

Owen Power

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PARTICIPANT: Right. I was born in Dublin, believe it or not, 1950, in a way I had a very idyllic childhood. A bit sheltered, but most certainly at the time it was not a country to live in and be gay, it was just not an option. I realised that, so I decided to emigrate to London. Moved to London, lived in West Kensington, which was just near to Earl's Court. At the time it was a little gay subculture anyway. The whole street consisted of bedsits, and it was sort of an alternative to the establishment, if you like. All very unreal, and all very safe, up to a point. Wasn't really aware in the 70s of the emergence of HIV; that came in the 1980s.

I started off the 80s working as a training manager, delivering government training schemes, with a particular remit for people with disabilities. Now, at that time, the culture was very hostile to LGBT people. If you think about it, we were dealing with section 28, [missed] [00:01:53] so people like myself that worked in the caring profession could not afford to be out, simply because of the idea basically then that [if] people were queer, they must be paedophiles, they must be this, they must be that. The tolerance might be, oh it's the twilight world of homosexuals. But it was certainly wasn't a good thing. In my case, I didn't feel particularly under pressure simply because people focused on the fact that I was deaf, disabled, and therefore not likely to be a sexual being at all. And there was no sort of, why haven't you married, so on and so forth. So in a way, it wasn't an issue.

At the time, during the 80s, I was in a long term relationship with a guy who was totally was out without sight. That really brought home to me about the lack of access to sexual health or sexual health awareness for people with disabilities. Because if you think about it, if someone is blind, and they cannot read, how are they going to find out how to keep themselves safe? Now at the same time, if you can imagine, we've had the sudden emergence, or awareness of HIV, we have the television advert, Don't Die of Ignorance, the tombstone – can you imagine how my partner felt, listening to all this on television, but not really being able to find out for himself how to keep himself safe? He relied on me for information.

We eventually separated, but at the beginning of the 1990s, I really felt the need to do something about it. So I got in touch with someone at the then Riverside Health Authority, and we discussed the possibility of setting up a project on providing information on sexual health, HIV prevention, etc. and have it recorded on compact cassette, and make this available for people people that were without sight or had difficulty reading.

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Fortunately, the project was funded by the health authority, and we decided to launch it for World AIDS Day in 1992. And at the time, the Minister of Health came along to the launch, and just was all very very supportive. It was surprising in a way, because if you think about it, at the time, we had a Conservative government, but yet the Minister for Health, Normal Fowler, was quite radical in pushing forward the tombstone advert, as grim as it was. And it seemed as if he side-lined Mrs Thatcher,

and said, you're keeping out of it, and actually got on with the campaign, provided the leaflet to every household, and from my understanding, that really has been very very effective in bringing HIV awareness to people, and was an example to the rest of Europe.

But anyway, the project was launched, and was very very successful. From my own point of view, and my relationship with the issue of HIV and AIDS, in some ways it has been quite difficult, because originally I was really concerned because I'm someone with Marfan syndrome, which is a congenital condition which in some ways is not unlike HIV, because it's all about having a condition which might do this, might do that, you might lose your sight, you might go deaf, your heart might fall apart. But if you take control of your health, and just follow medical care, you can live a normal life, so to speak, which is something that I believe passionately about. But at the time, I felt, because of having Marfan syndrome, if the medic thought that I was gay, that they may sideline me in the sense that, because monitoring Marfan can be quite expensive, I'm sure. So it's a sort of, all the hard work they're doing keeping me going so well could be all pulled away if I end up HIV positive. So I thought it was best to keep that side out of it.

Now the other issue is, I can never forget the time, looking for life insurance. It was unbelievable that the financial advisor, one of the first question she asked me was, have you ever been tested for HIV/AIDS? That was just about the first question I was asked. The really funny thing was, this woman knew that I was gay, but she looked me straight in the face, and I looked at her straight in the face, and said "no", and that was that. But it's still an issue isn't it? Because if I say yes, the premiums would have been ridiculously high, or more than likely, no cover at all. So that was one particular area that was a concern.

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But on the other hand, then the practical issue of being deaf, and accessing support, protecting sexual health, etc., that can be difficult simply because so many of the services, you've got to phone. They don't have email contacts, and it can be a little bit off-putting to make an appointment. Then of course comes the issue going through the actual testing process, and questioning because it's a lottery – I could end up with a healthcare professional that is self-conscious about someone who is deaf, mumbles, and so on and so forth.

In a recent test I had, I had an absolutely remarkably chilled-out guy that was doing the testing. [He] indicated we be as long as we liked, that he would do whatever it takes to ensure we got through it all quickly and easily. His common-sense approach was really remarkable; the first thing he did was set up his word processor, and literally just typed out the questions, which meant I could just glance at his screen and just check I fully understood his questions. Now, the thing that really was a help... because I'm one of these people that can so easily say, oh yes, yes, you know, when someone asks something, and just hope I've got it right. But if you think about it, in a medical issue, that is not helpful, simply because he could have asked me, am I a heroin user, and I say, yes, yes – or whatever.

Then of course, the issue of getting results is usually over the phone. So again, his approach was that he made an exception, he made an appointment for me to call him again, and get the results, which, that was helpful, in person. Because clearly, to get results by email and not being able to respond with questions... was just a good thing.

Getting back to the HIV awareness cassette, which was targeted for people without sight, at the time it was really interesting because I was working as a training manager. Part of the idea was the project was providing work experience for people with disabilities. Now part of the work experience was the production of material on compact cassette. So people on the training course took part in the production. The work experience also included sending a monthly magazine to blind people throughout the UK, so we were able to market the HIV awareness cassette, and send it out to people throughout the country, and at the same time, contact all the various local authorities, because it was the Riverside Authority in London who supported us, so we were really able to ensure that within each local authority, that the person concerned with looking after people with visual impairment, knew about the cassette and made it accessible to their clients.

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Fortunately, the feedback we received was very very good, because I think there was appreciation that someone had broken this assumption that people with disabilities are not sexually active, or worse still, have no right to a sexual life. And you'd be surprised how common that sort of thought is. And it still exists, which is quite tragic. But I think there's still a lot to be done to make people aware of... for people to become more aware of their own responsibility to find out about how to take care of themselves. And obviously, the way to do that is to provide information, in whatever media that are necessary. I don't think it's enough just to have material available in somewhere like the Lesbian and Gay Foundation, because that's in a way where all the people that are already clued-up and are aware have access to. But what about all the people that don't feel they belong to any particular group, are not joined up, as it were. And I feel so many are isolated, for whatever reason, and are not really taking responsibility for their own sexual health. There are so many men who are having sex with men, who may be married, and so on and so forth, and are just taking chances. I think it's really important that we do something about it.

It's quite a thorny issue and quite a challenging issue to bring up, about the assumption that people with disabilities are not sexual beings. And that actually is a little bit widespread in the so-called LGBT community. Because, if you think about it, so many of the venues are not at all accessible for people with mobility issues. Then, every social location, whether club, pub, whatever, it's really impossible for deaf people to meet up and to have anything. In effect, it would feel at times that it's arguable that the LGBT community itself is quite harsh, and it's sort of, just a place for the beautiful young people, fit, in good health – everyone else is sort of shunted aside. Now clearly, that's not totally widespread, because you could argue there's no such thing as an LGB community, as such. But it just... if we say here in Manchester, to socialise in the Village and so on and so forth, the Village is a nightmare, if the truth be told.

But I think that there is an assumption... the fact that it is difficult to arrange for health checks. I mean, the very fact that everything is, you've got to telephone, and a user at the moment has to rely on pot luck, of coming across an individual that's aware and together enough to make sure that it is accessible. But there's so many little things, we just... you'd be amazed, to walk into the reception at a health centre and the receptionist will... if I announce I'm deaf, most likely they'll [say?] yes, and sort of look down at the computer and talk to me, and you know that they haven't got the first idea of basic communication. If I was a lesser person, I'd probably just walk away, but fortunately I'm very very self-confident, and see sort of see the individual as being a bit of an idiot, rather than me. So it doesn't bother me too much. But from a campaigner's point of view it does bother me, because I know it's putting off to many other people.

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Since coming to Manchester, I've linked up with the LGBT Foundation as a volunteer, and my line manager, for want of a better word, is Andrew Gilliver. I feel really work well with them, because he's very very supportive, and he knows what I'm trying to achieve, and he's always there for advice and support. Now because I feel very strongly about individuals needing to take responsibility for their own sexual health, I was keen to link up with Andrew to talk with him about some various projects. Just for example, it struck me that I should be asking my dentist about gum health, and that is something we were able to talk about. To me, that's so obvious. So, I just took a chance, [and] at a recent check-up brought the subject up. Fortunately my dentist reacted as if that was the most natural question in the world. And that, of course, encouraged me. But the point really is, I think it's up to the patient to ask the dentist, because the dentist can't really take the risk. Because maybe the individual would feel the dentist assumes that they're gay, or whatever. But if only we could normalise sexual health, in such a way that it's not a big deal. So you would ask your GP, or you would ask your dentist, or whatever. But I think there has to be some signpost from the healthcare professionals, to indicate at least that they're LGBT-friendly, and it's OK to ask.

Now there's other areas that I really try and campaign on is, from the point of view of being in control, I think we should know about the issue of whether, if someone is HIV positive, whether it is detectable or not. Because that, I think, has a great impact on choices. Because it brings up the issue of whether to use condoms or not. I think too many people are taking risks, and are not taking control by asking someone that they're going to have sex with whether they're HIV positive or not. But the ideal world would be, that... say yes, say no, just tell the truth, and work out whether it is safe to go bareback or not.

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I'm pretty obsessed, as you know, about being in control of my own sexual health. At the same time, I am very sexually active. Now, clearly, when I go to saunas, which is something I enjoy, but the issue there is, there is so much barebacking going on. And I think it's sort of... I take the, the rule for me is that every partner I have, I don't really go into a great discussion on whether they're HIV positive or not. I'm assuming they are. And then taking the obvious protection there. I think that is

the best way to operate, from a casual point of view. Clearly in a close relationship, then you just... part of being close is to discuss various issues, and you decide on whether it's necessary to use a condom or not. But my mantra is, not to put myself at risk, simply because I just think to knowingly] take a risk is irresponsible. That seems pretty judgemental, I know, but at the same time, I really do want to get to see my old age, or I... I think with the complications of Marfan syndrome, that has instilled the need the really know what I can do and what I can't do. And I think sort of... I'm now 67, and feel in good health.

Going back to where we started, in the 1980s, clearly the campaign then was very very effective, simply because it frightened the life out of everyone. The downside of that is that we really shouldn't now operate in fear, because we know so much about the transmission of HIV.

I think though there's still an incredible amount of work to be done. We've got to reach out beyond the official LGBT community, if you like. As I just said to you, basically yes, if we're involved with the LGBT Foundation, the chances are we are very very clued up on sexual health. But the thing is, what about all these vast, vast numbers, particularly of older men, who are having sex with men, casually, in saunas, or whatever, who are more than likely married... [they] are not going to risk accessing material on sexual health on their computers at home in case their wives/partners/families see the material. I think there's a great deal of guys putting their head in the sand and hoping for the best, and taking risks actually. I can't believe the number of men that I know that are married but are taking risks or just not using condoms. And it's... shattering [?]. In fact, I really feel we could be in for another rise in the number of cases. It's disastrous, if you think about it, if a guy who is married is taking a chance, and then unknowingly infects his wife, where does this all lead to?

So I think we really still have a great deal to do on the issue of sexual health. And that really... it just brings back the whole point, how I think we need to normalise sexual health, make it just the same as having the flu jab. None of us want to get the flu, so we sort of, we don't make it a such great secret or mystery about it. I really do think, it's one of my obsessions is, that as a society, we really need to normalise the issue of sexual health. And in fact, we really do need to have a conversation about sex itself. Because I think so many people are in denial about themselves, don't really accept who they are sexually. I think the sooner we normalise it, and just don't make it such a big deal, the healthier we will become.

Even the idea of making visits to a GUM clinic, it's sort of, a special thing. In fact that, sort of, you don't even have to give your name. I personally think that's juvenile. It really is. But at the same time, I'm aware that from a point of view of professionals, [they] feel they may never get anyone in the door unless they provide services anonymously. But to me it doesn't make sense at all.

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INTERVIEWER: OK. [inaudible whispers]

PARTICIPANT: Have I covered detectable/undetectable? Yeah I have. Umm...

Another project that I'm involved with on the issue of sexual health is, I belong to the Manchester Liberal Synagogue. Now, the community is very very open, inclusive, and fortunately at the moment we have a rabbi in training who readily describes themselves as queer. And that really is healthy. Now, I take part in the social action, and one of the things that I am starting to do on the synagogue's Facebook page, [is] include issues about sexual health testing when it's HIV testing week. And even quite recently, there's a campaign against the reduction of local sexual health services. I'm starting to post information and petitions on the website.

In addition, the housing association where I live has got a really progressive attitude to inclusiveness. And I've joined up with their diversity and equality group. Now one of the projects there that I'm going to suggest is the idea that as a community, we get involved in testing week, and see how that pans out. But it all comes back to my idea of normalising sexual health, and sort of, get everyone involved, as if [it's] no big deal.

I'll just end up by saying, something like, come to think about it, I think we've come a long way. Because when I started out as a young man, I was a criminal. That will be a little sort of- [prp noise]. Will that be OK?

[00:36:41] End of transcript.