

Equality of Opportunity Committee

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Committee Inquiry into Discrimination against People Living with AIDS and HIV within Healthcare and other settings by Healthcare Professionals

Evidence from the Terrence Higgins Trust Cymru

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The HIV and sexual health charity for life

Ann Jones AM
Chair
Equality of Opportunity Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

19th November 2009

Dear Ms Jones

Enquiry into discrimination against people living with HIV in healthcare settings

Due to an apparent IT failure, we only recently became aware of the above enquiry. From the outset, we would like to apologise for the delay in responding to the Committee and to pass on our thanks to the clerking team for allowing us to contribute at this advanced stage in your considerations.

THT Cymru provides a variety of services across Wales from our centres in Swansea and Cardiff, and through peripatetic provision in Powys and North Wales. These services range from support for people living with or affected by HIV: counselling, group work and social support, to prevention and health promotion initiatives including HIV and STI testing.

THT Cymru also currently facilitates the National HIV Network which aims to promote cross-sector communication on HIV service development in Wales; identifying shared goals

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and disseminating information on best practice and quality standards. The network also hosts a positive participation group which gives people living with HIV the opportunity to take a proactive role in the development of services.

We welcome the Committee's enquiry and the consideration which Members are currently giving to the issue of stigma and discrimination experienced by people living with HIV in Wales.

We are aware that the Committee has been provided with anecdotal evidence from a number of providers in relation to people's experiences in accessing services in Wales. Whilst we will outline some of the reporting of incidents we have received from clients and network members, we considered that it could be helpful to focus our response on the research background to this issue. Due to time constraints, we have not been able to survey the issue more rigorously with the National HIV Network for Wales. However, we are keen to take any questions or additional scoping that the Committee may identify to the Network as part of its future working.

For the most part our clients report being very satisfied with the specialist care they receive; with issues of discrimination confined to some experiences in primary and non specialist care settings. The issue of access to dental services in particular, is one which has been brought up by participants of the HIV Network.

Case Study 1.

An HIV positive client waiting for a basic operation was admitted to hospital on five occasions and kept until the last on every theatre list. This person was told each time that they would be operated on. When the operation was cancelled by surgeons he was then told that it was due to a lack of theatre time. Each arranged operation was preceded by a pre-admission clinic where staff expressed confusion as to why this operation was kept to the end of each list and why this basic exploratory procedure had not been undertaken.

Stretching over a three year period, this person had to go through the pre-admission process on five occasions. Having

to take time out of a full time job and to explain to their employer and colleagues why this operation had not taken place.

Eventually, when the procedure was done and the person was prepared for surgery and anaesthetised, the medical team realised that no exploratory operation needed to be done as the area where the initial problem had occurred had completed healed. No examination had been done since the original referral had been made 3 years prior to getting into the operating theatre.

In 2008 Sigma Research, funded by Terrence Higgins Trust, undertook a UK wide survey of people living with HIV entitled What Do You Need? The survey examined a range of issues relating to wellbeing and quality of life including access to treatment, asylum and immigration issues, housing, money, self esteem and training and skills. The study also focussed on people's experiences of stigma and discrimination, reporting that:

the two most common problems encountered involved a lack of respect, and significant (often unnecessary) restrictions in access to high quality health and care provision. Where individuals complained about lack of respect, this ranged from a feeling that generic health staff (particularly GPs, nurses and dentists) often lacked the HIV specialist knowledge or time to provide appropriate support, and were flustered by being in the presence of someone with HIV infection.

Others were subjected to hostile and judgmental assumptions, comments and inappropriate queries about how they had acquired HIV. Respondents also reported ways in which health and care providers inappropriately altered the ways in which they delivered care because they were aware of the presence of HIV. In the worst cases, this involved denial of services (particularly in relation to dentistry, surgery and the taking of blood). Others reported exclusion from timely access to health care, including being told by GPs that all health issues must be taken to the HIV specialist out-patients clinic.

Finally, were those who reported undue / excess precautions, such as double gloves and only being able to take the last appointment of the day in order that dental instruments could be sterilised afterwards.

Finally, a small number reported breaches of their confidentiality by medical and reception staff.¹

67 people resident in Wales took part in the survey. 16.9% reported having experienced discrimination from health or care professionals in the previous year (compared with 19% of the UK wide sample). When this data was broken down by NPHS regional unit, nearly 22% of people resident in Mid and West Wales reported experiencing healthcare based discrimination compared with 12% in South East Wales. The figure reached 25% for Welsh residents from other areas including North Wales.

Whilst these findings do seem to suggest a level of parity with the UK at national level, they also give some indication of geographical differences throughout Wales. There is however a lack of Welsh specific research looking at the issue in more detail including potential regional differences and influences such as the impact of rurality on stigma and discrimination.

In an effort to address this THT Cymru has been working with the International Planned Parenthood Federation in rolling out a community research and advocacy initiative that has been developed to measure and document how people have experienced, and been able to challenge and overcome, stigma and discrimination relating to HIV. We understand that the findings of the Welsh stage of the People Living with HIV Stigma Index are to be made available to the Committee in the coming month and we would support consideration of this work and how it can be built on in future.

In the UK a number of major studies² have been undertaken to investigate the prevalence and impact of HIV related stigma and discrimination. These studies indicate that the issue is complex involving feelings of judgement, blame and guilt directed towards or felt by people living with HIV. Lack of public awareness of the virus and how it is transmitted also contributes to an environment where misinformation can gain traction and prejudices arise. Negative attitudes towards

¹ What do you need? 2007-2008: findings from a national survey of people with diagnosed HIV, Weatherburn et al, Sigma Research, 2009
<http://www.sigmaresearch.org.uk/files/report2009b.pdf>

² Outsider Status: stigma and discrimination experienced by Gay men and African people with HIV, Dodds et al, Sigma Research 2004
<http://www.sigmaresearch.org.uk/downloads/report04f.pdf>

HIV are also compounded by the existing difficulties experienced by at risk groups namely homophobia, racism and social exclusion.

An Ipsos MORI poll³ published by the National AIDS Trust in 2008 found that 69% of people surveyed agreed that there is still a great deal of stigma in the UK around HIV and AIDS. 48% of respondents felt that people who contracted the virus through unprotected sex only had themselves to blame, with this figure increasing to 64% when considering people who had become infected through drug use.

This negativity undoubtedly has an impact on people living with HIV and can affect individuals' personal relationships, employment and experiences of public services. This in turn can have a profound effect on a person's physical and emotional health and also acts as a major barrier to testing among those who may be at risk. This is particularly significant given that over a quarter of people infected with HIV in the UK remain undiagnosed⁴; with late diagnosis being a major determinant in HIV related morbidity and mortality⁵. According to figures published by NPHS Wales, 54%⁶ of new diagnoses in South East Wales between July 2007 and June 2008 occurred when people were at an advanced stage in their illness.

Case Study 2.

A client with very pronounced seroconversion illness symptoms for around six weeks was not offered an HIV test by his doctors despite being a gay man and from a recognised at risk group. The client felt that health care providers had taken a heterosexist viewpoint; assuming all patients were heterosexual, and had consequently failed to factor HIV into the possible prognosis. The person subsequently became very ill and considers this to be direct result of late diagnosis

At a UK level THT has worked with other HIV organisations to lobby for action on stigma and discrimination including

³ Public Attitudes Towards HIV, 2007. Ipsos MORI & NAT, 2008
<http://www.nat.org.uk/Media%20Library/Files/PDF%20documents/NAT-MORI-report.pdf>

⁴ HIV in the United Kingdom 2008, Health Protection Agency, November 2008.
http://www.hpa.nhs.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1227515299695

⁵ Mortality Audit, British HIV Association, December 2006
<http://www.bhiva.org/cms1192339.asp>

⁶ Providing for the needs of people with HIV/AIDS in Wales: National Care Pathways and Service Specification, Table 4, p.7

securing extended provisions within the Disability Discrimination Act 2005, contributing to the Department of Health's Action Plan on Tackling HIV Related Stigma and Discrimination and current work on the Equality Bill. Our campaigning document HIV and Sexual Health: 10 things the Welsh Assembly Government can do published in July 2007, called for an increase in HIV training for primary care practitioners in an effort to address discrimination experienced in health care settings.

The National Care Pathway and Service Specification for HIV developed earlier this year outlines a number of actions which will hopefully increase the availability of HIV training for non-specialist health care professionals in Wales. We consider this to be central to tackling the issue of stigma and discrimination, normalising testing and improving diagnosis and health outcomes for people living with HIV. The document was developed in close consultation with the National HIV Network with these provisions receiving particular support from members.

Case Study 3.

A client went along to a dentist on the recommendation of a social worker who was supporting him. After his first consultation, he was told not to tell anyone he attended that particular practice as he might frighten patients away. This person never went back to this dentist but was expected to pay for the consultation in which he was discriminated against.

In conclusion, we welcome the Committee's enquiry and look forward to working with its findings. We realise that the process is now at an advanced stage. However, we are very keen to assist the Committee where possible, including in providing any further information required, consulting the National HIV network and in giving oral evidence.

Whilst we would not wish to anticipate the findings of the Committee's report we would like to outline the actions that we consider could make a difference in reducing cases of HIV discrimination in healthcare settings in Wales. We would welcome:

- Additional research on stigma and discrimination looking specifically at the Welsh context and the impact of issues such as rurality.
- Increased training on HIV issues for non specialist healthcare providers
- Engagement with professional associations allied to healthcare, including the British Dental Association, to promote training, awareness raising and best practice among members
- Improved access to advocacy support and training for people living with HIV

Thank you for the opportunity to participate in the enquiry. Please do not hesitate to contact me directly if you would like further information or input from THT Cymru.

Yours sincerely

Pete Clark
Director for Wales