Living with Disability

Living with HIV:academic perspective

Joanna Bornat:
My name is Joanna Bornat and I'm professor of oral history at the Open University in the faculty of Health and Social Care.

I've spent quite a long time, maybe the last twenty odd years working, producing learning materials for people of all ages in various jobs I've had about ageing, and the position of older people in UK society. And through that, and also through my actual background, I'm a sociologist by background, I have developed an interest in oral history which is researching the past from memory, enabling people to speak for themselves from their own experience about what they know. So my interest is in using oral history as a means to getting perhaps a user's perspective of various aspects of care, as well the professional's, and practitioner's, and carer's too. Every time I do an oral history interview I feel I learn something new because I enter into someone else's life experience where I've not been before, and so I think just the stories themselves have all those kind of unexpected qualities which I think are so important in health and social care, you can't go in assuming you know everything about someone's life, and so for me oral history is part of the key to that sort of process.

The course includes a section which is about experience, about people's life stories and how important it is for people to have some way of communicating who they feel they are, whether they're children or older people, you know, maybe someone with dementia, maybe a younger person living in the community who's going through some kind of change in their life and their sense of who they are becomes disrupted in some way, or the identity that they're given by society somehow conflicts with how they feel about themselves. So the course includes a discussion between two people, two men with haemophilia, Mick and Owen, and Sian Edwards who worked as a nurse with men with haemophilia, and she had carried out an oral history project with this group of men. Haemophiliac men have a particular story to tell, particularly this age group, because they were exposed to contaminated blood products in the 1980's and as a result of that they, many of them acquired an HIV positive status, so Mick and Owen were part of a generation of young men who grew up with haemophilia which was, presented challenges enough as a condition, it's a very difficult condition to live with, and various ways in which treatment had changed gave them a sense of an extended and much more comfortable life; then came the blow of acquiring HIV positive status when they were given blood transfusions which were contaminated. Now this was at a time when AIDS was regarded something very shameful, and both of them talk very angrily about that experience, and also how they felt unable to talk to other people about it because it was a condition which was associated with stigma, there was very, very gross and outspoken homophobia at the time and these two as young men didn't feel able really to identify themselves as having HIV in that context and this, this, this they talk about very strongly, in fact Owen is not his real name, he won't actually give his name, or wouldn't to the program because he still hasn't told all his family that he's HIV positive and this is what - ten, fifteen, twenty years later. Now Mick is much more open about it, he feels much more strongly that, you know, this mustn't be hidden and the case of this particular group of men with haemophilia has had very important repercussions, but particularly in their lives, so to have acquired this additional identity, in a stigmatised identity when they were growing into young manhood really was very, very difficult for them, and so hearing them talk about that and hearing Sian Edwards who knows them well bringing out, you know, how they dealt with this, I think is a very interesting and revealing set of accounts. Listening to Mick and Owen I'd hoped that students would perhaps tune in with the need to actually hear people talk from their own experience about what it's like to live with a long-term condition, how it can shape your life, but also how people fight back, how they respond to attitudes in society which might not be supportive and in one's own, you know, way perhaps provide the kind of support or kind of response which they might be looking for, the kinds of resources people need, the kinds of networks of support which people find helpful, either supporting people to talk to others who are in similar situations or perhaps moving into kinds of groupings where people can speak out and learn from each other how to live and deal with conditions.