



**Cynulliad Cenedlaethol Cymru  
The National Assembly for Wales**

**Y Pwyllgor Cyfle Cyfartal  
The Committee on Equality of Opportunity**

**Dydd Mawrth, 17 Tachwedd 2009  
Tuesday, 17 November 2009**

**Cynnwys**  
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Cydraddoldeb a Hawliau Dynol  
Inquiry into Discrimination against People Living with HIV by Healthcare  
Professionals and Providers—Evidence from the Equality and Human Rights  
Commission

Cofnodir y trafodion hyn yn yr iaith y llefarwyd hwy ynddi yn y pwyllgor. Yn ogystal,  
cynhwysir cyfieithiad Saesneg o gyfraniadau yn y Gymraeg.

These proceedings are reported in the language in which they were spoken in the committee.  
In addition, an English translation of Welsh speeches is included.

**Aelodau'r pwyllgor yn bresennol**  
**Committee members in attendance**

Eleanor Burnham	Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats
Ann Jones	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
Jonathan Morgan	Ceidwadwyr Cymreig Welsh Conservatives
Janet Ryder	Plaid Cymru The Party of Wales
Joyce Watson	Llafur Labour

**Eraill yn bresennol**  
**Others in attendance**

Dr Olwen Williams	Pennaeth Staff, Meddygaeth Gymunedol ac Arbenigol, Meddyg Ymgynghorol ar Faterion Cenedlol-wrinol—Bwrdd Iechyd Lleol Prifysgol Betsi Cadwaladr ac Aelod o Bwyllgor Cymru, y Comisiwn Cydraddoldeb a Hawliau Dynol Chief of Staff, Community and Specialist Medicine, Consultant Genitourinary Physician—Betsi Cadwaladr University Local Health Board and Member of the Wales Committee, Equality and Human Rights Commission
Eleanor Williams	Pennaeth yr Adran Gyfreithiol, y Comisiwn Cydraddoldeb a Hawliau Dynol Head of Legal, Equality and Human Rights Commission

**Swyddogion Cynulliad Cenedlaethol Cymru yn bresennol**  
**National Assembly for Wales officials in attendance**

Catherine Hunt	Dirprwy Glerc Deputy Clerk
Helen Roberts	Cynghorydd Cyfreithiol Legal Adviser
Denise Rogers	Gwasanaeth Ymchwil yr Aelodau Members' Research Service
Bethan Webber	Clerc Clerk

*Dechreuodd y cyfarfod am 9.28 a.m.*  
*The meeting began at 9.28 a.m.*

**Cyflwyniad, Ymddiheuriadau a Dirprwyon**  
**Introduction, Apologies and Substitutions**

[1] **Ann Jones:** Good morning, everyone, and welcome to the Committee on Equality of Opportunity. I remind Members around the table to switch off their mobile phones, their pagers, their BlackBerrys and anything else that they may have, as they affect the simultaneous translation equipment. Simultaneous translation of Welsh to English is available on channel 1 on the headsets, while the verbatim language is amplified on channel 0 if you have trouble hearing. Sometimes, the acoustics in this room can be a little strange. We are not expecting a fire alarm test this morning, so should the alarm ring, we will take our instructions from the ushers, who will direct us out of the building. The assembly point is just

outside the building, by the Pierhead building. You can follow me, because I am usually one of the first out if anything like that happens. We have received no apologies; therefore, the committee has a full complement this morning. I invite Members to make any declarations of interest under Standing Order No. 31.6. I see that there are none.

9.30 a.m.

**Ymchwiliad i Wahaniaethu yn Erbyn Pobl sy'n Byw gyda HIV gan Weithwyr  
Gofal Iechyd Proffesiynol a Darparwyr Gofal Iechyd—Tystiolaeth gan y  
Comisiwn Cydraddoldeb a Hawliau Dynol  
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Commission**

[2] **Ann Jones:** We will now continue our inquiry into discrimination against people living with HIV or AIDS in healthcare settings and other settings by healthcare professions. We are delighted to have Dr Olwen Williams and Eleanor Williams with us, who are both from the Equality and Human Rights Commission in Wales, and we are very grateful for your papers. Do you want to add anything, or are you happy to go straight into questions?

[3] **Dr Williams:** May we do a brief introduction?

[4] **Ann Jones:** It would have to be brief, because we are short on time.

[5] **Dr Williams:** Thank you for the opportunity to give evidence to this committee. These issues are obviously very dear to my heart, as I work in the field. Some of the issues behind all of this are fear and prejudice and a lack of knowledge. That drives stigma, which, in turn, leads to discrimination and the breach of human rights, which then perpetuate that ongoing stigma. The impact of this, not only on the health of our nation, but on the onward transmission of HIV, is very important. We know that people do not come forward for HIV testing as a result of the fear of being stigmatised. We know that there is a risk then of presenting at a much later time in their disease. There is also the risk to the unborn babies of mothers who decline to be tested. There is also the fear of criminalisation for onward transmission, which is very important. Those are the only things that I would like to add.

[6] **Ann Jones:** I will start with the first question to you, Olwen. You have been involved in HIV care in north Wales since 1992. Have you witnessed any changes, over those 17 years, in the way healthcare professionals treat people who live with HIV and AIDS?

[7] **Dr Williams:** When I first started working in north Wales, there was a lot of prejudice, especially within the medical fraternity. I experienced incidents where my patients were having procedures denied or delayed by medical staff as a result of their being HIV positive. That situation, I am glad to say, has significantly improved, probably more so in the last four years since the Discrimination and Disability Act was changed and made it illegal to discriminate against those who have a diagnosis of HIV rather than full-blown AIDS. So, there has been an improvement. The improvement as regards overt discrimination is obvious, but I perceive that there is ongoing subtle discrimination—an ignorance that makes people inadvertently discriminate against individuals who are HIV positive.

[8] **Janet Ryder:** I think that you might have started to answer one of my questions, Olwen. The last time we took evidence, we had some health professionals here from both medicine and dentistry. They argued that, in some cases, people have perceived discrimination where there has not been any. A person living with AIDS might, for example, not be aware of the universal, cross-contamination prevention measures that health

professionals use with all patients. Given what you have just said, I would welcome your comments on that. One of the concerns is that we need to know whether this is a perception or a reality.

[9] **Dr Williams:** I frequently go to wards and find HIV positive patients who are not immuno-suppressed—in other words, who are no more at risk of acquiring infections than any other individual within that ward—being put in a side room with all the infection control gear outside and a sign on the door telling people not to enter without gowning up. This is based on the ignorance of the healthcare staff on that ward of what risks people with HIV pose. It is their ignorance that causes this. Quite often, when I go to wards, I have to explain that these individuals are not at risk and that they do not need to be barrier-nursed. Usually, I find that the signs get removed, but that infection control is a knee-jerk reaction by healthcare staff. It is good in one way, but not in another. It flags up that person, and that person in that room then thinks ‘Why is it happening now?’, and we have to explain it to them, and subtly remove the signs.

[10] **Janet Ryder:** So, it may not be a deliberate move; it may be a move led by a misunderstanding or a lack of knowledge of the dangers, but do you definitely have experience that this is happening?

[11] **Dr Williams:** Very frequently.

[12] **Eleanor Burnham:** Is it not rather ironic that we have a predominance of infection in our hospitals, but they take excessive care, in your opinion, over this through ignorance, and yet we have a rise in bugs and whatever other infections are around?

[13] **Dr Williams:** I agree with you. The other issue is that hospitals do this with people who are known to be HIV positive. A third of the people in Wales with HIV are unaware of their diagnosis in the first place. Therefore, it should be universal across the piece.

[14] **Ann Jones:** Thank you. We will move on to a set of questions from Joyce.

[15] **Joyce Watson:** Good morning to you both, and thank you for your papers. My questions are to you, Eleanor. Your paper to the committee says that the commission believes that people living with HIV face significant discrimination in healthcare settings. Can you tell us about the evidence that has led you to this conclusion, and provide some examples?

[16] **Ms Williams:** The commission is tasked with following equality enactments and the Human Rights Act 1998. So, for the purposes of HIV infection, our remit covers, for discrimination law purposes, people who are discriminated against on the grounds of marriage and civil partnership, pregnancy and maternity, transgender, sexual orientation, age, religion or belief, gender, disability and race. Although HIV infection can fall into any of those nine vertical categories, there is a link between HIV infection and sexual orientation discrimination. The commission has just published a report called ‘Beyond Tolerance: Making Sexual Orientation a Public Matter’, which deals with the discrimination found by lesbian, gay, transsexual and bisexual people in healthcare settings.

[17] **Joyce Watson:** You have started to answer the question that I was going to ask next, but I will ask it for the record. On the basis of the evidence that you have gathered—you have just alluded to some of it—are people living with HIV more likely to be discriminated against in some healthcare settings more than others?

[18] **Ms Williams:** Attitudinal research was carried out by the commission in Wales last year called ‘Who do you see?’ into the visibility of human rights issues. Ninety-seven per cent of those people who were questioned said that they thought that human rights legislation

was a good thing. Forty-six per cent of the same people said that human rights did not apply to them. So, statistics like that cut across sectoral healthcare settings.

[19] **Janet Ryder:** On discrimination in healthcare provision, we have received evidence—some of it anecdotal—that there is a difference in attitude between those healthcare professionals who work in the mental health section and those who work in the clinical section—in other words, between those who do not have a physical intervention side to their medicine and those who do. Have you detected any change there?

9.40 a.m.

[20] **Ms Williams:** I have not.

[21] **Dr Williams:** The difference is that people working in fields where there is exposure to individuals who are HIV positive have a different attitude towards the issue. You find that those attitudes are prevalent among my colleagues who deal with mental health issues and learning disabilities, who understand the human rights aspect. Difficulties arise when you go into other specialties that do not have day-to-day contact with people who are HIV positive. However, you find that it is not just around HIV; it is about all the equality and human rights issues across the piece. I think that that is one of the issues. Although we are looking at just HIV, we could have this conversation about many other stigmatised health issues and we would find the same sorts of attitudes. We become the advocate for the patient within our specialty.

[22] **Eleanor Burnham:** Perhaps you will agree that we should take on board the positive attitude that the dental practitioners have always had. We have had some interesting testimony from them. They treat everybody the same. Their barrier methods are obviously of the highest order because of the invasive procedures that they undertake. Is there something to be learned from them? If I have put you on the spot—

[23] **Dr Williams:** No, I can answer, but most of the anecdotal evidence that I have had from my HIV positive clients is that it is the dentists who are the most discriminatory against them. I batted that back to them, saying that being refused permission to go onto a dental practitioner's list is probably more to do with the lack of availability of spaces as opposed to discrimination.

[24] **Eleanor Burnham:** We did tackle the gentleman on that issue.

[25] **Dr Williams:** That is part of it. They are not allowed to bump people off their lists. I think that universal precautions are something that we should be looking at as well.

[26] **Ann Jones:** We will move on. Joyce, bring us back onto the straight and narrow.

[27] **Joyce Watson:** Eleanor, you started to say that, in your view, some people are discriminated against in healthcare settings. I would like to ask a more specific question. Have you found evidence that people have been discriminated against in healthcare on multiple grounds, for example, if they have HIV and they are a mother, are gay, or are from a black and ethnic minority community?

[28] **Ms Williams:** There has been evidence of multiple discrimination, and that is being remedied in clause 14 of the Equality Bill, which deals with bringing a claim on the grounds of more than one protected class.

[29] **Joyce Watson:** Have you been made aware of discrimination against people working in the healthcare setting—that is, healthcare professionals?

[30] **Ms Williams:** Discrimination is not proud at all—it can occur anywhere. There are also slightly peripheral issues to discrimination wherever that discrimination occurs, such as multiple discrimination and associative discrimination, when you are asked whether you are the partner of someone who has a HIV infection and are discriminated against because of the status of your partner. The commission brought a case last year that was not in a healthcare setting, but along the associative discrimination line.

[31] A legal secretary whose son was disabled was given a rough time in work and had to resign, claiming constructive dismissal. The commission took her case up, and the law has now been changed so that ‘disability discrimination’ includes discrimination because of your association with someone who is disabled. We are not just looking at people with HIV; discrimination is a much wider problem.

[32] **Joyce Watson:** Just to be positive, has the commission been made aware of any example of particularly good practice in a general healthcare setting? Have any efforts been made to ensure that people living with HIV are not discriminated against?

[33] **Ms Williams:** Yes, they have. We conducted a human rights inquiry recently that has turned into a human rights strategy, and we recommend that all public sector authorities adopt a human rights-based approach in policy making.

[34] **Ann Jones:** Olwen, do you have anything to add? Do you know of any good examples?

[35] **Dr Williams:** Yes. Two or three years ago, the Department of Health did some work around prejudice and stigma, and invested £150,000 in two relevant organisations. One was called MedFASH—the Medical Foundation for AIDS and Sexual Health—and the money went to develop guidelines and educational materials for primary care physicians and individuals not working in the field of HIV. That raised awareness of HIV infection, the management of the condition and the need for destigmatisation. The other organisation was NAM, a HIV information group that produces guidelines on rights for those who are HIV positive, and provides information on the Disability Discrimination Act 2005 and human rights. The Welsh Assembly Government has also issued guidelines on HIV infection, and implicit in them is the human rights-based approach. Our issue is getting to the grass roots. Personally, I have been working with our newly formed health board in north Wales, teaching staff about the stigma and discrimination aspect of HIV, and human rights, and some of the more pertinent issues. So, there are examples of good work out there.

[36] **Jonathan Morgan:** You have argued that the Welsh Government could use powers in the Equality Bill, if it is enacted, to address a lack of reliable statistical data. I am just wondering why you think that that is important, and briefly, how you think that it might work.

[37] **Dr Williams:** The only evidence that we have on sexual orientation and lifestyles is from NATSAL, the national survey of sexual attitudes and lifestyles. That gives us some idea of our background population across the UK. However, that did not extract the data that were specific to Wales; they are embedded in the UK data. Another way of collecting information would be to ask questions of everyone coming through healthcare, looking at sexual orientation—that would help us look at what is happening in the healthcare setting. I know that Ysbyty Glan Clwyd was one of the pilot sites for that assessment.

[38] **Jonathan Morgan:** In your written evidence, you said that the commission believes that it is important that public authorities make informed decisions regarding priorities on the basis of rights, outcomes, and consideration of proportionality. What are you getting at there?

[39] **Ms Williams:** We are coming back to the human rights-based approach rather than a needs-based approach—so we are not saying that these people deserve help, we are saying that these people are entitled to receive help.

9.50 a.m.

[40] **Jonathan Morgan:** We will move on. With regard to needing robust information about discrimination, you say in the paper that that

[41] ‘would be significantly enhanced by a duty on inspectorates to use equality as one of the yardsticks by which they measured the good practice of those organisations being inspected.’

[42] How do you envisage that working?

[43] **Ms Williams:** Our human rights strategy seeks the adoption of a human rights-based approach by at least five inspectorates in the UK. However, as far as the Equality Bill is concerned, we have seen that it is only by raising awareness of issues that you can create change, that you can only raise awareness by having an evidence base, and that you can only have an evidence base by having robust data.

[44] **Jonathan Morgan:** In a Welsh context, Healthcare Inspectorate Wales and the Care and Social Services Inspectorate for Wales are two of our inspectorates, and they work in a health and social care setting. Every now and then, they undertake routine inspections or spot inspections. Is it right to say that you would advocate modifying the inspectorate framework to allow the inspectorates to test whether issues around human rights and discrimination are being examined by the bodies that are being inspected in the work that they do?

[45] **Ms Williams:** I think that that would be a very purposive, outcome-driven advancement.

[46] **Jonathan Morgan:** Looking at the ways in which we can tackle discrimination faced by people with HIV, I wonder whether you have been able to assess whether people living with HIV—or their friends and families—have sought advice about discrimination issues from the organisations that you fund to provide such advice.

[47] **Ms Williams:** We have recently undergone a new round of funding, and Wales has been able to retain £250,000 in legal advice funding. With regard to legal advice, we currently fund an organisation in Swansea, the LGBT Excellence Centre, but I do not have any data on specific cases to hand.

[48] **Jonathan Morgan:** I am also trying to figure out where the responsibility for this should lie, because you say in the paper that the committee should consider

[49] ‘empowering people with HIV by increasing their knowledge of their rights’

[50] under both Acts. However, the EHRC has a legal duty to promote awareness and understanding of these rights, so it is your responsibility rather than ours, is it not?

[51] **Ms Williams:** I would not be arrogant enough to say that we could do it in isolation.

[52] **Jonathan Morgan:** If there is an insufficient number of outlets capable of giving authoritative legal advice in Wales, as you stated in your paper, who should tackle that? There is clearly a deficiency as to who can provide that advice and guidance. If the Assembly Government sets the strategic direction, and you have a legal responsibility under the Act to



promote understanding and awareness, it is, essentially, those people at the grass-roots level who can help secure the provision of guidance. How might we provide for that? Does it happen differently elsewhere in the UK? Are there things being done in England or Scotland that we could look at and that would help remedy this deficiency?

[53] **Ms Williams:** I think that a concerted partnership approach would be the way to solve this.

[54] **Jonathan Morgan:** So, perhaps we need to do a bit more to encourage and facilitate joint working between certain organisations that already exist, but that are not doing this kind of work at the moment.

[55] **Ms Williams:** Yes, exactly.

[56] **Jonathan Morgan:** Okay, that is really useful. In addition, are there any other ways in which the EHRC and other bodies might get the message across to people living with HIV that they have a right not to be discriminated against?

[57] **Ms Williams:** As well as the funding to which you alluded, we have a Wales helpline that people can use. In addition, we fund a course, which I teach on, at Cardiff University and Bangor University, specifically aimed at citizens' advice bureaux workers and trade union representatives, on how to run and recognise a discrimination law case.

[58] **Joyce Watson:** I have a final question to Eleanor. You, quite rightly, go back to the human rights agenda and the question that I want to ask is whether, in your opinion, people are very often focused on the equality end of the agenda, rather than the human rights approach in this regard. Would it not be more useful for all concerned if they were to focus firmly on the rights agenda rather than the equality agenda?

[59] **Ms Williams:** Indeed. In July of this year, I spoke at a human rights summit and was desperate to ensure that the delegates understood that human rights was not a macro issue, but a micro issue. I used the device of creating a street where people who lived at specific house numbers had human rights issues related to the article of the house in which they lived. It is called 'dignity drive', and it is now being made into a web-based interactive tool so that people can understand that human rights are those small, local things, as Eleanor Roosevelt put it.

[60] **Eleanor Burnham:** Another Eleanor—there are three of us.

[61] **Dr Williams:** How scary is that? [*Laughter.*]

[62] **Ms Williams:** On human rights, I am trying to monitor the idea of the Human Rights Act 2000 being repealed and a bill of rights coming in to replace it. This is something that I am especially aware of in the Wales context. In a way, we have had very clever draftspeople. They have ensured that section 81 of the Government of Wales Act 2006, which says that Ministers cannot do anything inconsistent with human rights legislation, links us directly to the European convention, and so we are not bound by the Human Rights Act. However, the danger there is that if a bill of rights includes economic, social and cultural rights, which are not covered by the convention, we may need to rethink our strategy.

[63] **Eleanor Burnham:** That is an interesting observation. Basically, if we had a constitution, that would be enshrined in it.

[64] **Ms Williams:** It could be.

[65] **Eleanor Burnham:** Yr wyf am ofyn fy nghwestiynau yn y Gymraeg, os yw hynny'n iawn. Mae'r pwyllgor wedi clywed, ac mae'r ddwy ohonoch wedi trafod hyn yn gynharach, fod pobl, hyd yn oed pan fyddant yn ymwybodol o'u hawliau cyfreithiol, yn aml yn amharod i wneud cwyn neu geisio ateb cyfreithiol i'r gwahaniaethu maent wedi ei brofi. A ydych chi yn y comisiwn yn ymwybodol o hyn?

**Eleanor Burnham:** I am going to ask my questions in Welsh, if that is okay. The committee has heard, and both of you have discussed this earlier, that, even when people are aware of their legal rights, they are often unwilling to make a complaint or to pursue a legal solution to the discrimination that they have experienced. Are you in the commission aware of this?

[66] **Ms Williams:** Mae hyn yn faes cymhleth iawn.

**Ms Williams:** This is a very complex area.

[67] **Eleanor Burnham:** You may use whatever language you want.

[68] **Ms Williams:** Mae angen i Lywodraeth y Cynulliad ddelio â hyn, ond o safbwynt hawliau.

**Ms Williams:** The Assembly Government needs to deal with this, but from a rights-based perspective.

[69] So, this rights issue will be hugely important for awareness and then for change.

10.00 a.m.

[70] **Eleanor Burnham:** Felly, beth y gallwch chi a sefydliadau eraill ei wneud i fynd i'r afael â phryderon pobl nad ydynt yn teimlo y gallant herio'n ffurfiol y gwahaniaethu y credant y maent yn ei brofi, yn enwedig ar sail yr hyn a ddywedasocho yn gynharach ynglŷn â'r anawsterau o fod ynghanol y gwasanaeth iechyd a'u bod yn dal i gael y driniaeth ac ati?

**Eleanor Burnham:** Therefore, what can you and other organisations do to address the fears of people who do not feel able to formally challenge the discrimination that they feel that they are experiencing, particularly in light of what you said earlier about the difficulties faced in being in healthcare settings and continuing to receive treatment and so forth?

[71] **Ms Williams:** The Equality and Human Rights Commission in Wales has a proven track record of success in bringing people together. We have brought together a devout Christian group and lesbian, gay, bisexual and transgender people. That was explosive and amazing in a good way. [*Laughter.*]

[72] This issue of allowing people to air their fears can be encapsulated in the work that we are currently undertaking. We are holding two seminars in December to raise awareness about the UN Convention on the Rights of Persons with Disabilities. Although we do not report on that until 2011, we are very anxious to get people talking about the rights enshrined in that document, and also the principles that lie behind it, so that the human rights of people with disabilities and their fundamental freedoms are fully enjoyed and there is respect for people's inherent dignity as disabled people. So, certainly, the commission is working well ahead of time to drive that awareness and a kind of myth-busting.

[73] **Eleanor Burnham:** I wish you luck, because I already have a case that I am dealing with, relating to a young child in my region of north Wales and social care and healthcare. I will not discuss the details of that case, but it was evident straightaway to me, because I am quite a way down the line on the difficulties faced by the mother and the little girl, that the first word that comes to people's minds is 'nuisance'. This child is heavily disabled; she has complex issues. Therefore, I do wish you luck because I think that it is long overdue. Even ordinary mortals who complain about the health service are often pushed into that 'nuisance'

box.

[74] **Ann Jones:** You are digressing now. Could you please move on, Eleanor?

[75] **Eleanor Burnham:** Dr Williams, rhoesoch enghraifft yn eich papur o ddigwyddiad pan wrthododd staff meddygol gynnal triniaeth colposgopi ar ddynes ag HIV gan nad oedd y driniaeth wedi'i hamserlennu ar gyfer diwedd y diwrnod. Nodwyd gennych bod y fenyw wedi gwneud cwyn swyddogol. Beth oedd canlyniad hyn?

**Eleanor Burnham:** Dr Williams, you provided an example in your paper of medical staff refusing to undertake a colposcopy procedure on a woman with HIV because it had not been scheduled for the end of the day. You noted that the woman had made a formal complaint. What was the outcome of this?

[76] **Dr Williams:** Cawsom air â'r meddyg a'r gwasanaeth colposgopi i d dangos nad oedd angen rhoi'r ferch hon ar ddiwedd y rhestr ac y gallai gael y driniaeth yn yr un modd â phawb arall. Nid oedd materion ynglŷn â rheoli heintiau, ac nid oedd materion ynglŷn â pherygl i bobl eraill. Y broblem yw bod gan unigolion sy'n gweithio yn y maes iechyd—

**Dr Williams:** We spoke to the doctor and the colposcopy service to demonstrate that this woman did not have to be placed at the end of the list and that she could be treated in the same way as everyone else. There were no infection control issues, and there were no issues surrounding risk to others. The problem is that individuals who work in healthcare have a—

[77] **Eleanor Burnham:** Ofn?

**Eleanor Burnham:** Fear?

[78] **Dr Williams:** Ie, a'r gofid y byddant hwy eu hunain mewn perygl. Ag ystyried bod yr epidemig hwn wedi bodoli ers dros 25 mlynedd, mae'n syndod bod pobl yn dal i feddwl fel hyn.

**Dr Williams:** Yes, and they worry that they will be at risk themselves. Considering that we are now 25 years into this epidemic, it is surprising that people still think like that.

[79] **Eleanor Burnham:** A gredwch felly bod angen mwy o hyfforddiant er mwyn sicrhau agwedd bositif tuag at y bobl hyn?

**Eleanor Burnham:** Do you believe that more training is needed in order to ensure a positive attitude towards these people?

[80] **Dr Williams:** Credaf fod elfen genedliadol yn hyn o beth. Ers cael y wybodaeth a roddwyd 20 mlynedd yn ô, mae pobl wedi parhau i feddwl yn yr un modd ac nid ydynt wedi ehangu eu gwybodaeth yn y cyfamser. Mae gan y doctoriaid a'r nyrsys sy'n dod drwy'r system agwedd mwy positif, tra bo'r rhai sydd wedi bod yn gweithio yn y system ers blynyddoedd efallai heb ddod ar draws pobl sydd wedi'u heintio, ac felly mae'r rhagfarn a'r stigma a oedd ganddynt ryw 20 mlynedd yn ôl yn dal i fodoli.

**Dr Williams:** I think that there is a generational element to all of this. Since having the information issued 20 years ago, people have continued to think in the same way, and they have not picked up any new information in the meantime. The doctors and nurses who are coming through the system have a more positive attitude, whereas those who have been working in the system for many years have perhaps not come across people who are infected, and therefore the prejudice and the stigma that they had over 20 years ago still exists.

[81] **Eleanor Burnham:** Mae'r cwestiwn nesaf ar gyfer Eleanor. A yw'r Comisiwn Cydraddoldeb a Hawliau Dynol wedi cymryd camau i orfodi deddfwriaeth cydraddoldeb mewn perthynas â phobl sydd ag HIV mewn lleoliadau gofal iechyd?

**Eleanor Burnham:** The next question is for Eleanor. Has the Equality and Human Rights Commission taken any action to enforce equality legislation in relation to people living with HIV in healthcare settings?

[82] **Ms Williams:** The commission is a modern regulator, so enforcement is just one of the tools in our bag. We will not hesitate to use our enforcement powers when they are absolutely the most appropriate powers to use. I sit on the statutory legal committee in London, which is chaired by Trevor Phillips, and argue which cases we will seek enforcement on.

[83] **Eleanor Burnham:** Dyma'r **Eleanor Burnham:** This is the final question cwestiwn olaf i chi, Eleanor. Gall Dr Olwen for you, Eleanor. Dr Olwen may also gyfrannu hefyd os dymuna. A ydych yn credu contribute if she so wishes. Do you think that bod sgôp i'r broses o orfodi'r gyfraith gael ei there is scope for the law enforcement defnyddio yn fwy effeithiol fel dull o fynd i'r process to be used more effectively as a tool afael â gwahaniaethu yn erbyn pobl sydd ag to tackle discrimination against people living with HIV mewn lleoliadau gofal iechyd neu a with HIV in healthcare settings, or do you ydych chi'n meddwl mai dyna'r cam olaf? believe that that is the last resort?

[84] **Ms Williams:** The definition of disability in the Disability Discrimination Act 1995 as amended states that a disability is a physical or mental impairment that has a long-term and substantial adverse affect on a person's ability to carry out normal daily activities. HIV is ring-fenced within this definition, because it constitutes one of three cases—HIV, cancer and multiple sclerosis—and, from the moment of diagnosis, you are covered by the protection of the Act and do not have to wait until you fulfil the definition. So, the HIV infection is seen as an evolved form of disability, and the law has evolved to be able to cope with that. The legal mechanisms to deal with discrimination are hugely important. When I represented clients who are HIV positive or who have AIDS, I found that the law has really stepped up to protect them.

[85] **Dr Williams:** Part of the issue is getting the leadership within the NHS on board. We have a really good opportunity now, due to the reorganisation, of embedding the disability and human rights strand provided for in the Equality Act 2006. However, we need to ensure that it is not just seen as an add-on, but to ensure that it is really embedded. The commission has suggested that there should be a series of workshops for the chief executives and for the executive leads across the health boards, because if they do not adopt it, the rest of the organisation will not follow. That would mean working with our equalities lead within the health board, and I have just realised how much of an uphill struggle it is for those leads, as they are sometimes lone voices.

[86] **Ann Jones:** Janet, do you have a supplementary question to ask before you move on to your question?

[87] **Janet Ryder:** My question follows on from what Eleanor was asking. I want to take you back to what you said about the cases that you have prosecuted under this law. In your view, and given what you have just said, does the current equality and human rights legal framework provide adequate protection from discrimination to people living with HIV in healthcare settings?

[88] **Ms Williams:** At the moment, under the Disability Discrimination Act, you can bring a case for disability-related discrimination. So, if you have received less favourable treatment for a reason related to your disability, you can bring forward a claim. You can also bring a claim for direct discrimination because you are disabled. The first case under direct discrimination was an HIV positive man working as a carer in a retirement home. Thirdly, you can bring forward a claim if a failure to make reasonable adjustments has occurred, and a reasonable adjustment is needed when you are put at a substantial disadvantage because of your impairment. The Equality Bill has recognised that this is not enough, so there is now a fourth form of discrimination especially for disability and not for any of the other eight

vertical strands, and that is if you have a discriminatory event arising from your disability. That closes a loophole in case law that we saw previously.

[89] If I may, I will, rather geekily explain what that loophole was. Mr Malcolm had schizophrenia. He was diagnosed in 1985 and he was on medication so that he could hold down a full-time job. One of the symptoms of his illness was that, sometimes, he capriciously stopped taking his medication and then his life would unravel. However, it was cyclical and he would get back on board again. One time when he stopped taking his medication, he thought that it would be a great idea to sublet his secured tenancy flat from Lewisham council. Subletting a flat is, according to the terms of the council's housing policy, reason for eviction. So, suddenly, Mr Malcolm found himself evicted. He said, 'This only happened because I stopped taking my medication, which I take because I have schizophrenia, which is a disability.' Under the law, as it stood, following a case called *Clark v. TDG Ltd (t/a Novacold Ltd)*, this would have been watertight and Lewisham would have had to back down. However, on this occasion, it stood firm and said, 'Disability has nothing to do with it. Eviction follows subletting. That is all we're interested in. You're out'. The commission saw this as a huge problem, so we lobbied with others to shoehorn in an extra form of discrimination arising from disability, so that Mr Malcolm could say that he was relying on this section and that his eviction arose from a chain of causal events that led back to his disability.

[90] **Janet Ryder:** So, are you satisfied that the new Bill will bridge the gap?

[91] **Ms Williams:** It will be important.

[92] **Janet Ryder:** To move on, in evidence, both of you and many other people have touched on how to change attitudes. You have both referred to the need for training—and you touched on that a lot, Olwen—along with the lack of knowledge and how you raise awareness among professionals. How can we go about addressing that problem?

[93] **Dr Williams:** In health, it boils down to ensuring that there is a human rights-based training aspect in medical schools and in dental and nursing training, so that equality is there from the beginning as someone enters the profession. On an ongoing basis, people working in the health sector have mandatory training on, for example, child protection and protecting the elderly and vulnerable. However, these may be too harsh tools with which to beat us. I worked out that you require 21 hours a year of mandatory training, which includes manual handling, fire safety and so on. It may be that there is an equality training strand, as is the case in Betsi Cadwaladr local health board. However, that does not yet come under mandatory training. People go on that course because they want to, and that is always the issue: people who are already engaged become more engaged.

[94] With HIV, there is nothing like the individual patient who becomes the spokesman for the cause to change attitudes. However, the catch-22 situation is that someone coming forward to talk about their experiences may subsequently end up experiencing stigma and discrimination and having their human rights breached. We are still very much in a situation where the environment in Wales is not as comfortable as it should be for those individuals. Over the years, I have worked with individuals who have experienced that. Sometimes, it is not them, but their families who have experienced this. However, most people are sympathetic. It is a fear, rather than it being a reality that something will happen. We are inquisitive about people in Wales, and that is part of the issue as well.

[95] So, there are two strands to this. One is about ensuring that this is embedded in primary education in health. There needs to be an ongoing strand of training across all areas of the NHS. The other is about social care, because there is an issue around social services, although they probably have more direct training than happens in the NHS. We need to work

with the voluntary sector in this field to ensure that we work on a partnership basis on patient advocacy.

[96] **Janet Ryder:** You raised many points there, and I wish to deal with some of those, but, first, I wish to take you back to something that you said in answer to Eleanor Burnham. If I have understood correctly, you said that you can detect a generational difference, with new doctors coming into the profession. The evidence from the British Medical Association last week was not necessarily that the primary training had changed in any way, and you have just touched on that. So, is that more about a generational difference, because the generation of doctors coming through now has been brought up in a world where HIV/AIDS exists and is known about, as opposed to the generation of doctors who qualified as it was first being diagnosed?

[97] **Dr Williams:** I think that the attitude still exists. When I came into HIV work in 1988, it was a case of being positive today and dead tomorrow. Of course, everyone in my generation went through the 'Don't Die of Ignorance' campaign, but that was probably the end of their HIV awareness. So, we are talking about anyone aged 45 and up still carrying some of those views, assuming that they have not worked in the field or had any contact with people with HIV. If they have had contact with people with HIV, they will have a very different attitude. It is different for people qualifying now, because HIV is the most written about medical condition worldwide. There are more articles on that per year than any other condition, so it is in their faces.

[98] There is another issue. Although it is there, we are aware that people are still not offering testing. So, there is another way to work on this. The British HIV Association, the British Association for Sexual Health and HIV, and the Royal College of Physicians have worked with the Royal College of General Practitioners to produce guidelines on offering HIV testing and to try to ensure that HIV testing is uniformly available and offered. In three areas of England, there are sentinel GP surgeries offering HIV testing across the piece, as opposed to identifying people who may be at risk. The guidelines also suggest that if the prevalence within your local health board area is more than 2 per cent, HIV testing should be routinely offered in all accident and emergency departments at the point of contact.

10.20 a.m.

[99] In Wales, the evidence that we have suggests that testing is offered only as a last resort, as opposed to being one of the front-line tests offered. The attitude seems to be, 'Well, we have worked through everything else, so what about giving an HIV test?'. That is outside sexual health and antenatal screening, as we have a good pick-up rate through antenatal screening, and the take-up rate for HIV testing is also quite high in genitourinary clinics, but the issue is one of introducing those tests.

[100] That would be a way of changing attitudes and two in particular: that of the healthcare professional offering the test, and of the general public about taking up the testing. We have all heard the story—and this has happened—of the wife of an obstetrician who went for an antenatal screening and the midwife told her, 'You do not need a HIV test, as you are married to one of the obstetricians' but she bit back and said 'How do you know that I do not need one?', and asked for the test. That is the kind of thing that we are still dealing with. By upping the level of testing, we might be able to change attitudes so that people are honest and can say 'I have had the test, and the results were positive'.

[101] **Janet Ryder:** That could be a practical recommendation for the committee to consider, as another step to change attitudes.

[102] **Dr Williams:** We have guidelines there.

[103] **Janet Ryder:** We could do it by bringing in guidelines and changing medical practices, thereby forcing a change in attitude. The other way in which we could do this, which you touched on yourself, is through the ongoing training of doctors. That might address the medical skills as well, because I would hazard a guess that more than half the doctors fall into that 45 plus age range. I presume that you are talking about the mandatory training for clinicians in a hospital setting, and then there is the mandatory training that GPs have to undertake for up to 50 hours a year. There are different ways of looking at this, because there is a strong argument from the BMA that specifying that training has to take place in a certain subject highlights that subject. In one of your earlier answers, you said that it is a general thing. Do we need to look at those training courses with a new approach, asking how we are applying these human rights issues as well as general principles, to ensure that it is written into the training across the piece rather than into specific units?

[104] **Dr Williams:** I think that the equality and human rights strand needs to be embedded in the training courses. Specific HIV training, such as on offering the HIV test, needs to be ongoing but if we are to be a fair, equal and non-discriminatory country, we need to ensure that equality strands are embedded in all training, and not just here and there. We do not want to beat people up about this; we want to engage them and promote good practice.

[105] **Janet Ryder:** Presumably, that would need to go across all fields, so not just clinicians or GPs, but nurses and other healthcare professionals, as well as into social service settings where health services are being offered. I think that you may already have answered my final question, which was whether we should be adopting a much more practical approach, based on writing human rights principles into training practices.

[106] **Ms Williams:** Perhaps a shrewd way to do this would be to echo the Nolan principles. By doing human-rights based training, you get to tick the box as regards the Nolan principles.

[107] **Janet Ryder:** That is interesting, thank you.

[108] **Ann Jones:** Eleanor, do you have a supplementary question on that?

[109] **Eleanor Burnham:** Yes. Perhaps some would say that there are financial implications to this, but would you say that, apart from the human rights aspect, you could ultimately save money if you undertook these HIV tests?

[110] **Ms Williams:** Yes.

[111] **Dr Williams:** Definitely so. The reason we estimate that one in three people do not know their HIV status is because we have been testing individuals anonymously in different settings. They give their consent to have a blood test and are aware that it will be tested for HIV, but they also consent to it being a blind test, so their test is anonymised to the person testing it. The tester gets only some details such as age, ethnicity, sexual orientation and country of birth. That is how we know that one in three people are not aware of their HIV status.

[112] **Eleanor Burnham:** I have just one last very brief question. As I am sure you are well aware, there are moral and ethical issues surrounding whether people want to know about their status, given all the draconian insurance implications and so on. The situation is worsening, really. What is your view on that?

[113] **Dr Williams:** In 1984, all insurance companies loaded their premiums by 25 per cent to cover the massive impact of the heterosexual HIV issue that was to occur in the UK. In the

past four years, I think, the Association of British Insurers has changed that and now no longer discriminates against people who have had a HIV test. The test itself should therefore not have any implications for their ability to get insurance. Some insurance companies will also give limited insurance to people who are HIV positive, although there remain issues if they want to travel, and there are caveats within the policies. Anyone conducting HIV testing now will bust the myth that the test itself has any implications for a person's ability to get insurance, although we do explain that a positive test might have implications. For most people who have life insurance or some insurance, there will be caveats within their existing life insurance to what the insurance will pay out. For example, someone who is HIV positive and who goes on to have a myocardial infarction may still get cover for the myocardial infarction, but they would not if the illness was related to the HIV.

[114] **Eleanor Burnham:** It is very complicated. Thank you very much for your answer.

[115] **Ann Jones:** I have just one final question. Do you have any examples of the actions that you have taken as the EHRC or that you might be taking in the future that would help to protect people living with HIV from discrimination in healthcare settings? You have mentioned working in partnership. Are you looking to do that in this particular field?

[116] **Ms Williams:** Always.

[117] **Ann Jones:** You have the ability to influence quite a lot at the moment and you have the ability to take on cases under the Equality Act 2006. Have you undertaken anything under that Equality Act? Have you used that Act?

[118] **Ms Williams:** Yes, all the time.

[119] **Dr Williams:** One particular case occurred this year—not in Wales, but in Northern Ireland—in which a young gentleman who was HIV positive was discriminated against on the basis of his HIV status by having his gastroscopy deferred and then cancelled. The commission undertook a successful prosecution.

[120] **Ann Jones:** That is good. Thank you very much. That concludes the Members' questions. I do not know whether either of you wants to add anything. Perhaps you think that we should have asked you about something. I see that you do not. I thank you both for coming. Dr Olwen Williams, I know that it is very difficult to get here for 9.30 a.m. from north Wales. There are three of us who can testify to that, so we do thank you.

[121] **Eleanor Burnham:** Did you walk?

[122] **Dr Williams:** I have a flat in Cardiff, so I was here at 11 p.m. last night.

[123] **Ann Jones:** That is all right, then. Thank you both for your evidence. We will send you a copy of the transcript and you may check it for accuracy. Before I close the meeting, I inform Members that the NHS Confederation was not able to identify anyone to give us evidence in this session.

10.30 a.m.

[124] **Dr Williams:** I should confess that I think that the confederation wanted me to do it.

[125] **Ann Jones:** Perhaps we will see you again, then.

[126] The written evidence came from the employers' unit of the NHS Confederation, and is among your papers to note. However, I have written back to the confederation with a set of



questions, and I have asked for answers before we have the Minister for Health and Social Services in on 1 December, at our next meeting.

[127] **Jonathan Morgan:** This process works extremely well when we get written evidence first and then we decide to take oral evidence. Usually, it is not the written evidence that provides the Brucie bonus, if you like, but the oral evidence that you get when you are quizzing someone about what they have written. I am really quite disturbed by the fact that the NHS Confederation has not been able to send a representative to committee. We are talking about discrimination against people with HIV in a healthcare setting, and I find it absurd in the extreme that the body that purports to represent healthcare organisations in Wales is not able to give evidence on that. Would we accept it if the Welsh Local Government Association said that it would not come to represent local government in Wales? It really is quite absurd, and I am afraid that this is not the first time that a committee of the Assembly has struggled to get the NHS Confederation to come to give evidence. It is really quite worrying.

[128] **Janet Ryder:** I find it amazing that the confederation has responded saying that it cannot identify someone to respond to this.

[129] **Ms Webber:** The confederation did identify someone, but that person had a specific angle on HIV and AIDS in the blood service, so that was not relevant to the inquiry.

[130] **Janet Ryder:** That speaks volumes about how the confederation perceives HIV and AIDS. As the confederation covers such a wide field of healthcare activity, I think that we do need to hear from it.

[131] **Eleanor Burnham:** I suggest that we write quite a firm letter of dismay, and question the confederation's rationale for not setting aside half an hour, or however long, for its representatives to come to committee. This is a serious issue, and it suggests that the confederation has a cavalier attitude to this important issue.

[132] **Ann Jones:** I have written to the confederation with a set of questions. In truth, the Minister for health wanted us to take evidence from the health bodies before she came to give her evidence, so she will be interested to hear this as well, I would have thought.

[133] **Joyce Watson:** We all agree that we get the most important information from asking questions that lead to other questions. Does the absence of the confederation—a major participant in this inquiry—create a risk that we might not have as full a report as we would like, and not have the full understanding that we need to take things forward?

[134] **Ann Jones:** That is a fair point. As Jonathan said and we all agree, it is the oral evidence that helps the most to set the direction of travel for the report. That is an important part of the evidence gathering. We will pursue this, and the issue is now on the record for us to note. I do not yet want to go down the road of looking at what we can do legally, but I would be happy to do so if it becomes necessary.

[135] **Joyce Watson:** As we feel strongly that we would like a representative from the confederation to come to committee, with the agreement of colleagues around the table, I suggest that you write as Chair to express our views and concern—

[136] **Eleanor Burnham:** And dismay.

[137] **Joyce Watson:** Then we could see what reply we get.

[138] **Ann Jones:** We will do that.

[139] The next meeting is on 1 December, and we will be taking evidence from the Minister for health. It is scheduled to be the last evidence session for this inquiry, but it may not be if we can get the confederation in. That has a 9.30 a.m. start.

[140] **Jonathan Morgan:** As it is the last meeting before Christmas, may we have mince pies?

[141] **Ann Jones:** I heard that request for mince pies, but they will have to be low-calorie ones. [*Laughter.*] I remind you that the Plenary debate on our home maintenance and adaptations services report is tomorrow. I now close the meeting.

*Daeth y cyfarfod i ben am 10.35 a.m.  
The meeting ended at 10.35 a.m.*