexual relations.

Mpume Nosiku (pseudonym), a young government official, broke down in tears when he was diagnosed HIV positive. He went home immediately and was found about to hang himself by his housemaid, who called for help from a passer-by, saving him from an ignominious death. This happened in June 2006, and not in 1985 when HIV was newly discovered and antiretroviral drugs were yet to be developed. Sadly, the advances made by scientists have not been matched by advances in social acceptance of the disease.

Speaking to 30-year-old Mpume, one gets the feeling that HIV has taken on the monstrous and overwhelming identity of witchcraft in traditional African society. This is evidenced by the many traditional African doctors that millions of people prefer when seeking HIV treatment, as opposed to western hospitals and medical clinics. Many African people still view HIV as a mysterious disease brought on by sheer bad luck.

A new study on culture, women's rights and HIV in Namibia undertaken by Safaids, the Southern Africa HIV/AIDS Information Dissemination Service (SAfAIDS), based in Zimbabwe presented new insights into the persistence of HIV-stigma in Namibia and the region as a whole. The study was launched in Windhoek on the 6th September 2006.

Researchers Cynthy Haihambo and John Mushaandja conducted qualitative research in three Namibian regions and confirmed the prevailing low status of women in Namibia's rural areas, which is reinforced by cultural heritage and feeds stigma. Women carry the blame for many things, among them the spread of HIV. According to the researchers, women are not free to speak of their HIV status to their partners for fear of violence and even death.

Lois Chingandu, director of SAfAIDS, recounted at the launch of the study how a young Zimbabwean woman was beaten to death by her brothers and husband because she refused to breastfeed her child. They accused her of witchcraft, not knowing that she was hiding her HIV status and could not breastfeed for fear of transmitting the virus to her baby. She preferred to withstand the death blows than to disclose her status. Maybe, she also realised that either way, she would not be able to convince her tormentors to let her be. This incident occurred in early 2006.

The strength of the stigma associated with HIV is such that many feel cursed to be [illegible]tified with it.

"AIDS is worse than witchcraft," said Mpume. I don't know how I feel, but it will take me a long time to get over this. My family still don't know. My parents will be disappointed. How can I embarrass them like this?"

And with HIV touching such deep-rooted aspects of southern African society, it is not surprising to find that traditional healers are mainstreaming HIV. No longer are the *sangomas* (witchdoctors) consumed with doling out dark portions and spells, instead, they occupy themselves with the numerous HIV conferences held all over the region, discussing tradition-friendly approaches to the epidemic. The *sangomas* are concerned with the influx of patients showing AIDS-related symptoms in search of a ‘miracle cure’ provided by the ‘spirits’.

According to a report from the Washington Post in July 2006, a Baptist Church-affiliated treatment centre in South Africa has started a programme for *sangomas*.

"The programme is designed to spread HIV awareness messages through traditional medicine in the South African community – 80% of whom consult *sangomas*, according to a 2005 World Health Organization report,” they stated.

The programme, however is dependent on the *sangomas* agreeing to study the Gospel of John twice a week before receiving lessons in human anatomy, symptoms of HIV infection and the function of antiretrovirals and other modern medicines.

While the influence of cultural and traditional dogma is still powerful Africa is also heavily permeated by Christianity, which can add a further burden of judgement, stigma and discrimination to people living with HIV (PLHIV).

In an interview, Pastor Mirriam Shikongo, a Pentecostal preacher in Windhoek, Namibia, said HIV was a curse from God and a punishment for man’s iniquities. The pastor reaches a radio audience of over 200,000 people every week.

Not only do PLHIV have to fight traditional stigma, but must also deal with religiously inspired stigma, as often propagated by members of the Christian church, while the workplace and general society present other strong challenges.

Colourful billboards at the traffic lights of a main highway command attention – ‘AIDS Kills’ – is the message. One wonders, why not a billboard with ‘Cancer Kills’, ‘Meningitis Kills’, or even, ‘Polio Kills’?

Nalisa Sikufwa, an advertising agent based in the northern Caprivi region of Namibia (with the highest national prevalence of HIV at 43 percent), thinks it is time that the HIV message emphasised the need to fight the disease rather than extolling its effects. Statistics show that in the last 10 years, despite a flood of social marketing in southern Africa, there has not been much improvement in the prevalence of HIV or the stigma it invokes.

“We know it can kill, but so does malaria. The advertising world needs to know that unless we stand up to fight HIV-stigma it will kill more people than AIDS itself.”

Namibia is only the third country in Africa to assure access to treatment for its recorded 230,000 HIV positive people (out of a population of 1.8 million). But according to national UNAIDS coordinator Salvatore Niyonzima, many more could benefit from treatment if it were not for the stigma attached to the disease. Thus, in the face of traditional dogma, religious discrimination and poor social marketing, stigma remains the greatest barrier to confronting the HIV epidemic in Africa.

Pregnancy and stigma in India and Swaziland

Swapna Majumdar, India

Pull Quote

So do women living with HIV have any sexual and reproductive health rights? Do they have any say in the decision to have children?

When Elango and Asha, both HIV positive, decided to get married, both their families were overjoyed. Happiest of all was Elango's mother. But by the end of the year when Asha showed no signs of becoming pregnant, her mother-in-law became suspicious. Convinced that Asha was barren, she began the search for a fertile bride who would be able to give her a grandchild. At first, Asha did not take it seriously. But when the hunt intensified, Asha, like millions of Indian women, succumbed to the pressure of producing a child for fear of being stigmatised as barren.

Thousands of miles away in Swaziland, Africa, women living with HIV were echoing the same sentiments. Burdened by societal expectations to bear children irrespective of their HIV status, these women too, were giving in to the demands for grandchildren.

So do women living with HIV have any sexual and reproductive health rights? Do they have any say in the decision to have children? What can positive women do when societal pressure and the fear of being stigmatised as barren forces them to disregard their own health concerns? These were some of the issues raised at the XVI International AIDS Conference (IAC) in Toronto.

"My mother-in-law knew I was infected. But she didn't understand why that stopped me from having children. She thought I was the one to blame for not being able to produce a child. Elango and I didn't want to have a baby but the pressure was so intense that we had no option," revealed Asha, a member of the Indian Positive Network (IPN).

Every year, 70,000-100,000 HIV-positive women become pregnant in India. A majority of them do so to avoid societal disapproval of being childless and suspicions and prejudice about their status. According to Dr IS Gilada, secretary of the AIDS Society of India (ASI), more often than not, the sexual and reproductive health rights of women are totally ignored especially in societies where women are expected to produce children and carry on the family lineage.

Dr Gilada, an IAC delegate, pointed out that women face greater discrimination if they opt out and decide not to have children. "A couple, who came to me for counselling, were in a dilemma because the husband had not disclosed his wife's positive status to his family because he was afraid she would be stigmatised. Now that his mother was pressurising her to produce a child, they didn't know what to do. The husband asked me which stigma was better—the stigma of being considered barren or the stigma of being known as HIV positive. I had no answers to his question," he said.

Stigma is just as strong in Swaziland where HIV prevalence is estimated to be a staggering 42.6 per cent amongst pregnant women. Women would rather risk becoming pregnant to satisfy their in-laws or to confirm their fertility. "We are oppressed by the mother-in-law and compelled into becoming pregnant. We live with the trauma of not knowing who would look after the child after our death." This was one of the comments made by an HIV-positive pregnant woman in a study conducted by Philip Shabanga, a Swazi researcher.

This study, which was shared at the conference by Dr Nonlanhla Sukati, found that women could not negotiate sexual safety. Men did not appreciate being told to use a condom "If we love each other, its okay to share the virus—I give you mine and you give me yours but no condom use", was the common refrain by men.

Clearly, gender inequality and the stigma surrounding HIV hampers the assertion of reproductive health rights in India and Swaziland. Evidence-based studies have shown that sound counselling, medical care and treatment can reduce and even totally prevent mother-to-child transmission of HIV. But positive women, who may want to bear children for themselves and not to satisfy their in-laws, need greater support from their families to reduce the stigma and discrimination surrounding the infection. Only then will women like Gcebile Ndlobu, a Swazi activist, who believes that her only crime is to be HIV positive, change their minds.

HIV: It could be you

Ruth Connolly, Ireland

Pull Quote

Personally speaking, of my five closest friends not one can say they have never had unprotected sex

Ireland is one of the richest countries in the world. Partly as a result of this wealth, many of the population are of the opinion they are immune to HIV. There seems to be a false perception that the virus only thrives in poorer 'underdeveloped' countries. This is obviously fiction and the fact is that HIV does not discriminate: everyone, poor or rich, no matter from which part of the world, has the potential to get infected.

An Irish gay man, when asked if he knew any HIV-positive people, replied, “There are a few, but with the things they get up to it’s no wonder they have it”. More than twenty years after the first HIV diagnosis there is still the misconception that the virus is passed through ‘promiscuous’ sexual behaviour. For such a highly-educated country there is a serious lack of information about HIV.

Children as young as eleven and twelve are having sexual intercourse. Some have received sex education in school, but it is not comprehensive and often comes too late. They are taught how to prevent pregnancy and for many young girls this means taking the contraceptive pill. But this does not protect their bodies from HIV and other sexually transmitted infections (STIs) – about which they receive little education. Advertisements appear all over the country offering help and advice for pregnant women. Where are all the awareness campaigns for HIV? Surely having an unwanted pregnancy is no more daunting than receiving an HIV-positive test result.

People are electing not to be tested for the virus because they think they have never put themselves at risk. Personally speaking, of my five closest friends not one can say they have never had unprotected sex. These five people all know five other people in the same position, who all know five people . . . The problem is immense. As a result, many people living with HIV are unaware they have the virus and are putting other people’s lives at risk. Yet if people living with HIV declare their status, they are discriminated against and can be refused entry to certain countries, refused insurance, refused the right to adopt a child, etc.

Enter one of the many crowded pubs in Ireland on a Saturday night and at some point in the night someone will make a joke about AIDS. “Your woman won’t go out on a date with me; you’d swear I had AIDS or something.” Lack of HIV education has led to widespread ignorance on the subject. Ignorance manifests as fear, which feeds stigmatising attitudes.

An official involved in drug seizures at an Irish airport, was recently heard talking about his job. He said the money just wasn’t worth it as he has to “deal with people with AIDS and all sorts”. This stigmatising attitude isn’t his fault. He has never been provided with information on the virus, how it is transmitted or how many people are vulnerable to HIV infection. To add to this ignorance, there are still many Irish people who believe misconceptions that the virus can be passed through kissing, toilet seats, sharing cups, etc.

It takes courage not only to accept an HIV-positive diagnosis but to talk about it and help to make people aware of the risks. If HIV was discussed more openly and more public awareness was promoted, then stigma and discrimination would slowly start to diminish. Ireland has to find the courage to accept this change.

A new public awareness campaign on HIV is sorely needed. Some young Irish people were recently asked if they had ever come across an HIV campaign but not one person could answer ‘yes’. There was an HIV campaign at the 2005 Eurovision Song Contest, but no one seems to remember this. To transform attitudes and understanding of HIV a comprehensive campaign will need to last longer than one day.

Involving PLHIV in prevention education appears to be very effective and is also an important means of breaking down the deep-rooted stigma associated with the disease. Nothing hits home more than meeting someone living with HIV and learning from their experiences.

‘It could be you’ is a message that really needs to be spread, not only in Ireland, but worldwide.

Discrimination – the evil twin of stigma

Key Correspondent Team

Pull Quote

Asking questions to people who are vulnerable is much more challenging than asking questions of the broader community

The words stigma and discrimination are often heard together. Is there a way to separate these conjoined twins and look at them individually?

Almost one in ten of the 10,000 abstracts at the International AIDS Conference in Toronto had the word ‘stigma’ in it. But what new findings were presented? There were two major presentations on stigma in Toronto that had similar findings. One was from Botswana, a southern African country with very high HIV prevalence. The other was from Thailand, an Asian country with some of the highest HIV rates in the region, though these rates are much lower than those in most countries in Africa.

Both studies looked at stigmatising attitudes in large numbers of adults in the community. They found that stigma was highest among people who did not know about antiretroviral (ARV) drugs and lowest among people who knew about ARVs. The researchers could not be sure that it was low knowledge about ARVs that caused people to stigmatise others; although the researchers from Botswana thought that it was. The researchers from Thailand decided to conduct an educational intervention to see if knowledge about ARVs would decrease stigma.

So will stigma decrease as ARVs roll out and coverage of ARVs increases? Who knows? Repeating the Botswana study in a few years would be one way to find out. Increases in human rights abuses due to the ‘Botswana model’ of ‘opt out’ testing may negate any positive changes that come from treatment roll-out. But universal access to prevention and treatment is highly unlikely to entirely eliminate stigma and associated discrimination against people living with HIV. It is also difficult to see how it will decrease stigma and discrimination against people who are vulnerable to HIV such as sex workers, injection drug users and men who have sex with men.

Levels of stigma are often studied. Braver researchers measure levels of discrimination. What is the difference? It is easy to measure stigma as all you have to do is ask questions in the community. But to measure discrimination you have to ask questions to people who experience the discrimination – HIV positive and negative. And asking questions to people who are vulnerable is much more challenging than asking questions of the broader community.

There were few papers presented in Toronto that looked at levels of discrimination actually experienced by people vulnerable to HIV or living with HIV. This is surely an area which deserves much greater attention.

Stigma as a barrier to prevention, treatment, care and support

Stigma rife in Uganda's schools

Alege Stephen Galla, Uganda

Pull Quote

A lot of effort and innovation has been put into the national HIV response; little, if anything, has been done about tackling stigma in schools

It is mid morning and the African sun is unleashing its full heat on the Ugandan capital, Kampala. Over 100 HIV stakeholders have gathered in a small conference hall to witness the launch of the annual HIV status report. Judging from the face of the presenter Dr Kihumuro Apulli, director general of the Uganda AIDS Commission, one can tell that all is not well. The prevalence of HIV has stagnated at 6.4 per cent for the fifth year running. This is low compared to the epidemic Uganda was facing just ten or so years ago, but hopes that the decline in HIV levels would continue have been dashed, for now at least.

However, in the midst of relative gloom some good news brings some relief to the uncomfortably warm conference hall. In the last year Uganda has scaled up antiretroviral (ARV) treatment almost four-fold from 10% to 56% of those in need of the drugs. The lives of many PLHIV have drastically improved.

"I have been on treatment for the past sixteen years and I have over the years seen my friends and family members access free treatment and live a better quality of life . . . we have at least made some progress here," exclaims Joyce, an HIV-positive mother.

What is missing from this picture, however, is the stigma and discrimination still suffered by PLHIV in Uganda, regardless of whether they have been granted access to treatment.

Joyce has a twelve-year-old son. John[4] has twice returned from boarding school this term and threatened not to go back.

"He first refused to take his medication to school at the beginning of the second school term. I asked him why and he simply said he didn't need it. I begged him to take them and after a lot of pleading he obliged," Joyce says with her voice almost breaking.

Towards the end of the term he fell seriously ill. As a friend went through his school trunk to pack some of his personal items to return home, he found the medication untouched. When Joyce found out, she asked John why he had not taken his pills. It was then that John confessed that he had not wanted his peers to see him take his medicine as

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[4] Not his real name

they were already making comments that his mother (whom they regularly see on television) has ‘slime’ – a local word for HIV.

Stigmatisation often leads to discrimination, which refers to any form of distinction, exclusion, or restriction affecting a person by virtue of a personal characteristic – in this case living with HIV. In many schools in Uganda, ARVs are referred to as ‘drugs that make PLHIV grow fat like pigs’ or ‘Genetically Modified Medicines’ (GMMs), in reference to their ability to improve the health of PLHIV.

John is just one of the many HIV-positive youth who live with the reality of stigma and discrimination on a day-to-day basis at school. While a lot of effort and innovation has been put into the national HIV response, little, if anything, has been done about tackling stigma in schools.

The problem of HIV stigma doesn’t originate from students alone. Teachers are equally ill-prepared to deal with HIV-positive students and the reactions of others. “If you tell them [teachers] the sero-status of the child they quickly go and tell their colleagues, who soon leak it to the students,” says Joyce.

However, Jacob, a head teacher at a private secondary school, criticises parents who do not disclose the positive sero-status of their children to the school administration. “We can’t support them because we have no clue whether the allegations being made by other students are true or not,” says Jacob. However, Joyce is adamant that once the administration learns that a child is HIV positive they start giving them preferential treatment, which in turn generates interest and curiosity from other students. This positive discrimination, she argues, reinforces stigma in the child.

For young people, being known to be HIV positive will earn you a stigmatising nickname, isolation and rejection by peers. In many instances, ignorance, fear and inadequate understanding of the modes of HIV transmission reinforce HIV-related stigma. To a lesser extent people still associate HIV with sexual ‘perversion’ and some believe the disease is a punishment for shameful behaviour.

However, it is inaccurate to see misconceptions and judgemental attitudes as the sole causes of HIV stigma and discrimination in schools. After all, over 90% percent of students in primary and secondary schools can invariably recite the modes of HIV transmission. A significant additional factor is the failure to address needs and concerns of young people living with HIV. Most interventions in the areas of treatment and care focus almost entirely on the very young or adults – adolescents have been almost entirely left out. This has created fertile ground for some of the worst forms of stigma and discrimination.

Stigma may not be present at an institutional level, where young PLHIV are denied admission to schools based on their positive sero-status. But parents with HIV positive school children are increasingly opting for day schools to avoid the vicious stigma and discrimination of the boarding schools. However, with numbers of young PLHIV increasing every year this is an issue that has to be addressed head-on. Unless national actors dedicate time and resources to address it, HIV-related stigma and discrimination (as they manifest in the school environment) will only get worse.

Young PLHIV need to be empowered so that they are able to challenge the discrimination and stigma that they meet in school. Institutional and other monitoring mechanisms can enforce the rights of young PLHIV and provide a powerful means of mitigating the worst effects of discrimination and stigma in schools. However, it is worth noting that school and national policies alone, or even laws, cannot combat this form of stigma.

A more enabling environment needs to be created to increase the visibility and perception of young PLHIV as a 'normal' part of society. We need to challenge and end fear-based messages and the biased social attitudes they generate, so as to reduce the discrimination and stigma of our young PLHIV.

Stigmatising VCT?

Masimba Biriwasha, Zimbabwe

Pull Quote

Stigma is secretive, subversive and operates in silence, undermining many efforts that have been made to fight the epidemic

Most people in Zimbabwe are reluctant to access voluntary counselling and testing (VCT) services because of fear of stigma and the implications of death often associated with a positive diagnosis. This, despite the fact that VCT has long been recognised as an important entry point that enables people infected with HIV to live positively and access appropriate services and support. The non-availability of treatment options has only worsened the culture of silence and secrecy around the disease by providing a further disincentive to test or reveal HIV status.

Stigma is secretive, subversive and operates in silence, undermining many efforts that have been made to fight the epidemic. It undermines prevention and care strategies and increases the devastating impact of the epidemic.

Speaking at the XVI International AIDS Conference in Toronto, Anand Grover, Director of the Lawyers Collective HIV/AIDS Unit (LCHAU) in India said: “The real challenge is to control stigma within the communities and within the individuals. We should focus our energies on that. What we need is a massive investment in programmes to destigmatise HIV and make people living with HIV acceptable in society.”

Despite high levels of awareness and knowledge of HIV and AIDS, the disease remains highly stigmatised in Zimbabwe. People’s lived experience of AIDS consists mainly of pain, isolation and death, which in turn evoke feelings of hopelessness. Consequently, there is tremendous fear and reluctance around being tested for HIV.

To make matters worse, voluntary counselling and testing centres in the country are not available in rural areas where 70 percent of the population resides. The vast majority prefer to remain under the cloud of ignorance and denial, and only get tested when they are seriously ill.

Often people living with HIV are perceived as having done something wrong, something which they and their families should be ashamed of. Most people are therefore unwilling to face the feelings of degradation that accompany knowledge of HIV status.

There’s no assurance that the consequences of undergoing HIV testing will not be discrimination, particularly in the underserved rural communities where neither VCT nor health facilities exist.

The widespread lack of HIV care and other support services has further compounded the situation, forcing most people to opt out of being tested for HIV at all.

Even in recent years, when a sizeable number of PLHIV have opened up about their status, stigma remains and tends to prevent them from receiving adequate care and treatment.

The Eden Home Health Centre in Zimbabwe has surveyed HIV-related stigma and discrimination in communal farming communities and found that community leaders, chiefs, headmen, and others are frequently making discriminatory statements, even during their graveside messages at funerals. The centre stresses the need for HIV education (in local languages) targeting traditional leaders in remote areas.

It appears that people already carry their own notions of stigma and fears that inhibit them from testing for HIV, even though VCT is an important entry point for the prevention, care, and support continuum.

There’s a great need for VCT to address the local manifestation of stigma and for the process to promote love and understanding for those infected and affected by HIV.

Sex workers labelled by stigma

Chilombo Mwondela, Namibia

Pull Quote

Evidently, in many parts of the world, the stigma against sex workers is stronger than HIV

“If you turn your back against sex workers, you are turning your back on the mother of four children,” said Melinda Gates, who, together with her husband, software mega-tycoon Bill Gates, has just contributed through their foundation, over US$500 million to the Global Fund to fight AIDS, tuberculosis and malaria.

Speaking at the opening ceremony of the International AIDS Conference in Toronto, Mrs Gates made a plea to non-governmental organisations and government bodies to recognise the powerful position held by sex workers in the fight against HIV and AIDS. She said they were the sexual partners of many married men, and are themselves mothers in turn.

Sex workers taking part in the AIDS conference lauded Melinda’s efforts, and hoped the label of ‘untouchables’ could gradually be removed from sex workers. They confirmed that stigma acted as a barrier to accessing HIV treatment, education, and care when they fell sick.

“A sex worker is seen as the carrier of every bad disease including AIDS. The stigma is not only mine: it is extended to my children, my parents, my whole family. It is very important that sex workers find the strength to fight for themselves because they are the ones who understand their issues,” said Awa Dambili from Mali.

“However, if people could work with us to help with education on these issues, a lot could be achieved.”

Mali’s constitution is silent on sex work. There is no specific mention in the statutes. Dambili has been a sex worker for more than 10 years and says it is easier for her to lead the sex workers’ organisation in Mali because she is a foreigner, originally from Burkina Faso.

“I have no family here and so I am a bit lucky. But you do not know how many women I and my friends have had to bury because their families had rejected them and pronounced them dead – while they were still alive,” she said.

“If people know that you’re a sex worker, your children are discriminated against and they end up leaving school due to the shame. Then they also often end up as sex workers.”

Dambili said stigma against AIDS and sex workers was deeply rooted in religion and traditional beliefs and it would take many years for sex workers to achieve acceptance by society.

“Religion is so heavy, we are called dirty, unclean. When you are sick no one can touch you – in our Muslim cultures they would also automatically become unclean.”

Nevertheless, *Danaya So* (House of Confidence), the sex workers’ organisation formed by Dambili and her friends, has gradually managed to gather support from government and other international organisations.

“We are included in national holiday celebrations organised by the government and we take part in marches organised for international women’s day.” In the old days, sex workers were afraid to go to hospital when they fell sick but many of them now stand up and tell the nurses that they have a right to treatment as citizens. Because many of these women have not been to school, they were unsure of themselves and suffered from serious self-stigma, hiding from everyone and coming out only under cover of darkness.

“The organisation has helped us and our children to find the courage to rejoin life and fight for equal treatment in medical care or education. Now, we can even teach our children to fight back,” she said.

On the other side of the world, sex workers in Thailand, where prostitution is criminalised but widely tolerated, have to make use of the Entertainment Act, a law that allows masseuses and other workers in the entertainment trade to work under police license. The Act requires that all entertainment places be registered with the police. Workers have their details recorded on a charge sheet at the police station, are fingerprinted, and officially registered as *nang bam luer* (of no consequence).

Philai Srikumzaw from Thailand pointed to the golden chip embedded into her national identity card by the Thai authorities.

“You see this card, which I took to the police to be registered, it has branded me a reject in society. I need the card to gain access to many things including travel. But immediately it is passed through the machine, the school where I want to take my child will know that I am a sex worker and the headmaster will give me dirty looks. My child will not have an easy time at school. When I have to travel to another province my profession will show up on the computer again and the officer will give me a second look. We are the only workers who have to report to the police instead of the labour office for registration, that adds up to enforcing stigma, and it is an official requirement.”

According to Melinda Gates, stigma has diminished the strength of the fight against AIDS, and as Dambili and Philai reveal, its tentacles have stretched to include future generations as many children borne by sex workers may be condemned to also work in the sex trade. Evidently, in many parts of the world, the stigma against sex workers is stronger than HIV.

Treatment denied . . .

Chilombo Mwondela, Namibia

Pull Quote

Pledges made more than two years ago by the richer countries, including the United States, are yet to be realised

“Treatment delayed is treatment denied,” said Dr Kevin Cooke, speaking at the XVI International AIDS Conference in Toronto, at a session entitled ‘Access to Treatment: People before Trade.’ The session revealed that Africa accounts for 70 per cent of the world’s unmet need for HIV treatment.

The practice of governments in Africa and around the world to ignore the need for relevant health services for Africans, especially HIV treatment, on the excuse of ‘budgetary constraints’ was severely condemned by various speakers during the conference.

The conference revealed that the price of antiretroviral drugs (ARVs) was a major barrier restricting access to treatment for many Africans whose countries could not afford the treatment without help from bilateral partners.

Adding their voice to the debate in a written statement, the Africa Civil Society Coalition on HIV and AIDS warned that unless specific African targets for universal access to treatment were acted upon, the continent would not reach its treatment goals by the year 2010.

“The deliberate lack of awareness on the African people’s direct need for immediate full scale prevention and treatment strategies has fuelled the stigma and the hopelessness of the AIDS situation in Africa, condemning millions of people to deaths that could be avoided if only their own governments and donors had the political will to fight the disease,” said Dr Ijike Fonke from Nigeria.

According to a statement from the African coalition, “ although the UNGASS[5] political declaration recognised the renewed commitment by African governments and regional

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[5] Declaration of the UN General Assembly Special Session on HIV/AIDS, New York, June 2001

institutions to scale up their own HIV/AIDS responses, as contained in the Abuja document, it did not commit to supporting them to meet the targets".

Pledges made more than two years ago by the world's richer countries, including the United States, are yet to be realised, pointed out the coalition.

According to Dr Peter Piot of UNAIDS at a separate press briefing, global agreements on what needed to be done already exist and it is up to governments to act quickly and decisively.

"We live in a world that must be changed to survive . . . Prevention alongside treatment is the way to go," he said.

Among the prevention strategies cited by experts are scientific as well as social methods, meant to fight the pandemic in a two-pronged approach. Experts seeking to change stigmatising attitudes towards HIV in order to facilitate treatment initiatives, also realise the equal need of continued research for a vaccine to control the disease.

Laura Nyblade, director of HIV programmes at the International Centre for Research on Women (ICRW), believes there is no reason for excuses and inaction on prevention of stigma as a barrier to access to treatment for HIV-positive people.

"We need studies to examine the relationships between reducing the stigma of HIV and AIDS and the uptake of HIV services," she said.

Nyblade insisted that HIV stigma could be reduced through practical anti-stigma tools and measurement of responses and strategies.

She said stigma was universal across the globe and there was need to build capacity among leaders, involve groups experiencing stigma, and target the media, police, and health workers in drafting national plans for universal access that would fight stigma and ensure prevention and treatment access for people affected and infected with HIV.

Despair feeds stigma

Chilombo Mwondela-Katukula, Namibia

Pull Quote

Be it in prevention or treatment of the disease, there is a tangible fatigue creeping into the AIDS effort

Frustrations in the search for an end to HIV may end up fuelling stigma attached to the disease when leading figures give public statements of despair.

“We are not going to find a vaccine for HIV . . . there will never be an AIDS vaccine,” lamented New York-based National AIDS Treatment Action Project, Jules Levin in a statement to United Press International at the International AIDS Conference (IAC) in Toronto.

Laura Nyblade of the International Centre for Research on Women (ICRW), said the world probably had to accept that stigma would never go away. It was almost a call to give up the fight against stigma, which pervades the struggle against HIV and paralyses every effort against the disease.

Stigma is what made the above statements possible.

Be it in prevention or treatment of the disease, there is a tangible fatigue creeping into the AIDS effort – as was apparent in concluding remarks at the IAC, when speaker after speaker mentioned the lack of a foreseeable end to HIV.

“This conference *cannot* be deemed a success unless we collectively realise our theme of *Time to Deliver*. Indeed we will have failed unless we rapidly and dramatically expand by millions the numbers of people around the world with access to antiretroviral drugs. Clearly progress *cannot* be achieved if more people continue to become infected by HIV each year than the numbers that are able to access treatment,” said Dr Mark Wainberg, conference co-chair.

“Gender inequality is driving the pandemic, and we will *never* subdue the gruesome force of AIDS until the rights of women become paramount in the struggle,” said UN special envoy for AIDS in Africa, Stephen Lewis.

“It is the one area of HIV and AIDS which leaves me feeling most helpless and most enraged,” he added.

He also said not enough was being done to prevent mother-to-child (MTC) transmission.

“It is a bitter indictment that so few HIV-positive women have access to antiretroviral drugs that would prevent MTC HIV transmission,” adding, “It is inexcusable to continue to use single-dose nevirapine rather than full triple-dose therapy during pregnancy as we do in Western countries”.

Why the discrepancies in the administration of HIV treatment? Is it not the ugly head of stigma preventing developing nations from accessing benefits accorded to so-called developed nations. Why should a woman in the developing world qualify for only one dose of nevirapine when it is known that this will not be adequate?

In southern Africa, where stigma is at its highest according to findings of several studies including those done by the ICRW, the focus in the fight against stigma has shifted heavily towards women, even though the rest of society is equally affected. There are few HIV prevention and gender sensitisation programmes being specifically targeted towards men, an unfortunate situation in view of the fact that both sexes are equal prey to HIV.

In a study examining the media coverage of HIV in six countries in southern Africa and Asia, the International Federation of Journalists (IFJ), found that "the key story of our time is not getting the coverage it deserves". Again the question is, why?

There are several reasons advanced as to the paucity of media attention given to HIV in the developing world but the simplest answer might be that the pandemic is being ignored as a hopeless case.

HIV is an ongoing crisis that does not seem to have an end. Access to treatment is still not a reality and in many places HIV is perceived as a death sentence. According to Busi Mhlele, a South African journalist, "There is no end to AIDS and what it can do. It is a terrible thing . . . just like death. That is why people do not want to talk about it all the time".

There it is – it is "just like death". This is the reason why it is being relegated to a non-topic, much like speaking about people on death row – they are going to die, there is no reprieve. Therein lies the stigma. Just as death is abhorred and feared in southern Africa, so is AIDS. .

The challenge is to reduce the monumental proportions that AIDS has acquired in the minds of millions to that of a mere disease that can be fought and overcome with combined effort.

Stephen Lewis pointed out that stigma had seriously stalled the work against HIV. He admitted that even though there had been many HIV prevention strategies agreed to internationally over the years, little progress had been made. "There were no new discoveries at this conference. We only realised that we need to implement and strengthen the strategies that are on paper," he stated.

Among those prevention and treatment strategies is the fight against stigma. To give up on stigma, even an inch, is to give in to AIDS, and that is something that mankind in the 21st century cannot afford to do.

Whispering from the back of the ward

Niparueradee Pinyajeerapat, Thailand

Pull Quote

Many PLHIV experience stigma and discrimination in the very place where people should be most informed about it: health care settings

Some say that if people had enough knowledge about HIV, they would not stigmatise or discriminate against people living with HIV (PLHIV). But many PLHIV experience stigma and discrimination in the very place where people should be most informed about it: health care settings.

Aunt Jit, a fifty-five-year-old lady who lives in a big city in southern Thailand has suffered regular stigma and discrimination in the government hospital where she receives treatment and she would like to speak out on behalf of all PLHIV who have had such experiences.

Aunt Jit contracted HIV from her husband and learned about her status after he passed away. She soon became jobless and found people distancing themselves from her once they knew she was infected. She survives day by day collecting cans and bottles from trash and lives in a small abandoned house with her five-year-old granddaughter.

Every month she has to go to the hospital for antiretroviral (ARV) treatment where her poor treatment by the hospital staff runs from the admitting office all the way to the ward. She is frequently scolded and humiliated –an experience shared by many other patients. PLHIV are always served last, as the nurses and doctors are afraid that they will infect other patients. They are treated like they are dirty and contagious and the doctors and nurses put on masks and gloves to examine or treat them, unlike other patients.

She explained that in general Thai people think that women who are HIV positive are promiscuous or are sex workers and do not deserve any respect.

Recently, a close friend of hers died of AIDS at the hospital, very soon after admission. With the treatment available at the hospital, her friend should have survived for much longer, she asserted. She believes that the depressing condition of the AIDS patient ward hastened her friend’s death.

She described the AIDS patients as being separated from other patients and put at the end of the room, near the toilet. Other patients make pitying faces and look down at them. “These conditions caused my friend to die faster not the disease itself” said Aunt Jit.

Since her friend passed away Aunt Jit has no one to share her intimate thoughts with. At her hospital, there is no counselling or other support for PLHIV. The increase in the number of AIDS patients (to about 500 today) has discouraged the hospital from providing day care. They receive their ARVs and then go home.

The PLHIV group that she recently joined has given her some hope for the improvement of hospital services, including support for her psychosocial needs. In response to complaints about the poor services offered by this hospital, the group plans to approach and work with the hospital to improve the quality of care and treatment for PLHIV.

There is also lots of work for the group to do within the community to reduce stigma and discrimination toward PLHIV. The HIV advocacy and support network in southern Thailand lags behind that in the north and northeast of the country, but it is improving fast. The group has a long way to go to improve the quality of life for PLHIV, but it is the only hope that they can hold on to. They should be treated equitably, without stigma and discrimination, and they will fight for their right to dignity.

Stigma as a barrier to universal access in Thailand

Niparueradee Pinyajeerapat, Thailand

Pull Quote

The unwillingness of the government to respond adequately to HIV is a form of stigma that will have a tremendous impact on the delivery of universal access

Thailand is often seen as a model of good prevention and control of HIV. However, HIV-related stigma is creating some serious issues around the coverage of HIV-related services for the most vulnerable groups in Thailand. At the International AIDS Conference in Toronto, the lack of supportive services for marginalised and vulnerable groups was raised repeatedly. These groups, including men who have sex with men (MSM), drug users, sex workers, migrants, women and children are among those most likely to be stigmatised, in Thailand and elsewhere. Stigma and discrimination act as a serious barrier to access of services and have thus been recognised as a significant impediment to achieving universal access.

Reviewing the opinions of conference delegates from Thailand, we can build a picture of HIV stigma and how it might be a barrier to achieving universal access in the country.

According to Thai delegates, stigma in the health care setting is still prevalent. Many women living with HIV experience discrimination in this setting, where they are stigmatised as sex workers, drug users or promiscuous women who do not deserve respect and dignity. There are some initiatives by networks of people living with HIV (PLHIV) to work with hospitals to address issues of access to treatment and services as well as to increase community acceptance of HIV; still the stigma has not gone away.

Fear of HIV infection and misconceptions about infection control lead health care professionals to discriminate against their HIV-positive patients, especially those of low social status. The human rights of PLHIV are often violated in the health setting because of their status. For example, HIV-positive women who are pregnant have been threatened, in some cases, with a removal of their antiretroviral (ARV) treatment if they continue their pregnancy to term. Other PLHIV have been refused treatment if they smoke, drink alcohol, or use drugs. Such discrimination would not have happened if they had been HIV negative.

Stigma in the health care setting needs to be seriously addressed if we are to achieve universal access. Both health care professionals and the general public should be engaged in educational efforts to reduce HIV stigma.

Marginalised groups are particularly vulnerable to stigma and discrimination. Sex workers and injection drug users (IDUs) are criminalised for their acts. In Thailand the Prostitute Act and the war on drugs have driven many underground where they cannot access prevention or treatment services. The children of sex workers and IDUs are particularly vulnerable to HIV and mother-to-child transmission is an issue of great concern. MSM are another group who are judged for their 'deviant' sexual behavior and there are very few health clinics that provide specific services for them.

Children with HIV are viewed as sick and incapable of survival and development. HIV positive youth are condemned as those who will spread the disease when they grow up. Their right to information is violated, especially when it comes to sexual health education. Thai society and policy-makers are reluctant to provide sex education and condoms openly. As the controversy continues the number of new infections among young people increases.

Pediatric care and treatment services and facilities are very limited in Thailand. There are too few pediatricians and nurses to care for HIV-positive children. Children living with HIV are also not covered for HIV care and treatment under national health care insurance (30 baht scheme). Only 10 percent of children in need of treatment have access to ARVs.

Mobile populations, especially foreign migrant workers, 3 million of whom are estimated to live in Thailand, have poor access to HIV prevention, care and treatment services because of their citizenship status and language barriers. Migrants are able to access health check-ups and basic care, but if they are infected, they are not eligible for ARV treatment. Human rights advocacy for this population is not easy in the face of political unwillingness and national security concerns.

Government HIV policy needs to be reviewed in the light of persistent stigma and discrimination. Thailand has a sound national AIDS plan developed with the joint cooperation of government agencies, community-based organisations (CBOs), non-government organisations (NGOs), PLHIV and civil society. The work of NGOs and PLHIV networks in advocacy for ARV treatment to be included in the 30 baht health insurance scheme has shown significant achievements. However, the national AIDS plan is jeopardised by the downsizing of funds. Last year the government gave around 3.6 billion baht for HIV prevention and control and this year the budget went down to 1.3 billion baht. Consequently, CBOs and NGOs in particular lack sufficient funding to support their work at the community level where most emphasis on prevention, care and support for HIV should be placed.

The future funding of national AIDS prevention and control is unpredictable. In addition, health care reform and decentralisation policies are disrupting the implementation of HIV programmes because the structures and mechanisms of health care service delivery and human resource/funding allocation have been changed. HIV prevention and control is dependent on the commitment of leaders through national policies and budgets.

The unwillingness of the government to respond adequately to HIV is a form of stigma that will have a tremendous impact on delivery of universal access. Thailand now has about 580,000 PLHIV and over half of those in need of ARVs do not have access to treatment. It is time that HIV was included in the national agenda and stigma removed at all levels, otherwise Thailand will never achieve universal access.

Approaches to addressing HIV-related stigma

Sport combats stigma and discrimination

Masimba Biriwasha, Zimbabwe

Pull Quote

"Sport, physical activity and play are low cost, effective tools to reach young people with key prevention methods about HIV and AIDS"

In 1994, Safari Gasisa, now 29, spent a month in the cellar of his neighbour's house hiding from the genocide that raged like wildfire across his native country of Rwanda. Through a stroke of fate, he escaped to the Democratic Republic of Congo where he started playing basketball as a pastime.

When the conflict ended, Safari moved back to his country. Instead of wallowing in despair, in 2002, he joined 'Right to Play', a programme that utilises sport to reach out to the most vulnerable populations in 23 countries around the world. Safari's responsibility was to teach children displaced by war about sport.

"I chose to teach children sport because of my own life experience. Sport helped me to overcome my trauma. It helped me to find new friends, and overcome the pain of the war," said Safari in an interview at the XVI International AIDS Conference.

Through sport, the 'Right to Play' programme works to educate vulnerable populations about HIV. The programme blends fun and education to equip children with HIV messages aimed at transforming values and attitudes that promote stigma. Because of its inclusive nature, sport can encourage open discussions, dispelling myths and breaking down the stigma that surrounds the illness.

Using physical activity and active discussion, children and youth are engaged in the development of key knowledge, attitudes and skills that promote better awareness of the disease.

'Right to Play' also builds soccer fields, basketball courts, and supplies balls and materials to disadvantaged children. Among the benefits of the athletic activities and team sports for children are reduced idle time and boredom, increasing feelings of self-worth and belonging, and connectivity with peers and adult role models.

"Many of the children that I am working with have been traumatised by the war in Congo. They have no information about HIV and AIDS at all," said Sarafi. "But we now discuss a lot about HIV and AIDS through the sports and games that we have with the children."

More than 12 million children in sub-Saharan Africa have lost one or both parents to AIDS, making them especially vulnerable to disease, malnutrition, neglect, and loss of education opportunities. Yet most HIV 'interventions' for this group only exist at the pilot stage and target just a few children.

Given the gravity of the HIV pandemic, there is a clear need for a more broad-based approach that can empower millions of children with much needed psychosocial support. Children's love for sport and fun can be harnessed to teach them about ways to fight stigma and discrimination.

Leading experts in health education and sport announced at the conference the need to scale up the use of sport in the fight against HIV

"Sport, physical activity and play are low cost, effective tools to reach young people with key prevention methods about HIV and AIDS," said Dr Bruce Kidd, dean of the University of Toronto's Faculty of Physical Education, and chair of the International Development through Sport Advisory Committee of the Commonwealth Games, Canada.

Breaking the silence surrounding HIV and promoting open discussion are key to addressing stigma and discrimination. Sport can play a significant role in identifying and changing harmful attitudes that promote stigma. It can increase the confidence of children infected and affected by the disease, and in the process help to minimise the fear, silence and denial associated with HIV. It promotes love, tolerance and understanding – integral components in the response to HIV.

Sport as a tool for development is increasingly gaining global recognition as an inexpensive, effective way to reach the most vulnerable populations. 'Right to Play' is using the power of sport to reduce the incidence of HIV by increasing knowledge and changing attitudes of people affected by the disease.

Building bridges, not digging holes

Masimba Biriwasha, Zimbabwe

Pull Quote

Disclosure is a valuable tool in achieving acceptance and reducing discrimination

Zvimba, Zimbabwe – In Zimbabwe, as in many other countries in the region, women’s vulnerability is often compounded by the stigma and discrimination they face once their HIV status is revealed. Women who admit to having HIV risk social exclusion and abandonment. Yet disclosure is a valuable tool in achieving acceptance and reducing discrimination.

When Floritah Chiradza, 40, found out that she was HIV positive, she began putting together a death wish list. She felt so depressed and isolated that her memory deteriorated and she couldn’t remember anything.

“I went through a hard time because I couldn’t accept my status,” she said. “I felt silent stigma, where people sideline you without openly telling you. I don’t think people realise they are stigmatising you. Maybe people think they are caring for you but in reality it’s stigma at work.”

Her husband abandoned her, leaving her with a six-month-old baby. He only returned after a year and a half when he was too sick to take care of himself. Floritah looked after him until he passed away.

According to UNAIDS, HIV-related stigma and discrimination is a ‘process of devaluation’ of people either living with or associated with HIV. Actions that emerge from stigmatising attitudes tend to be subtle, and efforts to combat it have been impeded by a lack of tools and tested interventions. Women living with HIV often find themselves either receiving too much or unwelcome attention within the family and larger community. As a result they lose power, respect and identity through the taking away or diminishing, of their roles, responsibilities and social standing.

After she openly disclosed her status, Floritah noticed that people around her began to express untoward sympathy towards her. At home, Floritah’s mother couldn’t come to terms with the fact that her daughter was HIV positive. So she preferred to tell relatives and friends that her daughter was suffering from something else. Floritah’s workmates began to isolate her by taking away some of her responsibilities at work.

“Stigma is something that I really went through. In most cases, people don’t admit stigmatising you, nor do they think they are discriminating against you, but some of the things they do show you that stigma and discrimination are real,” said Floritah.

Disclosure can cause an increase in stigma and discrimination, but it is also, paradoxically, an essential step in fighting stigma and discrimination. Before Floritah disclosed her status, people accepted her even when she fell ill, but things drastically changed after her disclosure.

“I didn’t get it easy with my family, particularly my mother. She just couldn’t accept that I was HIV positive. She would not allow me to do any tasks, preferring to keep me redundant,” said Floritah.

But Floritah did not give up. She began taking steps to seek information on how to live positively with HIV – a journey that took her to several support groups for people living with HIV. At her workplace, she felt isolated, but disclosure began the healing process for her.

“I found comfort in talking to people. I realised that I have to talk to people to pull through. So I started talking to my sisters, and my mother, though she could not take it. My mother is one person who made me stand bold and talk about my status because I was trying to convince her that she had to accept me as I was,” she said

“Coming out and sharing with friends is the biggest healer. I must say that people who are living positively must be busy building bridges with various societies, rather than digging holes around themselves. Because if you take the digging holes attitude, honestly, you won’t make it. But you have to reach out to people instead of waiting for people to come and help you,” she said

Floritah added that a good health care system is an essential ingredient in the fight against stigma and discrimination. A system that puts people first is essential to fighting stigma and discrimination, especially self-stigma. For Floritah, having a caring physician who supported her with love and understanding was essential in helping her to cope with the disease.

“It’s an ingredient that cannot be done without. My doctor was very encouraging. She helped me in the healing process by telling me to access alternative medication as well as to openly talk about my status,” she said.

Floritah said that people tend not to access information because they do not want to talk about the disease due to stigma and discrimination.

“If we can treat HIV and AIDS as any other condition, like diabetes or high blood pressure, everyone will be informed and infection will decline. We need to tame the jungle together,” she said.

Politics, economics and HIV in Southern Africa

Chilombo Mwondela Katukula, Namibia

Pull Quote

> “Thousands of dollars that could be spent building clinics or schools are instead spent on by-elections . . .”

The stigma attached to HIV and AIDS has cost the southern African region millions of lost dollars in by-elections and other ad hoc governance manoeuvres caused by the high death rate of leaders and voters in the 30- to 50-year age group.

According to an 11-country study done by IDASA, the Institute for Democracy in South Africa, HIV has the potential to undermine democracy and good governance. The study recognised that the lack of action by leaders in the region to disclose or accept their HIV status and act accordingly is a result of the stigma attached to the disease.

Kondwani Chirambo, IDASA programme manager in charge of HIV and AIDS for Southern Africa, pointed to results of the study that revealed how southern African countries had suffered huge monetary losses through the concurrent deaths of political leaders.

“By-elections cost money. Our studies show that members of parliament (MPs) in the region are dying at an age when they should be at the peak of their healthy lives and political careers. Ten years ago, you could have one or two people dying in a decade and even then, it was because of old age and related ailments. Today, there are countries that have lost more than 50 MPs in ten years, almost five per year; it is not normal and it is very expensive for the countries concerned.”

“Thousands of dollars that could be spent building clinics or schools are instead spent on by-elections that governments can ill afford,” he said.

Doreen Mukwena, Programme Coordinator on gender and HIV from Oxfam Australia in Zimbabwe, adds that the stigma placed on HIV has contributed to the non-development of an effective official strategy against the pandemic.

“We have to confront stigma as one of the key issues that prevent community mobilisation and participation in caring for people faced with and living with HIV and AIDS,” she said.

It is also clear that countries that have instituted a stronger HIV support network are recording lesser deaths among leaders and are showing increasing signs of stability in their political systems.

Hester Musandu, the director of country programmes for the Southern African AIDS Trust, believes that local political and economic conditions affect national budgets and targeted goals of governments.

“It is hard to implement programmes in countries that are politically or economically unstable, lack the requisite infrastructure and are generally unfocused in their fight against HIV. Policies need implementation for the general population to benefit," she said.

Giving an example of a country focused on the fight against AIDS, an officer from the Global Fund attending the 16th International AIDS Conference in Toronto praised Namibia as a model for southern Africa.

"The government has led in placing HIV and AIDS as priority issues to be tackled without holding back in any way. Namibia is a very well performing country with a group of highly performing civil servants," he said.

However, he lamented that the country suffers a lack of indigenous human resources in the medical field to ensure universal access and this forces reliance on foreign expertise for medical and related services. He also pointed out that more money was being poured into treatment than prevention strategies.

According to statistics from IDASA, four million Africans currently need treatment, but less than one million can access it. The report asserts that the sharp increase in mortality of registered voters in the 20-49 year age group (in some cases up to 200 per cent), and particularly women in the 30-39 year age group, can be explained by HIV and AIDS.

"Political party support bases are likely to be affected by shrinking voter pools, especially in high prevalence regions," the study says.

In an interview, Dr Cristina Pimenta from Brazil cautioned that governments should not only look to treatment in the fight against AIDS but also concentrate on prevention strategies that could be implemented sooner, such as programmes to enhance gender equality, HIV education for children, and examining barriers to information on the pandemic.

"Stigma and discrimination should be worked on to create behaviour change that would bring about long-term effects," she said.

A fact sheet from the Global HIV Prevention Working Group, a panel of 50 leading public health experts, reports that "there is evidence that funding for HIV prevention is decreasing in some areas . . . some countries are shifting portions of their HIV budgets to the provision of treatment . . . while others are not investing scarce prevention resources in the interventions that would have the greatest impact".

In South Africa, IDASA reported that political parties have acknowledged that HIV and AIDS have placed considerable strain on party structures by creating an increased need to replace cadres who have succumbed to illness or who have died.

"Voters too ill to cast a vote or people preoccupied with HIV- and AIDS-related demands such as care giving are often disenfranchised. This may have the effect of reducing overall voter participation and aggravating apathy . . . creating challenges for governance, peace and security."

According to Chirambo, southern African governments should make room for the reality of the HIV pandemic in their policies and implement actions that will help behaviour change to stabilise the health of the citizens who are living with or without HIV.

African grandmothers raise a generation of affected children

Swapna Majumdar, India

Pull Quote

Over 300 African grandmothers from 10 countries came from far and wide. They came by foot, by train, by plane.

They came from far and wide. They came by foot, by train and by plane. Over 300 African grandmothers from 10 African countries, came to meet their Canadian counterparts to share their stories of grief and pain over the loss of their children to the HIV epidemic.

In a unique meeting organised by the Stephen Lewis Foundation (SLF) in Toronto, a few days prior to the opening of the International AIDS Conference, African grandmothers broke their silence over how stigma and discrimination undermines their efforts to hold families together and care for orphaned children.

"To be honest, I don't know whether my children have the HIV infection or not. There is so much stigma attached to 'the condition', as it is called in my country, that my children are afraid to know their status," says Joyce Kajechi Gichuana from Nairobi, Kenya.

The soft-spoken, petite 63-year-old mother of three has six grandchildren of her own and has adopted six other children orphaned by the HIV epidemic in Kasarani district, Nairobi, Kenya. Three of these children are HIV positive. "These children are doubly burdened. Not only are they orphans, but they also face stigma and discrimination [associated with HIV]. If they get love and compassion I know they will be able to overcome it."

Joyce is not the only one. Whether it is Martha Nduhi of Kenya, Leah Motlalepulc of South Africa, or Antonia Igres from Tanzania, their stories are strikingly similar.

While statistics on the pandemic's effect on grandmothers are scarce, approximately 13 million children in sub-Saharan Africa have been orphaned by AIDS – a higher number than the total of every child under 18 in Canada, Norway, Sweden, Denmark and Ireland combined. 40 to 60 per cent of these orphans live in grandmother-headed households.

But how many people are aware of these statistics? More importantly, how many really care? Stephen Lewis, the United Nations Secretary-General's special envoy for HIV and AIDS in Africa, realised that unless people living outside Africa experienced the emotional battering that he felt when he saw the bodies of people who had died of AIDS-related illnesses, being abandoned in the morgue by their families would they be able to understand the trauma of HIV-related stigma.

The meeting between the African and Canadian grandmothers was a step towards bridging this gap. "Grandmothers have stepped forward to care for millions of children orphaned by AIDS. They have displayed the courage to overcome their own feelings of helplessness and emotional stress compounded by the stigma surrounding HIV. As caregivers, many of them face discrimination, which makes finding support that much harder. We wanted this meeting to help build a bond of solidarity between the grandmothers and let the African grandmothers know that they were not alone in their grief," says Stephen Lewis.

But even Lewis did not anticipate the overwhelming support the African grandmothers received from their Canadian counterparts during their two-day meeting. The age-old African way of speaking without words broke down all communication barriers. They sang and danced, laughed and wept together. "We were afraid that language barriers would separate us, and our capacity to help might be reduced to fundraising alone. This meeting has broken all barriers. Although I was aware of their problems, I had never got involved in doing something about it. This meeting has given me an opportunity to act as their voice so that I can share their stories and raise awareness about HIV within my community. I believe that awareness can reduce the stigma surrounding the epidemic," contends Jo-Anna Page, a 63-year-old Canadian grandmother.

While exchanges like this help in understanding HIV stigma and discrimination, it will need more than just one meeting to challenge the myths and misconceptions that continue to perpetuate discrimination against people living with HIV (PLHIV). There has to be a sustained multi-pronged effort by non-government organisations like the SLF. But more importantly, there has to be greater political will. Unless national governments demonstrate that they care for every person infected by HIV by implementing laws that reduce stigma and discrimination against PLHIV, it is unlikely that the children of Joyce Gichuana, will ever want to know their status.

Turning men around in the fight against HIV

Swapna Majumdar, India

Pull Quote

It is also about men not being threatened by the empowerment of women but taking the lead role in supporting women in development

In 1990 when Michael Onyango's wife fell ill, he had to take over the household chores. As he cooked and cleaned, he wondered whether his neighbours thought what he was doing was unmanly. It also prompted him to think about whether men could be sensitised into changing their traditional and rigid convictions about masculinity, one of the factors fuelling HIV infection. Thus was born the Movement of Men Against AIDS in Kenya (MMAAK). Within five years of its institution in 2001, MMAAK membership swelled from five members to 3000. "I am convinced that if behavioural change can be brought about, it would promote gender equality. More importantly, it will help to reduce stigma surrounding the infection," said Michael, director, MMAAK. "It will allow more infected persons to come forward for testing and disclosure," he told Swapna Majumdar in an interview at the XVI International AIDS Conference in Toronto.

Q. It is generally believed that HIV positive women, and not men, face stigma. What do you think?

A. Women face stigma because HIV is considered a sexual disease. When a man is infected by a sexually transmitted disease, it is considered normal by society. But when a woman is similarly infected, she is considered promiscuous. Men are also stigmatised but to a lesser degree. Most of the stigma is self-inflicted.

Q. Can you explain what you mean by self-stigma?

A. Positive men inflict stigma on themselves by not opening up once they have discovered their status. They feel they are unwanted and deserve to die. This is particularly true for men who have sex with men (MSM). In Kenya, MSM are widely considered to be abnormal. So they are already stigmatised. Then, when they find out they are positive, they feel everybody is against them. This is why support groups are so necessary. They can dispel these negative feelings and make HIV positive men believe that it is okay to feel vulnerable and it does not take away their masculinity.

Q. How critical is the role of men in the fight against HIV and reducing stigma?

A. Men have a crucial role to play because although women outnumber men in our country, they hold all the positions of power be it religious, political or business. They also own the property. However, these prominent men stigmatise the most. Despite being educated and knowing the modes of HIV transmission, they are afraid to hire HIV-positive people or buy vegetables from a HIV-positive woman.

Q. If the educated stigmatise the most, can education be effective as a tool to reduce stigma?

A. Yes, it can. This is because most of the time these people are not aware of what stigma and discrimination is all about. For example, if I come to your house and you buy new cups for me and ask me to use them instead of giving me the ones you already have, you are discriminating against me. But you may not be doing that intentionally. You may just be trying to protect yourself or trying to protect me from becoming ill.

Q. So how do you think this attitude can be changed?

A. When people living with HIV (PLHIV) take direct control of things they can deal with stigma head on.

Q. How have you dealt with it yourself? Can you share a personal experience?

A. I remember that we had booked rooms in a hotel in Kenya during a conference for PLHIV. When the manager came to know that we were HIV positive, he cancelled our booking. We went to talk to him and held a sensitisation session with him. Then he realised that he had lost good business. After all, business is money and money is not infected.

Q. What is the key to the success of MMAAK?

A. MMAAK is about change. Too many men were suffering in silence. MMAAK gave them a platform to be open about themselves while still being masculine. This is what we call positive masculinity. It is the belief that all men can show, express and utilise their masculinity to support positive change both within and without themselves. It is about men reaching out for help however strong and courageous they may be. It is also about men not being threatened by the empowerment of women but taking the lead role in supporting women in development. I think this is why we have been able to establish MMAAK in five Kenyan provinces and involve a diverse group of men that includes fishermen, commercial wife inheritors (those men who inherit the widow of their male siblings), taxi-drivers and young boys and men in the age group 13-34 years.

Q. Is MMAAK only about men or are women also associated with it?

A. Women are also a part of MMAAK. We have female counsellors and we also counsel women to understand men. Only if men and women understand each other, can there be behavioural change and, consequently, reduced stigma and discrimination.

Discussing the birds and bees

Swapna Majumdar, India

Pull Quote

Countries must shed inhibitions about incorporating information about HIV and AIDS in school curricula

“Good morning, madam HIV”. This is how Margeret Wambete, a teacher living with HIV, was greeted by her students when her status became known at her school in Kenya. So intense was the HIV-related stigma that not only did her students refuse to let her touch their books lest she contaminate them, but parents, too, wanted her to be transferred to another school.

Wambete was sure the principal of her school would support her. But instead of backing her, the principal succumbed to the pressure and assigned her to another school. “I was shattered. I felt humiliated, disrespected and unwanted. I also realised that there was a high degree of stigma and discrimination within the education sector even though it was seen to be more informed and aware than other sectors,” said Wambete speaking at the XVI International AIDS Conference (IAC) held in Toronto.

According to the International Centre for Research on Women (ICRW) HIV stigma is pervasive in communities across the world. The Washington-based organisation, which released findings of its studies at the IAC in Toronto, found that fears regarding transmission of HIV were deeply embedded within all segments of society. More significantly, ICRW research across Tanzania, Ethiopia, Vietnam and Zambia found women endured more stigma than men. “We’ve made important scientific and medical gains in the fight against HIV and AIDS, but we’re lagging in our understanding and ability to cope with the social norms and barriers that contribute to its spread. If we’re to end the AIDS pandemic, we must address AIDS stigma and discrimination,” said Geeta Rao Gupta, president, ICRW.

Wambete also realised that although it wasn’t going to be easy, unless she stood up to fight against the stigma and discrimination, it wasn’t going to stop. Thus was born the Kenya Network of Positive Teachers (KENEPOTE) in 2004. The first forum of HIV+ teachers in Kenya, KENEPOTE inspires teachers to combat the stigma and discrimination arising from disclosure of their status. “KENEPOTE offers hope to those without a voice. It provides alternatives to despair by offering opportunities to make a difference,” said Wambete.

Within two years of its institution, KENEPOTE’s membership has risen from 30 to over 3000. Its success in educating teachers, parents, children and the community has helped to get many teachers reinstated and some teachers transferred to places where they could access care and treatment. Its allies include the Teacher Service Commission, UNESCO, Kenya National Union of Teachers and the Ministry of Education and Technology. Not only has it has branched out into 16 districts in Kenya, it has opened chapters in Tanzania, Uganda and Zambia.

Tools to fight stigma and indicators that can measure its efficacy have been developed by the ICRW. But this is not enough. Stigma and discrimination take different forms. Therefore, lessons must also be learnt from successful initiatives like KENEPOTE. But what will be useful in designing focused interventions is the finding that education is the first line of defence against stigma and discrimination. Countries must shed inhibitions about incorporating information about HIV and AIDS in school curricula. It should dispel myths and misconceptions regarding its modes of transmission, even if it means discussing the 'birds and bees' more explicitly in classrooms. After all, prevention is better than cure.

The power to save lives

Ruth Connolly, Ireland

Pull Quote

HIV-positive people can also be healthy and attractive, so why not convey this image too?

Stigma is everywhere but the reach of the media is everywhere too. The media has the power to convey the right or wrong message. The power to influence. The power to save lives. To date, many images of HIV-positive people have been of wasted, sick people. HIV-positive people can also be healthy and attractive, so why not convey this image too? Will someone in the Irish media be brave enough to make the first move in the path towards stigma reduction? After all, stigma can be more contagious than HIV.

Many young girls have become anorexic as they aspire to be like the glamorous skinny models on the pages of magazines. This is proof that advertising has a huge impact on our perceptions and values. In Ireland, posters are commonly placed in public toilets advertising help for unwanted pregnancies. 'Engage in safe sex to prevent unwanted pregnancies' is a message frequently carried by the Irish media. As a result, girls and young women are taking the contraceptive pill under the illusion this offers protection against HIV.

Asked if they have any recollection of HIV awareness campaigns in Ireland, most people answered "Never". People are engaging in risk-associated behaviours unaware the virus is out there and that they may be vulnerable. The public have the right to know that anyone can contract HIV, not just those perceived to be vulnerable.

A journalist with the British Broadcasting Corporation (BBC) attending this year's International AIDS Conference (IAC) admitted the "media could do a lot more". She reflected back on the time in 1987 when Princess Diana publicly shook the hand of an HIV-positive man. Around the same time she remembers advertisements with images of tombstones – portraying the disease as a death sentence, thus increasing levels of stigma. Ireland is lucky enough to have access to HIV treatment and the virus is no longer a death sentence. HIV awareness needs to be spread faster than the virus and this can only be done through the media.

Speaking at the conference Richard Gere made a wise observation when saying the media have the ability to create "an empathy that is deep and real". Bill Roedy, the president of MTV Networks International, admitted the media are "not doing enough". Clearly this is a problem worldwide, not just in Ireland.

The AIDS Responsibility Project (ARP) based in California is launching its 'Start the Conversation' initiative at the IAC in Toronto to promote the launch of a CD entitled 'What are we Living for?'. The purpose of this CD is to 'Start the Conversation' about HIV. How to live with the virus, how to avoid transmission, how to avoid infection and the importance of being honest about one's own status. Ireland has a huge popular music culture. A project like this has the potential to reach the minds of many young people and reduce the widespread stigmatisation.

The theme of this year's AIDS conference is 'Time to Deliver'. The Irish government is launching an HIV campaign on December 1st, World AIDS Day. Hopefully this will be the time to deliver. A time to reduce stigma and, as a result, save lives.

Living the life we choose

Ruth Connolly, Ireland

Pull Quote

Many of the women living with HIV have only had one partner their whole lives, so why are they stigmatised and discriminated against?

25 years into the epidemic and HIV still remains linked in many peoples minds to 'social evils' such as sex work and promiscuity. Many of the women living with HIV have only had one partner their whole lives, so why are they stigmatised and discriminated against? A woman living with HIV can be a mother, a sister, a daughter, a wife, a carer – a vital

part of the community – and yet be shunned and abandoned on revealing her HIV-positive status.

Three HIV-positive women from different countries attending this year’s International AIDS conference in Toronto were asked about their experiences of stigma. The one issue they all shared was anxiety related to child bearing – the fear of being abandoned by society for deciding to conceive, the fear of mother-to-child transmission, the fear of infecting a partner, the fear of hurtful comments if they decided not to breastfeed and the anger at being denied the right to adopt a child.

Fear of stigma inhibits women electing to be tested for the virus. Every woman has the right to know her HIV status and the right to safely disclose this if she chooses. But this is rarely the reality and many mothers are passing the virus onto their children due to the threat of disgrace placed on them by their communities.

Women have a voice, and slowly they are speaking out in order to create a more accepting world for their children. But more needs to be done. Voices of Positive Women was set up in Canada to help enable women to live their lives fully through support, information, education, skills development and community involvement. One by one, groups like this are being set up all over the world and change is being made, but there is still a long way to go. Female speakers at this year’s conference have frequently been heard saying, it is time for women to “walk the talk”: To stand up for their human rights as women and live the life they choose to lead.

One particular woman played life by the rules. She is HIV positive and has always used condoms since her diagnosis. One night a condom broke and a few weeks later she realised she was pregnant. She had no money, no partner, was living with the virus and many people she knew presumed she’d have an abortion. But she found the strength within herself to stand up for her rights as a woman and she carried the pregnancy to full term. She took medication for the final trimester, had a caesarean section and seven years on she has a healthy HIV-negative daughter.

In the hospital she was treated like an outcast by nurses and doctors and left with two womb infections. Nobody helped her care for her newborn baby; she had to do everything by herself. But she kept this message in her head, “Nothing anyone says to me can be worse than the way I have beaten myself up . . .”. This message has brought her through life and she now stands proudly in front of crowds and tells her story, inspiring women all over the world. She encourages other HIV-positive women to think, “I am a beautiful, HIV-positive woman who can contribute to society and be a good mother.”

This woman took charge of her life and has reaped the rewards.

Mary Robinson, patron of the International Community of Women living with HIV (ICW), speaking in Toronto said, “What would happen if women were in charge of the AIDS response? Women would be in charge of the world.”

Such sentiments were echoed by one of the founding members of ICW, “I’m very angry that HIV-positive women are never heard.” She was denied the right to adopt a child due to her HIV-positive status but has come to terms with this. She now feels that women are being forced into activism. Women all over the world are coming together and displaying great strength and courage.

A stigma reduction toolkit has been developed by HIV activists from more than fifty NGOs in Ethiopia, Tanzania and Zambia. This toolkit will hopefully further inspire women surrounded by stigma and discrimination to go ahead and live the lives they choose.

The power of self-talk

Ruth Connolly, Ireland

Pull Quote

“Unless he’s in a coma or you have a gun, there is no right time”

HIV-related stigma emerged as an important theme at the XVI International AIDS Conference in Toronto. Hour after hour was spent talking about stigma and how it might be reduced. “It’s time to walk the talk”, was heard over and over again. But can stigma ever truly be eradicated? During the conference opening, Frika Chia Iskandar, an Indonesian HIV activist, asserted that stigma will always exist and people need to learn to live with it and get on with things. At the end of a week of talk about stigma, it became obvious that one of the most insidious forms of stigma is self-stigma.

‘What will people think?’, ‘How will friends treat me?’, ‘Will I loose my job?’, ‘Will I ever have a partner again?’ These are some of the questions that trouble the thoughts of people living with HIV. But does it really matter what people think? Life seems too short to be spent worrying about what other people think. An experienced Irish counsellor always tells his clients to imagine the worst response possible. You need to be prepared for that response, but it will probably be nothing as bad as imagined. And even if it is, then at least the client has prepared for it.

A delegate at the conference had recently started dating a man for the first time since her HIV diagnosis. This was a huge step forward for her. All of the usual questions were running through her mind. Would he reject her? Would he tell all his friends? But listening to other people at the conference who had been in the same situation and taken the plunge, she began to gain confidence and was eager to return home and tell him face to face that she was living with HIV. She kept repeating the words of HIV educator, River Huston in her head, “Unless he’s in a coma or you have a gun, there is no right time.”

On the evening of the AIDS vigil in Toronto she dropped into a local pub for a pint. A Canadian man at the bar noticed her red ribbon and asked her about the conference. She didn’t reveal her HIV status. He seemed to think that only African children have HIV, so she pointed out that anyone around him could be infected. He said he had never met a person living with HIV. She told him, “There’s a first time for everything”.
There was silence for a long time. She apologised if she’d shocked him, but he thanked her for her honesty and asked to accompany her to the vigil.

Four days later her man back home decided he wasn’t waiting for her anymore, so she never got to tell him the truth, but it didn’t matter. Relationships break up all the time, HIV or no HIV. Stigma will always be there but she had learned to reduce her fear of it. If someone was worth knowing they would accept her as she was.

AIDS 2006 was a small step forward in reducing stigma, but unfortunately HIV-related stigma will almost certainly always exist. It is how people affected deal with it that matters. The power of self-talk is phenomenal. Almost everyone has been rejected at some time in their life before living with HIV and has survived that, so why should things be so different with HIV?

Breaking the silence

Ruth Connolly, Ireland

Pull Quote

Everyone felt equal due to a breaking of the silence. Everyone was preparing for change.

‘Time to Deliver’ was the theme of this year’s International AIDS Conference in Toronto. Attending sessions and workshops, it would seem that a more appropriate theme would have been ‘Preparing to Deliver’. The conference was very informative, and life-saving energy emitted from every corner of the conference centre. Every day people gained more confidence by talking about their HIV status, whether positive or negative. At the start of the week some felt guilty about being negative, whereas positive people felt at ease living in the world of HIV for a week. By the end of the week, all boundaries had broken down. No one cared who was positive or negative, what their sexual orientation was, if they ever used drugs, etc. Everyone felt equal due to a breaking of the silence. Everyone was preparing for change.

The majority of delegates interviewed about stigma felt it primarily existed due to a lack of education. There is an immense silence surrounding HIV due to a lack of awareness. A transsexual lawyer who is a resident of Toronto summed up the reality of “Silence equals death”. He had recently come out to his friends as being transsexual and had a huge fear of negative responses, especially due to his profession. But what he dreaded more was living in silence. He couldn’t live in a silent world where he didn’t belong, so he broke all barriers and made his announcement. It’s taken time, but people are accepting him now as he is, and he is happier than ever before living the life he was born to live.

Many people have committed suicide as a result of living in a world of silence. Living a life full of anxiety and dread – afraid to come out as being homosexual, afraid to admit using drugs, afraid to admit living with HIV. But wouldn’t the world be a very boring place if everyone was the same? Times are changing. Ireland for a long time contained only Irish natives. Now the country is very multi-cultural and has become a vibrant and colourful place.

Conference delegates, whether HIV positive or negative, have taken a lot of the positive energy generated at this year’s conference back to their home countries and are talking to people about the virus. Breaking the silence is creating awareness and thus reducing stigma. There is still a long way to go and more action needs to take place. As Mary Robinson pointed out, “We have two years to plan that Mexico could be different”. That there will be more action and less talking. This year’s conference definitely started on the right path and hopefully Mexico in 2008 will be truly ‘Time to Deliver’.

Ireland today

Declan Montgomery, Ireland

Pull Quote

Political leaders have to work to make our societies more open, caring, inclusive and non-judgemental

A defining moment for Ireland in terms of stigma and discrimination were the reports in the late 1980’s and early 1990’s of the bodies of people who had died from AIDS, being placed in body bags and carried out by ambulance drivers, fully suited in protective clothing. In this era prisoners who were diagnosed as HIV positive were also being segregated. The whole atmosphere at that time was one of fear bordering on panic, and it seemed that society, particularly the media, focused very negatively on those most affected by HIV, primarily men-who-have-sex-with-men (MSM) and injection drug users. As in most other countries, the issue of sex, particularly gay sex, and drug use were social taboos.

In many ways Ireland has changed dramatically since then, driven by massive social change and rapid economic development. The growing economy has drawn in thousands of new immigrants from all over the world, and now over 10% of the population is foreign-born. Despite this change stigma and discrimination are still very powerful barriers to people living with HIV (PLHIV).

Since the advent of antiretroviral (ARV) treatment, the cost of treatment has precluded sufficient investment in prevention or measures to combat stigma and discrimination. Furthermore, the 'medical model' – that is, the tendency to see HIV as a clinical issue rather than as a social one – tends to dominate in Ireland, as elsewhere in the West, to the extent that the psychosocial impact of living with HIV is not of real concern to physicians and policy-makers.

Ireland does have legislation covering discrimination, and the Equality Authority has indicated that it would pursue cases of discrimination on the basis of HIV status. No cases have yet been brought however and it is suspected that this is because of the stigma associated with the illness. According to the Dublin AIDS Alliance (DAA) many PLHIV who experience discrimination are loathe to seek redress through the legal system for fear of their names appearing in the newspaper or employers and friends discovering that they are HIV positive. In other words, the stigma surrounding HIV serves to fuel discrimination in that it acts as a deterrent to mounting a legal challenge.

There is very little evidence-based data on discrimination available; however, DAA routinely deals with cases that clearly show the low level of public knowledge and consequent stigma associated with HIV. In one recent case, a school contacted DAA requesting help with the wording of a letter to be sent to parents informing them that a student in the school was HIV positive. In another incident, a doctor who had discovered a patient's HIV-positive status, was planning on calling the patient's employers to inform them. He only agreed not to do this, after an HIV consultant called him personally. One can only guess at how any of the people involved in these cases felt having to go through these terrible experiences.

The media also carry a great responsibility for responsible reporting. An article in the Evening Herald, a major daily newspaper, appeared on 1st December 2005, (ironically, World AIDS Day) about the sentencing of an HIV-positive man from the Democratic Republic of Congo who was found guilty of inflicting grievous bodily harm on an Irish nurse with whom he had unprotected sex. The headline read 'HIV Beast Infects Irish Nurse'. Headlines like these may sell newspapers, but they only reinforce prejudice and make it more difficult for PLHIV to live their lives free from stigma and discrimination.

Another consequence of this negative reporting is that it can only make it more difficult for people to test for HIV as HIV is being presented as not just an illness but also a moral indictment.

There is clearly a great need for a comprehensive strategy of public awareness of HIV, as a means of combating stigma and discrimination. Society can enact laws to protect people from discrimination but changing attitudes is the real challenge. The law is a blunt and inadequate instrument for that purpose, and investment in education and public awareness is crucial.

In advance of the recent midterm review of the United Nations Declaration of Commitment on HIV/AIDS, PLHIV representatives and civil society stakeholders throughout Ireland called on the Taoiseach (the Irish Prime Minister), Bertie Ahern to publicly commit to the development and resourcing of a national education and awareness campaign to combat the stigma associated with HIV. In his address to the United Nations, the Taoiseach stated,

“If we are to succeed in reversing this epidemic, we must also tackle the stigma and discrimination associated with it. Political leaders have to work to make our societies more open, caring, inclusive and non-judgemental.

We plan to do more to deal with this issue in Ireland. As a first step, we will have a national campaign to combat stigma and discrimination against people infected with HIV in Ireland coinciding with World AIDS Day on 1 December this year.

Civil society has been central to Ireland’s response to HIV, at home and in the countries we support. They have shown that they can reach marginalised groups; speak out for the victims; form partnerships; and do the on-the-ground work. The work of non-governmental organisations and missionaries must be commended, especially their efforts in caring for the sick and vulnerable children”

Following from this speech, domestic and development NGOs, statutory service providers, HIV+ representation, the Department of Health and Children and Irish Aid have formed a multi-stakeholder forum to tackle HIV-related stigma and discrimination in Ireland. An initial budget of €300,000 has been allocated to fund a series of co-ordinated actions to promote better understanding of people living with HIV, while actively challenging direct and indirect discrimination experienced by HIV+ people throughout Ireland. This initiative, while embryonic, is widely welcomed but also long overdue.

Ireland has changed as a society since the 1990’s in terms of dealing with HIV. Discrimination and stigma may generally be reduced in a more open multi-cultural society, and the general availability of ARVs has made a huge impact on people living with HIV and their families. However, the cost of treatment has precluded sufficient investment in prevention and awareness strategies and consequently a whole new generation of young people are emerging in Ireland wholly complacent about HIV. Stigma and discrimination thrive in a climate of silence; we need to speak about HIV in the workplace, at home, in school, in our daily lives if we are to successfully challenge the irrationality that shapes discrimination of any kind. The stigma and discrimination campaign is a first step towards changing public perceptions and attitudes to HIV, while empowering people who live with HIV to do so without fear of rejection or of prejudice.

Empowering people living with HIV

Declan Montgomery, Ireland

Pull Quote

If society stigmatises PLHIV, and they in turn stigmatise themselves, how do we break the cycle?

The issues of stigma and discrimination and the need to involve people living with HIV (PLHIV) were a constant theme at this year's International AIDS Conference (IAC) in Toronto. Speaking at the conference, Peter Piot, the executive director of UNAIDS, said that "Ultimately, it has been the activism of people living with HIV and AIDS that has brought about change". Martin Flynn, news editor of Positive Nation in the UK concurs. He says that if you are not working with PLHIV then you are not tackling the problem of HIV. So what obstacles are there to PLHIV becoming more actively involved in the fight against the epidemic? One big challenge is stigma.

So what is stigma? Goffman defined stigma as: "An undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society".

The reason for stigmatising HIV is too often to do with perceptions of how someone may have acquired the virus; it involves a moral judgement about the person's behaviour. It was something the person did that caused them to become infected; it was their own fault. It is this judgement that leads to stigma. Experiencing stigma and discrimination can in itself cause someone to stigmatise themselves and so almost 'cooperate' in perpetuating it, in effect, to self-stigmatise.

Mary Robinson, speaking about stigma at the conference, talked of "how it hurts and imprints on the soul." This gets to the heart of stigma. If society stigmatises PLHIV, and they in turn stigmatise themselves, how do we break the cycle? How can we reach a stage where PLHIV lose their fear and take up the fight against the virus?

Juan Hernandez Chavez may have some answers. He works as the co-coordinator general of Collectivo Sol, an organisation working with many marginalised groups in Mexico. He talked about the negative social and cultural attitudes against men who have sex with men (MSM), sex workers, injection drug users (IDUs) and PLHIV.

Working with these groups, he tackles the issue of self-stigma. In order to empower people, you need first to get them to challenge their own thinking. It is a three-part process:

1. Listen;
2. Let go;
3. Learn.

It involves being aware of stigmatising thoughts and feelings, acknowledging and challenging them, and letting them go. He actively works with the group in the learning process rather than lecturing them. A style of learning that is itself empowering. It is a continual process of learning. Perhaps a painful one, where accepted 'truths' are questioned and reframed.

Juan gave an example of how effective this can process can be. Transgenders who are also sex workers and who previously only had a criminal relationship with the police have now become the educators of the police. Empowerment can really work.

Rose Aykukwei, a health worker from Kenya attending the IAC said that empowered people don't even notice stigma. This brings to mind a quote from Shakespeare, "you have not half the power to do me harm as I have to be hurt" – old wisdom indeed, but still relevant today. If PLHIV gain greater inner strength and self respect then, what other people say or do matters less, hurts less. As Eleanor Roosevelt once said, "No one can make you feel inferior without your consent".

Dealing with stigma and discrimination must involve a multilayered approach, on a personal level, but also at a legal/institutional level. Referring to activism within the gay community, Lisa Power at the Terence Higgins Trust, in the UK, said that gay men and the gay media "had learned to fight back". So we know that activism can be empowering.

Looking to future challenges in dealing with stigma and discrimination, Juan Hernandez Chavez listed three issues/observations:

1. Stigma and discrimination can be reduced, but it is a long-term process;
2. It requires sustained effort and funding;
3. It needs to become an institutional and not just a personal process.

There is another side to this issue of empowerment, and that is respecting the rights of people who don't want to become activists, who want to live their lives quietly. Not every PLHIV wants to be out there waving a flag or protesting. This choice must also be respected, and the process of dealing with stigma may for some people be a personal journey alone.

PLHIV, who have personal experience of living with HIV, must have direct input into the fight against stigma and discrimination. After all, despite all the suits and titles at this conference, the real experts are those living with HIV.

In praise of marathon runners and trapeze artists

Declan Montgomery, Ireland

Pull Quote

So how can we put HIV back into the public arena in countries like Ireland?

After an intense and exciting week as part of the Key Correspondent team covering the International AIDS Conference (IAC) in Toronto, it's back home to Dublin. Apart from the familiar rain, what strikes me as 'missing' in Dublin, are all the banners announcing, 'AIDS 2006, Time to Deliver', that festooned the lampposts of Toronto. There, at least for a few days, the issue of AIDS was making the headlines. 24,000 delegates and 3000 media were hard to ignore, and the whole conference got wide publicity in Canada. But in Ireland, little real media coverage appeared, apart of course from the star appearances by the two Bills, Clinton and Gates. I've been wondering why this is. Why is it so hard to grab the media and the public's attention on HIV in Ireland, and other Western countries?

Antiretroviral (ARV) drugs, might be part of the answer. Ever since the advent of ARVs, with free access in Western countries like Ireland, the threat of AIDS has diminished into what is often referred to as a manageable illness. This is both a blessing and a curse. People are not falling ill and dying in the same numbers as before, and the news value of the illness, on the home front at least, is consequently diminished. It is not front-page news anymore.

The fact that HIV is off the front page, or even the second page, is bad news in other ways. Peter Mueller a Canadian AIDS activist attending the conference in Toronto, said, "We sanitise the disease, we see the pictures [of people with AIDS] for Africa but not for the developed world. We have a whole generation who do not see the impact of this disease. AIDS in the West is the same as AIDS in Africa, we have got to get the message out". On this score, Canada and Ireland don't seem so very different.

HIV thrives in this silence. With little outward media coverage or an ongoing public health awareness campaign, Ireland and perhaps other Western countries have been lulled into a false sense of security around HIV. Maybe we see it as someone else's problem, not something we need worry about. But can we afford to be so complacent? There may also be some feeling within the general population that since ARVs are available, we needn't worry about HIV anyway. But new infections continue to occur. The latest figures from the Health Protection Surveillance Centre (Ireland) show that 318 new cases of HIV were diagnosed in 2005.

HIV is a usually a preventable infection: education and awareness can largely prevent transmission, and this we know. As is often repeated, education is essential for tackling HIV. So how can we put HIV back into the public arena in countries like Ireland? Maybe we need a change of tactics.

"We need to run the marathon rather than to sprint in this epidemic", said Geeta Rao Gupta, president of the International Centre for Research on Women (ICRW), speaking at the IAC in Toronto, about the way the world responds to HIV. There seems to be a lesson that can be taken from this. There is a real need for an ongoing, long-term public campaign to raise awareness around HIV and this needs funding and support from the government, as well as the involvement of the media and other public forums, such as workplaces, colleges and schools so that the message gets to the people it needs to reach.

The Taoiseach (the Irish Prime Minister) has committed €300,000 provided jointly by the Ministry of Health and Irish Aid, to fund a multi-stakeholder group to tackle stigma and discrimination as part of a national campaign to be launched on 1st December 2006, World AIDS Day. However, running the marathon in the fight against HIV-stigma will need far more money and a much longer-term commitment.

Peter Mueller offers some salutary advice, "There needs to be a balance between destigmatising the illness, and the reality of the disease". On the one hand, there is a need to raise public awareness across the board, and, on the other hand, a need to address the issues of stigma and discrimination.

The challenge of any long-term campaign needs is to keep HIV in the public eye without adding to stigma and discrimination, particularly of already marginalised groups such as men who have sex with men, immigrants and injecting drug users. HIV is a highly adaptable virus; the response to the epidemic must be just as agile. In this case, marathon runners may also need some of the skills of trapeze artists.

Reducing stigma and discrimination: Successful examples from the health care sector in Asia

Key Correspondent Team

Pull Quote

Stories of segregation in wards, refusal of care, and disclosure of status are common in the region

There is no shortage of studies demonstrating that stigma and discrimination is common in health care settings in Asia. Ask anyone living with HIV where they experience the most discrimination based on their serostatus, their occupation as a sex worker, or their injection drug use: They will often reply that health workers are the ones that make them feel the worst. Stories of segregation in wards, refusal of care, and disclosure of HIV status are common in the region.

What really works to reduce stigma and discrimination? There is in fact a very small evidence base for what has been proven to work. During the session: 'Stigma and Discrimination: The Undoing of Universal Access' we heard that there is no longer any reason for inaction. The tools to measure and address stigma and discrimination are available and ready to be adapted to local situations.

One of the most successful illustrations of action has taken place in India. The capital, New Delhi is in a relatively low HIV-prevalence area but is in a good position to try out methods that may be applicable to other parts of the country where there are more people living with HIV (PLHIV). The Population Council undertook formative research to measure the level of stigma and discrimination in three public sector and one private hospital. They then worked with a local non-governmental organisation and PLHIVs to undertake a series of activities with all levels of health workers to successfully reduce stigma and the resulting discrimination.

The hospitals developed a set of guidelines that they could apply as 'gold standards' of non-discriminatory care and support for PLHIV. They created a checklist that could be used to see if they improved the quality of the care they delivered and they developed pride as they discovered that they could disseminate their 'PLHIV-Friendly Achievement Checklist' for others to assess their work.

The methods used in Delhi were simple. Training was provided for all health workers in the hospitals, not just the doctors. Infection control was improved. And voluntary counselling and testing services were enhanced. Stigma and discrimination reportedly decreased in all four hospitals. The only weakness of this approach was that self observation was used to determine whether anything changed. Patients and PLHIV were not asked directly whether the behaviour of hospital staff had changed. But that is not to detract from the success – just a suggestion to improve it.

The brilliant example of Delhi has not yet been taken up by other health care institutions in India. But nothing is stopping UNICEF from promoting the use of these guidelines in the hospital-based prevention-of-mother-to-child-transmission (PMTCT) programmes they are promoting in India and Myanmar. In addition, the World Bank, in a new publication released at the recent International AIDS Conference in Toronto, 'AIDS in South Asia: Understanding and Responding to a Heterogeneous Epidemic", has recommended that all countries in South Asia develop programmes to reduce stigma.

These tools are also being tested in several sites in Vietnam. With two successful examples in both South Asia and East Asia, there is no reason why the activities cannot be replicated to reach the majority of health care institutions in the most populous continent. They are inexpensive to implement and it is simple to set targets for their use. By the end of this year many Asian countries will hopefully have national universal access plans. How many of them will include achievable targets for reduction of stigma and discrimination?

Personal experience of stigma

Pushing back against HIV-related stigma in Viet Nam

Key Correspondent Team

Pull Quote

They also got more support from the community because the whole community has a better understanding of HIV these days

Huong[6] is a 28-year-old woman who found out that she was HIV positive six years ago, just before she delivered her first and only child. She remembers what a surprise it was when the district hospital referred her to Hanoi obstetric hospital without telling her the reason.

In Hanoi the doctors and nurses behaved strangely towards her and shouted at her. She was discharged from this first hospital in Hanoi at 12am and told to go to the central obstetric hospital, without anyone explaining where to find it. This pregnant woman, who could go into labour at any time, had to wait for three hours outside the gates of Hanoi obstetric hospital until her husband was able to come and take her to the next hospital.

Huong didn’t get any counselling or support and the only advice her doctor gave her was that she should bottle feed her child, if it was financially possible for her. As was common in Vietnam at the time, the whole community knew about her HIV status before she came home.

Because of financial difficulties and lack of support from both families, Huong had to breastfeed her child. And because nobody gave her any information about HIV and how the HIV test works, when she took her daughter for an HIV test at six months of age she was given a positive result.

Huong continued to bring up her child without any knowledge about how to avoid transmission. When the child was 3 years old, Huong tried to send her to kindergarden but she was refused. The teacher told her that there were too many children and her child was too young. Huong told the teacher “I will keep my child at home if other children of the same age stay at home as well”.

Finally, the child was allowed to attend a kindergarten, but she was made to sit outside the classroom. The girl cried a lot and didn’t want to go back. Huong had to talk with the

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[6] Not her real name

teacher again. “A child is similar to a white page”, she told her. “Whether the paper becomes pure or black depends on the adults around her. You have to think carefully, before you exclude a child”

Even though the girl was finally allowed into the classroom, the other children would not play with her because of the fear of transmission. Huong asked the teachers why they had disclosed her daughter’s status to other children and threatened that if the situation continued she would pursue it at a higher level.

At the time, Huong thought only that going to school is the right of all children – she didn’t know anything about the rights of people living with HIV.

Huong didn’t receive any support or advice from family members. She continued to think that her daughter was HIV positive until she was four years old when the central obstetric hospital encouraged Huong to take her child for a second test. Huong cried a lot when she found out that her child was in fact HIV negative.

The strength that keeps Huong living and fighting for the right to be treated equally for the whole family, is her love for her daughter and husband.

Huong and her husband joined two self-groups two years ago. They received a loan (5 million Vietnamese dong, equivalent to around US$300) to raise pigs and cattle. Her husband sometimes takes seasonable jobs and receives an ad-hoc income. Their lives are still very tough and most of their money is spent on school fees for their daughter. But Huong feels happy and comfortable now because she knows more about HIV and other people living in the same situation from weekly meetings at the self-help group.

Huong does outreach, provides care and support to other people, and participates in different trainings and workshops. Both Huong and her husband get free antiretroviral (ARV) treatment. They also get more support from the community because the whole community has a better understanding of HIV these days. Representatives from commune’s women’s union have even offered to provide a loan to Huong’s family if they need it. This is because of the ‘positive living’ attitudes of Huong and her husband. They work hard for a living and don’t wait for other people’s support.

Stigma and discrimination toward PLHIV are decreasing in some communities where intensive efforts by the local authority and development organisations have been made over past years. It is notable that the first HIV prevention programme was implemented in Huong’s district about 10 years ago. Stigma and discrimination still strongly exist in other places.

Huong said that in her self-help group, which has around 100 members, all women, nobody dares to fight for their rights. Some children are going to school because their HIV status is still unknown to the community. But lots of children have to stay at home because teachers are under pressure from parents who show stigmatising attitudes. They incorrectly believe that their child could be infected from bites or scratches when playing with HIV-positive children.

The government has just passed a new law on HIV, but it will not become effective until January 2007 and thus guidelines for implementation are not available.

According to the Institute for Social Development Studies in Hanoi, some 2,800 out of 2 million babies born annually get HIV from their infected mothers in Vietnam. The country is estimated to have around 8,500 HIV positive children aged 1-15, and some 22,000 orphans due to AIDS.

Recently, the government rejected a proposal that tried to build a separate school for HIV-positive children. However, not enough is being done to protect the right to education and the right to be free from discrimination for HIV-positive children. In Ba Vi district, which is 40 km from Hanoi, there is a class for children of HIV positive mothers who are living in the rehabilitation centre. Some HIV-positive mothers in Hanoi have to send their children to this class as a temporary solution. At the moment, it seems to be the only official place for HIV-positive children to get a basic education.

Meanwhile, Huong’s daughter is starting primary school in September and is finally enjoying her childhood. We can only hope that all children in Vietnam will one day have the opportunity to access education without stigma.

The impact of stigma on disclosure of HIV status

David Mukasa, Uganda

Pull Quote

The extent of the existing stigma in the community will greatly influence the way, and to who, any disclosure is made

In view of the benefits that are said to be derived from a person ‘coming out’ or disclosing their HIV status, people living with HIV (PLHIV) should take advantage of this opportunity for self-exploration. This was the perspective presented by Almeleh of South Africa during a satellite meeting at the XVI International AIDS Conference. Disclosure has many dimensions and there are many considerations to take into account, including the potential for stigma and discrimination, if it is to have a positive effect both on the one disclosing and the community at large.

The advantages and disadvantages of self-disclosure must be carefully weighed – especially if the impact is likely to be so stressful as to diminish all anticipated benefits. The most important aspect influencing an individual’s extent or degree of disclosure must be how it will impact on the person in question, those around them and the community. The extent of the existing stigma in the community will greatly influence the way, and to whom, disclosure is made.

We might assume that it is most natural to first disclose to the closest person in your life but this is not the case for all individuals. It would be totally unethical to coerce an individual into disclosing ‘prematurely’ as sometimes happens, and as was described by Dorothy Odhiambo of IFRC, Nairobi. Natalie Mburu of Women Fighting AIDS in Kenya suggested that disclosure is best achieved step by step. “Disclosing is everyone’s [PLHIV] responsibility”, she says but in the face of stigma**,** the timing and degree will vary according to each individuals circumstance and community.

In a study conducted in South Africa and presented during one of the sessions on disclosure, most of the PLHIV who disclosed first to ‘significant others’ had faster ‘recovery’ rates from being fearful and dependent on others, gaining vitality and a generally better outlook on life and thus improved immune systems. Whereas those who disclosed out of family circles and/or those ‘driven’ to it by their care providers ended up withdrawing from family members and loved ones. These people are also less likely to get adequate support and care when it is required.

Discussants raised the issue that gender disparity can play an important role in how, when, where and to whom PLHIV disclose their status. For example, though more women are known to be attending specialised AIDS clinics and centres, their ability to disclose to their husbands or co-habiting partners may be diminished by fear of being subjected to violence or rejected from their homes .

When asked about the relationship between treatment, stigma and disclosure, Mike Angaga the Coordinator of the Network of Africa PLWHA (NAP+) said there are many assumptions made in this regard but there is need to have a more focused, evidence-based approach to the issue – though there are indications already in NAP+’s work with national networks of PLHIV in Eastern and Southern Africa that stigma doesn’t automatically disappear because people are swallowing pills.

There is a need for shared responsibility. So, don’t go recklessly looking for HIV.

Fighting stigma with disclosure

Henry Kabwe, Zambia

Pull Quote

Having lived with HIV for 10 years, Zulu says she owes to her disclosure the opportunities she has had in life

As AIDS rocked Zambian society in the 1990s, Princess Kasune Zulu stood up against the culture of stigma to declare that she was HIV positive. Zulu said in an interview at the International AIDS Conference (IAC) in Toronto, her decision to ‘come out’ about her status cost her a lot as people started stigmatising her but she was determined to ‘win the battle’ as she knew that even the people that were stigmatising against her, could be HIV positive.

Having lived with HIV for 10 years now, Zulu says she owes to her disclosure the various opportunities she has had in life.

She has met with presidents, business people and high-ranking world leaders like George Bush and Stephen Lewis. She now works with World Vision which has made it possible for her to relocate from Zambia to the United States where she has settled with her two children.

“When I was discovered to be positive in 1997, I was just 21 years old and not many people were willing to talk about HIV/AIDS. Dr. Masauso Phiri [a Zambian AIDS activist] was running a radio programme which was not popular due to stigma and when I was encouraged to go public, people thought I wanted to make money but what I did has made it possible for others to come out now,” says Zulu.

Even with a prevalence rate of 16 percent (Zambia Demographic Health Survey), many Zambians still view the pandemic as a disease for ‘immoral’ people and stigma is rife.

According to National AIDS Council (NAC) Programmes Director in Zambia, Dr Maxwell Simwinga, the National AIDS Policy addresses issues of stigma. In an interview at the conference he said that the policy hopes to ensure that people living with HIV (PLHIV) are placed in positions of authority for them to contribute to the development of the nation. “That way, people will know that people living with the virus have got brains and can contribute to the nation. The problem of stigma in Zambia stems from the notion that people who have HIV got it from sex,” said Dr Maxwell.

According to the Regional Psychosocial Support Initiative (REPSSI), a sub-Saharan regional network based in 13 countries that works to mitigate the impact of HIV and AIDS on children through psychosocial support, stigma has a serious impact on youth.

“Mostly, our culture encourages young people to speak ill of those that are infected by gossiping or simply talk against the pandemic in tales and other gatherings. Once one of them in the group discovers that they have it, they start feeling shy to tell others or go for voluntary counselling and testing because of what they have believed from what has been said," says REPSSI deputy executive director, Daphtone Siame.

Princess Kasune Zulu believes that culture has played both positive and negative roles in the fight against HIV in Zambia. Having lost her mother in 1993 and her father in 1994, she has had the burden of taking care of nine siblings (three brothers, one sister and nephews and nieces), Zulu says the ability to stay together as a family in the midst of stigmatisation was as a result of strong cultural values.

She also points out that cultural attitudes have also exposed women to increased risk through sexual cleansing rites (in which men have sex with a virgin in the ridiculous belief that it can cure them of HIV) and that women generally shoulder the blame once a couple is discovered to be living with HIV.

Zulu, who started an organisation called Eternity Foundation in the copper belt towns of Luanshya and Kitwe says that instead of blaming people for stigma we need to find a way to move forward in addressing the problem.

"When I was told that I was HIV positive, I used the opportunity to go to companies and started hitchhiking with truck drivers who thought I was a sex worker, and offered them sex education. I targeted the men because once a man is protected, the wife at home will be protected and their partners," she says.

Many high profile speakers at the IAC strongly condemned the stigma and discrimination experienced by PLHIV. It is the responsibility of all of us to ensure that this has some meaning in their lives. What remains is the follow up to the resolutions made at the conference to ensure that the neglected populations of the world benefit from a gathering that has attracted more than 20,000 delegates.

Fighting HIV self-stigma against the odds

Henry Kabwe, Zambia

Pull Quote

"I felt embarrassed and started fighting the stigma from within, that's where the most dangerous aspect is"

"The worst form of HIV stigma is self-stigma", according to Mirriam Banda, an HIV activist from Zambia.

Mirriam Banda, who disclosed her HIV-positive status at a candlelight service graced by Zambia’s President Levy Mwanawasa in Lusaka in 2004, also belives that once self-stigma is overcome, no form of stigma can bring an HIV-positive person down.

“It is the worst type of stigma because when people are laughing as you pass by, you think that they are laughing at you. If someone who has overcome self-stigma gets fired or demoted because of their status, they can follow it up by seeking help instead of hiding the issue,” she says.

She feels that issues of self-stigma should be explicitly addressed at the international AIDS conferences to help people that have been impacted. At one session that explored the role the media has played in exacerbating stigma, a study by the University of Pretoria, South Africa revealed that the main reason why the media never printed positive stories about HIV was that the people selected for interviews themselves concentrated on negative experiences.

“Those people had self-stigma, and were perpetuating the problem,” Banda explained.

She suggested that organisations of people living with HIV (PLHIV) should only select people to speak to the media who have overcome the issue of self-stigma, because those that have not overcome it may end up fuelling the problem.

According to Banda, this accounts for much of the responsibility that has been laid at the feet of the media when it comes to perpetuating HIV-related stigma.

Asked to define self-stigma in her context, Banda says it is when somebody who is HIV positive has not fully accepted their situation. “It is not denial per se, but where they can’t move forward and say ‘I am HIV positive and my status is not a qualification to blame people who try to stigmatise me,’” she says.

Banda, who is now chairperson of the Network for People Living with HIV/AIDS Zambia (NZP+), says the worst form of stigma debilitates people to a point of inaction and lack of productivity. She says people develop low self-esteem, self-imposed challenges, stagnancy and self-pity.

Left with four children after the death of her husband in 1999, in a culturally hostile nation where widows are already victims of stigma, Banda stood against all odds to fight stigma.

Some of Banda’s insight into self-stigma came when she was asked for a bottle of water by someone in Lusaka. She warned him that he should not use the same bottle, since she had used it.

“He rebuked me saying I was now stigmatising against myself when I had been preaching against it,” said Banda, adding, “I felt embarrassed and started fighting the stigma from within, that’s where the most dangerous aspect is.”

According to Banda, the first step out of self-stigma is for someone to realise that they are special and find grounding in their faith or whatever they believe in. “For me as a Christian, I looked at the promises in the Bible – that I am wonderfully and fearfully made – and got encouraged.”

She said her family has always been supportive as they have been God’s tool for extending His help. “Even if your mother or father rejects you, God will never reject you,” she said.

Banda recently started a job with the International HIV/AIDS Alliance in Lusaka and hopes to use her unique position to continue her work as an anti-stigma advocate.

Since self-stigma is the individual’s internalisation of the attitudes one experiences – or anticipates – in society, making strides in undoing it removes the feelings of shame, dejection, self-doubt, guilt, self-blame and inferiority.

For Banda, the battle she won with herself will not end until she sees people free to access services like voluntary counselling and testing, treatment and social support – without fear of stigma.

Stigma and HIV-positive children in Thailand

Niparueradee Pinyajeerapat, Thailand

Pull Quote

His neighbours and relatives know about his positive status but none of them has ever said a word and have never treated him differently

[A report from the XVI International AIDS Conference held in Toronto, Canada, August 2006]

The stories told here, of children growing up with HIV in Thailand, may be similar to the stories of affected children from all over the world. The psychosocial impacts of HIV-related stigma and discrimination compound the difficulties of their lives, which are already burdened with HIV.

Deang is a seven-year-old boy who became infected with HIV after being sexually abused. His neighbours and relatives know about his positive status but none of them has ever said a word about it and have never treated him differently. Deang feels safe and is free of stigma in his small community; however, he has never wanted to inform other people, even his friends in school, that he is HIV positive. He is afraid that his disclosure would invite stigma and rejection. He has heard that HIV-positive children are ill-treated, isolated and bullied. He does not think he could face the consequences of stigma so he would rather keep quiet about his HIV status. He tries to live as calmly as possible, but deep inside his anxiety will not go away. He worries about the future and what will happen if his status is discovered. The fear of being ‘nobody’ haunts him every day.

Daam is a seventeen-year-old girl who contracted HIV from her mother at birth. Her mother died when she was very young and her father married another woman and moved out to live with his new family. Her grandmother, who is now over 80, has been taking care of her ever since.

Daam found out that she was HIV positive when she was nine years old. She became very sick and had to visit the hospital often. She began to lose weight and had skin problems. When her neighbours found out she was HIV positive they told their children not to play with her. In school, she was teased, called names and rejected by her friends. “What my friends did to me did not hurt me as much as what they said about my mother. I cried a lot at that time. I was angry and also blamed my mother for giving me this disease.”

Daam became aggressive and started to stand up to those who bullied her. “I gradually learned to fight back and never let anyone abuse me anymore.”

Now, Daam is studying at a vocational training school and has received a scholarship. No one knows about her positive status except her teachers. However, she still feels that she is different from her friends. She is worried that she will never get a job if people find out she is HIV positive. Daam also has to look after her grandmother who is getting old now.

“I must live and cannot die before my grandmother because nobody will look after her.”

Daam has never enjoyed her childhood as much as her friends of the same age because of HIV. What lies ahead of her, she does not want to think about.

Kwaw is a fifteen-year-old girl who also contracted HIV through mother-to-child transmission. Kwaw is skinny and looks smaller than her age. Her mother died when she was young and her father looked after her and her older sister who was not infected. Kwaw found out that she was HIV positive when she was ten years old.

She was far behind her classmates at school. She could not concentrate on her studies and often slept during classes. Finally, she dropped out of school when she became sick and started to develop AIDS-related signs (the dark spots on her body), because she and her father did not want anyone to know that she was HIV positive.

Kwaw has had no friends since she left school. Even at school she didn't associate much with the other kids because she was often too sick to play. Now she stays at home and plays with her little niece and wonders if she will ever get the chance to study again.

Listening to these children, one of the things they share is the personal impact or fear of HIV-related stigma. None of them are willing to disclose their positive status for fear of rejection and exclusion.

HIV stigma starts at home for Indian women

Swapna Majumdar, India

Pull Quote

Ironically, it was the family of the infected person that discriminated the most compared to other sections of society

Stigma and discrimination are the two major hurdles that continue to hamper rehabilitation of people infected and affected by HIV in India. For women and girls the degree and impact of this stigma is even more acute.

When Urmila tested positive for HIV in her fifth month of pregnancy, she thought her in-laws would extend their full support as even her husband was diagnosed as HIV positive. But after a few months when her husband died, not only did her in-laws ostracise her, they also tricked the traumatised Urmila into signing away her and her son's rights to her husband's share of the property.

Women bear the brunt of the pandemic not just in terms of greater discrimination, but also of hardships and responsibilities they assume after the death of their husbands, according to a recent study conducted by the India office of the International Labour Organisation (ILO). The study was conducted in collaboration with the Indian network of people living with HIV in four states, Delhi, Maharashtra, Manipur and Tamil Nadu, and was presented at the recent International AIDS Conference (IAC) in Toronto.

According to the study, conducted to understand the socio-economic impact of HIV on infected people and their families, particularly on women and children, 74 per cent of the women revealed they faced discrimination. Ironically, it was the family of the infected person that discriminated the most compared to other sections of society. Women felt betrayed by this lack of understanding from the family despite the fact that they are the prime care-givers.

The study of 292 people, 42 per cent of whom were women, also found that women felt hurt that aspersions were cast on their chastity by their in-laws despite being aware that they had no control over their bodies. Although the majority of Indian women get the infection from their husbands, they are often blamed for his death. In many cases, the woman is accused of causing her husband’s illness and discarded by the in-laws.

“The majority of HIV-positive women are not only discriminated against by their in-laws but also experience it in their parental family. Traditionally, women tend to rally around each other in times of trouble. But we found that even other women, in the household where there were HIV-positive women, are not sympathetic perhaps because of the stigma associated with the infection and fear of society,” said SM Afsar, project director, ILO.

Although the study revealed that the level of discrimination by the family was higher towards women (23 per cent), men, too, faced discrimination from their families (20 per cent).

Naveen Kumar, who now works for the Delhi Network of Positive People (DNP+), hid the fact that he was infected with HIV. The only person he confided in was his pregnant wife. He was afraid that he might have infected her and the unborn child. Naveen said he did not reveal his status to other members of his family because he was not confident of their support. Eventually, his family found out and threw him and his pregnant wife out of the house. He was also not allowed to work in the family business. Naveen hopes that someday his family will understand the impact of their actions and change their attitudes.

Education is considered an important tool for attitudinal change. The study found that the higher the educational level among the infected, the lower the discrimination they faced. This fact was also underscored in several presentations at the IAC.

As a consequence, women in India are generally more vulnerable to HIV-related stigma as they receive less education. But unless the government incorporates a gender component into all their interventions, even education may not be able to reduce stigma and discrimination against women living with HIV.

Diary of a stigma virgin

Ruth Connolly, Ireland

Pull Quote

Most felt that the public had a serious lack of knowledge and therefore stigmatised and discriminated

Silence leads to stigma. People fear the unknown. HIV is unknown to many people and will keep on spreading as long as the silence continues. But how widespread is HIV stigma? An Irish delegate travelling to this year's International AIDS Conference in Toronto had never experienced stigma, even though she knew it existed, and therefore regarded herself as a stigma virgin. Her friends and family had always been supportive of her after she revealed her HIV-positive status. But what if she had kept her status to herself? Perhaps her lack of stigma experience would have been completely different. She educated her family and friends about HIV, so they never had a fear of the unknown.

Bright-eyed and eager to learn more about HIV stigma, this young HIV-positive woman set off on her travels to Toronto. At the opening ceremony she talked with several delegates about their opinions on stigma surrounding HIV. Common issues arose with each person interviewed. Most felt that the public had a serious lack of knowledge and therefore stigmatised and discriminated against people living with HIV. Everyone was very sympathetic and keen to help educate the public on the subject. She was beginning to wonder "Does stigma really exist?" Everyone seemed so compassionate and interested in the subject that she found it hard to believe people could be stigmatised and discriminated against for revealing their HIV-positive status.

At the end of the ceremony she decided to grab a hot dog. The stall attendant started flirting with her, obviously unaware of her HIV status. When she walked away he followed her and struck up a conversation. The talk soon led to the subject of HIV and the conference. She decided to continue her conversation as one last confirmation that stigma is only in the mind of the beholder.

"What's your opinion of stigma and HIV?" she asked.

"People with HIV have all had many, many partners," he replied.

Had she misheard him or misinterpreted his reply?

"What do you hope evolves from this conference?" she asked, praying for an inspiring reply.

"Nothing", he said.

“If I got a bad feeling about a woman I’d know she had HIV and I wouldn’t go near her. I would never touch a woman with AIDS”.

He went on to say he had never used a condom and never would as it would make him ‘less of a man’. He added that he would never share a cup with an HIV-positive person unless it was sterilised first.

He continued to flirt with her, as she stood there completely numbed by his ignorance. But she knew this wasn’t his fault. He had never been educated on the subject so here was her chance to make a difference.

“Would you touch someone with HIV?”, he asked.

“I have. I’m HIV positive.” she answered.

His eyes widened and within seconds his hand rose to touch her cold shoulder.

“I’m sorry . . . ”, but this wasn’t an apology for his remarks – “ . . . how long before you die?”

She explained that no one knows how long they have and as a result of advances in medication she could live a long healthy life. He remained touching her skin, ten minutes after saying he would never touch a woman with HIV.

He then announced, “I would make love to you and I would wear a condom”. What a sudden change in opinion.

“How about a drink during the week, if you’re free?”

She declined his offer but left feeling satisfied that she’d made a difference to one person’s life and he would in future think twice before having unprotected sex.

Exactly one year after her HIV diagnosis it seemed ironic that her first encounter of stigma would be at the International AIDS Conference. She learned that stigma unfortunately does exist, but she left satisfied in the knowledge that disclosure can reduce stigma. Breaking the silence really can make a difference. She saw him again two days later and held her head high as she walked on by.

When the truth hurts

Declan Montgomery, Ireland

Pull Quote

Defeating this epidemic is about bringing it into the open, not driving it into the shadows

Is honesty always the best policy when it comes to revealing your HIV status? Gcebile Ndlovu’s story suggests that sometimes the truth can hurt.

Sharing her experience at a meeting hosted by the International Centre for Research on Women (ICRW) at the International AIDS Conference in Toronto, Canada, Gcebile talked of how she was able to ‘come out’ about her HIV status in her own community in Swaziland with the support of her family. It was when she applied for a visa to the United States that she learned of the consequences of her honesty.

Travelling to the US as part of a group of people, Gcebile disclosed on her visa application form that she was HIV positive. She was told she would have to get a letter from her doctor, stating that she would not get sick while in the US, before they could issue a visa. There was a smattering of laughter in the audience as she told this and I wondered if the embassy would have been better asking her to go to a fortune teller rather than a doctor. When you think about how many people routinely travel to the US and other places around the world, suffering from all the various conditions and diseases that affect us all, it seems absurd that such an exception should be made for HIV.

Anyway, Gcebile eventually got her visa – for 3 months – while all her HIV-negative colleagues were issued visas for 10 years. It seems that her HIV-positive status, and perhaps more importantly her honesty in disclosing this, meant she was discriminated against. This raises important questions for people living with HIV (PLHIV) – as Gcebile put it, “our only crime is being HIV positive.”

If you disclose your status you run the risk of being discriminated against, and additional barriers will be placed in your way – barriers that do not exist for others whose status is unknown. Maybe in terms of travel, this might only be an inconvenience, but there seems to be another message given out when PLHIV are discriminated against. This subtle message is ‘keep your lips sealed – it’s better to say nothing’. This message feeds the silence that can accompany HIV and AIDS and promotes the stigma that surrounds it.

In a developed country like the United States, ‘the home of the brave and land of the free’, one might think that a more enlightened visa policy might exist – one that values such courage and honesty as Gcebile Ndlovu so clearly displays.

Defeating this epidemic is about bringing it into the open, not driving it into the shadows. So how about making honesty the best policy for a change?

The power of a personal story

Declan Montgomery, Ireland

Pull Quote

He said that by telling our stories, we empower ourselves

A hot topic at this year’s International AIDS Conference (IAC) in Toronto was the need to involve more people living with HIV (PLHIV), in the fight against the epidemic – particularly in tackling stigma and discrimination.

I was thinking this over when I overheard a conversation in a queue at the conference. Evidently, eavesdropping can be revealing. The basic conversation centred around one of the guys, a European, who was HIV positive and was recently refused entry to the US after his antiretroviral (ARV) drugs were discovered. The other guy wanted to raise this issue publicly, and by way of explanation, said something that really got me thinking. He said that by telling our stories, we empower ourselves.

What was most moving and had the most impact on me at the conference was listening to the stories of individual experiences of stigma and discrimination. It is inspiring when someone has the courage to stand up and ‘speak their world’; in a sense they are ‘coming out’, and the reality of who they are is what empowers the message. Mary Robinson, patron of the International Community of Women living with HIV (ICW), speaking at a meeting of Irish organizations taking part in the conference, talked of the need to empower positive people so that the fight against HIV doesn’t become too technical, losing its human face.

As rational thinking human beings, we might need targets and statistics, but as emotional beings, we are ‘moved’ to action by our feeling and reactions – and therein lies the power of storytelling.

I’ve been wondering what happens in this process, in the context of HIV, both from the perspective of the storyteller, and for the people listening.

Let’s start first with the storyteller; there is of course a price to telling your own story, particularly about HIV. The first casualty is anonymity. Suddenly you are no longer Joe or Anne; you are Joe or Anne, the guy, the woman, with HIV.

In certain situations telling your own story could literally cost you your life. Shirley Ann Brown, attending the IAC, works in a correctional facility (a prison) in the United States.

“People could be killed if their HIV status was known”, she told me. Confidentiality in this context is essential. However, in less extreme environments, does telling your own story really empower you?

David Mukasa from Uganda is openly HIV positive. He says that when you tell your story, “you empty other people’s mouths”. You disarm people. In his experience, when you speak, you find people come closer, and are very supportive.

M Giri Kumar, attending the conference from Hyderabad in India, is openly HIV positive and is involved in community education on HIV. Sometimes he is judged to be a bad person when he goes to communities, but this doesn’t stop him. “Why should I feel stigma, anyone can get the virus”, he said.

Gcebile Ndlovu, a woman from Swaziland speaking at the conference, said that she could never have ‘come out’ openly about her HIV status without the love and support of her family. “Love and understanding lighten the burden of living with HIV/AIDS” she said.

Finally, Robert Codero of Housing Works, a New York-based HIV advocacy organisation, spoke about his hopes for the IAC conference. He wanted the most marginalised people to have a voice and to speak directly to those in power. Anger at perceived injustice can also move people to speak out and demand action. And in a sense, this is the positive side of stigma and discrimination: it can bring people together in a common cause.

For the listener they react to the story, even if they react negatively with anger, they *do* react. A personal story well told can put a face to HIV. And it is harder to be indifferent to people. Facts and figures inform us of the technical ‘reality’ of HIV, but real people fill in the emotional blanks.

If we listen to people’s stories, we can empathise – we ‘see’ into someone else’s world. Several delegates attending the conference spoke about the need for education in overcoming stigma. The most powerful ‘educators’ we have are people living with HIV, why? Because they have a real story to tell.

I started this piece thinking aloud about whether telling their stories empowers people. Perhaps the power in storytelling is in being real and reaching out to other people. For those listening there is a chance to walk in someone else’s shoes for a while, and perhaps to be moved by what they hear, hopefully moved to action.

Inside back cover

Other HIV stigma publications

Four editions of The Correspondent *dialogues* addressing:

- Self-Sigma and HIV/AIDS
- Stigma, HIV/AIDS and Drug Use
- Stigma, HIV/AIDS and Disclosure
- HIV-related Stigma and Discrimination in the Workplace and Institutions

Living on the outside: Key findings and recommendations on the nature and impact of HIV/AIDS-related stigma – a Speak Your World Primer

All publications are available in electronic format at www.hdnet.org

For printed copies of the primer or the first two editions of The Correspondent please write to publications@hdnet.org

This page to include graphics of four stigma Correpondent covers in a fan – as on inside back cover of stigma primer (but without the rest of this image with the globe) and cover image of primer.

Back cover

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