

Disability History, Bleeding Hearts and Parasite People

Lecture given by Professor Mike Oliver at the University of Kent on 27th November 2017 as part of UK Disability History Month celebrations.

Introduction

In 2013 I spoke at the opening of disability history month and suggested that our history is too important to be left to others and that it is something we must do for ourselves. Here I want to make my own contribution to that project by reflecting on my own personal history and how that relates to wider disability struggles and their impact over the last 50 years. In so doing I will talk about how I discovered sociology, reflect on working in the discipline here at UKC and how sociological insights shaped my involvement in organisations of disabled people. Finally, I will raise my concerns about the way our shared history is being rewritten by others to suit their own interests and agendas.

Sociology and Me

Although I went to grammar school I was never really academic and left with 3 O'levels while the vast majority of my peers stayed on; the brighter ones aiming for Oxbridge and the rest heading for teacher training colleges. I only met sociology a few years later when I found myself working as an unqualified lecturer in my local prison and I began attending evening classes to keep one step ahead of my students. Two sociologists from UKC were teaching an adult education class in my local technical college so I signed up for it, partly out of boredom with the A levels in Economics and History I was studying at the time but also out of curiosity.

My experience in encountering sociology for the first time was similar to the one described by Leonard Cohen when he first encountered the works of Federico Garcia Lorca who "ruined his life by getting him into the racket of poetry". Well when I first read a book called The Sociological Imagination by the American sociologist C Wright Mills I had a similar experience though I wouldn't claim my life was ruined by the racket of sociology. However, his insistence that, as sociologists, we must seek to translate "private troubles into public issues" struck a chord with me. So, when my boss at work told me I needed a professional teaching qualification if I wanted to continue to work for in education, I decided I'd rather do a degree in sociology than teacher training and came here in 1972.

I came here to study sociology and social anthropology and completed my degree in 1975. I then stayed on and completed my PhD in 1979. I was then appointed to convene a new masters course for qualified social workers and other professionals working with disabled people. As far as I am aware this was the first postgraduate course in the UK teaching what later became known as disability studies. It lasted for 3 years until local authority training

budgets were decimated by the first phase of the Thatcherite attack on the welfare state.

It wasn't my intention to work specifically on disability issues and research for my PhD was intended to investigate the construction and management of epileptic prisoners in penal establishments as, prior to coming to university, I had worked in one as an unqualified lecturer and I was fascinated that while lots of prisoners who came into my classroom were diagnosed as epileptic and yet I had never met another one outside the prison walls. However, before I could undertake my fieldwork outside events took over. Two what we would today call celebrity sociologists had been teaching evening classes in a lifers' prison and published a highly critical book about the prison regime. Needless to say, the Home Office were not best pleased and retaliated by withdrawing access to all researchers not employed by them.

This necessitated me broadening out my own research to investigate the issues in a variety of settings including a mental hospital and the community. The effect of this was that I had to widen the scope of my reading to incorporate medical, psychological and sociological aspects of disability as well as the personal experiences of disabled people. When I did this I couldn't believe the dissonance between the literature and my own experiences of disability and the experiences of most of the disabled people I had met through my participation in disability sport and the newly emerging organisations of disabled people.

Broadly speaking most of the professional writing on disability was dominated by assumptions that disability was a medical problem and the focus was on illness and impairment. Where personal experiences of disability were discussed the assumption almost always was that disabled people were tragic victims. This stereotype was reinforced by popular culture in books, films and the media. This genre became part of what journalists referred to as "triumph over tragedy stories" or TOTS for short. Colin Barnes had a different name for them calling them "the bleeding hearts brigade".

Occasionally however we were allowed to break free from these tragic roles hence the triumph bit of the stories. In the 1980s on the disability cabaret circuit this became known as "the Douglas Bader syndrome" drawing on a song from the late Ian Stanton. Most disabled people then, and indeed now, will have been told to 'man up' by well-meaning relatives, friends or even passing strangers saying, "look what Douglas Bader did or Beethoven or Helen Keller and on".

More recently it's been turned into a whole project with the Shaw Trust publishing its list of the 100 most powerful disabled people in Britain to inspire other disabled people. Its launch each year involves an awful lot of corporate schmoozing and public relations effort which benefits the Shaw Trust, but most disabled people never get to see the glossy publication, let alone be inspired by it. I even make this list myself but if I'm that powerful surely I'd be

able to put a stop to such nonsense.

UKC and Me

Coming to the university as a wheelchair user in 1972 was an interesting challenge. It had opened in 1965 and, reflecting the contemporary understandings of disability, it was not designed to include disabled people. However, the 1960s and 70s gradually saw more and more disabled people emerging from the shadows and beginning to demand opportunities to participate in the increasing affluence that Britain was experiencing as it recovered from the economic consequences of World War Two.

The university was built around 4 colleges with a central registry and a library. Only one of the colleges and the library had a lift and virtually all the lecture theatres and seminar rooms had steps or other barriers. Although the physical environment was unwelcoming the same could not be said of the university authorities or my fellow students as these were generous times ushered in by the economic and cultural revolutions of the 1960s. Despite this during my undergraduate career it never occurred to the university authorities or me to seek to rearrange my classes into more suitable venues. Yet, with the help of staff and students alike, I always managed to get to where I was timetabled to be, whether it was in buildings without lifts, crossing a windswept and rain swept campus in mid-winter and so on.

But access has always been about more than just getting into buildings. Not here or anywhere else for that matter did universities have operational policies or procedures relating to disabled students; there were no support staff, accessible materials, extra time for examinations or anything like that. To the best of my recollection I can only remember five other disabled people on campus during my under graduate and postgraduate career; a disabled lecturer and four other students. This wasn't a deliberate to keep disabled people out of universities but there was little demand for places at the time and a lack of awareness about what might be needed to accommodate more disabled students.

Disability Organisations and Me

As I have already suggested, changes were blowing in the wind and disabled people were beginning to join or form organisations of our own: partly because we wanted to join in but also because we were fed up with the big charities who existed in our name but never seemed to do very much. As a person with a spinal injury when the Spinal Injuries Association was formed in 1972 I joined and soon found myself on the Management Committee.

In 1975 the disabled lecturer I mentioned earlier, the late Dave Reason, asked me if I was interested in going to a meeting in London about disabled students in further and higher education and I agreed. At the meeting I found that there were no other disabled people there and reluctantly found myself on the Governing Council of what became the National Bureau for Handicapped

Students, an organization intending to promote the integration of disabled students into further and higher education.

My experiences in these two organisations were very different and mirrored the divide that was developing between organisations controlled by disabled people and those that were about us but definitely not controlled by us. The SIA was clear about its mission and not afraid to vociferously put forward its demands. The NBHS was much more cautious and I often felt its title should have been the National Bureau for the Management of the Problems Handicapped Students were causing for colleges and universities. I found working with NBHS a very frustrating experience and I resigned from the Governing Council after 3 years but remained on the Management Committee of SIA for more than 15 years.

Returning to the divide between organisations of and for disabled people, in the mid 1970s a major row had broken out between the Disability Alliance and the Union of the Physically Impaired Against Segregation. The Alliance was an umbrella organization led by the UK's leading expert on poverty and they argued that the problems disabled people faced were due to them being poor and that the solution was a national disability income. UPIAS was a collective made up of exclusively disabled people and argued that it was not for non-disabled people to tell us what our problems were let alone what the solution was. They suggested that the root cause of our problems was the way society was organized and the disabling barriers we faced.

This debate was written up in a booklet called "The Fundamental Principles of Disability" and was published in 1976. UPIAS also pointed out the solution when it argued that "Disability is something imposed on top of our impairments by the way we are *unnecessarily* isolated and excluded from full participation in society". This changed my life in two significant ways. It meant I no longer had to accept full responsibility for my impairment: for example, the difficulties I had in getting into lecture theatres at UKC were not because I could not walk but because someone else had put steps in front of most of them. I now understood that my personal troubles were also public issues.

The Social Model and Me

This insight led me to formulate the social model of disability. When I began to convene the masters course in 1979 I wanted the curriculum to be informed by the idea that personal troubles were directly linked to public issues and that the personal troubles of disabled people were often caused by the disabling barriers of society and not our tragic impairments. At the time social workers and indeed nearly all other professionals working with disabled clients worked exclusively on our personal troubles and not how and why they were linked to public issues. I wanted my course to challenge and change this.

There was a limited amount of reading and other teaching material available at the time though the Open University had produced its own undergraduate

module entitled “The Handicapped Person in The Community” in 1976. I had been appointed to teach on from the very beginning and this too was trying to move away from the personal troubles of disabled people as its title implies.

So, I wanted my course to reflect our changing understandings of disability based on the Fundamental Principles document, but I also wanted it to be relevant to the everyday reality of my students when they returned to work: what one writer on professional practice once called the “what to do on Monday morning question”. Hence the social model of disability was born both as a way for my students to reflect on their work with disabled people but also the barriers that they themselves faced in their own work environments.

For three years I taught along these lines developing my own thinking as I went. But recruitment was becoming a real issue because of local authority budget cuts stemming from the first stage of the Thatcherite revolution so I moved on to work in teacher education. During my last year at UKC I had agreed to write a book called “Social Work with Disabled People” but this was not published until the following year when I was no longer involved in social work education, so the book was rather left to fend for itself.

What happened over the next few years came as a complete surprise to me. The book took on a life of its own and sold not just to the social work market but to a much wider audience including disabled people themselves. Within five years the social model of disability had become the mantra for many disabled peoples’ organisations and was beginning to make its way into official government documents.

I knew it had arrived when attending meeting with a government minister in the late 1980s who harangued us for being anti everything the government was doing and challenged us to tell him what we wanted. After a stunned silence a voice from the back of the room said its very simple, all your policies should be based on the social model of disability.

I’m not intending here to describe what happened to it after this nor replay the disputes that have centered around it. As I have made clear on numerous occasions too much time has been spent on talking about it and not enough using it. This is disability history month and I want to return to the theme I started with: not only must we make our own history, we must record it for ourselves as well otherwise it will not be ours.

The rewriting of disability history

Karl Marx once said something like “we all make our own history but not in circumstances of our own choosing”. I’m sure he was right but he should have added something like, but we should also make sure we record it for ourselves or it will be rewritten to serve the purposes of others. In fact this rewriting of our recent history has already begun.

SCOPE, a leading disability charity made a series of short films in 2015 to mark the passage of the Disability Discrimination Act 20 years earlier. There was no mention in the films of the fact that SCOPE, in its earlier incarnation as the Spastics Society, was bitterly opposed to anti-discrimination legislation in the 1980s and only reluctantly came on board when it became obvious that such legislation was inevitable and it was therefore in their own interests to support it.

Similarly, the BBC made a radio programme celebrating twenty years of the Act and any listener would be forgiven for thinking the whole thing was the brainchild of William Hague, then Minister for Disabled People, and Bert Massie, then director of RADAR. Hague even claimed he regarded it as one of his greatest achievements when the historical reality is that he, on behalf of his government, turned the legislation into a pale shadow of what it should have been.

Even some of our friends and allies are beginning to rebrand our history as the struggle for disability rights but it has always been much broader than that. Even if we go back to what I consider to be the origins of the global disabled people's movement on the Berkley campus of the University of California in 1961, the 2 big demands of our American comrades were for support services and barrier removal so that they could participate in the full life of the University. Yes they drew inspiration from and used the tactics of the civil rights movement but rights were not the be all and end all of their campaigns.

The failure of rights legislation is well known as Jane Campbell recently pointed out "Like other civil rights movements, legislation has not delivered equality for all. The 1970 Equal Pay Act hasn't exactly delivered the same pay packet for men and women. The Race Relations Act, has not brought equality in education and employment between black and white people". BCODP, who Jane chaired during its most successful period always knew rights were never enough to achieve our full inclusion and led BCODP to actively campaign for services to support independent living, policies to be based on the social model of disability as well as enforceable civil rights legislation.

Rights on their own are easily incorporated into the agendas of governments without requiring them to do change very much at all. Hence when the United Nations produced a damning report on the British Government's failure to protect the rights of their disabled citizens in 2017, they were able to claim that Britain was a world leader in giving disabled people rights and ignore the evidence and recommendations coming out of the UN report. I don't agree with much that comes out of the mouth of Donald Trump but when he claimed we all live in a post truth world he was certainly accurate.

Rewritten History and Government Policy

The rewriting of our history has taken on a much broader narrative and is being used to legitimate attacks on our living standards too. At least since the

financial crash of 2007 there has been a concerted effort by all governments in Britain to cut back on public spending and this has resulted in a massive attack on services and benefits for disabled people. To legitimate this these governments have positioned disabled people in ways that take us back to tragedy stereotypes positioning us as pathetic victims while also resurrecting the disabled superhero within the TOTS genre.

Because they have largely succeeded in taking us back to these individualistic approaches, they are also able to claim that their relentless assault on the living standards of disabled people is nothing of the kind but a heartfelt attempt to take public money away from scroungers and fraudsters and give it to the most severely disabled people who really need it. The bleeding hearts brigade is back in force. Of course, there is not a shred of evidence to support this claim but in Donald Trump's post truth world, who needs evidence?

The big disability charities with their plush London offices, highly paid executives and glossy publication have proved predictably useless at defending the living standards and lifestyles of disabled people from these vicious attacks while continuing to do very well for themselves. It brings to mind a withering attack the late Paul Hunt once made on people who furthered their own careers on the backs of the struggles of disabled people to lead ordinary lives calling them "parasite people".

He defined parasites as "interested hangers on; an animal or plant living in or on the back of another and drawing nourishment from it". These charities need us to be dependent and tragic otherwise there is no justification for their existence. When he coined the term he was referring to two researchers who were supposed to help a group of disabled people who were trying to escape from their local Cheshire home in the 1970s but instead they simply wrote a book labelling disabled people as socially dead, before moving on to the next phase of their careers.

If you think universities are not like that anymore, just a few weeks ago the University of Leeds decided to convene an annual series of lectures celebrating the work of the late Vic Finkelstein. However they failed to consult his family about it or Centre for Disability Studies based there who were to host it. They also chose one of his harshest critics to deliver the first lecture failing to realise how offensive this was. It took the intervention of 4 senior professors who knew him and his work best to get Vic's name removed, much to the relief of his family and friends. One can only assume that a combination of political opportunism and personal ambition was behind the decision to (ab)use Vic's name.

However, it is not just academics and the big charities who are parasitic on the backs of disabled people sometimes unwillingly or unwittingly. The Paralympics despite a brief spell when they appeared in the sports pages and bulletins where they should be, are now being used, along with the new kid on the block, the Invictus Games, to tell a familiar kind of story about disabled

people and our lives. The competitors are portrayed as 'superhuman' and the implication is that if disabled people really try we can all be like them and travel the world.

This disguises the reality of our lives for many of us which are very different. Not all injured ex-service men and women can or want to compete in elite sport and many who don't live lives of deprivation, poverty and misery. And while sport as part of rehabilitation is very effective for those interested in it, for many who are not the whole experience can be alienating and counter-productive. And while we have the Paralympics and Invictus Games it's alright to send our young people to, often illegal, wars to get blown apart for their country.

We can't escape this portrayal of us as either tragic victims or super cripples either when we go to the cinema. One of the recent films about disability "You Before Me" manages to position us both as tragic and heroic. The young tetraplegic at the centre of the story falls in love with his "carer" and she with him. But true love does not conquer all and he takes himself off to Dignitas to be killed. Hence it's tragic that love doesn't conquer all but he's heroic in that he saves her from a life worse than death.

Making Our Way in a Wicked World

At disability conferences and meetings Len Barton, usually after a few glasses of red wine, used to tell us that "we are just ordinary people trying to make our way in a wicked world". I think that was Len's way of telling us in non-academic language that we all have personal troubles, but we must see that they are public issues that we must confront by attacking the disabling barriers we face if we are to make our own way in this wicked world. What disability history teaches us is that we cannot rely on the bleeding hearts brigade and parasite people to do it for us. We have to do it for ourselves. We have to insist that our personal troubles are public issues that need to be resolved. I hope this lecture has made a contribution to that project.