



# PLANS AND PRIORITIES 2010-11

Report of NAT HIV Policy Network seminar

16 March 2010, Birmingham

## Contents

Overview of the Seminar	2
1. Introduction: Key achievements of the last year	3
2. Workshops: Issues raised by Policy Network Members	5
2.1 Workshop one – HIV and stigma (and discrimination)	5
2.2 Workshop two – Protecting and improving HIV support services in the current economic environment	10
2.3 Workshop three – New Government: New opportunity? New threat?	15
3. NAT's future plans: Overview and priorities	19
4. Strengthening the role of people living with HIV in NAT's work	21
5. Conclusion and next steps	25
Annex A - Policy Network seminar attendees	26
Annex B - Policy Network seminar agenda	27

## 2. Workshops: Issues raised by Policy Network Members

### 2. 1 Workshop one – HIV and stigma (and discrimination)

HIV stigma and discrimination was the single most popular issue identified by Policy Network members. Those who raised the issue made comments such as:

*“discrimination is at the root of so much else – need to force the pace of action”*

*“even health care workers are encouraging stigma”*

*“layers of HIV stigma relate to racism and homophobia”*

*“stigma should be a priority issue! How can policies and programmes be improved?”*

The workshop built on the findings from the 2008 HIV stigma and discrimination seminar and topline results of the Stigma Index project. It explored members' key concerns and the role of members and NAT in addressing this important issue.

Participants considered the ways in which NAT and the Policy Network can address on the one hand HIV **stigma**, which is a function of shared attitudes and perceptions about HIV - i.e. 'a mark of disgrace'; and HIV **discrimination**, which are actions following from these attitudes - i.e. less favourable treatment of people living with HIV, which is neither reasonable or proportionate.

**Jackie Pollock**, HIV Carers and Families Scotland, offered a service provider's view on stigma and discrimination. Jackie spoke to the group about discrimination against families and carers of people living with HIV. She noted that there is a perception that it is only the person with HIV who needs support. In fact, discrimination takes many forms and affects many people *affected* by HIV.

**Yusef Azad**, Director of Policy and Campaigns, NAT, gave an impression of the scale of discrimination experienced by people living with HIV by summarising the results of City University London's 2005 research (the East London project), in which nearly a third of participants reported HIV-related discrimination. Of these, half had experienced discrimination from a healthcare worker (most commonly dentists & GPs). 42% had faced discrimination from a partner, family or friends, and 22% from a colleague.

Yusef then presented an overview of avenues through which stigma can be and has been addressed - those which have previously been used by NAT and Policy Network members, and work which is ongoing.

#### **Public campaigns**

In 2004-5 NAT ran a campaign called “Are YOU HIV Prejudiced?” The campaign focused on the general public and included a poster campaign, a front cover on the *Metro*, and resources packs. NAT has also done specific work targeting stigma and discrimination in employment and healthcare (posters from this campaign were on display in the workshop room). The project finished when DH funding ended in 2005. The question now is, are large public campaigns useful?

### ***Challenging stigma in the media***

A key part of NAT's communication and public awareness work is consistently challenging inaccurate media coverage of HIV issues. NAT has also produced *Guidelines for journalists* around HIV. The *Press Gang* has increased in membership and activity over the last year. This ongoing work is funded by MAC AIDS Fund.

### ***Stigma in schools***

NAT's work tackling stigma in schools was prompted by concerning case studies, for example, a case of a child excluded for school because of their HIV status. It was thought this was a 'one off' but it was found that exclusion or attempts to disclose widely to others a child's HIV status were routine. In response, NAT produced resources to encourage cross curriculum teaching. The issue attracted media interest. NAT also lobbied MPs with the help of an EDM on the issue and persuaded DCSF to provide guidance for schools and to modify the information they provided to teachers on their website.

### ***Discrimination and harassment in employment***

NAT's research into the work experiences of people living with HIV found that a third had disclosed at work, and many with positive experiences. A key finding, though, was that people living with HIV mostly would not choose to approach their unions for help with HIV-related discrimination at work- NAT has engaged with unions on this issue. Also, while there is protection under the DDA, privacy concerns may prevent people living with HIV from bringing their cases to employment tribunals. NAT is working to improve access to the measures that are available. Finally, a major success of the past year was campaigning to outlaw pre-employment health questionnaires in the Equality Act.

### ***Public attitudes***

Public attitudes about HIV are a mixed picture, raising the question of whether HIV stigma should be considered a 'glass half full' or 'half empty'. Knowledge of how HIV is passed on is getting worse. But some attitudes are improving, for example, the percentage of people who find it acceptable to work with someone with living with HIV. The Ipsos Mori poll into public attitudes about HIV has been carried out in 2000, 2005 and 2007, enables us to measure changes in public knowledge and attitude towards people living with HIV. The poll has been a very important tool in work against HIV stigma.

### ***The role of the Government***

The Government has a key role to play in tackling discrimination, especially, as discrimination can be enforced by law. The progress of Government action against HIV stigma and discrimination has been:

- 2005 draft Department of Health (DH) HIV- related stigma and discrimination action plan
- 2005 Disability Discrimination Act
- 2007 DH web based 'implementation plan'
- 2010 Equality Bill - prohibits discrimination based on association & perception; outlaw pre-employment health questionnaires

What would we want a new Government to do?

**Edwin Bernard**, consultant, then gave a Policy Network member's perspective on the issue of HIV stigma. Edwin suggested that the issue of 'contagiousness' is at the heart of HIV stigma - people fear the contagious, and respond in a way to make people living with HIV the 'other'. He noted that in addressing HIV stigma we need to be aware of the tension between public health and human rights. This is seen especially in the area of criminalisation of HIV exposure. For NAT and the Policy Network, the challenge is how to 'normalise' HIV. In particular, we have to consider if normalisation is possible, if we are in other ways promoting the 'exceptionalism' of HIV?

### ***Group discussion***

After these contributions, the workshop participants discussed how NAT and the Policy Network can work to address HIV stigma and discrimination.

One way to address stigma is through the engagement of '**positive speakers**'. As stigma can create silence around an issue, speaking out is an important weapon. The experience of the group was that using positive speakers to get across key messages about the reality of HIV is very effective in community and school settings. Best practice is to give guidelines for speakers about their audience to ensure their talk has the maximum impact. However, the main power of positive speakers is that they tell a true story and engender empathy from an audience. There is a benefit to the speakers as well as the audience. Positive speakers feel they are contributing to reducing stigma and discrimination and teaching about HIV (which is cathartic).

There was some concern, though, that positive speakers may actually encourage some sorts of stigma. For example, if we choose positive speakers who defy stereotypes by saying "I haven't slept around" or "I'm not gay", it may leave an unsaid message that "It's ok to discriminate against other people living with HIV when they have slept around or are gay".

There was some discussion around the need for approaches to recognise the **distinction between stigma and discrimination**, and between **different types of stigma**. There are two main types of stigma which should be approached in different ways:

- Ignorance (can be tackled by education)
- Values (harder to tackle) (religious groups, racism, homophobes, those who fear illness etc).

These distinctions may also come into play with discrimination - when these attitudes lead to people living with HIV being unfairly treated. One participant noted, for example, that when people living with HIV experience discrimination by dentists, the cause is usually lack of understanding. With doctors, however, who have more knowledge about HIV, the root of discrimination is often individual values, attributing HIV transmission to a particular lifestyle choices, etc.

The workshop group also discussed what would make an **effective campaign** against HIV stigma. Specific types of campaigns to target particular groups were identified: for example, campaigns against institutional discrimination based on ignorance – such as dentists limiting access to treatment and schools excluding pupils; versus campaigns to target various groups who discriminate based on values, such as religious groups, racism, homophobes, those who fear illness etc.

It was also suggested that where campaigning directly references stigma, it should be in a way that makes it clear that it is 'old fashioned'. Something inspired by 'kick racism out of football' about stigma and discrimination could help campaigners show that HIV stigma is now unacceptable within their communities (Gay, African etc.)

The complications raised by using **highly effective treatment** and **Treatment as Prevention** (TAP) as tools against stigma was discussed by the group. HAART has greatly improved the lives of people living with HIV, and research into TAP may be a source of confidence. However, concerns over impact on prevention work had perhaps discouraged people from being too positive about the impacts of effective treatment. There was also some concern that HIV organisations may be tempted to over-emphasise the good experiences of people living with HIV, at the expense of those who have had bad experiences, out of fear of encouraging stigma.

Turning to remedies against discrimination, the group raised the possibility of strategic **legal action**, for example, against dentists and healthcare workers. However, it is a 'big ask' for individual to go through the difficulties of taking legal action, so there would need to be advice, and perhaps targeted support for those cases which are likely to set an important precedent.

### ***How do we address stigma?***

Possible actions arising from the discussion were:

- Communicate more effectively and widely the effectiveness of treatment and its impact on quality of life, life expectancy and infectiousness. There may be a link between improving treatment and decreasing stigma
- Move from HIV exceptionalism to mainstreaming HIV across all sectors
- Understand those occasions where stigma is driven by ignorance and where it is driven by values (e.g disapproval of homosexuality or multiple partnerships)
- Conduct targeted anti-stigma campaigns within most affected communities to make HIV stigma and discrimination unacceptable
- Reconsider how we as an HIV sector talk about stigma – whilst accepting its reality maybe we should not 'talk it up' as much as we do but rather contribute to the changing of social norms but communicating how 'out of date' stigma and discrimination are. We need to disseminate good stories of acceptance not just bad ones.

### ***How do we address discrimination?***

Possible actions arising from the discussion were:

- Support people living with HIV to access their rights and ensure equalities legislation is enacted and implemented effectively
- Establish not just a Policy Network but a legal network to support people to challenge discrimination and seek redress
- Ensure inclusion of HIV in PSHE – not just medical/biological information but social/rights also.

### ***Recommendations***

NAT and the Policy Network should:

- Encourage and support 'significant others' (celebrities, organisations) in communities to speak out and influence
- Build on work with community media to address HIV differently
- Work as a sector to support people living with HIV accessing their legal rights
- Work with the EHRC on this issue
- Empower people with HIV to respond to stigma and support resilience
- Share experiences across the sector of supporting and developing 'positive speaker' networks