



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

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

**Dydd Mawrth, 29 Medi 2009
Tuesday, 29 September 2009**

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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)
Janet Ryder	Plaid Cymru The Party of Wales
Joyce Watson	Llafur Labour

Eraill yn bresennol
Others in attendance

Vicky Coelho	Swyddog Gwasanaethau, Body Positive Sir Gaer a Gogledd Cymru Services Officer, Body Positive Cheshire and North Wales
Ian Hawkins	Cynrychiolydd Fforwm yr Aelodau, Ymddiriedolaeth AIDS Cymru Members' Forum Representative, AIDS Trust Cymru

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 9.39 a.m.
The meeting began at 9.39 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introduction, Apologies and Substitutions

[1] **Ann Jones:** Good morning, and welcome to the first meeting of the Committee on Equality of Opportunity of the new term. I apologise for starting a little later than usual. It was to do with the fact that our witnesses were having trouble with the public transport system, and we also had a few issues that we needed to sort out prior to the meeting.

[2] We have received apologies from Jonathan Morgan, but we have not been notified of any substitution. I will just go through the usual housekeeping rules. I ask you to make sure that your mobile phones, pagers, BlackBerrys, and everything else that is electronic—other than your pacemakers—are switched off, as they interfere with the translation equipment. While we are talking about the translation, I remind you that the committee operates both in English and Welsh. The translation from Welsh into English is on channel 1 of your headsets, and channel 0 gives the language spoken on the floor; if you have difficulties with hearing, use that channel to amplify the audio.

[3] We are not expecting a fire alarm test this morning, so should it go off, please follow the instructions of the ushers. The assembly point is opposite this building, almost on the waterfront. Let us hope that that will not happen.

9.40 a.m.

**Ymchwiliad i Wahaniaethu yn erbyn Pobl sy'n byw gyda HIV gan Weithwyr
Gofal Iechyd Proffesiynol a Darparwyr Gofal Iechyd—Tystiolaeth gan AIDS
Trust Cymru**
**Inquiry into Discrimination against People Living with HIV by Healthcare
Professionals and Providers—Evidence from AIDS Trust Cymru**

[4] **Ann Jones:** This inquiry came about following a request from a former member of the committee, Bethan Jenkins. She met with AIDS Trust Cymru and asked if we would look into this issue. We are delighted to do so, and are also delighted to have Ian Hawkins with us to start off our evidence session. Ian is the members' forum representative from AIDS Trust Cymru. Thank you for your paper, which I am sure has been helpful for Members. We have sets of questions to help us take evidence. If that is okay, we would like to go straight to those questions.

[5] I will start with the first question. The report that you submitted to committee highlighted a number of concerns about the behaviour and lack of awareness of some GPs. Could you elaborate on that?

[6] **Mr Hawkins:** With GPs, the primary problem was that, when people are actively referred back to them for ongoing treatments for side effects, many GPs are unaware of the treatment of HIV and, therefore, do not have enough information to know what medication there is for this. We have also had refusals from GPs to treat people with side effects and people have been referred back to the HIV consultant for common ailments and things that can be treated in the primary care setting.

[7] **Janet Ryder:** Could I ask—

[8] **Ann Jones:** Have you finished, Ian?

[9] **Mr Hawkins:** Yes. There is not enough information for GPs. They do not have enough training and they are referring back to the hospital for common ailments that can be treated in a primary care setting.

[10] **Janet Ryder:** Is the issue that you raised about GPs not having adequate training something that the committee needs to raise with the British Medical Association, the General Medical Council or with training colleges? Can you see, dare I ask, a difference in the age profile of the doctor and the kind of training that they have received?

[11] **Mr Hawkins:** I do not have that information about the age profile. The British Medical Association commented on some of these issues—which were raised on a BBC television programme recently—and said that this was not actually happening. However, from members, we hear that it is. I think that it is a training issue. Re-training is necessary for people who are in post, as part of an ongoing training session, and it is also required in the initial training of GPs and doctors. I hope that that answers your question.

[12] **Ann Jones:** Perhaps I should have informed the committee that we have asked the Minister for Health and Social Services to take part in this inquiry. She has indicated that it will be to her advantage to attend towards the end of the inquiry, and we can take up that issue

with her as part of that session. We will follow it up. It is strange that we have an action point on the very first issue to come up; thank you Janet.

[13] May I ask you about experiences that your members have had with other staff within general practice settings, such as nurses, therapists or even reception staff? Do your members think that they are not being fairly treated there?

[14] **Mr Hawkins:** People are having difficulty disclosing their condition, especially in rural areas, because the communities are so close knit. Referring back to the previous question, and about GPs looking after day-to-day issues of the person living with HIV, like any other chronic illness, people are finding it difficult with reception staff. Assumptions are made about that person's route of transmission, and there is no real need to know that. There was a heterosexual young lady who presented with HIV and it was assumed that she was a drug addict. That is the type of instance we get.

[15] We are also finding that with the district nursing service, the health visiting service and community midwives—across the board, people do not have enough information. All that needs to happen in those settings is to take universal precautions and that should be adequate. It is not happening and I think that it is a pure lack of training and information.

[16] **Janet Ryder:** Can we look at some of the other medical sectors where people have to go for treatment? I would like to ask about dentists and accessing dental treatment. Is there anything that you would like to say?

[17] **Mr Hawkins:** Dentists have been an issue that we have talked about on the all-Wales HIV network for a considerable amount of time. This is not only because of the lack of dentist provision in Wales—there is a shortage of them anyway—but there is an even smaller section willing to take on HIV patients. People are telephoning to try to find space on a dentist's list, but when they disclose their HIV status there is suddenly no space. The other thing that people find is that dentists are not just double gloved, but triple gloved—extreme measures such as that—for barrier protection. There is no need. It does not provide any more protection than just wearing one pair of gloves. Obviously, if blood or bodily fluids are involved there needs to be some barrier. However, it is over the top.

[18] **Janet Ryder:** What you are describing is unacceptable behaviour from professionals and it is extending to other areas. You have talked about rural areas. What about when people access accident and emergency departments?

[19] **Mr Hawkins:** I have had two people respond about accident and emergency departments. One was about quite good provision, where the junior doctor was very knowledgeable about HIV. There was another instance where, again, assumptions were made about the route of transmission. That is not important when somebody is presenting to an accident and emergency department. It does not matter how they got HIV; the issue is that they are HIV positive, whether it is well maintained and what the risk is. I only have two examples of accident and emergency services.

[20] **Janet Ryder:** Are there any other areas of hospitals that would be of concern?

[21] **Mr Hawkins:** Yes—midwifery. There was one incident where a lady was refused treatment by one of the midwives because she had HIV. She had to be treated by another midwife. We have also talked about surgical areas. People are bumped to the end of the day's list because that is where high-risk procedures are carried out. What generally happens then is that, if something has overrun, they get put back. They have been waiting for surgery all day—nil by mouth and everything—then they are put to the end of the list and possibly do not get their procedure that day. That mostly covers the hospital setting.

[22] **Janet Ryder:** Thank you.

[23] **Mr Hawkins:** May I just elaborate on one more point here? I forgot to say. The other episode that we had was where a patient was admitted to a ward, put into an isolation room and barrier-nursed with risk-of-infection signs outside. There was no clinical need. It was just because it was HIV.

[24] **Janet Ryder:** In all the situations that you have described there is physical contact. What happens in health services where there is no physical contact, for example mental health or other support services?

[25] **Mr Hawkins:** We had a lady comment about a psychotherapist through a GP in a primary care setting. The psychotherapist kept referring to her condition as ‘the AIDS’ and ‘AIDS’— AIDS is the syndrome whereas HIV is the actual infection. There was no understanding of the difference between them. This was in the therapy session.

[26] **Janet Ryder:** I can appreciate how that particular case was unsettling and not a very acceptable way forward. Have you found any instances of the other things that you mentioned—being put to the end of the list, having treatment delayed and so on—in mental care or support services?

[27] **Mr Hawkins:** No. I have not had any comments on that side of mental health.

[28] **Janet Ryder:** So, by way of non-reporting from your members, can you detect a difference in the way health professionals approach physical or psychological support? The attitudes of healthcare workers may need looking at.

[29] **Mr Hawkins:** I cannot comment because I have not had anybody come forward with a mental health issue.

[30] **Janet Ryder:** That may speak for itself.

9.50 a.m.

[31] **Eleanor Burnham:** I am going to speak in Welsh, so you might like to put on the headsets to hear the translation.

[32] Yr wyf am ofyn am wahaniaethu yn erbyn pobl o grwpiau neilltuol. Mae'r adroddiad yn cyflwyno darlun cyffredinol o ragfarn neu wahaniaethu yn erbyn pobl sy'n byw gyda HIV. A yw pobl o grwpiau neilltuol yn profi rhagfarn neu wahaniaethu penodol; er enghraifft, dynion hoyw, pobl o Affrica, defnyddwyr cyffuriau, mamau a phobl o gefn gwlad? I wanted to ask about discrimination against people from particular groups. The report presents a general picture of discrimination against people who are living with HIV. Do people from particular groups experience particular types of discrimination; for example, gay men, Africans, drug users, mothers and people who live in rural areas?

[33] **Mr Hawkins:** Could you repeat that? I am sorry.

[34] **Eleanor Burnham:** I will say it in English. Your report presents a general picture of discrimination against people living with HIV. What I would like to know is: do people from certain groups experience particular types of discrimination—for example, gay men, Africans, mothers, and possibly people who live in rural areas?

[35] **Mr Hawkins:** From the information that I have gathered, targeted groups were not highlighted. It was across the board in general. However, in rural areas it is more difficult. There was some evidence that, especially in rural GP practices, there was stigma and discrimination. It did not come across that there were specific sectors of the community receiving more discrimination than others.

[36] **Eleanor Burnham:** Could you explain why you think that is happening in rural areas?

[37] **Mr Hawkins:** It is generally because the communities are smaller and maybe more insular. Perhaps they do not have access to as much information as in bigger areas, where there are HIV centres and training provided by consultants to GPs.

[38] **Eleanor Burnham:** In effect, it is a similar answer to the one that you gave to Janet—that GPs do not perhaps have the experience to enlighten themselves about the whole issue.

[39] **Mr Hawkins:** I would agree with that.

[40] **Joyce Watson:** Good morning, Ian. You expressed concerns that experience, or fear, of discrimination could result in increased risk to the general health and wellbeing of people living with HIV if they avoid the health services. Can you tell us more about your members' experiences?

[41] **Mr Hawkins:** I can only elaborate on the information that I have already provided. The primary areas of discrimination were GPs, dentists and surgical settings. I do not have a lot more information. Refusal of treatment was an issue for some patients and that has a bearing on their total wellbeing and health. HIV-related discrimination is often down to a lack of knowledge, misconceptions and myths. With extra training and information, we can dispel those myths and there is no need for a barrier between people with HIV and healthcare.

[42] **Joyce Watson:** You also say in your paper that some of your members have received support to challenge the behaviours that you have just described of the healthcare professionals under the Disability Discrimination Act 1995. Can you tell us any more?

[43] **Mr Hawkins:** The team at AIDS Trust Cymru and the Supporting People team—I do not have the specifics in front of me—challenged the decision of a dentist. Once they mentioned the Disability Discrimination Act the dentist relented and took the patient on.

[44] **Joyce Watson:** How aware are your members in general that their rights to access goods and services are protected under the Disability Discrimination Act?

[45] **Mr Hawkins:** Could you say that again?

[46] **Joyce Watson:** How aware are your members that they have the right to access goods and services under the Disability Discrimination Act?

[47] **Mr Hawkins:** There is a very low level of understanding about the Disability Discrimination Act and the protection that it provides. That is not just with people who are covered by the Act but also with service providers. There is very little information available. When the Act was reviewed to cover HIV, there did not seem to be any great publicity to say that HIV was covered.

[48] **Joyce Watson:** Are you saying that a lot of the people whom you represent would not actually know?

[49] **Mr Hawkins:** Not without accessing services by providers, and the provider informing them of it. There is generally very little awareness of the fact that the Act covers HIV.

[50] **Eleanor Burnham:** I will try Welsh again.

[51] Mae'r ateb i ymgynghoriad y pwyllgor gan Ymddiriedolaeth GIG Gogledd Orllewin Cymru yn honni nad yw wedi'i hysbysu ynglŷn ag unrhyw fath o ragfarn neu wahaniaethu gan staff gofal iechyd yn erbyn pobl yn eu hardal sy'n byw gyda HIV. Felly, pa mor debygol yw eich aelodau i wneud cwynion swyddogol yn erbyn staff gofal iechyd sydd wedi gwahaniaethu yn eu herbyn?

The consultation response received by the committee from the North West Wales NHS Trust says that it has not been made aware of any issues of discrimination against people living with HIV in its area by healthcare professionals. Therefore, how likely are your members to make official complaints against healthcare staff who have discriminated against them?

[52] **Mr Hawkins:** I cannot comment about North Wales NHS Trust—

[53] **Eleanor Burnham:** The North West Wales NHS Trust.

[54] **Mr Hawkins:** It is unlikely that they would make an official complaint, because they feel that it might jeopardise their healthcare. I am involved with a patient group in south Wales—it may not be specifically relevant—and we have been able to raise issues through that forum if people are suffering discrimination or have a problem with the hospital. That is then taken forward to the trust board.

10.00 a.m.

[55] **Eleanor Burnham:** Is there ignorance or a lack of understanding about the whole matter?

[56] **Mr Hawkins:** People are afraid to make a complaint about a problem that they might have, as they do think that it might jeopardise their healthcare.

[57] **Eleanor Burnham:** Healthcare professionals may also be fearful because they do not understand about HIV and the matters being discussed.

[58] **Mr Hawkins:** I agree. In the HIV and genitourinary medicine departments, healthcare professionals have a greater understanding, but, obviously, other departments within the hospital have less of an understanding. I think that they are fearful and do not have enough information.

[59] **Janet Ryder:** If it is a lack of information, what more could be done to raise awareness among your members that they have the ability, if they feel that they have been discriminated against, to proceed with a complaint, or among professionals, to raise awareness that they could face some sort of action? As it stands, any discrimination, if proven, would be breaking the law.

[60] **Mr Hawkins:** A greater understanding of primary care and NHS trust discrimination policy and law, and what the DDA covers, would be helpful. There is not a great deal of awareness of the Act and what it covers. Its profile needs raising, through extra training or an awareness raising campaign, publicly.

[61] **Ann Jones:** You talked about repeat prescriptions. On page 2 of your paper, you mention that most patients opted to have their HIV medication delivered directly to their home, or to collect it from their HIV clinic during their three-monthly consultation. Your next paragraph says that, in many cases, when that was presented to their GP to set up a repeat prescription, they were met with various questions about why each drug was needed. Do you see that as being part of the GP's review of medicines? There is a requirement for GPs to review repeat prescriptions. Is that discrimination, or is it the GP undertaking that review? I am playing devil's advocate.

[62] **Mr Hawkins:** What happened in the case that I mentioned in the report was that the repeat medication had not long been set up. The patient had a medication referral from the hospital to take to the GP and, the following month, the patient ordered the repeats. Then a different GP, within the same practice, telephoned and asked 'Why do you need all this medication—what is it for?'. I think that that is due to a lack of understanding about the side effects of HIV medication. Although the medication works, the side effects can be quite significant. It may partly be a review, but there may also be an element of discrimination, down to a lack of understanding.

[63] **Ann Jones:** I just wanted to test that out, because medications need to be reviewed. Do Members have any questions that we have not covered? No. Thank you for coming in, Ian, and for your paper, which is useful.

[64] You will be sent a copy of the transcript. You cannot add anything, but if anything attributed to you is incorrect, let the Clerk know. We will keep you informed of how this goes. Thank you for attending today.

[65] **Mr Hawkins:** Thank you for listening to me.

[66] **Ann Jones:** Thank you, that is great.

10.04 a.m.

**Ymchwiliad i Wahaniaethu yn erbyn Pobl sy'n byw gyda HIV gan Weithwyr
Gofal Iechyd Proffesiynol a Darparwyr Gofal Iechyd: Tystiolaeth gan Body
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Wales**

[67] **Ann Jones:** We will now move on and invite our next witness, Vicky Coelho, the service officer from Body Positive Cheshire and North Wales, to the table. Welcome to the committee and thank you for your paper. We have a set of questions to inform the evidence, and they are probably similar to the ones we asked Ian. What we are trying to do is to find ways that the committee can help to address some of the issues that you are raising. Your paper is very good—it highlights two cases of discrimination against people living with HIV. One is that of a gentleman who was receiving treatment for substance misuse, and the other was that of an elderly woman who was receiving care in a home following a hip operation. Is there anything you could add to that, to help us understand why those two cases have been cited?

[68] **Ms Coelho:** I think that they provide a stark contrast: a younger, gay gentleman and an older, heterosexual white woman. I thought that the two examples show that discrimination is not aimed at only gay men, black women, white women and so on. It is generic across the board, and purely down to HIV. There are no other factors that could be construed as

discriminatory.

[69] **Ann Jones:** Is that common?

[70] **Ms Coelho:** It is very common. I picked those two examples because they stood out for me. What often happens is that people are discriminated against in a subtle way, being put at the end of the list for dentists' appointments, not being added to the list at all, and having their appointments cancelled at the last moment. People are asked by GPs how they contracted HIV, when that would not be asked of any other illness. People do not feel that there is a need to ask how it was contracted and what kind of lifestyle led to that.

[71] I am from north Wales, and we have around 200 HIV positive people. Our organisation works with some 70 per cent of the positive population of north Wales. A lot of them live in rural areas. I came in halfway through Ian's presentation so I am not sure if he covered this, but rural areas tend to be significantly worse than the coastal areas, where there is a higher density of population. We believe it is down to a lack of understanding, a lack of knowledge and fear. We do a lot of work, and I go out with other voluntary organisations, to provide training on basic HIV awareness concerns. People still think that you can catch HIV by shaking hands, sitting on toilet seats, coughing, sneezing, and sitting in the same room as someone who is HIV positive. That is still common. Also, people still think that it is a death sentence. As I mentioned in my report, one GP told a patient that he did not know why he was bothering to come for treatment, because he had AIDS and would be dead soon. The patient had been diagnosed as HIV positive, which, I am sure you will be aware, is different from being diagnosed as having AIDS.

[72] The myths surrounding HIV are still out there. Everyone is aware of the tombstone adverts from the late 1980s and early 1990s, and people remember that image. HIV has gone off the radar somewhat since then, and those are the prevailing images that lead to a lot of fear. In some cases, it is understandable why people react in the way that they do.

[73] **Eleanor Burnham:** Will you further illuminate what you said about the difference between having an HIV and an AIDS diagnosis? Believe it or not, there are people who are watching and who are interested in what we are doing.

[74] **Ms Coelho:** HIV, as I state in my training, is the human immunodeficiency virus. It is the virus that people become infected with. The virus then slowly depletes the immune system, and people become prone to opportunistic infections, such as TB, various cancers, candida of the throat, and so on.

[75] To have an AIDS diagnosis, you must have a combination of syndromes. AIDS is the acquired immunodeficiency syndrome; it involves a collection of illnesses. They can be various illnesses, not the same ones, but you must have several in order to be given an AIDS diagnosis. Antiretroviral medications now mean that people are living longer with HIV. They live full lives and have normal life spans, providing they adhere fully to the medication, which often has quite horrific side effects. So, people are living longer without having an AIDS diagnosis.

[76] It is a big matter for people to be told that they have AIDS when they do not; they have had an HIV diagnosis. AIDS is the latter stage, when people become very poorly. That is significant for people, and can be upsetting for them.

[77] **Eleanor Burnham:** Do you believe that that is why some health officials—particularly in the countryside; I come from north Wales—have a prejudice? The prognosis you have described for certain people who have HIV is different to those at the end who suffer from AIDS.

10.10 a.m.

[78] **Ms Coelho:** Absolutely, that is the key—people do not understand the difference. The newspapers call them ‘AIDS victims’, which is a horrible term. Princess Diana held an ‘AIDS baby’, not someone with HIV. That is the image held by the general public; it is not only the medical profession. People at all levels of society think that HIV and AIDS are one and the same. That is absolutely not the case, but I do not think that there is a general understanding of that.

[79] I have to admit that I, before coming to this field of work almost three years ago, did not fully understand the difference. Sometimes, it is easy to think, when you work in the field day in and day out, that everybody should know the difference. However, without the education, I do not think that that is possible.

[80] **Ann Jones:** Janet, you have a set of questions.

[81] **Janet Ryder:** Thank you. May I take you back to something you mentioned about general practice? You made the distinction—and our first witness commented on this—between the kind of care offered in an urban setting, or a more populous area, and the kind offered in a rural setting.

[82] We explored the possibility earlier of whether that was down to the age profile of the clinician, and whether new clinicians have approached it differently in their training and are thus more aware of it and how to treat it. Is there a rural and urban split, with fewer cases presenting at the surgery and doctors therefore not being fully aware of it? Is it the case that it ought to be addressed in doctor training? Or does it need to be addressed through more of a personal, discriminatory approach? That may be inside the person, as to how they perceive the patient and the illness. Can you elaborate a bit more on the kind of GP problems that we have?

[83] **Ms Coelho:** I do not think it is down to one specific aspect. It would be naive to say, ‘It is because of that, and if we sort it out, that is the problem solved.’ It is a multi-layered problem. I think that there is a difference in terms of age when it comes to approach. I went to see a GP the other week for my own health, and he asked what I did for a living. I explained to him and he said, ‘It must be terrible living with the dead and dying all the time.’ I had to explain that I work with the living, and people are living well. I think that younger GPs have learnt about it post antiretroviral therapy, and they have a greater understanding.

[84] Personal prejudice will come into it, as people have personal prejudices. Whether they are in a professional or a personal setting, those prejudices will sometimes come through. I think it is being caused by the general education of people and a lack of understanding.

[85] In a rural setting, not only do you have older GPs who have been in the same small practice for a number of years, but you have Mrs Jones the receptionist, who people will not go to in order to access services because, despite confidentiality rules, it is known that people around the village will know. So, you may as well have a big black cross painted on your door. It is appalling, and people have been run out of villages as a result. We had a gentleman lose his job, and his employer said, ‘If you take me to court, I will tell everybody else in the village about your status.’ It is difficult to combat.

[86] People see medical professionals as someone to look up to and who are there to provide help and advice. Where someone is discriminated against by medical professionals, it is somehow worse, because these are the people who ought to know about the illness and how it is treated.

[87] **Janet Ryder:** May I ask you about dentistry? You mentioned people not being able to register with dentists. Are the same problems that are occurring with GPs occurring in the dentistry profession?

[88] **Ms Coelho:** They are, although there is a general problem—as I am sure everyone will know—with registering with a dentist in north Wales anyway. However, people are offered appointments at the end of the day. As an organisation, we are more than prepared to speak to dentists and say that because of our service users' compromised immune system, if they are not following standard hygiene procedures, they are putting all of their patients at risk, and all such appointments should be earlier in the day in case there are complications. So, it should be done for the sake of our patients and their health. However, they are put at the end of the queue. If they do disclose their HIV status—and many people do not when registering with a dentist—they are often put on a waiting list that does not appear to have an end. It is difficult for people, because good oral health is beneficial to everyone.

[89] **Janet Ryder:** Does that extend to other clinical or physical healthcare fields, such as accident and emergency? Have your members had many problems with these?

[90] **Ms Coelho:** We have three accident and emergency departments across north Wales, and I am pleased to say that we have not had many problems at all. Staff members have been advised that a patient has HIV and, therefore, have been given the medication, because a patient must adhere to it at certain times. It has been put down in their notes, and staff have sought advice from consultants. So, generally, that has been good.

[91] **Janet Ryder:** What about any other health services that may not be on the physical side? I am thinking of mental support services, or other social support services. Have your members detected a difference in attitude here?

[92] **Ms Coelho:** There have been several. Again, there was an urban/rural divide. We have worked closely with mental health services in Wales, due to the impact that HIV has on the mental health of many of our service users. They are well informed, but we are always on hand to offer training should they have any questions.

[93] We had a case where someone was being looked after by mental health services in the more rural parts of Wales, and the nurses were told not to touch his belongings in case they catch AIDS. They have been instructed not to go near him. To be honest, two members of staff will not work with him at all because 'he has AIDS', but he is HIV positive. It is absolutely appalling.

[94] **Janet Ryder:** Is this in a community hospital?

[95] **Ms Coelho:** In the community, yes. People are afraid to take it forward and to complain.

[96] **Joyce Watson:** You have expressed concerns—we have heard a lot of them during the morning—that the experience or fear of discrimination could result in an increased risk to the general health and wellbeing of people living with HIV, because they might avoid using some of the services. Will you say more about the experiences that you have come across?

[97] **Ms Coelho:** People often will go to their GP with a minor illness, like you or I would, and they are bounced back to their clinics. The GP tells them to go to see their consultant. That is obviously putting pressure on the consultants. Some people have to drive two and a half or three hours, one way, to get to their HIV clinic. It is not a matter of nipping into their local village or town to access care. It takes a whole working day to visit a consultant over an

exceptionally minor problem that should be dealt with by the GP.

[98] I understand about contraindications and so on, where GPs may be fearful of giving the wrong medication, as there may be consequences when they are mixed with antiretrovirals. However, the consultants are on hand to give telephone advice. What our service users report is that it is almost as if they are not welcome at their GP surgery because of the HIV; they are being pushed back, and everything is treated as HIV related.

[99] We had one lady who had problems with her thyroid and continually went to the GP, saying she was tired. He would not test her for anything and told her, endlessly, that it must be the HIV. In the end, the HIV consultant took her bloods and discovered that she had a thyroid problem. That is something that should have been diagnosed in the GP surgery. That lady, who was disabled, found it difficult to access HIV care as she to travel on not-so-great public transport, and she had to do this in order to have an illness diagnosed that should have been diagnosed in her primary care setting.

10.20 a.m.

[100] **Joyce Watson:** To turn that on its head, do you have any examples of the treatment working well? Perhaps they could be adopted as best practice.

[101] **Ms Coelho:** It varies from place to place. Some GP surgeries are absolutely fantastic and have taken on board our service users' needs, what they can do, and what needs to be referred on. I cannot give you specific names right now but I would be happy to pass them on after the meeting.

[102] **Joyce Watson:** That would be good. You also say in your paper to the committee that the woman whose experiences you describe in the second case study took her case to the former Disability Rights Commission. How often do your members alert the Equality and Human Rights Commission of the discrimination that they have experienced in a healthcare setting?

[103] **Ms Coelho:** In more than two years, that is the only case.

[104] **Janet Rider:** Really?

[105] **Ms Coelho:** Absolutely.

[106] **Joyce Watson:** So, following on from that, do you think that there is a general awareness among your members of their rights to access goods and services and of the fact that those rights are protected under the Disability Discrimination Act 1995?

[107] **Ms Coelho:** As an organisation, we advise people of their rights under that Act. People find it very difficult. They are in a very vulnerable situation, and they are not well. They are trying to access care, maybe at their local surgery, but they do not want to kick up a fuss. This is not just about the medical community, as it also applies to employment, access to education and so on. People do not want to kick up a fuss. They do not want to upset the apple cart. They do not want to fall out with their local GP whom they have been with for maybe 20 or 25 years. Although they are advised of their rights, the majority—99.9 per cent of people—will just say 'no' and leave it there. So, it is very difficult.

[108] **Eleanor Burnham:** You have partly answered some of my earlier questions, but I do have another. May I ask it in Welsh?

[109] **Ann Jones:** Sorry, I did not explain to the witness previously, but you need to switch

your headset onto channel 1 to hear the translation.

[110] **Eleanor Burnham:** Gofynnais y cwestiwn hwn i gynrychiolydd Ymddiriedolaeth AIDS Cymru hefyd cyn ichi gyrraedd. Yr ydym wedi cael ymateb i ymgynghoriad y pwyllgor gan Ymddiriedolaeth GIG Gogledd Orllewin Cymru, sy'n honni nad ydyw wedi'i hysbysu o unrhyw wahaniaethu gan ei gweithwyr gofal iechyd yn erbyn pobl sy'n byw gydag HIV. Pa mor debygol yw'ch aelodau chi—a chredaf eich bod wedi ateb y cwestiwn hwn hefyd, a dweud y gwir—o gwyno yn swyddogol yn erbyn staff gofal iechyd sydd wedi gwahaniaethu yn eu herbyn? Soniasoch gynnau am feddygon teulu, ac efallai y gallech ymhelaethu am bobl eraill sy'n gweithio yn y gwasanaeth iechyd.

Eleanor Burnham: I also asked this question of the representative of AIDS Trust Cymru before you arrived. We have received a response to the committee's consultation from the North West Wales NHS Trust, which claims that it has not been informed of any discrimination against people living with HIV by its healthcare professionals. How likely are your members to make an official complaint—and I think that you have answered this question, actually—about healthcare staff who have discriminated against them? You mentioned general practitioners earlier, but perhaps you could expand on that point by talking about other people working in the health service.

[111] **Ms Coelho:** Mae'n ddrwg gennyf ond nid wyf yn siarad digon o Gymraeg i ateb eich cwestiwn yn Gymraeg.

Ms Coelho: I apologise but I do not speak enough Welsh to answer your question in Welsh.

[112] **Eleanor Burnham:** Mae'n iawn.

Eleanor Burnham: That is fine.

[113] **Ms Coelho:** People do not report cases. If you had another illness where there was no such stigma attached, such as cancer or other diseases and viruses, you would be more inclined to complain. Our service users are very disempowered by having HIV. When someone is diagnosed with an illness, they would normally tell their family and friends who can be there to offer support. That does not happen in the case of many of our service users. That then extends beyond family and friends to employers and so on, and it is almost like living a lie continually. So, I do not imagine that the North West Wales NHS Trust has been made aware of any formal complaints, but that is probably because our service users do not feel that they have the voice to do that.

[114] **Eleanor Burnham:** I can see that there is a member of the media up in the public gallery, and I am concerned about whether you feel able to engage with the media to develop a more positive awareness of all these issues. They must be devastating for a sufferer who has underlying problems and then other things ensue. You have just said that, generally, they are living a lie, and that must be very stressful. How do you think we can all engage with the media in a more positive way?

[115] **Ms Coelho:** By raising the general awareness of the wider public and not just of the medical community. It goes hand in hand. The media need to portray it in a positive light as well, and move away from the death and doom of the 1980s campaign, which was the last time that HIV was in the media in any great sense. We would be happy to work with the media—or so she says. [*Laughter.*] Awareness needs to be raised a lot, but not necessarily by having one campaign and then forgetting about it. It needs to be a continuing process of education and awareness, whether in schools or elsewhere. I noticed that the recent sexual health advertisement campaign mentioned every sexually transmitted disease except HIV, for instance.

[116] I go out to talk to young people and find that they are not aware of the issues. They think that HIV can be cured. They think that it is okay, because you can take tablets for it, but

that is not the case. It has almost become too sterile. People either think that it is a death sentence or that you can take a tablet and will be cured. There does not seem to be any middle ground with HIV.

[117] **Eleanor Burnham:** Are there people, in your experience in north Wales, who could live a more fruitful life if they had a little more support?

[118] **Ms Coelho:** Absolutely, if they could be a little more open.

[119] **Eleanor Burnham:** Would you even use the parallel of drug users? We know, much to our angst, that there are people who, given enough love and support, could live in society fairly fruitfully and even hold down a job.

[120] **Ms Coelho:** Absolutely. What we are doing now is helping people to return to work and to education. It is not about dying from HIV; it is about moving on and living with HIV. As a comparison, when we had our office in Chester—because we cover Cheshire as well, although my post is solely for north Wales—we were located next to the drugs service. There were drug users who were HIV positive, and they would be happy to visit the drugs service but not the HIV centre, because they did not want people to know. Such is the stigma, people were happy to go into the drugs service but not to come into our centre.

[121] **Joyce Watson:** To get back to the stigma—and I agree that it exist—you rightly said that the last media campaign on this was in the 1980s, which was very much about playing the blame game. It was reported that if you were gay, you were more likely to be HIV positive or to get AIDS. Do you think that that stigma has been attached to individuals because society itself has projected the blame for contracting the virus onto the individual? If they were found to be infected with HIV or AIDS, it was seen to be their fault, because of their lifestyle. If so, we have a long way to travel, and could you make a firm recommendation about how we start that journey?

[122] **Ms Coelho:** You have hit the nail on the head. I speak quite often to professionals such as social workers and healthcare professionals, and they all know of someone who has HIV or who has died from AIDS but who got it ‘innocently’ because they were a haemophiliac. That is the term that is used: innocently. It implies that some people deserve to have it. We pick it up in a lot of women who are pregnant. Unprotected sex is a fact of life, unfortunately, and it is almost as though they are not innocent. They deserve to have it. They have just done what everybody does, but it is not seen like that. It is considered that, if that was your lifestyle choice, that is why you are HIV positive. That comes across again and again from social workers, doctors, teachers, and so on. We are very far from winning the battle against discrimination. There has to be a long, sustained programme of education to try to keep it continually highlighted in whichever way we can. We can all do our small part, perhaps by providing training, even though it may reach only one person. We are very small fish given the size of the whole country.

[123] **Joyce Watson:** I was going to ask a question following on from that, but you have partly answered it. Some elements of society think that it is people’s own fault if they are infected and there is very little sympathy or anything. They are seen as a victim of their own causing. Health and teaching professionals are often drawn from that section of society, and tend to think that. So, do you think that it might be a good place to start if we had a rolling programme of education? It might even be headed with a line like ‘It is not your fault’ or ‘You are not to blame’.

10.30 a.m.

[124] **Ms Coelho:** Absolutely. Many years ago, cancer was treated in much the same way.

Now, no-one would dream of saying to someone, ‘You have cancer because—’, or ‘You have diabetes because you eat too much chocolate’. So, it is possible, although we are a long way off. Society needs to change its attitude and then, hopefully, everything else will follow. It has been done before, with cancer, and I think that it could be done again.

[125] **Eleanor Burnham:** Is it possible for you and your organisation, and maybe other organisations, to have a role in delivering personal and social education in schools?

[126] **Ms Coelho:** Everything comes down to funding, unfortunately. We do provide training. We are lottery funded, and part of our remit is to provide training for organisations. I go out to train ChildLine and North Wales Community Justice Partnership staff, for example. I try to get out to those people who will go on to work with others, taking a cascade approach. With only one of me and several organisations to teach, that is a good way of spreading it out.

[127] **Eleanor Burnham:** Would you recommend that the committee include that as a recommendation in its report?

[128] **Ms Coelho:** Absolutely.

[129] **Eleanor Burnham:** It would help to raise awareness.

[130] **Ann Jones:** I think that she has been very clear on that. She has already answered it.

[131] **Janet Ryder:** I am trying to catch the Chair’s eye.

[132] **Ann Jones:** I can listen and watch someone else at the same time. I am good at multitasking. [*Laughter.*]

[133] **Janet Ryder:** On that issue, have you ever been approached by the BMA, the General Medical Council or the hospital trusts to provide training to professionals?

[134] **Ms Coelho:** No. In the case of a lady who was refused home care, we offered to provide training, but it was never taken up. The difficulty that we have with going out to hospitals and so on is that we are not medical professionals. There is a difference between medical and social care, and I do not think that I need elaborate on that.

[135] **Ann Jones:** May I ask you one final question, which may sound a bit glib? On the media, do you think that soap operas help when they run a story about someone who has HIV?

[136] **Ms Coelho:** I think that they are very alarmist. They had the storyline with Mark Fowler’s character, but they never saw it through. They sent him away to die in shame.

[137] **Eleanor Burnham:** That was in *EastEnders*—my favourite.

[138] **Ann Jones:** That was the storyline that I was thinking of, because of the shame element.

[139] **Ms Coelho:** They sent him away to die. I thought that that was awful. I read recently that, in *Hollyoaks*, I think—although I do not watch it—a gentleman fell over and everyone was running away from him shouting, ‘We’re going to catch AIDS’. So, no, that kind of thing does not help at all.

[140] **Ann Jones:** Television producers have a lot to come to terms with. Perhaps they ought to get involved with your organisation.

[141] **Ms Coelho:** I think so.

[142] **Ann Jones:** Has anyone else got any further questions on this? *[Interruption.]* Eleanor, please could you give Vicky your business card afterwards? Sorry, but it is off-putting when people move around the table.

[143] Thank you, Vicky, for coming and for your paper. We need to look at the cases and then we can follow it through. As I said to Ian at the end of his session, we will give you a copy of the transcript of today's meeting. Obviously, you cannot add things that you did not say, but if we have attributed something to you that we should not have done, please let us know. We will let you know how it goes.

[144] **Ms Coelho:** Thank you very much for listening.

[145] **Ann Jones:** Just before we close the meeting, we have a paper to note. Members will have seen that we have received a response from the Welsh Assembly Government on the home maintenance—

[146] **Janet Ryder:** Before we leave this issue, I have a question. I missed the last meeting, so I am not sure who is down to give evidence as part of this inquiry. Have we got the British Medical Association and people like that coming here?

[147] **Ann Jones:** Yes.

[148] **Janet Ryder:** Do we have anyone from Cardiff medical school coming in?

[149] **Ann Jones:** I do not think so, just the BMA and the dentistry people.

[150] **Janet Ryder:** I do not want to extend the work of the committee but, in view of what has been said today, it might be a good idea to invite someone from the medical school. Bearing in mind the issues that were raised yesterday, in the joint meeting with Northern Ireland and Scotland, it would be a valuable exercise to take this as an example and ask the trusts what assessment they make of their strategies to see how effective they are, rather than just asking them what they are doing.

[151] **Ann Jones:** We could write to them as part of our inquiry.

[152] **Ms Webber:** I can send you a list of the people whom we have contacted about coming in, if that would help.

[153] **Janet Ryder:** Specifically, we should change the question around. Instead of asking them when they will do this, we should ask when they have assessed the strategies that they have in place and how they have changed their procedures as a result.

[154] **Ann Jones:** Yes, we could do that.

[155] **Eleanor Burnham:** What about someone representing nursing?

[156] **Ms Webber:** I will send you a list, because we have contacted some people and we are waiting for them to confirm whether they can come. I do not wish to say on the record whether they can or cannot come.

[157] **Ann Jones:** Bear in mind that the Minister will be coming towards the end of the inquiry. We have already picked up one issue straight away today and we hope to have a list

of them by then. We could supply it to her ahead of the meeting, so that she can be prepared and come here with some answers. Fine, that is a good point. Thanks, Janet.

[158] As I was saying, we have a paper to note. We have received the Welsh Assembly Government's response to the home maintenance and adaptations services for older people in Wales report. Could Members look through the Deputy Minister for Housing's response and advise the clerk on whether there are any issues that we need to pick up? We have a Plenary debate scheduled on it this term, but I cannot think what the date is. It is not immediate, anyway.

[159] **Ms Webber:** It is on 18 November.

[160] **Ann Jones:** Thank you. However, if we think that we need to invite someone back in to discuss the issues, we can look at that—although time is tight.

[161] **Joyce Watson:** I note that the response of the Deputy Minister is positive. It is really nice to see a positive response to such an important issue.

[162] **Ann Jones:** That is good. Anyway, let me know by the end of the week whether there is anything that you feel we ought to be chasing up. The next meeting is on 13 October, when the Minister for Social Justice and Local Government, Brian Gibbons, will be here. We will be focusing on our scrutiny of the relevant policy bits of the budget. This is our stab at the budget, and then I will be writing to the Chairs of subject committees asking them to bear equality issues in mind when they discuss their subject portfolio's element of the budget.

[163] **Eleanor Burnham:** Bearing in mind our joint meeting with Scotland and Northern Ireland yesterday, do you think that the Scottish in particular have an example of how we could be getting to even better grips with budgeting? I believe that their Chair was quite positive about how they can advance their cause through the budget. Can we look at that?

[164] **Ann Jones:** Yes, we can. We cannot put anything in place for this round of budget scrutiny, but we can look at that. So, 13 October is our opportunity to discuss equality issues with Brian Gibbons. I think that there may be a 9 a.m. start for that, so please bear that in mind. Thank you very much.

*Daeth y cyfarfod i ben am 10.37 a.m.
The meeting ended at 10.37 a.m.*