THE FACE IN THE MIRROR: UNDERSTANDING AND RESPONDING TO HIV RELATED STIGMA

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INTRODUCTION

There was a time when I struggled to look at my face in the mirror. I did not like the person who looked back at me, because in some ways I was now what my family, community and faith had defined as bad, sinful and against the will of God. I was a homosexual. My punishment, according to many, was an HIV diagnosis, because in their eyes I was 'promiscuous', living a life of sin, a vector of disease.

This was during the mid-1980s, and much of these attitudes and reactions I believed at the time. With my HIV diagnosis in 1986, I carried the burden and internalised the negative things that society expressed about my identity, my behaviour and my condition. In many ways I was a 'victim'. I was a victim to my circumstance and belief system. I was a victim when, at the time that I most needed support from family, community and faith, it was withheld, and I felt guilty and ashamed. I struggled to find my voice and lay claim to my orientation and my identity, at a time when this needed to be explored and celebrated. But what I was living, what I felt and what I saw were only negative. The media fed into this cycle of negativity, and demonstrated the power of language. I was encircled by language such as 'HIV victims', 'AIDS sufferers', 'patients', 'gay disease' and 'guilty versus innocent victim'. These terms reinforced to that face in the mirror that he was bad. It was language that allowed society to find comfort in this game of blame, as it became an issue of 'us vs. them' and 'those type of people' who were the guilty ones, allowing those who did not fit this category to find false comfort in the belief that the rest of society was protected, immune and isolated.

Growing up believing that my homosexuality was dirty, sinful and wrong left a powerful imprint inside me. It made some part of me an ally of those awful voices who said that my infection with HIV was a judgement upon me, and a deserved judgement. This is the devastating, destructive working of internal stigma, or self-stigma.

UNDERSTANDING STIGMA AND DISCRIMINATION

I would like to believe that much of the reaction at the time was related to ignorance and fear, two powerful drivers that perpetuate and reinforce the vicious cycle of

HIV related stigma. Civil society has, over the last 30 years, played a critical role in defining and implementing an effective response to HIV, and in many parts of the world it is because of civil society mobilisation and action that we now have access to treatment, care and support for many people with HIV. But has civil society done enough around understanding and addressing the myriad of issues related to HIV stigma?

It is important to stress from the outset that we as people are civil society, because too often we forget that it is individuals, with individual concerns, struggles, joys and insecurities, who are the building blocks of this overused term of civil society. It is important to bear this in mind as we try and understand our individual role and responsibility in addressing HIV related stigma. Looking at issues that centre on individuals, such as self-stigma, is as important, if not more so, than addressing the broader societal and systemic issues.

HIV related stigma remains one of the more complex challenges when working to ensure an effective and humane response to HIV. We as civil society have an important role to play, both in addressing and challenging issues of HIV related stigma, and in understanding how stigma informs the reality of whether and how people living with and affected by HIV are able to access appropriate prevention, treatment, care and support services.

> **Definition of HIV related stigma and discrimination[1]**
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> HIV related stigma refers to the negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV, such as the families of people living with HIV, and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people.
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> HIV related discrimination refers to the unfair and unjust treatment, by act or omission of an individual based on his or her real or perceived HIV status. Discrimination in the context of HIV also includes the unfair treatment of other key populations, such as women, sex workers, people who inject drugs, men who have sex with men, transgender people, people in prisons and other closed settings and, in some social contexts, women, young people, migrants, refugees and internally displaced people. HIV related discrimination is usually based on stigmatising attitudes and beliefs about populations, behaviours, practices, sex, illness and death. Discrimination can be institutionalised through existing laws, policies and practices that negatively focus on people living with HIV and marginalised groups, including criminalised populations.

The World Health Organization (WHO) acknowledges that fear of stigma and discrimination is the main reason why people are reluctant to get tested, disclose their HIV status and take antiretroviral drugs.[2]

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1   'Reduction of HIV-related stigma and discrimination', UNAIDS, 2014, http://bit.ly/1JXS4Gr.
2   'Progress Report 2011: Global HIV/AIDS Response', World Health Organization (WHO), 2011, http://bit.ly/24OdRxo.

UNAIDS has set ambitious HIV related targets in its latest strategy.[3] The strategy describes the unfinished agenda of reducing new HIV infections in order to bend the trajectory of HIV. It is a bold call to action to ensure that those who are left behind are met with the services and support that they require, that the world is able to reach the global targets to extend access to treatment to all those who need it, and that funding is secured to properly resource an effective response. However, I fear that without understanding and addressing the different forms of HIV related stigma, these slogans and targets will remain just that: rhetorical slogans and unachieved targets.

Stigma and discrimination are terms that are often used interchangeably, but discrimination focuses on behaviour - treating people differently - while stigma is an attribute or fear - perceiving people as different. Stigma is referred to as a social process, closely linked to social inequality. It plays a key role in producing and reproducing relations of power and control and operates in relation to difference.[4]

Stigma may manifest itself internally or externally, and has different effects. External (enacted) stigma refers to actual experiences of discrimination.[5] These forms of discrimination can include exclusion, resentment and blame; punishment can sometimes lead to violence against people living with HIV.[6]

Internal (self) stigma is the shame associated with HIV. This can result in feelings of self-blame, worthlessness and negative self-judgement that impact on an individual's health and well-being. This is often played out in a person's inability to access services or disclose his or her HIV status.

THE GREATER INVOLVEMENT OF PEOPLE LIVING WITH HIV (GIPA) – AN EFFECTIVE CIVIL SOCIETY RESPONSE?

The idea that the personal experiences of people living with HIV could and should be translated into helping to shape a response to the AIDS epidemic was first voiced by people living with HIV in 1983 at a national AIDS conference in Denver, USA. This was the beginning of what has often been described as the 'patient response', and was the catalyst for many activists and self help and support groups around the world. At the core was a response to address HIV related stigma through participation and engagement. During this ground-breaking conference, HIV-positive activists announced a set of principles destined to revolutionise the way the world responds to this epidemic. The Denver Principles set forth standards for human rights and self-

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3   'On the Fast-Track to end AIDS. 2016-2021 Strategy', UNAIDS, http://bit.ly/1MYWQb8.
4   'Siyam'kela. Measuring HIV/AIDS related stigma. HIV/AIDS stigma indicators. A tool for measuring the progress of HIV/AIDS stigma mitigation', Policy Project South Africa and the Centre for the Study of AIDS, University of Pretoria, http://bit.ly/24LypTA.
5   'HIV-Related Stigma, Discrimination and Human Rights Violations. Case studies of successful programmes', UNAIDS, April 2005, http://bit.ly/1Oi4zBY.
6   Policy Project South Africa and the Centre for the Study of AIDS, op. cit.

empowerment in a health crisis. This important historical moment has defined and shaped how patient groups respond to their health condition, and it also led to a more mobilised movement of people living with HIV all over the world.

The sentiments expressed in the Denver Principles were the core of the Greater Involvement of People Living with HIV/AIDS (GIPA) principle, which formed an integral part of the Paris AIDS Summit. The summit, which took place on 1 December 1994 and was organised by the government of France along with the WHO, brought together 42 heads of state to renew their political commitment to the fight against AIDS. They all signed the Paris Summit Declaration, confirming the need for political leaders to make the response to HIV a priority. They had agreed to adjust their national policies and make the necessary resources available to tackle the pandemic. This included the commitment to providing adequate support for civil society, including people living with HIV, non governmental organisations and community based organisations working with vulnerable populations. GIPA was not meant to be a project or programme, but rather an ingrained principle that would facilitate more successful local, national and global responses to HIV. The GIPA principle means involving people with HIV at every level of the response.

During 1999, representatives of networks of people living with HIV worked with UNAIDS to develop an analytical framework that would refine the understanding of GIPA. The GIPA pyramid describes increasing levels of involvement, moving from describing people living with HIV simply as 'target audiences' and 'contributors' to progressively higher levels of involvement as 'implementers' and 'experts', and eventually as 'decision-makers'.[7]

It was through this process of defining, shaping and embracing a 'patient response' that HIV was given a face and that people living with HIV started to have a voice at important tables and deliberations. It is important to understand that 'patient response' and the subsequent GIPA principle were developed at a time when HIV treatment was not available, so for many of us activism at the time was a form of treatment, as it kept us engaged, focussed and motivated.

Civil society championed the GIPA principle when it was most needed. We have seen many examples of how people living with HIV have moved up the GIPA pyramid and are now an important part of various decision-making bodies at the country and international levels. I can chart my own pathway, having served on the board of the Global Fund to Fight AIDS, TB and Malaria, an international financing mechanism designed to accelerate the end of the three diseases. This, I know, contributed to breaking down barriers of ignorance and fear, but also gave me a sense of self-worth and purpose.
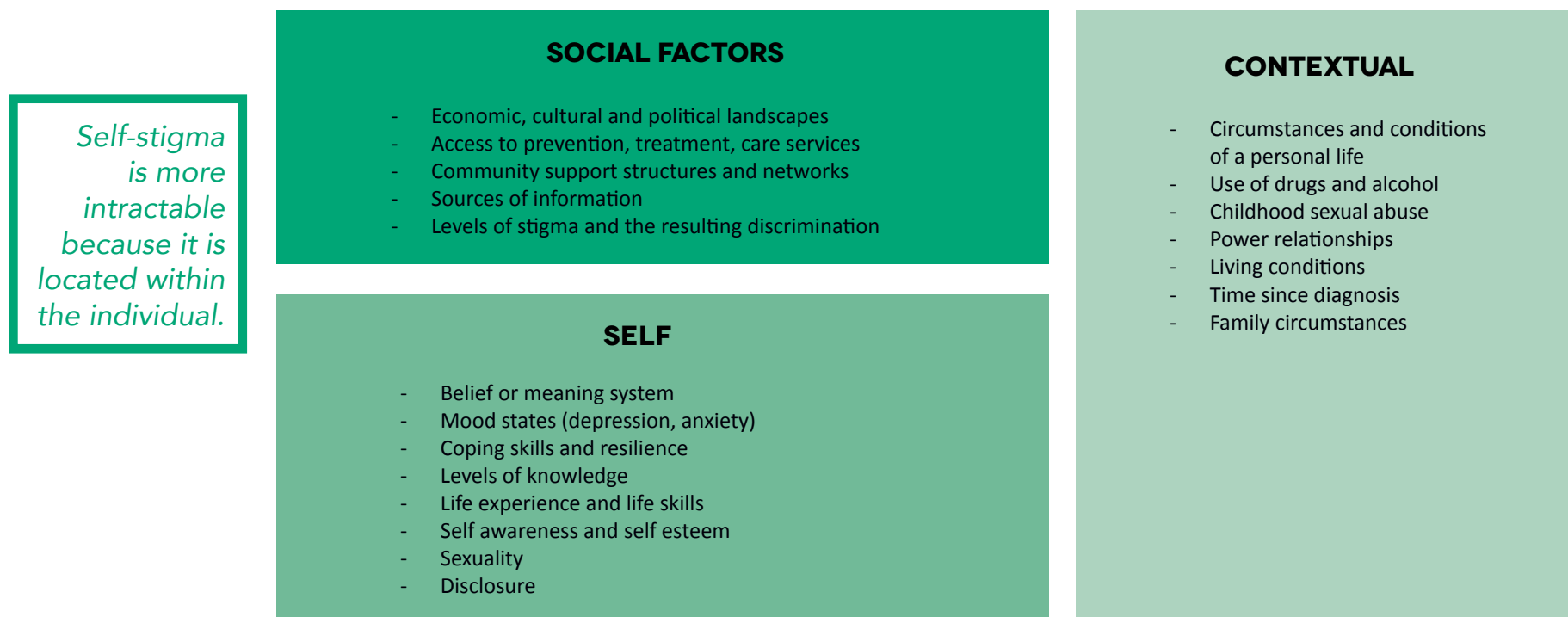
In the real world it is easier to respond to external (enacted) stigma when developing programmes. We have seen many countries and institutions develop policies, implement legislation and introduce programmes to train and sensitise those who are responsible. United Nations agencies and civil society partners have developed numerous approaches to address external stigma, from education campaigns to engagement with community decision-makers, and from systems to monitor HIV related stigma to peer advocacy and support.

These programmes are still vital and civil society continues to push for the necessary funding to retain and extend them. However, there is much more that needs to be done with regard to addressing self-stigma.

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7   'The Greater Involvement of People Living with HIV (GIPA)', UNAIDS, March 2007, http://bit.ly/1VTjRj2.

According to the well known HIV and gay rights activist, Justice Edwin Cameron, self-stigma is more intractable because it is located within the individual. He states that self-stigma is more insidious and more destructive than external stigma, as it eludes the direct, politically conscious confrontation with which we rightly respond to overt discrimination. He argues that our inability to respond effectively to self-stigma is not only impacting on our ability to understand the epidemic but is, more shockingly, also costing lives.[8]

Self-stigma is the result of complex interactions between social and contextual factors and the self, and in the midst of all of this is the individual, who is trying to deal with living and functioning.[9] Understanding this as civil society is paramount if we are to address HIV meaningfully. Our inability to deal collectively with this issue has, according to Justice Cameron, resulted in a gaping omission, where internal stigma forms virtually no part of individual, professional or programmatic responses to AIDS.[10]

Figure 1. Factors in self-stigma

Self-stigma is more intractable because it is located within the individual.

SOCIAL FACTORS

- Economic, cultural and political landscapes
- Access to prevention, treatment, care services
- Community support structures and networks
- Sources of information
- Levels of stigma and the resulting discrimination

CONTEXTUAL

- Circumstances and conditions of a personal life
- Use of drugs and alcohol
- Childhood sexual abuse
- Power relationships
- Living conditions
- Time since diagnosis
- Family circumstances

SELF

- Belief or meaning system
- Mood states (depression, anxiety)
- Coping skills and resilience
- Levels of knowledge
- Life experience and life skills
- Self awareness and self esteem
- Sexuality
- Disclosure

Nadine Ferris France developed the above framework in an effort to understand the gap in HIV response at the self-stigma level. This showed that research and action at all three levels are really important to tackle self-stigma, stigma and

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8   'Moving from promises to actions', Edwin Cameron, XVII International AIDS Conference, 6 August 2008.
9   Nadine Ferris France, 'An unspoken world of unspoken things. A study identifying and exploring core beliefs underlying self-stigma among people living with HIV and AIDS in Ireland', Dissertation submission, University of Dublin, Trinity College, July 2012.
10   Edwin Cameron, op. cit.

discrimination effectively. She argues that we should not attempt to deal with each factor in isolation when designing programmes because, while laws and policies could be perfect and enshrined in a constitution, people might still not be able to function well, access services or feel in control of their own lives due to attitudes and fear that pervade society. Similarly, addressing contextual factors such as living conditions and drug use will not be enough to help people who ultimately believe they are not worthy, suffer from depression or have difficulty coping.

Admittedly, civil society finds it easier to address the external issues. It is far more challenging to address the issues that require us to go inside, to show our vulnerability.

CONCLUSION

We, as the collective who make up the mosaic of civil society, need to ensure that we confront and challenge stigma wherever it appears. In our efforts to confront the face in the mirror, there are three broad areas that I believe we need to focus on:

1. RESEARCH

We know that stigma is not just related to HIV but to broader issues related to health, morality, people's fears and our fundamental beliefs, often shaped and informed from a very young age and influenced by our family, our community, our faith structures and our cultures.

- Academics and community based researchers need to develop more effective frameworks to explore and analyse the implications of self-stigma at the social, self and contextual levels, and find solutions that are applicable and relevant to all three.

2. ADVOCACY

Civil society needs to support people living with HIV with strong messages of solidarity and support. We now know that people can live healthily with HIV when they have appropriate access to prevention, treatment, care and support services and structures. Making this a reality by reinforcing the messages of positive living, health and dignity, particularly for those living with HIV, is the responsibility of the entire community and its related structures. There are a few tools available to support trainers and community leaders to begin to tackle this problem, such as the one used by the International HIV/AIDS Alliance, which evolved out of a two-year research project on stigma conducted in Ethiopia, Tanzania and Zambia.[11]

- Civil society organisations (CSOs) should encourage, support and empower people living with HIV to talk about the impact of self-stigma on their lives.

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11   'Integrating stigma reduction into HIV programming. Lessons from the African Regional Stigma Training Programme', International HIV/AIDS Alliance, March 2011, http://bit.ly/24OojVA.

- CSOs should themselves speak passionately about issues related to self-stigma, and ensure appropriate understanding and funding to address these issues within a broader holistic approach.

3. PROGRAMMES

The message of 'you are not alone' from Edwin Cameron, while not being an easy message to convey, is pivotal in ensuring that a person with HIV realises and understands that their feelings can be addressed and treated. We need to ensure that the community and faith structures that many rely on for support and guidance provide messages of acceptance and encouragement.

- CSOs need to address self-stigma head on and include the topic in training materials, workshop sessions and community dialogues. Civil society leaders, and other leaders, need to talk publically about the need to address stigma

Finally, when I now look in the mirror I am able to look back at the person with a sense of appreciation, gratitude, achievement, and - yes - love. I see someone who is a little older, informed by lived experience, visible through the wrinkles and greying hair. I am proud of who and what I am, and indeed of who I have become. Yes, I still struggle with issues related to self-stigma, but I understand them a little more now. I am able to put them into context and find ways of dealing with them. Most important of all, I am able to face myself in the mirror.