



A PUBLICATION OF THE AIDS LEGAL NETWORK

I am an *MSM*...

The implications of HIV healthcare strategies for securing the rights of sexual minorities

**Ross Reeves and
Robert Common**

Our understanding of sexual orientation and gender identity has long since moved beyond the heterosexual/homosexual binary. Yet even the more nuanced categories 'lesbian, gay, bi, and trans' (LGBT) fail to include many people who may, at times, engage in same-sex sexual activities. As a result, the 'MSM' (men-who-have-sex-with-men) category was developed, predominantly by medical institutions keen to incorporate all people at heightened risk of HIV exposure or transmission regardless of how these individuals understood their own sexual identity.



It soon became apparent that the response to HIV/AIDS could not be won without decriminalising 'sodomy' or 'unnatural acts' in order to allow these men access to prevention services, as well as testing and treatment services free from the threat of political and legal reprisal. This realisation in turn resulted in strong links being created between human rights and HIV/AIDS activists and advocates who sought (and continue to seek) to

Editorial...

Recognising the continuing need for critical discourse on human rights and HIV, this edition of the **ALQ** focuses on the realities, risks and needs of some of the populations 'most at risk' of HIV and human rights violations.

Acknowledging the progress made in the human rights and HIV response, the various contributions in this edition explore some of the tribulations and challenges of 'getting to Zero' discrimination and human rights abuses and 'leaving no one behind' in the context of criminalisation – both of 'key populations' and of HIV.

Analysing the implications of HIV healthcare strategies for securing the rights of sexual minorities, the article by **Ross Reeves** and **Robert Common** discusses the public health rationale behind introducing the terminology of 'men who have sex with men' or 'MSM' and the human rights and HIV response consequences thereof. Exploring the development and subsequent evolution of *MSM* as a concept, category and/or 'label', the article contends that although in some contexts the *MSM* category 'played a critical role in the protection of same-sex attracted men', it also 'creates as many problems as it solves'; as many times the focus of discussion becomes 'their behaviour and identity', instead of the 'multiple vulnerabilities and needs that individuals might have', which should be the determinants of the human rights and HIV response. With the 'box ideology' continuing – as argued by the authors – there may also be 'far reaching consequences' for both the human rights movement and the effectiveness of the HIV response.

Recognising the renewed commitments to and focus on 'key populations' and the simultaneous accelerated organising of and

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procure rights for *MSM* based on an HIV-led argument: i.e. ‘allow *MSM* their rights so that we can more effectively fight the epidemic’.

While the symbiotic relationship between human rights and HIV practitioners and strategists has created more space for debate around *MSM* (and indeed gay, bi and trans) issues and rights, the connection arguably creates as many problems as it solves.

This paper reflects on this connection and its implications, and questions the utility of forging new links between already marginalised and stigmatised populations, such as *MSM* and *PLHIV* (people living with HIV). Furthermore, as the term *MSM* comes to be adopted by men who predominantly identify as ‘gay’, the original apolitical and medicalised use of the term finds itself compromised. We do not completely reject the term *MSM*, but seek to emphasise the importance of careful and considered use of language in this arena.

GLOBAL COMMITMENTS

For the past 15 years there has been increasing acceptance around the world that a human rights-based approach to HIV prevention is the best way to meet the needs of people living with the virus. In 2001, the United Nations General Assembly Special Session on HIV

...creates as many problems
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(UNGASS) made this clear, stating in its Declaration of Commitment by member states the need to:

...eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights [for] people living with HIV/AIDS and members of vulnerable groups...¹

The UNGASS commitment recognises that ‘vulnerable groups’, such as sex workers, intravenous drug users, same-sex attracted men, etc., are disproportionately affected by HIV, and therefore in need of specific human rights protections to minimise these risks.

While acknowledging both the importance of securing human rights for such groups, as well as the relative effectiveness of such a strategy, there are also pitfalls relating to this approach, which need to be recognised and borne in mind to ensure that we do not do more harm than good.

MSM: THE RATIONALE

It was within the human rights approach to HIV prevention and treatment that the term *MSM* was first developed. The initial term was ‘men-who-have-sex-with-men-but-who-do-not-define-as-gay’. It was coined specifically to incorporate same-sex attracted men into HIV programmes, especially where these ‘non-gay

mobilising among 'key populations' (despite the increasingly 'hostile' and 'criminalised' environments) **Kene Esom** is providing an overview of the progress and 'set-backs' of MSM/LGBT people and communities organising in Africa. The article highlights the extent to which the legislative and socio-political framework – including religious and cultural institutions that 'drive homophobic discrimination and violence' – will continue to 'promote an environment in which stigma and discrimination can foster', as long as the many social and structural barriers limiting access to services for MSM/LGBT are not 'dismantled'. Albeit the challenges, he argues that 'turning the tide' is indeed a real possibility 'in our generation', based on 'the very essence of our humanity'.

HIV testing and counselling has been at the core of public health and human rights discourse for a long time, with a growing body of evidence indicating the multiple implications of 'criminalisation' in all its forms on access to healthcare services,

including HIV testing. It is as much the prevailing 'criminalised contexts', as it is the 'treatment as prevention revolution' which arguably demand a critical and 'careful examination' so as to ensure that human rights and HIV testing are not mutually exclusive. To this effect, the **UNAIDS Reference Group on HIV and Human Rights** issued an updated statement on HIV testing and counselling in June 2015. Providing a brief overview of 'key trends' impacting on HIV testing realities, and acknowledging that 'the barriers to testing remain largely unchallenged', the Reference Group clearly states that human rights are imperative for the scale-up of HIV testing and counselling; that 'greater efforts need to be devoted to removing barriers'; and that despite 'new technologies' and 'increased urgency', the 'same human rights' are to be protected and upheld.

The debates on whether or not condoms should be available at schools seems to be an equally ongoing discussion with little consensus. Questioning what youngsters will do,

Gahsiena van der Schaff revisits some of the arguments, whilst highlighting not only the 'enabling' policy and legal environment affording 'youngsters' as of 12 years of age access to sexual and reproductive health services, including condoms, but also the 'disabling' social environment limiting (and at times even denying) young peoples' agency to make informed decisions. Introducing various scenarios, she argues that young people may 'unambiguously decline the offer' or 'be tempted to try out "these adult tools" – but either way, the choice is made by young people and thus, 'will have benefits for young people'.

The progress made on the 'Zero new infection' target is a key element of 'Getting to Zero' and 'ending AIDS'; which requires among others adequate resources and funding from both domestic and international sources. The article by **Simone Thomas** examines some of the challenges associated with the transition from international donor funding to domestic funding – 'a daunting task' faced by many

identifying men were being overlooked. However, the term is now widely used for *all* same-sex attracted men, whether they identify as gay, bi, male-to-female (MtF) trans, or (as initially planned), none of the above.

The rise in popularity of the term *MSM* has grown in step with a steady increase in the visibility of self-identified sexual minorities. This, in turn, has led to much debate amongst national governments, international non-governmental organisations (NGOs) and global institutions, such as the United Nations (UN), as to how such a phenomenon should be addressed. Indeed, few global social advances have proved as polarising as that which is often referred to as the '*lesbian, gay, bi and transgender (LGBT) movement*', with many countries either establishing new legislation and/or reaffirming existing laws, which discriminate against same-sex attracted people.

Paralleling these trends has been a drive by international medical institutions for the recognition of *MSM* within national HIV prevention frameworks. The term *MSM* became popular owing to its intentionally sanitised and apolitical character that could thus incorporate all same-sex attracted men into clinical discussions of the HIV epidemic free of the politically charged disputes over sexual minority rights.

Thus, *MSM* were recategorised as one of several

...do not do more harm
than good...

...free of the politically
charged disputes over sexual
minority rights...

other '*key populations*' alongside subgroups such as sex workers, fishermen, migrant workers and so on. Such groups were identified as in need of specific healthcare strategies and preventive measures to mitigate their risk of HIV transmission; and reducing their risk would, in turn, reduce the wider society's exposure to the virus. For



countries classified as *'middle income countries'*. Looking at the South African context, she highlights the implications and risks of *'significant funding withdrawals'* on access to and quality of healthcare, as well as on the role and impact of civil society in the response to HIV. Arguing that a *'universal withdrawal of donor funds to South Africa makes little sense'*, she concludes that the transition can only be as successful as people (*'rather than numbers and quotas'*) are at the *'forefront of the transition'*.

The fact that *'legal protection alone will not end stigma'* is well recognised, as HIV risks and vulnerabilities are as much resulting from the *'legal'* as the *'social'* environment. Persistent prejudices, discrimination and violence against the *'other'* will – irrespective of enabling legal environments – continue to *'foster'* stigma and discrimination in the context of, and the response to, HIV. In his article, **Pierre de Vos** explores *'the ability of prejudice to devastate others'* with the story of a runaway date narrating the forms and impacts

of *'slow violence'*. The evolving *'story'* clearly shows that laws prohibiting discrimination do not prevent *'anyone from believing what they want to believe'*; thus *'acting upon'* these prejudices remains a *'devastating'* reality, despite the law.

The central theme to all articles is the impact of *'prejudices'* and *'criminalised contexts'* on the extent to which people are in a position to claim agency, exercise their rights, and access healthcare – thus the effectiveness of the human rights and HIV response. Albeit the many *'commitments'*, *'efforts'*, and *'changes'* trying to ensure that *'no one is left behind'* in the process of *'getting to Zero'*, reality shows that the *'barriers'* to rights and healthcare *'remain largely unchanged'* for many people who are *'marginalised'* and *'criminalised'* based on their *'identity'*, *'behaviour'* and/or HIV status – the very same populations for whom the mantra of *'no one left behind'* was developed.

These *'barriers'*, as long as they persist, will continue to determine *'who'* will be *'left behind'*, stigmatised

and discriminated against; irrespective of the *'ambiguous'* and *'well-intentioned target'* of *'getting to Zero'* discrimination and human rights abuses. Notwithstanding that law and policy *'reforms'* are *'critical enablers'* (so are *'commitments'*) in need of more concerted efforts, ultimately what is required is *'reforming'* the *'social environment'*, and ensuring transformation *'in practice, and not just on paper'*, that carries the potential for *'legal protections'* to become a lived reality for all. A reality in which a person's *'identity and behaviour'* are no longer the centre of debate (and at times the HIV response), but instead the complexities of human beings with all of our multiple *'identities and risks'*, and our *'common humanity'*. As without this *'change'*, many of *'us'* will remain *'labels'* or *'acronyms'*, instead of *'people'*, further increasing stigma and discrimination, limiting access to services, and heightening *'risks'* of HIV and related rights violations, whilst continuing to limit our agency...

JOHANNA KEHLER

instance, by decreasing the number of women exposed to HIV following unprotected sex with male partners who may have contracted the virus during sex with another man.²

Given this well-founded, medically-based reasoning for the protection of marginalised populations, it is perhaps little wonder that such a pragmatic approach has been adopted by human rights activists and organisations in their pursuit of broader sexual minority rights. Such an agenda has proved highly effective at times, generating public discussions relating to sexual minorities in countries where such topics have historically been deemed too controversial for debate, or where the existence of same-sex attracted people within their populations was denied altogether.³

Furthermore, small, localised and often clandestine sexual minority groups which had hitherto found little support within the international political arena often found themselves backed by powerful inter-governmental and non-governmental agencies. These agencies helped secure funding for such groups, largely on the basis of their specific vulnerabilities to HIV transmission. Intentionally or otherwise, this also elevated these groups' broader human rights agendas.⁴

...elevated these groups' broader
human rights agendas...

RIGHTS DISCOURSE AND EMERGING CHALLENGES

These developments are significant given the disproportionately high numbers of same-sex attracted men who continue to be at risk of HIV exposure or transmission. However, adopting an HIV prevention strategy as a *means* of procuring rights for sexual minorities can prove highly problematic for a number of reasons.

Firstly, given the stigma that people living with HIV are often subjected to, as well as the discrimination experienced by people of non-normative sexualities throughout much of the world, it is questionable whether an emphasis on the associations and intersections between these two groups would prove socially beneficial to either. Arguably such linkages not just reinforce the prejudices experienced by both and add further layers of stigma to different '*target populations*', serving to create further barriers to the services, which were designed, based on a clinical justification for this terminology.

It can also be argued that such an approach fails to take into consideration the diversity of many individuals who do not fall neatly into clearly delineated '*Key Population*' categories. For instance, a married man who identifies (to some) as gay, has a history of sex work, and is living with HIV. It is also worth noting, that the rights agenda for each '*Key Population*' may differ for each group in different contexts. Indeed, different rights agendas for different groups can sometimes not only be divergent, but potentially harmful to other so-called key population groups, therefore profoundly impacting the lived experiences of the most marginalised.

These tensions have been underscored recently by the example of the Indian Hijras. As Reddy⁵ explains, Hijras are widely regarded as a third gender within India, and indeed are protected as such under law. However, they have recently found themselves incorporated under the professional rubric of *MSM*, categorically placing them within an uneasy grouping alongside gender-conforming biological men. Such a categorisation undermines their ‘third gender’ identity, and subsequently leaves their political status in a paradox: their gender identity is protected under law, but their sexual orientation is assumed to be homosexual behaviour – which is currently illegal under the Indian penal code.⁶



Indeed the inclusion of people of non-normative gender identities under the *MSM* label has proved highly problematic in various settings, with male-to-female (MTF) trans persons often cited as logical biomedical candidates to classify as *MSM*, while female-to-male (FTM) trans persons are regarded as less relevant to the primary objective of mitigating HIV transmission. Yet, such classifying decisions often conflict with how these individuals perceive their own gender identities.⁷

...adopting an HIV prevention strategy as a means of procuring rights for sexual minorities can prove highly problematic...

Because the HIV epidemic affects same-sex attracted men in greater numbers than same-sex attracted women (for intelligible biological reasons), discussion of *women-who-have-sex-with-women* (WSW) within the human rights/HIV prevention equation is all but silenced⁸ in comparison to the attention given to *MSM*. Indeed, it is probable that the specific needs of such women cannot be accommodated by such a rhetoric, which is also at odds with the emergent evidence that WSW are increasingly affected by HIV and, in particular, gender-based violence (GBV). Moreover, such an approach does not demand human rights in and of themselves, but instead makes them contingent upon the response to HIV. It is perhaps an opportune moment for proponents and activists from

WSW and/or lesbian movement to garner and learn from the challenges that can come from ‘boxing’ *MSM* as one *Key Population*, an approach that often fails to take into consideration the multiple vulnerabilities and needs that individuals might have.

Within this contingent framing, commitment to the aim of broad political protection for sexual minorities may be vulnerable to changes arising from future medical advances in HIV prevention and treatment, or to other successes in the HIV response. Such changes might affect both the logic and the imperative for securing these groups’ rights: the imperative may be substantially weakened and/or simply face increased resistance from wider society. India provided a concrete example of this in 2009, when Delhi’s High Court overturned Section 377 of its Penal Code, thus decriminalising sodomy. One of the principle arguments for doing this was to ‘combat’ HIV/AIDS. Gruskin and Ferguson explain:

...the criminalisation of consensual sexual acts between adults in private [is deemed] inappropriate – because it was wrong to exclude or ostracise on the grounds of difference, and also because it was seen to drive people underground, making it harder to reach them with HIV prevention, treatment and care services.⁹

Nonetheless, in 2013, this ruling was overturned, with Supreme Court Justices claiming ‘*Indian society was not yet ready for the law to be repealed*’¹⁰. Thus, it seems that adopting a rationale of HIV prevention for legal reform – delinked from the principle that *all* citizens deserve human rights regardless of sexual orientation or gender

...profoundly impacting the lived experiences of the most marginalised...

identity – does not provide a strong enough basis to secure protections for those groups identified under the *MSM* banner.

SMART INVESTMENT?

Furthermore, international investment into nascent rights movements can be counter-productive in certain circumstances. For example, in some circumstances a ‘*workshop culture*’, often driven by a lack of coordination between international donors and stakeholders, can lead to key individuals spending precious little time working at grassroots level in their own contexts. Increasingly significant travel and time demands are placed on the leadership or key staff of such organisations. Anecdotal evidence has indicated that as the emergence of ‘*KP issues*’ and trends have become more pertinent to the response, there has been a correspondingly significant increase on the demands placed on some organisations, often by international NGO’s in an incoherent and sometimes territorial manner. This is not an issue that is exclusive to LGBTI or *MSM* movements, but arguably an issue for different ‘*populations*’, as the response has evolved over time.

In less developed movements there is a risk that this can cause a vacuum of capacity, and at its worst, it can cause resentment within home communities. Perceptions that some activists become ‘*celebrity*’ representatives of

...the MSM label has proved highly problematic in various settings...

specific movements, or movements within a particular country, can lead to a sense amongst some that these individuals are positioned to benefit from foreign travel and other related benefits. Whereas there may be clear benefits for the cause they might be championing, the counter argument that can be posited is that individuals are also enabled to develop and polish their personal brand and gain access to international fora, media and political powerbrokers. Much of the responsibility lies with the international community's failure to coordinate their demands on individuals and organisations. However, it must be emphasised that there are a great deal of profoundly brave and extraordinary activists, who have gained an enhanced profile that is well deserved. These are some of the complexities that highlight and reinforce the need for a nuanced approach when considering the bio-medical imperative to strengthen both the HIV response and the broader sexual minorities' rights agenda.

These concerns notwithstanding, the *MSM* category continues to gain traction from the grassroots level up to the major international agencies. And, as it does so, its value as an impartial, clinically-based term is increasingly challenged. The phrase, *MSM* is moving ever further from its original purpose of defining a specific sexual behaviour¹¹ towards solidifying into a distinguishable 'identity' – which is precisely what the term was originally

coined to avoid. Further interrogation of how this impacts programming trends and design is required. The evolving and now arguably 'false' identity of the *MSM* rubric may have implications for programming effectiveness. There may be important lessons that can be disseminated and may propagate new ideas that can inform the *MSM* response, as well as other so-called populations, such as *WSW* or Transgender.

Indeed the very development of *MSM* as a concept raises questions as to the type of information that may be generated or lost through its usage. Boyce and Khanna¹² evidence the complexities of drawing all sexual practices between men under one rubric, particularly once the term itself begins to carry the weight of connotation. For example, the localised sexual practice of *masti*:

...translates to 'fun' or 'intoxication' and can be simultaneously used to refer to sexual play between boys or men without significant implications to the sense of self. One does not become a homosexual by simply doing *masti*.¹³

...regarded as less relevant to the primary objective of mitigating HIV transmission...

The concept of *MSM*, as applied in HIV prevention (and, indeed, treatment programmes) which want very much to reach the type of men who practice *masti*, may

fail to do so because these men may now reject the label *MSM* as much as they would reject the labels ‘*homosexual*’ or ‘*gay*’. This creates further tensions and debate and gives rise to a range of questions:

- Has the problem with the *MSM* label become the lack of representation from other groups – because the current ‘*MSM community*’ is dominated by gay men, the very same not intended to ‘*attract*’ with the introduction of this label?



- And how does this affect service strategies that are mainly dominated by those who are openly gay? How does one reach the entire *MSM*

population when the ‘*non-gay-identifying men*’ are discriminated against and frowned upon by ‘*gay-identifying-men*’, or vice versa?

- New phraseology is already appearing in debates, including ‘*hidden MSM*’ and ‘*hard-to-reach MSM*’. Are these men who identify as gay or are they men who practice *masti* and do not wish to engage with LGBT dominated and tailored services? Furthermore, are we effectively addressing the needs of all transgender people within programming, if the architecture of these services is rooted in the needs of those who are able to participate in their design

These are some of the important questions that need further interrogation if we are going to effectively tailor services and strategies that meet the needs of the most excluded male populations and their sexual partners.

...classifying decisions often conflict with how these individuals perceive their own gender identities...

CONCLUSIONS

It is the objective of this paper to make HIV and human rights activists aware of the issues and complications which are linked to the use of the term

MSM and generate further debate around the growing tensions that have been touched upon in this paper.

Indeed, prior to the medicalised use of the term, and indeed before the perceived need for their inclusion into human rights programmes as a result of the HIV epidemic itself, there was virtually no social or political acceptance of same-sex attracted men in many contexts. The category *MSM* has, in some contexts, played a critical role in the protection of same-sex attracted men, both within the biomedical sphere, and increasingly within politics and wider society also – and in some contexts it continues to do so.

If the term were to be rejected, it is likely that replacement terminologies would take its place with their own complexities and inherent problems. Some might argue that a less graphic phrase, which is not so explicitly sexual, might be a useful evolution or adaptation when engaging some stakeholders who, for socio-cultural and other reasons, may be extremely hostile to even thinking about same-sex relations between men. In particular, this may prove useful when developing strategies to create legally and socially enabling environments. In most

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challenged...

cultures such words are widely used, but they are diverse and many come with negative connotations.

We hope that by remaining mindful of the challenges and complexities around this term, that activists, sexual health practitioners, academics – and, in particular, those men who place themselves into the *MSM* category (in whatever iteration they might identify with) – might have the opportunity to avoid some of the potential pitfalls.

This paper does not advocate an all-out rejection of the use of the term *MSM*. Far from it; rather, we advocate for further discussion to be had about what the term has become in a rapidly evolving HIV response and what that means for the broader human rights discussion.

Much debate and effort is focused on the boxing, categorisation or compartmentalisation of human beings into behaviours or identities. We have attempted to highlight some of the dangers that might result from such an approach, these are not just relevant to *MSM*, but have far reaching consequences for all of us who might be considered to be non-conforming or marginalised by society. Within the HIV response there has been a profound and obvious commitment by some to a ‘*box ideology*’ that creates significant challenges to accessing services and has an impact on the effectiveness of those

Who have you discriminated against lately?

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...played a critical role in the protection of same-sex attracted men...

services. There may also be far-reaching consequences for the human rights movement as it grapples with its bedfellow, the HIV movement. There is of course strong synergy, cross over and collaboration. However many rights advocates seemingly subscribe to the box ideology, whether willingly or unwillingly, as funding often dictates and flows from the HIV donors, who can be subject to a variety of influences and agendas.

For some, this has meant a growing failure to recognise the diversity of humans and our concurrent behaviours and evolving identities. By 'boxing' people into a category, we make their behaviour and identity the focus of the discussion and debate, potentially layering more stigma upon them, and subsequently not debating the fact that it is the public health system or government that is failing the individual, not the person saying, 'I am an MSM'.

FOOTNOTES:

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A set agenda and advanced discourse... MSM/LGBT organising in Africa¹

Your perspective on life comes from the cage you were held captive in.

[Shannon L. Alder]

Kene Esom

In recent years, countries in the sub-Saharan African region have seen considerable impact of their responses to HIV. In Eastern and Southern Africa, the rate of new HIV infections has been reduced by more than 30% overall and by more than 50% in seven countries in the sub-region.² AIDS-related mortality declined by more than 50% between 2005 and 2011 in several countries³ and by 39% in the sub-Saharan region between 2005 and 2013.

FRAMING THE CONTEXT: EPIDEMIOLOGICAL, LEGISLATIVE AND SOCIO-POLITICAL

The region has witnessed an expansion in the coverage of HIV treatment to a record number of people in recent years. In 2013 alone, 1.7 million additional people living with HIV received anti-retroviral therapy. Treatment is available to almost four in ten people living with HIV in the region.⁴

Despite significant progress, the epidemic continues to disproportionately affect sub-Saharan Africa – the region with 70% of all new HIV infections. The highest median

*Freedom
is always and exclusively
freedom for the one
who thinks differently*

Rosa Luxemburg – 1918

HIV prevalence among men who have sex with men (MSM) across regions globally was reported in Western and Central Africa (19%) and in Southern and East Africa (15%). HIV prevalence amongst MSM is generally higher than among men in the general population with studies showing 11-25% prevalence in Kenya, 21% in Malawi, 20% in Botswana and 12% in Tanzania.⁵ The only existing incidence report from the region showed 20% incidence among MSM in Kenya. The few epidemiological studies among transgender (TG) persons in the region generally have shown disproportionately high HIV prevalence ranging from 6% to 68%.⁶

Over 30 Member States of the African Union (AU) criminalise same-sex relationships in some way, often with penalties of up to 14 years imprisonment. Some

countries allow for life imprisonment and even the death penalty for those convicted.⁷ These legal frameworks expose these populations to targeted harassment, violence and marginalisation from healthcare and other services.⁸ Recent years have seen increasing efforts to broaden same-sex criminal offences, increase criminal penalties and strengthen law enforcement against sex between men in countries in the region.⁹ In Nigeria and Uganda, the adoption of new restrictive legislation is thought to have resulted in increased harassment and prosecution based on sexual orientation and gender identities. HIV outreach workers and service providers working with gay men and other MSM in these two countries have also reported heightened challenges in reaching this population. A recent article on the impact of Nigeria's Same Sex Marriage [Prohibition] Act reported significantly higher levels of fear of seeking HIV services among MSM.¹⁰

A similar situation is being seen in the Gambia where a 2014 amendment to the country's Criminal Code toughened existing laws punishing people for the 'crime'

...higher levels of fear of seeking
HIV services...

of homosexuality and lengthened the criminal sentences for those found guilty. Some outreach organisations and health service providers have stopped or reduced the scope of their activities owing to the fear of harassment

and prosecution.¹¹ In some countries, laws also ban organisations that represent or support lesbian, gay, bisexual or transgender individuals and discourage service providers from reaching these communities.¹²

...discourage service
providers from reaching
these communities...

Governments in the region often cite the existence of criminal laws as justification for their failure to provide specific health services, such as HIV prevention programmes tailored to meet the needs of MSM and for prisoners. Evidence shows that the legal frameworks and prevailing stigma and discrimination act as barriers to services. In Botswana, Malawi and Namibia, 42% of MSM surveyed reported at least one experience of human rights abuse, including blackmail and denial of housing and healthcare. About 20% of MSM surveyed in those countries reported fear of seeking health services, because of their sexual orientation.¹³ Decreases in health-seeking behaviour because of human rights abrogation have also been reported from Lesotho, Senegal, and South Africa.¹⁴ In Seychelles, 44% of MSM surveyed reported being arrested in the previous six months.¹⁵

A health needs assessment has been recently conducted by 15 LGBTI organisations from Botswana, Namibia, South Africa, Lesotho, Swaziland, Mozambique, Zimbabwe, Zambia and Malawi, reaching over 2,500

LGBT people in 27 locations. Results from this survey confirm – on a wide scale in the region – that LGBT people have low uptake of HIV/STI testing, limited knowledge on safer sex practices, misconceptions about risk and risk-behaviours, difficulty accessing commodities such as dental dams, condoms and lubricants, limited ability to negotiate the use of protection, particularly in situations involving transactional sex. Some of the LGBT people reported being denied health services. The research also confirms the earlier mentioned delayed health seeking behaviour, due to fear of stigma and negative attitudes from healthcare workers.¹⁶ Criminalisation not only drives MSM underground making them an invisible and harder-to-reach population, but it has also foreclosed the discussion on anal sex among heterosexual partners, thus making it impossible to determine their contribution to the HIV epidemic.

...making it impossible to determine their contribution to the HIV epidemic...

The impact of criminalisation of same-sex conduct also affects refugees and forced migrants, particularly those fleeing situations of armed conflict. In the past few years, the extent of rape and other forms of sexual violence as weapons of war in Africa's armed conflicts have come to the fore. High levels of sexual violence, including forced anal intercourse, have been reported

among male refugees fleeing the armed conflicts in the Democratic Republic of Congo and the Great Lakes region.¹⁷ Unfortunately, these refugees are unable to access adequate healthcare service in their countries of refuge, due to criminalisation of sodomy.

...suppress and penalise gender non-conformity using criminal provisions...

In many countries, the law offers little, if any, protection to transgender persons. They are marginalised by legal systems that do not recognise '*transgender*' as a valid form of gender identity and which suppress and penalise gender non-conformity using criminal provisions against cross-dressing, impersonation, indecent dressing, and so on. This has a number of implications, including the inability of transgender persons to access healthcare, obtain identification documents that reflect their gender or secure employment and education.

Criminalisation of MSM/LGBT persons promotes an environment in which stigma and discrimination can foster. When the law punishes certain sexual behaviours and identities, MSM/LGBT persons can neither count on law enforcement agents for protection from violence nor seek legal redress when they are the victims, especially when the perpetrators are police officers.¹⁸ Together, punitive laws, discriminatory enforcement and

systematic barriers to justice further entrench stigma and discrimination against MSM/LGBT persons.

Criminal provisions are not the only aspects of the legal and policy framework that impact on access to services for key population. Even in the absence of criminalisation of key populations, other policies, such as the national strategic plans, ministerial decrees and regulations, guidelines, protocols and operational plans, may present significant systemic barriers to access to service for MSM/LGBT persons.

...promotes an environment in which stigma and discrimination can foster...

The role of religion and culture in the socio-political landscape of many African countries cannot be over-emphasised. Religious and cultural institutions continue to drive homophobic discrimination and violence in Africa. Focus group discussions held with MSM/LGBT groups in seven African countries identified religion and culture-based homophobia as the sixth of top-ten barriers to accessing HIV services.¹⁹ The Pew Research Centre's 2013 LGBT Survey found a strong link between a country's religiosity and opinions about homosexuality; and showed that there is far less acceptance of homosexuality in countries where religion was central to people's lives.²⁰ According to the survey:

Publics in Africa and in predominantly Muslim countries remain among the least accepting of

homosexuality. In sub-Saharan Africa, at least nine-in-ten in Nigeria (98%), Senegal (96%), Ghana (96%), Uganda (96%) and Kenya (90%) believe homosexuality should not be accepted by society. Even in South Africa where, unlike in many other African countries, homosexual acts are legal and discrimination based on sexual orientation is unconstitutional, 61% say homosexuality should not be accepted by society, while just 32% say it should be accepted.²¹

Religious leaders played an active role in the drafting and promotion of the Anti-Homosexuality Act in Uganda. In a number of other countries, religious rhetoric plays a vital role in conversations around the enactment of homophobic legislations and policies. In The Gambia and Senegal, from Uganda to Zimbabwe, and in other parts of Africa, homophobia and transphobia has become a common feature of politicking and election. These statements by politicians, top public officials and community leaders, coupled by the silence of heads of States, national human rights institutions, national AIDS councils and mainstream human rights civil society organisations, reinforce to the general public that discrimination and violence against MSM/LGBT

...religious and cultural institutions continue to drive homophobic discrimination and violence in Africa...

persons is permitted by the State. It is trite knowledge that homophobia is becoming a major campaign tool during electioneering and so does violence against LGBT persons during election season.

RESPONDING TO THE CONTEXT: MSM/LGBT ORGANISING IN AFRICA

The past few years has witnessed the emergence of many MSM/LGBT organisations in African countries; increased interactions with government departments, especially the national AIDS councils, Ministries of Health and Justice and national human rights institutions; increased judicial activity; and improved country level coordination among MSM/LGBT organisations, HIV/human rights CSO-partners, development agencies and donors.

I will take a moment to highlight the work and different approaches of a few organisations I have come to know and work with over the past years and whose work I admire and respect. I salute the efforts of MSM/LGBT

...homophobia and transphobia
has become a common feature of
politicking and election...

organisations, who are running clinics and drop-in centres for key populations and in many cases have opened their doors to their surrounding communities as a way of promoting brotherhood and sisterhood and banishing the invisibility that allows stigma and discrimination to thrive.

Organisations in Togo, Malawi, Ghana, Zimbabwe and Mozambique have demonstrated the possibility of moving national conversation on MSM/LGBT issues forward through engagement with policymakers, national agencies and participation in law reform and constitutional review processes. In Botswana, Uganda and Kenya, for example, organisations have demonstrated that victories can be won through the courts to advance equality and non-discrimination based on sexual orientation and gender identity/expressions.

...banishing the invisibility that
allows stigma and discrimination
to thrive...

In North Africa, a sub-region with limited information on the situation of MSM/LGBT persons, organisations in Algeria, Tunisia and Egypt are using the creative and performing arts to address stigma and discrimination against MSM/LGBT persons in their contexts. Similarly, organisations in Sudan are engaging their communities through the arts, social and cultural events with a view to promoting understanding and respect of sexual and gender diversity and the rights of MSM/LGBT persons.

This is by no means, an exhaustive list and I am sure many other organisations come to mind. I have merely mentioned these few symbolically to encourage us to take the time to appreciate the courage and resilience that MSM/LGBT organisations continue to demonstrate in

the face of truly challenging national contexts.

At a continental level, coalitions and networks, such as the Coalition of African Lesbians [CAL] and the African Men for Sexual Health and Rights [AMSHeR], have given a face and voice to African LGBT persons and their issues in spaces where historically these issues were taboo. As a result of their advocacy, and collaboration with a range of CSO partners and allies, their *May 10 Statement [2012]* caused the UN Human Rights Council to re-consider proposed mechanisms for addressing violence and discrimination

based on sexual orientation and gender identity [SOGI] with an analysis of the voices of African communities; the African Union's first document on SOGI – Resolution 275 condemning violence based on SOGI was adopted by the African Commission on Human and Peoples' Rights in April 2014.²²

...in the face of truly challenging national contexts...

In a variety of other spaces progress is being made locally, regionally and globally driven by African MSM/LGBT organisations, the agenda is being set and the discourse is being advanced. I am convinced that we are at a precipice with regard to MSM/LGBT organising,

because as these successes are being witnessed and progress is being made, the forces opposed to the cause



are also getting better organised, more coordinated and significantly well resourced. However, the tide is turning but in order to sustain this, we must each acknowledge the cages that hold/held us captive and break free from them. Only in doing this are we able to learn from each other, develop stronger partnerships and find innovative ways to address discrimination based on sexual orientation and gender identity and advance access to quality health services for MSM/LGBT persons.

**TURNING THE TIDE:
THOUGHTS ON THE WAY FORWARD**

At AMSHeR we believe in five guiding philosophies that underpin our work and I share these here because I am convinced that they are crucial to sustaining the advances that have been made. They are:

Human rights-based approach to health: Ensuring that human rights principles are the basis of public health interventions for MSM/LGBT

...the agenda is being set and the discourse is being advanced...

persons. This approach focuses on addressing marginalisation, exclusion and discrimination in healthcare and health service delivery. It requires an analysis of the different forms of discrimination, power imbalances and structural factors that perpetuate marginalisation.

Intersectionality: This rests on the idea that contexts are complex and made up of a range of factors that enhance or hinder the ability of MSM/LGBT persons to access their rights. People are impacted and affected by multiple reality sets. A focus on only one reality set will invariably result in limited analyses and responses and inadequate outcomes in regard to rights access and enjoyment. The intersectional approach requires a consideration of these multiple realities in planning, implementation of interventions and in advocacy.

...abdicated their responsibilities and failed in their obligation...

Incremental approach: A recognition that while there is an ideal society where stigma, discrimination and violence are eliminated, and where human

rights are respected, protected and promoted, this may not be attainable immediately. Thus effective context-specific strategies require strategic engagement and planning to achieve realistic outcomes [lower hanging fruits] within particular operational contexts while working steadily towards an ideal society.

Empowerment model: Promoting partnerships and strategies that reinforce autonomy and agency of African MSM and LGBT individuals and communities instead of charity models that perpetuate dependency.

Positive narrative: Entails portraying 'the other narrative' that celebrates the courage and success of African MSM/LGBT individuals; and the rich diversity and humaneness of the African peoples; an acknowledgement that the 'victim, homophobic' narratives that dominates discourse on sexual orientation and gender identity in Africa is only one side, and not the full story of Africa or African MSM/LGBT individuals.²³

With the above in mind, I will speak to five specific levels at which we must demand accountability.

The State as primary duty-bearer

Discrimination on any grounds including gender, sex, sexual orientation, social class, medical condition and nationality, comprise human rights violations. The responsibility for the protection and promotion of the rights of its citizens primarily rests on the State. Stigma, discrimination, violence and other human rights violations

against MSM/LGBT persons continue on our continent because African States, politicians, policymakers and public officials have abdicated their responsibilities and failed in their obligation to respond to the HIV epidemic through scientific and empirical evidence and respond rather through fear, ignorance and moralisation.

...create the enabling legal and policy environment necessary to achieve substantive equality of African citizens and end HIV...

It is the responsibility of the State and its agencies to create the enabling legal and policy environment necessary to achieve substantive equality of African citizens and end HIV. This begins, but does not stop at, decriminalising communities of MSM, LGBT persons, sex workers and other key populations. A successful national HIV response must necessarily address all other policy points that create barriers to access to service for MSM/LGBT persons, such as mechanisms for enforcement of human rights, raise the ambit of protection against sexual and gender-based violence, ensure privacy and confidentiality of clients' medical and personal information, consent for HIV testing, treatment and clinical research. This also includes policies dealing with effective engagement of the said communities in intervention design, access and implementation.

A positive national legal and policy framework must ensure that condoms and lubricants are included as HIV prevention commodities in the National Essential Medicines List; the procurement and supply management of medicine and commodities adequately anticipates the needs of MSM/LGBT persons in stocking, as well as stigma-free distribution channels; that the overall design of sexual reproductive health and rights [SRHR], STIs and HIV services are MSM/LGBT-sensitive and friendly; and the information, education and communication materials, including the training curriculum of healthcare services providers, speak to the needs of those who practice anal sex within both same-sex and opposite sex relationships and LGBT persons. For many of these policy points I have mentioned, the final policymaker is often someone within our sphere of influence.²⁴

...violence, stigma and discrimination will remain rife and ending HIV will remain an illusion if religious and cultural institutions do not change their messaging...

There is also an equally important duty to ensure that adequate enforcement mechanisms exist to operationalise these policies and provide continuing training of relevant stakeholders, including law enforcement agencies, prison officials, health service providers among others.

The Media

The right to freedom of expression and the press carries with it special duties and responsibilities and may be subject to certain restrictions for the respect of the rights and reputation of others.²⁵ This right must necessarily be exercised within the law.²⁶ Hate speech and any advocacy of hatred that constitutes incitement to discrimination, hostility or violence is prohibited by international law and the State has a responsibility to prevent these and punish perpetrators.²⁷

In our recent memory we have seen the power of the media to incite hatred and violence demonstrated in places like Rwanda and Kenya resulting in the deaths of hundreds of thousands of people. Our collective psyche should be as repulsed by similar incitement of hatred and violence against MSM and LGBT persons in places such as Cameroon, Nigeria, Senegal, The Gambia, Zambia and Zimbabwe for the truth is that the consequence in loss of human life is no less fatal than was in Rwanda.

...perpetuating stigma,
discrimination and exclusion
in spaces where MSM/LGBT
organisations should ideally
find solace...

The media should be held to a high standard of ethics and objectivity in reporting issues affecting MSM/LGBT persons. The same aggressive

...showcase a positive narrative,
rather than a single story
of victimhood...

media partnerships and campaigns that helped to achieve a reduction in the HIV-related stigma and prevalence in the general population is necessary to achieve non-discrimination based on SOGI and advance access to quality health services for MSM/LGBT persons.

Religious and Cultural Institutions

The role of religious and cultural institutions in reducing stigma and discrimination against MSM/LGBT persons cannot be downplayed nor over-emphasised. The irony is that the same arguments, doctrines and dogma being used today to promote stigma, discrimination and violence against MSM/LGBT persons were the same arguments used to persecute and ostracise people living with HIV in the early days of the epidemic in Africa.

It is trite that a crucial corner in the HIV response in Africa was turned when religious and cultural institutions, shunning fear, ignorance and silence became part of the response. Across Africa today, MSM and LGBT persons are denied access to HIV services, especially those run by faith-based organisations or serviced by people of faith. As earlier mentioned, in focus groups discussions conducted by AMSHeR with MSM/LGBT persons in seven African countries on barriers to access to services, proselytizing by healthcare service providers was one of

the main barriers identified. In some towns across the region, Fridays and Sundays, traditional days of worship for most adherents of Islam and Christianity have become days of trauma and anguish for MSM/LGBT as they persistently live with the reality that their members and communities may become victims of violence by mobs who have been incited to violence by the hate messages of religious leaders. Given the principal place of culture and religion in the social-political fabric of most African countries, violence, stigma and discrimination will remain rife and ending HIV will remain an illusion if religious and cultural institutions do not change their messaging.



Donors and Development Partners

There is a role for donors and development partners in ending stigma and discrimination against key populations through responsible funding of MSM/LGBT organisations and issues and the development of technical guidance and guidelines for effective programming for MSM/LGBT interventions respectively.

Responsible funding is important to ensure that funding models promote partnerships and strategies that reinforce the autonomy and agency of African MSM and LGBT persons and communities instead of charity models that perpetuate dependency. It is also necessary to ensure that the generation old principles of *Do No Harm* and *Nothing About Us Without Us* are respected. Relationships between donors and grantees should contemplate the risks involved in undertaking the work that MSM/LGBT groups undertake in challenging contexts, and incorporate contingency planning and funding as part of grant arrangements. Core support, especially those aimed at organisational development and internal systems strengthening, should be prioritised.

Donors and development agencies should prioritise the organisations in the trenches, value and support them to document and tell their stories in ways that showcase a positive narrative, rather than a single story of victimhood.

We have learned from our members and communities across the region that some of the most difficult offices to access in their countries are those of the donor organisations and development

...promote understanding and camaraderie with the society in which they live...

agencies and their local partners who are supposed to be allies of the MSM/LGBT community. Headquarter rhetoric rarely filters down to country offices and partner organisations, thus perpetuating stigma, discrimination and exclusion in spaces where MSM/LGBT organisations should ideally find solace.

Whereas there is certainly a place for allies, mainstream HIV/human rights organisations in advancing MSM/LGBT issues; in many spaces, it is important that MSM/LGBT persons themselves are the voices and faces of advocacy with their policymakers and stakeholders. *Lack of capacity* should not be used as an excuse to further *invincibilise* our communities and deny them needed exposure and resources. Allies should, and must work in genuine partnership and consultation with communities who at the end of the day will live with the consequences of their interventions.

CONCLUSION

In conclusion, the essence of this paper was not to merely provide empirical evidence of the disproportionate burden of HIV on MSM/LGBT persons or the impact of stigma and discrimination against MSM/LGBT persons on the HIV response, nor was it necessarily to convince you that there will be no end to HIV without dismantling the social and structural barriers that limit access to health services. The paper highlighted the fact that through blood, toil and sweat, MSM/LGBT groups have borne the disproportionate burden of addressing stigma, discrimination and violence by creating safe spaces for members of their communities to access crucial health

...ending HIV and discrimination based on sexual orientation and gender identity is possible in our generation...

services and to promote understanding and camaraderie with the society in which they live. All this is trite knowledge to most of us.

The aim of this paper was to frame the context of MSM/LGBT organising with a view to challenging each of us to rid ourselves of the cages that hold/held us captive and change our perspective on MSM/LGBT persons and issues and how to work in partnership with their communities. Ending HIV and discrimination based on sexual orientation and gender identity is possible in our generation, but each of us must eschew hatred, fear and ignorance and in the famous lyrics of late pop idol, Michael Jackson, take a hard look at the [hu]man in the mirror and ask him or her to make the change; *'no message could have been any clearer, if you want to make the world a better place, take a look at yourself and then make a change'*.²⁸

We cannot continue to turn a blind eye to stigma, discrimination and violence against MSM/LGBT persons. These are fuelled by hatred, fear and ignorance and together we must stand up and speak out against these. This is the very essence of our humanity, the very essence of *'ubuntu'*.

I leave you with these parting words from Nelson Mandela who reminded us that:

*No one is born hating another person because of the colour of his skin, or his background, or his religion. People must learn to hate, and if they can learn to hate, they can be taught to love, for love comes more naturally to the human heart than its opposite.*²⁹

FOOTNOTES:

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New technologies, increased urgency, same human rights... HIV testing and counselling¹

The UNAIDS Reference Group on HIV and Human Rights has actively promoted a rights-based approach to HIV testing and counselling since its first meeting in 2003. The Global Fund Human Rights Reference Group, which advises the Global Fund Secretariat on operationalizing its strategic commitments to protect and promote human rights, endorses this statement in its independent capacity.

UNAIDS Reference Group on HIV and Human Rights

BACKGROUND

In 2004, the UNAIDS Reference Group issued its first statement on HIV testing and counselling, outlining the key factors to simultaneously address in order to ensure a rights-based approach to scaling up access to HIV testing and counselling.² In 2007, the UNAIDS Reference Group was compelled to issue a further statement and recommendations on HIV testing and counselling in response to a *Guidance on Provider-Initiated Testing and Counselling (PITC) in Health Facilities*, issued by WHO and UNAIDS.³

The 2007 WHO and UNAIDS PITC *Guidance* noted that:

Positive outcomes are most likely when HIV testing ... is confidential and is accompanied by counselling and informed consent, staff are adequately trained, the person undergoing the test is offered and referred to appropriate



follow-up services, and an adequate social, policy and legal framework is in place to prevent discrimination.⁴

The UNAIDS Reference Group welcomed this *Guidance*, emphasizing that HIV testing and counselling must be implemented in ways that maximize benefits to individuals and public health and respect, protect, and fulfil human rights.⁵

In subsequent years, approaches to HIV testing and

counselling have continued to evolve, and human rights have remained a central concern. In 2012, WHO and UNAIDS reaffirmed their opposition to mandatory HIV testing.⁶ Also in 2012, WHO issued a policy framework document on service delivery approaches to HIV testing and counselling, which advocated continuing effective and appropriate PITC in healthcare facilities while expanding HIV testing and counselling beyond healthcare facilities.⁷ This document reiterated the need for human rights protection, regardless of the testing model and how testing

is offered; emphasized the fact that the ‘5 Cs’ (i.e., consent, confidentiality, counselling, correct test results, and connection to care) of good testing practices continue to be relevant and should always be guaranteed; stressed that testing must always be voluntary; and noted that testing should not be promoted in situations where a positive test result could lead to discrimination, or where choosing to test is treated as indicating criminal behaviour.

Amidst calls to ‘normalize’ testing and target interventions in order to increase impact, the UNAIDS Reference Group refocused on HIV testing and counselling issues at its fifteenth meeting in December 2013. The Reference Group considered new developments such as ‘treatment as prevention’ and increased testing settings and modalities as they relate to maximizing the benefits to individuals, communities, public health, and human rights protection.⁸

...human rights have remained a central concern...

The Reference Groups endorse these fundamental messages about increasing access to voluntary HIV testing and safeguarding human rights that it has consistently advanced. We strongly support efforts to expand access to voluntary HIV testing as part of a continuum of care⁹ from prevention to sustained treatment. The Reference Groups also believe that addressing barriers to voluntary

HIV testing is both an integral element of the HIV testing scale-up agenda and critical to meeting the objective of increasing the number of people who know their status in order to link to care those who are living with HIV. Barriers

...addressing barriers to voluntary HIV testing is...critical to...increasing the number of people who know their status...

include, but are not limited to: laws and policies, including those relating to age of consent and confidentiality, that hinder access to HIV testing, particularly for adolescents; inadequate HIV testing policies that violate informed consent, privacy, and confidentiality, or that restrict the availability and uptake of innovative or client-controlled HIV testing models; lack of legal services (for gender-based violence, property-rights abuses, discrimination in housing and employment, and criminalization of homosexuality, sex work, drug use, and HIV non-disclosure, exposure, and transmission); insufficient care and support services (including for opportunistic infections, antiretroviral therapy [ART], and for other conditions such as tuberculosis [TB], hepatitis C virus [HCV], drug dependency, etc.); and widespread HIV-related stigma and discrimination.

The UNAIDS Reference Group is issuing this updated statement on HIV counselling and testing to reiterate its position on HIV testing, which is fully endorsed by the Global Fund Reference Group. This statement is informed

by three key trends that have emerged since the UNAIDS Reference Group issued its last statement on HIV testing in 2007:

1. Prolific unjust criminal laws and prosecutions, including the criminalization of HIV non-disclosure, exposure, and transmission;
2. Expanded HIV treatment availability (both geographically and second- and third-line treatments), and evidence supporting the effectiveness of HIV treatment as a means of preventing transmission as well as treating HIV illness (i.e., *'treatment as prevention'*); and
3. International policy directions focused on greater impact and greater speed in order to *'end the AIDS epidemic as a public health threat by 2030'*, recognizing that effective interventions need to respond to epidemiological context (in particular, better addressing the needs of youth and key populations), and to the barriers to accessing voluntary HIV testing, prevention services, and sustained treatment faced by key populations.

...despite evidence that criminalization is not an effective public health response...

KEY TRENDS

Proliferation of unjust criminal laws, including the criminalization of HIV non-disclosure, exposure, and transmission

The criminalization of HIV non-disclosure, exposure, and transmission is not a new phenomenon, but the vigour with which governments have pursued criminal responses to alleged HIV exposures – at the same time as our understanding of HIV prevention and treatment has greatly advanced, and despite evidence that criminalization is not an effective public health response – causes considerable concern to HIV and human right advocates.⁹

...considerable concern to HIV and human right advocates...

In the last decade, many countries have enacted HIV-specific laws that allow for overly broad criminalization of HIV non-disclosure, exposure, and transmission. This impetus seems to be *'driven by the wish to respond to concerns about the ongoing rapid spread of HIV in many countries, coupled by what is perceived to be a failure of existing HIV prevention efforts'*.¹⁰ In some instances, particularly in Africa, these laws have come about as a response to women being infected with HIV through sexual violence, or by partners who had not disclosed their HIV status.¹¹

Emerging evidence confirms the multiple implications of the criminalization of HIV non-disclosure, exposure,

and transmission for HIV testing and counselling.¹² For example, HIV criminalization can have the effect of deterring some people from getting tested and finding out their HIV status. The possibility of prosecution, alongside the intense stigma fuelled by criminalization, is good reason for some to withhold information from service providers or to avoid prevention services, HIV testing, and/or treatment. Indeed, in jurisdictions with HIV-specific criminal laws, HIV testing counsellors are often obliged to caution people that getting an HIV test will expose them to criminal liability if they find out they are HIV-positive and continue having sex. They may also be forced to provide evidence of a person's HIV status in a criminal trial. This creates distrust in relationships between people living with HIV and their health care providers, interfering with the delivery of quality health care and frustrating efforts to encourage people to come forward for testing.

...emerging evidence confirms the multiple implications...

Alongside the criminalization of HIV non-disclosure, exposure, and transmission, we also see vigorous criminalization of LGBTI people, sex workers, and people who use drugs in many parts of the world. This sort of criminalization is stigmatizing, drives key populations away from testing and services, and can make HIV testing a life-endangering rather than life-saving act. It is critical

to consider this harsh context when devising interventions to scale up HIV testing and counselling.¹³

As the UNAIDS Reference Group stated in 2007:

Increasing HIV testing and counselling must also go hand in hand with much greater investment in real protection – in practice, and not just on paper – from HIV-related discrimination and abuse, particularly for women, children and adolescents, sex workers, men who have sex with men, people who use drugs, and prisoners.¹⁴

...getting an HIV test will expose them to criminal liability if they find out they are HIV-positive and continue having sex...

This comment is even more relevant today and requires intensifying advocacy with governments and donors to decriminalize, fund legal support services, provide training to criminal justice system actors, and ensure the privacy and safety of those who seek HIV testing as a prerequisite to massively scaling up HIV testing or implementing new testing modalities. This criminalized context is critical to understanding HIV testing and counselling today.

Expanded HIV treatment availability and 'treatment as prevention'

The HPTN 052 clinical trials, which examined the impact of highly active antiretroviral therapy (HAART)

treatment on the transmission of HIV in sero-discordant couples, confirmed that the use of HAART decreased HIV transmission by at least 96%.¹⁵ Additionally, the study showed that starting HAART earlier was associated with more than a 40% reduction in the rate of disease progression. The findings of HPTN 052 confirmed those previously reported by Montaner et al.¹⁶

This ground-breaking research, and subsequent studies, support important new opportunities and public health, economic, and human rights arguments for expanded and improved integration of treatment and prevention efforts. The ‘*treatment as prevention*’ discovery is comparable to other historic turning-points in the epidemic, such as the development of a test to detect HIV antibodies (1985), antiretroviral therapy to prevent perinatal HIV transmission (1991), and highly active antiretroviral therapy to suppress viral replication, significantly reducing AIDS-related morbidity and mortality (1996).

...can make HIV testing a
life-endangering rather than
life-saving act...

As when each of these milestones which created a paradigm shift in how HIV policies and programmes were developed, prioritized, funded, and implemented, the ‘*treatment as prevention*’ revolution requires a careful examination of the scientific evidence, programmatic structures, and the importance of protecting and

promoting human rights. How one goes about achieving equity, empowerment, protection from discrimination, and accountability must correspondingly shift.¹⁷

...much greater investment in real
protection – in practice, and not
just on paper – from HIV-related
discrimination and abuse...

As noted by the UNAIDS Reference Group co-chairs and an additional author in a commentary on this issue:

Successful HIV prevention and use of ART, for either prevention or treatment, both depend upon the ability of individuals and affected communities to seek out services and then use those services over the course of a lifetime. While increasing rates of HIV testing utilization is one important component, it is not the numbers of tests performed that, in and of itself, will lead to increased demand for and successful use of prevention and treatment services. HIV testing is not a goal, but a tool. It is a tool that can only be valuable if the conditions are in place to put the information one receives from testing to use. Those conditions include the availability of sustained and high-quality health-care and prevention services, including ART, along with policies and programmatic approaches that connect people to services and protect them from human rights abuses.

While testing is crucial, knowing one’s status is often



not enough. Even where treatment is free, countries have reported large gaps between numbers of people who test positive and those who start, and are able to maintain, treatment. Much more needs to be done to bridge the gap between testing and treatment, and to keep people on treatment. There is still very little research on the factors that affect whether or not people choose to start treatment, but it is clear that the biomedical argument (regarding the benefit of ART in reducing morbidity and mortality) is not

...ensure the privacy and safety of those who seek HIV testing as a prerequisite to massively scaling up HIV testing or implementing new testing modalities...

always sufficient motivation for people to start ... An environment of safety in which people at risk for HIV can demand and use services without fear of stigma, discrimination, and abuse of their human rights is a necessary prerequisite for implementation of all HIV treatment services, including those for prevention. Without

sufficient human rights protection, seeking HIV services can often be more immediately dangerous than HIV itself.¹⁸

The Reference Groups believe that these considerations should also be paramount throughout the Global Fund processes, including concept note development, grant making, and implementation. They are reflected in five minimum human rights standards that are incorporated into Global Fund grant agreements. In particular, the grant agreements state: ‘*Programs supported by the Global Fund are expected to: ... d) respect and protect informed consent, confidentiality and the right to privacy concerning medical testing, treatment or health services rendered*’.¹⁹ Individuals who experience or witness a violation of this standard in Global Fund-financed services are encouraged to use the Global Fund Office of the Inspector General Whistle-blower hotline to file a complaint.

The UNAIDS Reference Group analyzed the human rights issues related to ‘*treatment as prevention*’ at its thirteenth meeting in December 2011. Recommendation 4.4 of that meeting reads:

*The Reference Group recognizes the need to further increase access to HIV testing and counselling, but urges WHO and UNAIDS Secretariat to carefully analyze the human rights risks and benefits from new approaches to testing, such as community testing and home testing.*²⁰

The potential impact of ‘*treatment as prevention*’ does not alter this recommendation. The added prevention value of antiretroviral therapy only heightens the need to find successful approaches to improved HIV service delivery *and* human rights protection. Similarly, ethical issues relating to prioritizing treatment for prevention purposes, particularly in contexts where treatment may not be available for all of those who require it for their own health, must be given appropriate consideration.²¹

...this criminalized context is critical to understanding HIV testing and counselling today...

The drive to end the AIDS epidemic as a public health threat by 2030

Despite so many changes, the barriers to testing remain largely unchanged. The ‘*more, better, faster*’ approach to

HIV will not end AIDS as a global public health threat without addressing these barriers. The desired scale-up of voluntary HIV testing will not be achieved if the barriers to access to voluntary HIV testing, prevention services, and sustained treatment faced by vulnerable and most at-risk populations are not addressed.

...the ‘*treatment as prevention*’ revolution requires a careful examination...

As UNAIDS, together with its co-sponsors, partners, and allies, strives to re-energize and redefine the HIV response in order to face some of the most challenging aspects of the epidemic that have yet to be resolved, the UNAIDS Reference Group notes with approval the analysis presented in *The Gap Report*.²² The report identified twelve groups who are being left behind:

- People living with HIV;
- Adolescent girls and young women;
- Prisoners;
- Migrants;
- People who inject drugs;
- Sex workers;
- Gay men and other men who have sex with men;
- Transgender people;
- Children and pregnant women living with HIV;
- Displaced persons;
- People with disabilities; and
- People aged 50 years and older.

As such, the agenda is set, the priorities are identified. The race towards the end of AIDS will be indefinitely stalled until these key groups are included in all HIV-related planning and programming, and the legal and human rights issues that hinder their access to and uptake of HIV and other health services are addressed.

Concretely, to scale up HIV testing and counselling while protecting human rights, the Reference Groups suggest that the following issues must be urgently addressed:²³

- A well-defined, well-resourced, and consistently applied strategy for meaningful involvement of people living with HIV and key populations in designing, implementing, and monitoring testing and treatment programmes is required.
- Law, policy, and practice reform is required to create an enabling and non-discriminatory environment in which a legal and policy framework ensures respect for and protection of the right to health (including the

...despite so many changes,
the barriers to testing remain
largely unchanged...

right to information, access to testing and treatment, and other related socio-economic rights), as well as civil and political rights such as autonomy, privacy, the right to be protected from violence, the rights to speech and assembly, and access to justice for people living with HIV and vulnerable to HIV infection.

- Laws and policies that can act as barriers to access to HIV testing and treatment services, such as those which criminalize same-sex relationships, sex work, and drug use, should be repealed.

...redefine the HIV response in order to face some of the most challenging aspects of the epidemic that have yet to be resolved...

- Access to justice for people whose rights have been violated must be strengthened.
- Human rights training for healthcare workers focusing on informed consent, confidentiality, non-discrimination, duty to treat, and universal precautions is essential, as is the training and sensitization of law enforcement agents on HIV and the human rights of vulnerable populations, particularly in terms of supporting access to services, non-discrimination, non-violence, and freedom from harassment, arbitrary arrest, and detention.
- Programmes to promote the rights of women in the context of HIV are essential. These programmes include interventions to change laws, policies, and practices that discriminate against women, including those that restrict women's economic opportunities, property, and inheritance rights, inadequately criminalize or punish violence against women, and perpetuate harmful and inequitable gender norms.

- In many countries, the legal age for consent to testing denies sexually active youth access to HIV testing. These restrictions must be removed.
- Social, cultural, and legally-based inequalities between men and women and high levels of gender-based violence often make it difficult for women to access HIV testing. Gender analysis and principles of equality must be applied to all testing interventions and every effort must be made to reduce gender-based violence and inequality globally.
- Alternative testing options should be provided at the point where testing is being offered. This allows people to ‘save face’ when declining testing (i.e., they are not saying ‘no’, just ‘later’, or ‘at another place’) and make the best decision for their own situation. Providing alternatives helps address the power differentials inherent in patient-provider settings, and improves informed consent and confidentiality.
- Programmes to reduce stigma and discrimination are essential for the creation of a social environment which facilitates access to prevention and treatment services. These should address their underlying causes – ignorance, fear, myths, and social judgment.
- Change must also be promoted from the ground up. People affected by HIV must be supported to know their rights in the context of the epidemic, to formulate concrete demands for access to services and non-discrimination on the basis of HIV and other social status, and to have the information and support necessary to make and follow through on testing and treatment decisions and implement behaviour change to improve health.
- There is a need to strengthen local, community-based, and peer-based networks and organizations as a mechanism to support testing and treatment preparedness.

...law, policy, and practice reform is required to create an enabling and non-discriminatory environment...



- Empowerment and mobilization approaches to service delivery are essential to the success of expanded testing and treatment access. Legal protection alone will not end stigma. Ultimately, the reduction of stigma will depend on the willingness and ability of individuals to seek out health services. Service provision based on principles of community mobilization and empowerment can provide the sustained engagement in care necessary for a lifetime of treatment adherence.

In the context of the Global Fund concept note development and grant making process, the Reference Groups note the specific guidance from the Global Fund on the inclusion of a package of interventions to address these issues under the Removing Legal Barriers Module, which includes interventions to strengthen community systems for community-led human rights monitoring and advocacy to enhance social accountability.²⁴ The Global Fund Human Rights Reference Group underscores that these interventions are essential to achieving impact in HIV testing, counselling and treatment.

...providing alternatives helps address the power differentials inherent in patient-provider settings...

CONCLUSION

As UNAIDS and the Global Fund renew their respective strategies, this is a critical time in the response to HIV and AIDS. Bold new targets for prevention, treatment, and non-discrimination will lead the world on

a ‘fast-track’ towards the end of AIDS. *Now more than ever*, UNAIDS and the Global Fund can lead the health and human rights response to HIV.

...much greater efforts need to be devoted to removing barriers to testing for marginalized and criminalized populations...

To support UNAIDS and the Global Fund in this undertaking, the Reference Groups offer the following three key messages:

1. There is an ongoing, urgent need to increase access to HIV testing and counselling, as testing rates remain low in many settings. The Reference Groups support such efforts unequivocally and encourage the provision of multiple HIV testing settings and modalities, in particular those that integrate HIV testing with other services.
2. Simply increasing the number of people tested, and/or the number of times people test, is not enough, for many reasons. Much greater efforts need to be devoted to removing barriers to testing for marginalized and criminalized populations, and to link those tested with prevention and treatment services and successfully keep them in treatment.

3. Public health objectives and human rights principles are not mutually exclusive. HIV testing that violates human rights is not the solution. A 'fast-track' response to HIV depends on the articulation of testing and counselling models that drastically increase use of HIV testing, prevention, treatment, and support services, and does so in ways that foster human rights protection, reduce stigma and discrimination, and encourage the sustained and supported engagement of those directly affected by HIV.

FOOTNOTES:

1. The statement by the *the UNAIDS Reference Group on HIV and Human Rights, fully endorsed by the Global Fund to Fight AIDS, Tuberculosis and Malaria Human Rights Reference Group, was released on 10 June 2015.*
2. The statement was published as an appendix to the 2004 UNAIDS/WHO policy statement on HIV testing.
3. WHO/UNAIDS, *Guidance on Provider-Initiated HIV Testing and Counselling in Health Facilities*, 2007. [http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf]
4. *Ibid*, p30.
5. UNAIDS Reference Group on HIV and Human Rights. 2007. *Statement and recommendations on scaling up HIV testing and counselling*. [www.hivhumanrights.org.vs2.korax.net/commitmenttohumanrights/wp-content/uploads/downloads/2012/03/20070905_rghr_statement_testing_en.pdf]
6. WHO/UNAIDS. 2012. *Statement on HIV testing and counselling: WHO, UNAIDS re-affirm opposition to mandatory HIV testing*. [www.who.int/hiv/events/2012/world_aids_day/hiv_testing_counselling/en/index.html]
7. WHO. 2012. *Service delivery approaches to HIV testing and counselling (HTC): A strategic policy framework*. [www.who.int/hiv/pub/vct/htc_framework/en/]
8. The issue paper 'HIV testing: The way forward' and the Summary Report and Recommendations of the Reference Group's Fifteenth Meeting can be accessed at www.hivhumanrights.org/meetings/fifteenth-meeting/.
9. See Edwin Bernard, *Advancing HIV justice: A progress report on achievements and challenges in global advocacy against HIV criminalisation* (GNP+ and HIV Justice Network), 2013, for an overview.
10. Open Society Institute. 2008. *10 Reasons to Oppose Criminalization of HIV Exposure or Transmission*. p1. [www.opensocietyfoundations.org/sites/default/files/10reasons_20081201.pdf]
11. *Ibid*.
12. Studies documenting these negative effects on HIV prevention and justice are emerging from different parts of the world, reinforcing policy recommendations. See, for example, Dodds, C. et al. 2013. 'Keeping Confidence: HIV and the criminal law from service provider perspectives'. *Sigma Research*; Gallety, C.L. & SD Pinkerton, S.D. 2006. 'Conflicting messages: How HIV criminal disclosure laws undermine public health efforts to control the spread of HIV'. *AIDS and Behaviour*, 10:451-461; Mykhalovskiy, E. 2001. 'The problem of 'significant risk': Exploring the public health impact of criminalizing HIV non-disclosure'. *Social Science & Medicine*, pp1663-1671; and O'Byrne, P., Bryan, A. & Woodyatt, C. 2013. 'Nondisclosure prosecutions and HIV prevention: Results from an Ottawa-based gay men's sex survey'. *Journal of the Association of Nurses in AIDS Care*, 2013, 24(1), pp81-87.
13. For example, in a number of countries, condoms are used as evidence in the arrest and prosecution of sex workers. See OSF [www.opensocietyfoundations.org/sites/default/files/criminalizing-condoms-20120717.pdf]. On the criminalization of key populations and HIV risk, see, for example: Shannon, K. et al. 2015. 'Global epidemiology of HIV among female sex workers: influence of structural determinants'. *The Lancet* Volume 385, No. 9962, pp55-71; Mathers et al. 2008. 'The global epidemiology of injecting drug use and HIV among people who inject drugs: a systematic review'. *The Lancet*, 2008, 372(9651), pp1733-1745; and UNAIDS. 2012. Homophobia and punitive laws continue to threaten HIV responses and human rights.
14. UNAIDS Reference Group on HIV and Human Rights. 2007. *Statement and recommendations on scaling up HIV testing and counselling*. para 23. [www.hivhumanrights.org.vs2.korax.net/commitmenttohumanrights/wp-content/uploads/downloads/2012/03/20070905_rghr_statement_testing_en.pdf]
15. Cohen, M. et al. 2011. 'Prevention of HIV-1 Infection with Early Antiretroviral Therapy'. 365 *New England Journal of Medicine*, pp493-505.
16. Montaner, J. 2011. 'Treatment as prevention: a double hat-trick'. 378 *The Lancet*, pp208-209. [[www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60821-0/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60821-0/fulltext)]
17. Barr, D., Amon, J. & Clayton, M. 2011. 'Articulating a Rights-based Approach to HIV Prevention and Treatment Interventions'. 9 *Current HIV Research*, pp396-404. [www.eurekaselect.com/94789/article]
18. *Ibid*.
19. Global Fund Grant Regulations (2014), Article 6(2)(1).
20. UNAIDS Reference Group on HIV and Human Right. Thirteenth Meeting, 14-16 December 2011: Summary and Recommendations. [www.hivhumanrights.org.vs2.korax.net/commitmenttohumanrights/wp-content/uploads/downloads/2012/04/HRRefGrp-13thMtg_Rec-ENG-1.pdf]
21. Barr, D., Amon, J. & Clayton, M. 2011. 'Articulating a Rights-based Approach to HIV Prevention and Treatment Interventions'. *Current HIV Research*, pp396-404. [www.eurekaselect.com/94789/article]
22. UNAIDS. 2014. *The Gap Report*. [www.unaids.org/en/resources/campaigns/2014/2014gapreport/gapreport]
23. Most of these are elaborated on more fully in Barr, Amon, and Clayton, *supra* n14.
24. The package of interventions includes: legal environment assessment and law reform; legal literacy and legal services; training for officials, police, and health workers; community-based monitoring, policy advocacy, and social accountability. Reference may be made to the *Global Fund Information Note on Human Rights For HIV, TB, Malaria and HSS Grants* [www.theglobalfund.org/en/fundingmodel/support/infonotes/] for more information on those interventions.

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Questioning what youngsters will do...

Condoms in schools

Most of us, adult and non adult, would probably agree that if we offer young people a packet of cigarettes or a six-pack of beer, perhaps making such an offer would not be wise.

Gahsiena van der Schaff

One, because these items however pleasurable have bad health outcomes; two, items mentioned may legally only be provided or sold to or consumed by individuals 18 years and older; and three, many might rightfully ask: 'who in their right mind would offer these to children?'. However, how would young people respond to the offer?

I guess the ones who already smoke or take a drink on the side will be happy to light up or pop the beer. Some who never considered drinking or smoking might feel tempted or under pressure to light up for the first time or open a bottle. Yet, ones who are not interested for whatever their reasons, will unambiguously decline the offer.

Regarding issuing condoms to children 12 and older ('Hard line on condoms', Plainsman May 27), children/teenagers who may or may not be engaging in sexual activities (yet), most of us would say 'no', 'that is wrong', 'it will encourage children to engage in sexual activities', or even that 'sex is for marriage'.



But let's forget for a moment about our own views on what is 'wrong and bad' or not for young people (school-going or not), since this is not about us or our beliefs.

Should condoms, female and male, be made freely available then how would young people respond? I would imagine that some would view it as a joke, many will take the condoms (for whatever their reasons might be) and some, perhaps many, would empathically decline the offer, and even more would be too embarrassed to be offered condoms.

So, what would youngsters do once they have the condoms in their possession?

No doubt some will blow them up and play balloons,



others will even fill these with water and play pranks, perhaps even on their teachers.

I suspect that many who already engage in sexual activities (of which friends might be aware of but not parents) will attempt to use the condoms next time they have sexual encounters: some others who have never considered to engage in sex will now be tempted to try out these *'adult tools'*, but youngsters who are not interested will remain uninterested.

...whichever one is chosen will
have benefits for young people...

Whichever way we look at these scenarios; one, we cannot deny that whichever one is chosen will have benefits for young people; two, condoms are not bad for ones health, on the contrary; three, it is not unlawful for young people 12 and over who choose to engage in sexual activities in a responsible, forward-looking manner; and four, who in their right mind would refuse young people these protections?

...tempted to try out these
'adult tools'...

Let's hope the department makes these life-saving or three-in-one prevention tools as accessible as possible, wherever children or young people are (not with teachers and principals around) sooner rather than later. As otherwise, youngsters may start or even continue to engage in sexual activities *'unprotected'*, not by *'choice'*, but due to a lack of access to condoms.

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A daunting task...

South Africa as a Middle Income Country and its effect on people living with HIV

South Africa has been classified as a middle income country for over 100 years and thus, is considered a 'mature' middle income country (MIC). Historically, South Africa is a country economically fuelled by mining and other resource dominated industries. The dissolution of apartheid left the new ANC-led democracy with the monumental task of integrating a previously disadvantaged sector of the population back into society.

Simone Thomas



classification with the likes of Brazil, Argentina, Thailand, Namibia, and Iraq to name a few.

But how is this possible when South Africa still has approximately 20 million people living below the poverty line⁴, and an overall unemployment rate of 26.4%⁵? Despite the rapid growth in the economy, this has not translated into an improvement in the quality of life for a large part of the population, predominately

Through the transition, the economy continued to rely heavily on mineral and agricultural exports, but failed to diversify into the manufacturing and education industries that would have helped create jobs and advance the economy's growth.¹ Even still, between 1993 and 2012, South Africa's GDP growth rate averaged out at 3.22%², helping to achieve a Gross National Income (GNI) per capita of \$7,410 USD³. According to the World Bank, this technically places South Africa in the *upper MIC*

black Africans, who are no stranger to inherent societal disadvantages. If that is not enough, South Africa has the worst HIV epidemic in the world, which has become common knowledge in the last couple of years.

INTERNATIONAL DONORS AND THE TRANSITION TOWARD PARTNERSHIPS

There is no shortage of research linking poverty to HIV transmission rates. Having said this, how can we expect the South African government to handle the

combined effects of poverty and HIV transmission, when left to its own merits? This would be a daunting task for even the most developed of countries. South Africa has been continuously applauded for initiating the largest antiretroviral treatment (ART) rollout programme in history. And although the majority of the effort (over \$1 billion USD) was funded by domestic sources⁵, it would not have been possible without the intervention of several international donors. Some of the major international donors in both the global and South African HIV intervention efforts are:

- President's Emergency Plan for AIDS Relief (PEPFAR)
- UK Department for International Development (DfID)
- The Global Fund to Fight AIDS, TB and Malaria (Global Fund)
- UN Agencies

PEPFAR is the largest healthcare initiative to be launched by one country to respond to one disease⁶, and is a large part of the reason why South Africa has seen the relative success it has in responding to the HIV epidemic. At the end of the 2010 fiscal year, PEPFAR reported that its partners were providing direct treatment to upwards of 917,700 people living with HIV.⁷ They have invested nearly \$4 billion USD since 2004 in both the public and private sector to scale up treatment, care, and support programs.⁸ The UK DfID has had a similar impact on the improvement of the HIV response in South Africa. Since 1994, DfID has mainly focused on improving reproductive health (including HIV) and thus, has supported over

26 development programmes totalling approximately \$100 billion USD⁹ over decades. The Global Fund has made a global commitment of \$12 billion USD between 2014 and 2016.

...a daunting task for even the most developed of countries...

While the contribution that international aid organisations have made to South Africa, and the impact it has produced, is undeniable; the fact remains the same that we are currently in the midst of significant funding withdrawals from all of the organisations mentioned above.

It is unfortunate but true. One would hope that with all the growth and progress South Africa has seen with the implementation of a successful ART programme, the government would be able to sustain that growth and success. After all, we are an upper *MIC* right? Unfortunately, this is not the case. Boasting an *MIC* status holds little merit given the circumstances, as the most vulnerable have already begun to feel the effects of the reduced funding. Under these circumstances, fault should not necessarily be placed solely in the South African government's hands nor should the burden be placed solely on their shoulders; at least not until the government demonstrated a clear ability to effectively manage the prevention, treatment, and care of the AIDS epidemic. A



...not translated into an improvement in the quality of life...

middle or even upper *MIC* status should not be enough to announce the withdrawal of billions of dollars of funding dedicated to the elimination of HIV and AIDS. However, this is exactly what has been happening. In 2010, the United States Secretary of State and the South African Minister of International Relations signed the *Partnership Framework in Support of South Africa's National*

HIV and AIDS and TB Response (2012/13 – 2016/17).¹⁰

This Partnership Framework works alongside South Africa's National Strategic Plan (NSP) to support its goal of reducing the effects of HIV, but in doing so both parties have decided that:

*PEPFAR's investments in South Africa should gradually transition from support of direct clinical care and treatment services toward support for system strengthening, prevention, orphans and vulnerable children, and health services innovation.*¹¹

PEPFAR's current five year period is set to end in 2017, which means that by 2017 a full transition from PEPFAR funded programmes to domestically funded initiatives is expected.

To make matters worse, on 30 April 2013, International Development Secretary Justine Greening made the announcement that the UK DfID would be ending all direct aid to South Africa by 2015. She stated that '*South Africa is now in a position to fund its own development*'.¹²

An Action Aid spokeswoman said in response:

*It seems to imply a more general UK policy of withdrawing aid from middle income countries abruptly without the progressive phasing that would help communities adjust to new realities.*¹³

...no stranger to inherent societal disadvantages...

It seems as though both the UK and USA are, for the most part, adopting a school of thought whereby funding is funnelled into fragile and low income countries, because that method is deemed to make the most impact. Homi Kharas and Andrew Rogerson, authors of the Horizon 2025 Report, argue that the focus should be on fragile states rather than fragile countries.¹⁴ Aid to middle income countries should continue, because poor, disadvantaged people continue to live there.¹⁵ Poor people matter where ever they live. Consider this: 80% of

living with HIV live in *MICs*¹⁷, and South Africa is home to one in six¹⁸. Given these statistics, a universal withdrawal of donor funds to South Africa makes little sense.

*It appears that for every example of a country that has achieved poverty reduction linked to economic growth rates, there are examples of countries that have experienced rapid growth without any associated reduction in poverty and inequality.*¹⁹



**CIVIL SOCIETY:
ROLE AND IMPACT**

Saying that the South African government should be able to support its own ARV treatment programme is a lofty goal, but what about the organisations that make it their mission to hold the government bodies accountable for their actions. Do we expect the South African government

...in the midst of significant funding withdrawals...

the world's population who live on less than \$2USD/day now live in middle income countries, as compared to 90% living in low income countries in 1990.¹⁶ Furthermore, fifteen years ago, two thirds of people living with HIV resided in low income countries. Today, 58% of people

to actually provide funding to those NGOs, who take pride in advocating and lobbying for underserved populations, even if it means much needed political reform? My guess is no. The government will do their best to provide essential treatments, but when it comes to the barriers to accessing treatment, those will remain largely in place, as government is likely to pay lesser attention to addressing these. Lack of confidentiality

and stigmatisation are very real issues and still act as barriers to effective treatment, care and support. The HIV response that has been initiated up until now would not have been possible without the intervention of various civil society organisations throughout the country. Building on HIV response efforts began under strong pressure from a thriving activist community.

The Partnership Framework stipulated that 80% of funds allocated to non-governmental organisations were slated to South African NGO's, rather than international NGOs.²⁰ This means that civil society organisations native to the country will be hit the hardest. The PEPFAR pull-out has decreased NGO activity and the resulting advocacy efforts are already being felt.²¹ When it comes to DfID, they allocated approximately 2% of their funding efforts to South African NGOs, which may sound minute, but in actuality translates to approx. \$100 million USD/year for the past decade.²² Between PEPFAR and DfID withdrawing their funds, it is no surprise that NGOs

...boasting an MIC status holds little merit...

all over the country are severely challenged to as much respond to the prevailing needs – both in terms of service delivery and advocacy – as to pay their employees a decent salary, stay current on their rent, and ultimately, keep their doors open.

More importantly, being funded by external sources allowed NGOs a sense of autonomy from the government. If the South African government holds sole responsibility of funding for civil society organisations, it seems as though we are allowing a clear entry point for bias and an incentive to promote

...focus should be on fragile states rather than fragile countries...

government agendas. Not to say that government initiatives should be rejected by civil society, but many NGOs have experienced difficulty accessing government support and forming partnerships.²³ NGOs in this country play a large role in holding public institutions accountable for both their actions and inactions. At the very least, even if the South African government can manage to fully fund its public health sector, the community will deeply miss the sense of accountability that NGOs strive to embody and project onto the public sector.

PEOPLE ARE AT RISK...

Despite the number of civil society jobs being lost and NGOs closing their doors, the largest and most unfortunate impact of donor withdrawal is felt in the most disadvantaged of communities. People living with HIV

...a universal withdrawal of donor funds to South Africa makes little sense...

stand to lose the most in the face of scaled back funding. Literally, their lives are on the line. As PEPFAR and DfID continue to cut back on funding they are putting hundreds of thousands of people at risk of not receiving the same standard of care, or in some cases no care at all. According to the Partnership Framework, as PEPFAR funding declines and the South African government allocates more of its resources to the HIV response:

*...the transition is expected to be implemented in a manner that puts the wellbeing of patients and vulnerable and affected populations at the center of all interventions.*²⁴

PEPFAR has also said that

*...transition should not compromise the quality and continuum of care. Beneficiaries of current services should not be detrimentally affected by the transition of services.*²⁵

Despite this being clearly outlined in the Partnership Framework, there failed to be any distinct plan of action to monitor the treatment of patients after they have been released from PEPFAR funded care. An NIH funded study done by Harvard researchers estimated that at least 19% of those previously enrolled in ART never made it to their first planned public sector visit.²⁶

If this estimate is correct, it means that approximately 190,000 people fell out of the system and are no longer receiving treatment.

The Western Cape was the only province where the process of assessment and planning was the guiding factor in determining the ability of the public sector to absorb the programme. To the contrary, public clinics in the Eastern Cape, Free State, Mpumalanga, and Gauteng all reported receiving influxes of hundreds of patients over a three month period without any increase in clinic capacity.²⁷ As a result, it is common place throughout these provinces that patients will wait three or more hours at a clinic before being seen with no guarantee that the appropriate medication will be available.

A study done in May 2013 indicated that 40% of clinics in Gauteng, Limpopo, Eastern Cape, Kwa-Zulu Natal, and Mpumalanga still experience stock outs for extended periods of time.²⁸ Patients are being sent home without medication and are told to come back another day. Patients have been told to go ask their neighbour for pills when it seems the dispensary is out of stock. In order to make up for the lack of support staff and inadequate infrastructure, people living with HIV are often times designated a certain room or 'container',

...a clear entry point for bias and an incentive to promote government agendas...

thereby indirectly disclosing their HIV positive status to those also in the clinic simply by virtue of which room they enter or which queue they wait in. This acts as a barrier to care, further discouraging people living with HIV to access the treatment that they so desperately need. Anecdotal evidence indicates that people are ‘fed up’ with the public health system and would sometimes rather spend their hard earned money to go to private care or worse yet, go with no care at all. These are the people that are most at risk. These are the people that should be at the forefront of the transition.

CRITICISMS...

The opportunity for South Africa to completely fund its own public health sector is a unique one to say the least. There have been some valid criticisms of international funding, in the sense that when a programme is funded by donor aid, its ability to provide quality treatment is at

...the sense of accountability
that NGOs strive to embody...

times undermined, as the ‘requirements’ associated with donor aid, which may not necessarily take into account the country specific context. Moreover, there is also the risk that the ‘donor aid’ driven requirements may – in their implementation – compromise human rights for the sake of delivering ‘targets’. Helen Epstein, author of

...holding public institutions
accountable for both their actions
and inactions...

The Invisible Cure: Why We Are Losing the Fight Against AIDS, interviewed several members of a community in rural Kwa-Zulu Natal highlighting some of the faults of international donor funding.

You cannot give quality counselling anymore because PEPFAR has counselling quotas. If you have to do one thousand people by the end of the month, you end up not doing good counselling. It compromises people’s dignity.²⁹

When Americans come, we sing, we dance, they take our picture, and they go back and show everyone how they are helping the poor black people. But then all they do is hijack our projects and count our children.³⁰

The South African government has the opportunity to build on the faults of international donors and provide services that place people at the centre, rather than numbers and quotas.

CONCLUSION

There is no doubt that international funding continues to be needed in order to progress on the ‘Zero New

Infections' target. An end of all external donors places South Africa at an extremely high risk of regressing back to the 1990s, when the HIV epidemic was on the rise. Although it is commendable that South Africa is funding 85% of its HIV response, there is still estimated to be a \$2.28 billion USD AIDS resource gap in 2017 according to the DFIP.³¹

To abandon the donor-recipient relationship with South Africa – given these estimates and the impacts it will cause – international donors have arguably been gravely irresponsible. South Africa should be striving to one day become an independent nation in the response to HIV, but the decision should be made after intense scrutiny into whether or not the country can realistically manage the HIV response needed to ensure that people and human rights are at the centre of the response.

There also needs to be a meticulous transition plan ensuring that no person becomes '*lost in the system*' and fails to receive the care that they so desperately need. If we are going to succeed as a country in becoming an independent nation in '*ending AIDS*' as both a public health and human rights '*threat*' – people need to be '*put first*' and '*at the centre*' of all aspects of the response.

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Slow violence...

The story of a runaway date¹

This is a presentation I gave earlier this year at a conference in Stellenbosch on Slow Violence, the idea that unspectacular life circumstances can also have a devastating effect.

Pierre de Vos



I can't change my HIV status BUT
You can change your attitude

I know where this particular narrative must end. More or less. But where should it begin? I am not sure what kind of detail I must include in the narrative and what would better be left in the private domain. How brave am I?

The story could begin with the man, a greying, middle aged constitutional law professor who often comments in the media on current affairs and the law, receiving a message from B on Gaydar, a popular gay male dating and sexual hook-up site. B writes that he is a young lawyer who loves movies and fashion. He suggests an email correspondence with a view to meet *'for a date, the old fashioned way'*.

The man studies B's profile picture for clues of his personality. He thinks B is sexy – in a nerdish kind of way. Or maybe he only decides this later, after their first date. In the picture B's head is clean-shaven. Delicate hands peek out from the sleeves of the well-tailored black jacket. (On their first date the man would approvingly note that B's nails had been carefully painted black. Trust him to hook up with probably the only camp, coloured, Goth on Gaydar.) B's smooth olive skin radiates health. But it is the eyes, partly obscured by thick-rimmed glasses, that convinces the man to take a chance – despite his

apprehension. Huge eyes. Slightly watery and a little bit sad. Kind eyes, the man assumes. It is the eyes that reveal that at least some of B's forbears arrived in South Africa from South East Asia centuries ago, perhaps as slaves. *'Slaves'*. The word sticks in the man's throat, a reminder of what his kind is capable of doing.

The man spends hours composing the emails he exchanges with B. He strives for a light, witty, but intellectually clever tone. He keeps the polite boasting to a minimum, but hopes he comes across as erudite and informed, yet attuned to popular culture and not over serious. About the calamity, the man, says nothing. B agrees to a *'date'*. They will go to *'On Broadway'* to watch a revue performance of scantily clad men singing about love and love lost. The man is nervous. He has never been on a real first date with any man in his life before. In the past he has always first slept with a man and then decided afterwards whether he would see him again. But now it's become more complicated. The date goes well. They drink moderate amounts of wine – not enough to get drunk, but enough to get over the first awkwardness. Did they drink white wine or red wine? Several years later, the man cannot remember these details. The man is just tipsy enough not to pull away when his knee touches that of

B under the table. B is a little giggly when the man drops him off outside his flat in Vredehoek. They kiss hurriedly – like teenagers on a first date – and this too, goes well. A second date is on the cards.

Having gotten this far, I am not sure how to proceed with my story. It is still a problem of where to start, of how to structure my story, of what to reveal and what to keep to myself. Do I even remember these events relatively accurately? Do I have to stick to the facts – as if this is a legal document? Or can I lie to get to another kind of truth? How do I present my case to you, my jury, without sounding too self-indulgent or narcissistic? How do I elicit a sympathetic verdict and why do I care? How do I write a story without it sounding like an article published in the South African Law Journal – which, let's face it, is not really a publication read for laughs.

... 'cases are decided not only on their legal merits but on the artfulness of an attorney's narrative'...

Only the most formalistic lawyer will deny the fact that legal 'cases are decided not only on their legal merits but on the artfulness of an attorney's narrative' presented to the court. Does life not imitate the law in this regard? I recall reading an article by Robert Cover – not his famous article which starts with such a bang: 'Legal interpretation takes place in a field of pain and death' – no, not that one, but rather another article published in the Harvard Law Review about narrative, meaning and the law in which Cover wrote:

We constantly create and maintain a world of right and wrong, of lawful and unlawful, of valid and void.

... No set of legal institutions or prescriptions exists apart from the narratives that locate it and give it meaning. For every constitution there is an epic, for each decalogue a scripture. Once understood in the context of the narratives that give it meaning, law becomes not merely a system of rules to be observed, but a world in which we live.

The story could also begin at an altogether safer, more familiar, place. The man is standing in front of a class of 250 students at the University of Western Cape. He is teaching students about the right of gays and lesbians not be discriminated against, protected in South Africa's Bill of Rights. This happens several years before he went on a date with B, during an altogether happier time.

A short chubby woman with protruding teeth – one of the talkers in the class who, many years later, would bombard the man with a string of Facebook messages, asks whether you can reconcile the Constitution and the Bible. 'The Bible is mos a mess about gay rights', she laughs. Whatever happened to this student? In the Facebook messages the man later receives, the former student suggests that she had lost her job as part of an unnamed conspiracy aimed at her, because she has become a reborn Christian. 'I know you will find this strange, but God speaks to me in visions', she writes on Facebook.

But that is far into the future. In class, the man proceeds with some delicacy. The majority of students do not support the prohibition of discrimination against gays and lesbians. 'So you want to discriminate against me', the man laughs. 'If I did not know you better I would feel offended'. He flashes a smile. 'And let me tell you, my boyfriend is not going to like this'. A snigger runs through the class. Another smartly dressed woman with long braids – the one who approached him early in the year, wetted her middle finger and tried to rub off the beauty spot from his left cheek – speaks up. 'If the law prohibits discrimination it does not prevent anyone here from believing what they want to believe'.

'Let me ask a different question', the man laughs. 'Is it acceptable to discriminate against someone because, for

whatever reason, you do not like that person?" A murmur runs through the class. A man with rosy cheeks and a goatee pipes up: 'If you fail me, because you don't like me, I will really be pissed off'. Everybody laughs. Nothing like some swearing in class to liven things up. It is time for the quote from the Constitutional Court judgment in Hoffmann v SAA. It is the case of the SAA who claimed it could not appoint Mr Hoffmann as an air steward, because he was HIV positive and because their clients would not fly with SAA if it employed HIV positive staff. The man loves the quote. He tells the students it encapsulates all that is good about South Africa's Constitutional Court and, for once, he says it without any irony.

...We must guard against allowing stereotyping and prejudice to creep in under the guise of commercial interests.... Prejudice can never justify unfair discrimination. This country has recently emerged from institutionalised prejudice. Our law reports are replete with cases in which prejudice was taken into consideration in denying the rights that we now take for granted. Our constitutional democracy has ushered in a new era – it is an era characterised by respect for human dignity for all human beings. In this era, prejudice and stereotyping have no place. Indeed, if as a nation we are to achieve the goal of equality that we have fashioned in our Constitution we must never tolerate prejudice, either directly or indirectly...

I am stuck again. I used to quote that passage from the Hoffmann case so easily and with so much joy and pride. Now it sounds a bit cheesy. I open the Safari browser on my laptop and start searching Google Scholar and the Taylor and Francis electronic database for academic papers and books on how to tell a story of shame and loss and internalised stigma. During this search I chance upon Jerome Bruner's book Making Stories: Law, Literature and Life. Bruner also writes about the way in which the law – like our lives – is about the telling of stories, about

... 'if the law prohibits discrimination it does not prevent anyone here from believing what they want to believe'...

arranging facts in a manner that appeals to a judge (or, in the US context, a jury). A storyteller – like a lawyer presenting a case – needs to decide what to include and what to leave out. But what strikes me with some force is the following passage from his book: 'Stories are surely not innocent: they always have a message, most often so well concealed the teller knows not what axe he may be grinding'. Is this story, then, about an axe I still have to grind with B? Or is it really about my fury at M, who, in the months before he left me, could not look me in the eye when we had sex? Or – dare I ask this? – is this story really about the axe I still have to grind with myself?

The story could also begin on a Sunday morning on a sunny day in January – 18 months before the man met B – in the front room of the house the man shares with M in Sea Point. The man nervously wipes the sleep from his eyes. Or maybe he is just fidgeting with his hands because he is anxious about what is to come. The smell of shit from his most recent bout of diarrhoea lingers on his fingertips. He wonders whether M can smell the shit from where he is perched on the armrest of the chair nearest the door, ready to flee to freedom. M, the man's partner of 9 years, is uneasily fidgeting with his cell phone. He is wearing the yellow and green havianas the man brought back from a recent trip to South America. M has the habit of placing his hand in front of his mouth when he laughs in order to hide his protruding teeth. A few years before on their way to Grahamstown for the Arts Festival, a petrol attendant in Graaf Reinette told M that he looked

like the Brazilian soccer star Ronaldinho – although he did not call him Ronaldinho but Tandjies. M is not in the mood to laugh this morning. His left leg bops up and down as he speaks. ‘*I can’t go on like this*’, M says ‘*because of what you have done to me. Because of everything*’. A classic case of: it’s not me, it’s you. M stares out of the window towards the frangipani tree in full bloom, studiously avoiding eye contact. Maybe he is not staring at the frangipani tree, but at something else. In any case, M is definitely not looking the man in the eye when he speaks. At least M is embarrassed. But probably not because he had to reach for a cliché to finally say the words, which for the past three months have been hovering in the air, just this side of being spoken. There are no tears. The man jumps up from the couch and rushes past M. ‘*Sorry*’, he says, then dashes to the toilet to deal with another bout of diarrhoea.

Only several months later M would tell him about the love letters M wrote three years previously to a communal friend living in London. And it would be another year before M would phone him on a bright morning on new year’s day, teary and incoherent, and confess that he, M, had told his friends the previous night, while he was high on too much acid and cocaine, that he had never loved the man and that the nine year relationship was one more of convenience than emotional commitment. But when

...‘an era characterised by respect for human dignity for all human beings. In this era, prejudice and stereotyping have no place’...

exactly was it that the gas heater M demanded for himself during the break-up exploded, gutting M’s new apartment in the ensuing fire? And when did the man’s oldest friend,

hearing of M’s calamity, joke that the fire was to be expected ‘*Dit wys jou net*’, (It just goes to show) ‘*Want God slaap mos nie*’ (Because God does not sleep).

I return to Bruner’s book on law and literature. Perhaps I can find an appropriate quote to cloak my sad and self-indulgent story in a somewhat more intellectual garb. Bruner writes that

...A self is probably the most impressive work of art we ever produce, surely the most intricate. For we create not only one self-making story, but many of them... The job is to get them all into one identity, and to get them lined up over time... [It] is not only who and what we are that we want to get straight but who and what we might have been, given the constraints that memory and culture impose on us, constraints of which we are often unaware.

But a self is now conceptualised as a fragmented, ambiguous and ever changing cultural construct. Who you are is forever being created by power relationships over which you have no control. ‘Autobiography, then, is not a genre or a mode, but a figure of reading or understanding that occurs, to some degree, in all texts.’ The self becomes a storyteller. Which is no longer a demeaning term, not someone who tells lies but who creates the self.

Every Sunday afternoon the man turns the house in Sea Point over to the estate agent, while he wanders in a haze on the promenade. He returns home with only a vague memory of the afternoons. The taste of regret in his mouth. The house quiet and empty. The ‘*For Sale*’ sign on the front gate telling its own story. The bare stubby branches of the frangipani tree casting melancholy shadows over the stoep. Not, it must be said, that the man would have noticed the frangipani at this stage of his life. He hardly notices anything not directly linked to his misfortune.

The man invites B for dinner at the house. B does not have a car, so the man drives to B's flat to pick him up. B is carrying a small stylish leather bag. The man imagines it contains a toothbrush and a pair of clean underwear and socks. B is talkative. He keeps on touching the man's arm. He throws his head back and laughs. The man pours wine, fries two pieces of steak in the kitchen while B perches on the marble counter top, his colourful socks peeking from beneath his skinny black jeans. The man pours himself another glass of wine. He only half listens to the story B is telling him. In his head he is rehearsing his speech. The man lights the candles. The blood oozes from the pink meat onto their white plates. He dishes up the salad and smiles vaguely while B starts telling a complicated story about how he went to watch the Oscar awards ceremony at a friend's house and spilt red wine on the white sofa. The man is too preoccupied to wonder who the hell is stupid enough to serve red wine to a half drunk friend sitting on a white sofa. When B is finally silent, chewing on a piece of steak, the man takes the gap. Stuttering, his sweaty hands clutching the cutlery, he tells B that he is HIV positive. Before he can talk about ARV's and how it saved his life, B shakes his head. Is he crying? No he is just shaking his head from side to side as if to shake off the words just spoken. 'I cannot deal with this', B says. 'How can you do this to me?'

In another story, a story not more or less committed to the facts, in other words a supposedly less legal kind of narrative, he would have flicked the glass of wine (and it would have been red wine) into B's face. Or he would have taken his plate of food and turned it over on B's lap, B's white pants stained bloody red by the juices from the steak. Or he would have plunged the steak knife into B's right hand, pinning the hand to the table, blood spurting over the white tablecloth while B squeals in pain.

But in THIS story, in the narrative of what actually happened, he smiles at B and says. 'I understand'. He comforts B with more empty words, careful that their hands or knees do not touch. He smiles encouragingly and nods and nods like an interviewer on a current affairs TV

programme signalling interest in what her guest is saying. Eventually he drives B home. In front of B's flat, he waits in silence as B clutches his leather bag in the hand that remains whole, unstabbed, before fleeing up the stairs of the Art Deco block of flats. Even when he drives home he is not angry with B. He dumps the half eaten bloody steaks into the rubbish bin, pours the glasses of half-drunk wine into the sink, and packs away the candles. Later, after brushing his teeth, he sends B a text message. 'Hope you are ok?' It is more than a year later before he sees B again.

I am not sure what the common script is for the kind of story I wish to tell. I am used to writing legal articles in which you have to spell things out, in which there must be a clear beginning, middle and an end. In my world the things I write about are supposed to be logical and to make sense. I again turn to Cover. Maybe there is help there.

...The various genres of narrative – history, fiction, tragedy, comedy – are alike in their being the account of states of affairs affected by a normative force field. To live in a legal world requires that one knows not only the precepts, but also their connections to possible and plausible states of affairs. It requires that one integrate not only the 'is' and the 'ought', but the 'is,' the 'ought,' and the 'what might be'. Narrative so integrates these domains. Narratives are models through which we study and experience transformations that result when a given simplified state of affairs is made to pass through the force field of a similarly simplified set of norms. The intelligibility of normative behaviour inheres in the communal character of the narratives that provide the context of that behaviour. Any person who lived an entirely idiosyncratic normative life would be quite mad. The part that you or I choose to play may be singular, but the fact that we can locate it in a common 'script' renders it 'sane' – a warrant that we share a nomos...

It's a year after the man last spoke to B. The man joins his friends to watch Ms Vanilla Von Teese performing her drag show at Bubbles Bar in Green Point. At the crowded bar, waiting to buy drinks for his friends from the beautiful barman whose bare lean torso is covered in glitter, B taps the man on the shoulder. 'Hi', says B, smiling sheepishly. He is wearing new glasses with modern lightweight frames. B is dressed smartly, a thin black tie matches his black



jacket with thin lapels. The man nods stiffly towards B, but does not smile. Or if he smiles, so he imagines, it is not a warm and inviting smile. Then he turns back to the barman and orders drinks. To B he says nothing.

man would have deleted the message without responding. Or it would have ended with the man replying with an eloquent message lecturing B about his prejudice and the ability of prejudice to devastate others. But the man knows how this story ends. It ends with him replying to the Facebook message with a one word message of his own. 'Thanks!' It is only several weeks after sending that message that the man wonders for the first time why he attached a friendly exclamation mark and – for

god's sake – a smiley face, to the end of that 'Thanks!'

FOOTNOTE:

1. An earlier version of this article was published on the Constitutionally Speaking Blog on 02 April 2015.

...how to tell a story of shame and loss and internalised stigma...

It is more than a week later that he receives a Facebook message from B. It contains only three words. 'I am sorry'. If this was another story, not one hewing close to the truth, or at least close to the facts, the

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