spark
new thinking and debate on health communication

Background material

Panos London / Healthlink Worldwide discussion
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How can we tackle stigma and discrimination through effective communication?

'We live with it every day. It's not just HIV. Those are stuff we have everyday. First of all, I'm Black. Second of all, I'm a woman. Third of all, I was a single Mom for a while. So, hello! I'm on social assistance. Right there I cover all the grounds for you. So, it's like racism, you can't hide from it.' | HIV-positive Jamaican woman[1]

Stigma and discrimination are still an everyday experience for people living with HIV and AIDS, around the world. This is so even in places where many people have AIDS, where it is often assumed it would be more publicly recognised and accepted.

Numerous studies have shown that stigma and discrimination are major obstacles preventing effective HIV and AIDS responses; they make people less likely to participate in prevention activities, less likely to get tested for HIV, and less likely to enrol for treatment even where it exists. People may be fearful of disclosing their status, and may postpone seeking care, and they may also suffer violence, particularly gender-based violence, related to their HIV status[2]. Stigma builds on existing social inequalities so that marginalised groups who are at risk of HIV infection, are doubly stigmatised. Women face more stigma and discrimination than men in many settings.

Stigma and discrimination have also been identified as key barriers to the achievement of universal access to HIV prevention, treatment care and support by 2010 - in country consultations during 2005 and 2006 conducted by UNAIDS[3].

Initiatives to tackle HIV stigma and discrimination have been neglected up until recently however, and there is a shortage of well documented and evaluated interventions. That said, there are some promising initiatives, and it is increasingly recognised that a multi-levelled approach, engaging and communicating with a range of different stakeholders, is needed to tackle them effectively.

What are stigma and discrimination?

Stigma is commonly recognised as a process of devaluing an individual or group through beliefs and attitudes that discredit them.

Discrimination is understood as 'enacted stigma' – actions and institutional patterns that have a detrimental impact on those who are stigmatised.

Spark is a joint discussion series initiative by Panos London and Healthlink Worldwide to facilitate the sharing of good practice, innovations and cutting edge thinking in health communication among health and development NGOs, policy-makers and practitioners.

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Once seen as being about individual behaviour, awareness and prejudice, stigma and discrimination are now more usefully recognised as a broad social process that 'maintains power inequalities'.[4] This focuses our attention on the way stigma and discrimination actively sustain boundaries between those in power and those without, and how they justify and support social patterns of exclusion and inequality.

Despite being seen as a central obstacle, stigma and discrimination have long been neglected in HIV and AIDS responses. This is partly due to their complexity, with stigma being found everywhere from everyday beliefs and actions, differences of power in institutional settings, legal and economic frameworks, to societal attitudes around gender, illness and sexuality.

Tackling HIV and AIDS stigma and discrimination

It is increasingly recognised that tackling stigma and discrimination requires approaches that promote action at several levels together:[5]

- working with individuals, households and affected communities to engage and challenge their own stigmatising assumptions, understandings and practices
- non-discriminatory policies and procedures in institutional contexts, such as schools, workplaces and healthcare settings
- legal and national policy frameworks that uphold human rights and do not perpetuate discrimination.

The involvement of people living with HIV and AIDS in designing, facilitating and delivering anti-stigma initiative has also been vital to their effectiveness.[6]

A recent review of initiatives conducted by the International Centre for Research on Women, ICRW, for DFID[7] has shown that tacking stigma and discrimination is possible, and that despite its diversity, stigma has a 'common core' in different settings. Interventions need to address stigma and discrimination at all the above levels, through a range of approaches, and with a range of different 'target groups', in an integrated way.

Tackling attitudes

'After two or three days when I see him he's changed, you know, he thinks I'm finished. Whatever plan I tell him I'm gonna do in life, he doesn't accept it. I have a goal to fulfil in my life but I see in his attitude, you know?…from my experience, people think I'm finished, you know?' | HIV-positive Ethiopian man

The underlying norms that tend to perpetuate stigma – linked to attitudes to gender, sexuality, illness, death and morality – are enforced at household, community, institutional and legal and policy levels.

The mass media have played an important role in raising public awareness and challenging the stigma around HIV through high-profile human interest stories featuring prominent individuals who put a human face on the epidemic. Awareness on its own has a limited effect however, given that stigma is a social process. Evidence and learning in HIV and AIDS communication more generally have highlighted the importance of interpersonal dialogue to promote reflection and change, and this interpersonal dimension has been key to the effectiveness of a range of different peer-to-peer interventions.[8]

Sustained dialogue within communities can allow community members to work with and challenge their own understandings and assumptions to address stigma, using participatory approaches such as Stepping Stones and Reflect.[9] Radio Listening Clubs have promoted discussion around stigma in Malawi, and Community Discussion Forums have raised awareness of the situation of older people

as carers in Zambia.[10] The recent ICRW study of stigma interventions shows that a combination of empowerment of and contact with people living with HIV, and education, have proved effective at promoting change in the attitudes and actions of individuals and communities.

Tackling discrimination in institutions

'The nurse at the [HIV] clinic, she made a very sarcastic statement. She said she always tells her daughters that everybody from Africa is HIV positive. …You know, that is not helping us. We don't need rejection like that'. | HIV-positive Kenyan woman, individual interview

Participatory education and dialogue has also shown promise in a range of institutional contexts, such as with teachers in Zambia, healthcare workers in India, Tanzania and Vietnam[11], and faith groups in Ethiopia and Rwanda[12]. Such interventions foster understanding and changed attitudes, but also can lead to action at the level of institutional policy. In conjunction with changing attitudes, such attention to policies in institutions such as workplaces, schools and health clinics, and wider laws and policies that challenge discriminatory practices is vital. HIV/AIDS workplace policies are increasingly the focus of development initiatives to reduce stigma[13] particularly for national governments, and business networks.

Tackling legal and policy frameworks

At the legal and policy level, initiatives have focused on creating an enabling environment for people to claim and exercise their rights. UNAIDS outlines a number of initiatives as part of its best practice collection, placing them within a human rights framework. Initiatives include: building the capacity of legal services to work on AIDS related issues, developing community based legal services and para-legal counselling to improve the access to legal redress for PLWHA.[14]

At the same time, implementation of existing legislation is often neglected and under-resourced,[15] and in many countries counter-productive laws and policies remain in place. Such legislation may criminalise consensual sex between males, prohibit condom and needle access for prisoners, prohibit drug substitution or criminalise those who consume drugs, or use residency status to restrict access to prevention and treatment services.[16]

Independent social movements and cultural action

'Believe me you are not to blame, you should not feel ashamed, it is us to blame: we who tolerate ignorance and practice prejudice, we who have taught you to fear. We must break the silence now, making it safe for you to reach out for compassion.'
| Asunta Wagura, Kenya Network of Women with AIDS

As well as these formal development interventions, it is important to recognise the initiative and relatively independent dynamics of civil society, through social movements and alternative cultural and public action. Social movements of people living with HIV and AIDS, have generated solidarity and mutual support, and sometimes developed 'resistance identities' to challenge their marginalisation and to redefine their allotted position in society. Gay men, women, sex workers and injecting drug consumers have refused to accept their discredited status and developed a variety of innovative responses to HIV and AIDS in different settings, as well as organising to challenge stigma and discriminatory institutional practices and laws.[17] The Treatment Action Campaign in South Africa, provides a celebrated recent example of civil society mobilisation that has also led to legal and policy battles to widen availability and access to HIV treatment.[18]

At the same time, at a more everyday level, cultural beliefs and practices affect people's capacity to accept or stigmatise PLWHA, their willingness to engage in responses to HIV and AIDS and the

patterns of care and support that are embedded in family and community relationships. Culture can thus affect the local dynamics of discrimination or solidarity that may encourage or challenge stigma and discrimination in different settings.[19]

Current challenges for action on stigma and discrimination

Stigma and discrimination are increasingly recognised as key barriers to effective HIV and AIDS responses, but challenges remain:

- finding effective ways to measure stigma and discrimination, and thus changes in it, are lacking, though there are some new tools and initiatives in this regard
- evaluation and documentation of the impact of the existing stigma and discrimination initiatives on prevention, treatment, care and the uptake of services is limited
- integrated programming that can address the multiple levels and engage a wide range of stakeholders is a challenge, even while many of the component initiatives show promise
- there is a need to create an enabling environment for independent social movements and public action, even while this may have different dynamics and challenge the priorities to official development action.

Despite the recognition that stigma and discrimination must be tackled at all levels in society, and the varying dynamics of stigma and discrimination in different contexts and settings, there is an over-arching need to challenge entrenched relationships of power. Some have commented that, in Africa for example, stigma is anchored in reactions of denial and avoidance that may be a desperate coping mechanism for those faced with the prospect of caring for family or friends when their own households are near collapse. Without improvement in livelihoods and health and social infrastructure, many may continue to face such dreadful choices. Yet, initiatives that tackle the broader legal and structural underpinnings of stigma and discrimination are relatively few, and tend to focus on the individual legal redress, rather than broader social infrastructure. Without initiatives at this level, existing inequalities are likely to be perpetuated, and with them, the mechanisms of stigma and discrimination.

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