British disability studies: research and practice

Introduction

Thank you to Dan Goodley, who has outlined for you some of the key theoretical debates in British disability studies, a field of research where the academic is often political, and the political, sadly, is often rather personal. Although I have been involved in these conceptual arguments, I do not want to concentrate on those in my talk today. If you have read my work, you will know that I understand disability to be an interaction, between people with impairments and their environments. I take a critical realist view of the world, and try to think in terms of the different dimensions of disability - from the molecular biology of a genetic condition such as my own achondroplasia, right up to the political economy which dictates the spending priorities of a government and their policies on social protection, for example.

In this talk, I want to concentrate on the ground which I share with Michael Oliver, Colin Barnes, UK colleagues who are often see as diametrically opposed to my work. There may not be much of this common ground, but it is very important to us all, and it is an aspect of British disability studies of which I am very proud.

The shared ground, the common principle, is that most of the time, disability studies research should make a difference. I think Mike and Colin would both share my commitment to Marx's Eleventh Thesis on Feuerbach, where he wrote "Philosophers have hitherto interpreted the world, in various ways; the point is to change it". This statement is written on Marx's tomb and may have hung above his writing desk. I should say here that unlike Colin and Mike, I do not consider Marx a useful guide to life, or even research, but I do share his emphasis on engagement.

I think that if research is to make a difference, the first requirement is that it should be empirical. It needs to find something out which people do not know. I say this in a context in which much sociology in Britain is about reflecting on the state of the world, or theorizing social phenomena, in other words, reinterpreting rather than discovering, let alone changing. Mike Oliver once told me sociology is about three things: counting people, watching people, counting people. If you are not doing one of these three, or a variant thereof, then you might be doing continental philosophy or you might be doing journalism, but I question whether you are doing much good.

At this point, I should mention that I work now for the World Health Organization, although I am speaking today in a personal capacity. At WHO, I have been helping write and edit the World Report on Disability, which will be launched in the first quarter of 2011. The Report has chapters on data, on health, on rehabilitation, on assistance and support, on enabling environments, on education and on employment. In each case, we have tried to gather the best scientific evidence so that we can understand what works to improve the lives of disabled people. But we have found that it is very hard to say what works, or even to know definitively the situation of people with disabilities. This is particularly the case in low and middle income countries. We may not know much, but what we do need is very alarming:

- The percentage of children with disabilities not attending school is extremely variable and is between 65 - 85% in some African countries (UNESCO 2008).
- Mortality for children with disabilities may be as high as 80% in countries where under-five mortality as a whole has decreased to below 20% (DFID 2000).
- In many low-income and middle -income countries, only 5-15% of disabled people who require assistive devices and technology have access to them (WHO 2009).

I would give you a statistic on poverty, but to be honest, the data just isn't good enough to say much conclusively about associations between disability and poverty in low income countries.

Looking at some of those World Report chapters, and restricting our attention to high income settings:

- We need to know how to improve access to general healthcare, to prevent people with disabilities suffering from secondary conditions and from comorbidities, many of which are preventable and some of which are responsible for premature mortality
- Disability studies has virtually abandoned rehabilitation to the public health and rehabilitation specialists, although we need to understand the experiences children and adults have with rehabilitation, and how it may be improved. As someone who went through rehabilitation after spinal cord injury in 2008, I am particularly interested in this topic, which I was completely ignorant of, despite having worked in disability studies for 15 years!
- In the field of assistance and support, I am particularly interested in two questions - I want to find qualitative studies of what it is like to receive personal assistance, as a disabled person, and what it is like to provide personal assistance, as a worker. I am also interested in the majority of people who still receive formal or informal care, rather than personal assistance. How can we promote independence and dignity in these contexts, where money is lacking to employ personal assistants?
- We still lack evidence for what works in improving participation in education as well as on educational outcomes in inclusive settings.
- We need to know how to ensure that people with disabilities get access to income and employment opportunities

Of course, once we are looking at low income settings, there are even more pressing questions, questions of life and death but also questions about different cultural contexts, where values and attitudes and family structures may be very different from high income settings.

Therefore my conclusion is that there is a huge need for empirical research, using both quantitative and qualitative methodologies. Without evidence, it is very difficult to achieve change in the world.

What questions should we be asking?

I mentioned earlier that I took a relational view of disability. For me, this means attending both to the individual, bodily experience of having a health condition, but also to the role of social and structural barriers which prevent people with disabilities participating and flourishing.

At some points, disability activists or researchers have suggested that we should not be researching the private experiences of people with disabilities, because the field of disability research was dominated by what they have called "sympathetic narratives", and this individualises disability and can become voyeuristic.

I disagree with this perspective. I think that ordinary lives are very important. I think that questions of impairment, of pain and suffering are part of disability and should be explored and understood. I think that medicine and rehabilitation are important to many disabled people, and are important questions in personal terms, as well as in economic and political terms. I think identity and self-esteem are very important, together with wider questions of relationships, parenting and family life.

This is what I think about disability studies:
1. Disability studies is not activism by other means

2. Disability studies is about understanding the experiences and views of disabled people
What it is like to have a particular impairment;
What people with different impairments think and say about their lives;
What impact impairment has on family life, on self-esteem, on participation etc.

3. Disability studies is about society's responses to the challenges of impairment and inclusion - medical, psychological, educational, social, legal, economic, political

4. Disability studies depends on sound empirical research and normative argument
not slogans or ideologies or anecdotes

5. Disability studies researchers should be engaged and committed, but their first duty is to the truth

6. Good Disability studies research will lead to better Disability Politics

So I think we should be asking many different questions. Questions about access to healthcare and the experience of healthcare. Questions about the body, and people's subjective experiences of different bodies and different states of the body. Questions about emotions and feelings and relationships and family. Questions about self esteem and ambition and motivation. Questions about prejudice and staring and abuse and the impact of cultural representations. Questions about discrimination and access to education, employment and other aspects of life. Questions about support and assistance and care and dependency and independent living. Questions about environmental barriers and information barriers and what works to overcome those.

And in each case, as disability studies researchers committed to growing our field of work, I think we should be asking whether these research agenda involve disabled people; whether they take a structural approach; whether they are engaged, as it explored that question a few moments ago; whether they use good argumentation; whether they ask deeper questions, not just the obvious ones; whether the research makes a difference.

Case studies

Colin Barnes (1991) Disabled people in Britain and Discrimination

Colin conducted this project when the University of Leeds Disability Research Unit was actually formally connected to the British Council of Organisations of Disabled People. This was the period when the disabled people's movement in UK were campaigning for anti-discrimination legislation. The Conservative government did not believe that disabled people experienced discrimination. They took a traditional, medical-focused, charitable view. Colin did secondary research, bring together data and research from many different sources, and set out the evidence that disability was about discrimination, in the areas of housing, transport, education and so on. This gave ammunition to the campaigners and the activists. Nobody could deny discrimination existed any longer. Partly as a result of Colin's book, the government finally brought in legislation, in the form of the Disability Discrimination Act 1995 - certainly not strong enough, because it had to be revised in 2005 by the new Labour government, but nevertheless a vital step forward. So nobody could deny that this book made a difference.

Gerry Zarb and Mike Oliver on direct payments

In the 1980s and 1990s, British disabled people were campaigning for direct payments. Instead of care being provided by the state, people wanted the money to be given to them, so that they could employ personal assistants and have more control over their lives. This may seem an obvious point now, but it was revolutionary then. In particular, there were legal obstacles to state money being given to individuals, and a fear about escalating costs.

Gerry Zarb, together with Mike Oliver, evaluated the pioneering personal assistance schemes operated by Greenwich Centre for Integrated Living, and conducted other subsequent research in the field of independent living. Most of these studies were conducted according to the principle of emancipatory research, in which disabled people commissioned and conducted the research, rather than leaving it to academic experts. A typical quotation from the Greenwich evaluation: "Employing my own personal assistant has given me the freedom to fulfill the type of lifestyle I wish to follow. I can go where I want, when I want. I am in total control of making all the choices in my own life. I feel I am much more my own person once again, able to put all my abilities to some useful purpose."

The policy messages of these empirical studies was that "giving disabled people what they say they want is cheaper than giving them what you think they need". In other words, it was both practical and cost effective to introduce direct payments schemes for personal assistance, as well as being preferred by users themselves. Personal assistance schemes were invariable cheaper than other care packages. This was a key step forward for disabled people. In 1996, the Direct Payments Act became law, and personal assistance became a more and more important part of government welfare policy. As a result, tens of thousands of disabled people in Britain have become personal assistance employers.

Tom Shakespeare, Kath Gillespie-Sells and Dominic Davies (1996) *The Sexual Politics of Disability*

Feminists talk about "the personal being political". They have also criticized the split between the public and the private. When my friends and I researched and wrote this book, we felt both those insights were relevant to disability. Whereas by 1996, there had been a considerable amount of publications and campaigns about the public dimensions of disability - for example housing, employment, access etc - there had been very little about the personal dimensions. We felt that for most human beings, the aims in life are threefold - a job, a partner, and a family. Disability research had concentrated on the first aim, and neglected the others. We also knew that there was a prevailing assumption that disabled people were asexual.

We tried to fill this gap by talking to 44 disabled people about their lives and loves. We then compiled their responses into different categories, and tried to create an overall story line, which was partly about discrimination and prejudice, but was also about resistance and triumph. We also want to bring personal feelings into the story. It was not just about externally imposed oppression. People's feelings about their bodies and about emotions are complex. The area of intimacy is one of the most important things about being human, and we felt it was absolutely right to open it up for scrutiny.

We had mixed responses to this book. Some activists felt we had betrayed the cause, by talking about private issues. Mike Oliver felt we had too many lesbian and gay people in the book, and this would make readers think that disabled people were all perverts. Most people with disabilities however welcomed the role models and positive stories, and also the fact that we had begun a conversation and created an agenda for change. Since then, there have been many more studies of disability and masculinity or disability and parenting or disability and access to sex. There's still more to say, and I hope it is now recognized as a valid area for study. I think our book changed the world, not through law or policy, but through helping individuals come to terms with an important issue in their lives. Unlike the other examples, it was a book which people could read for fun, and recognize their own experience in it.

Nick Watson's research on disabled people's views of health and identity

Nick is a close collaborator of mine. He came to this research from medical sociology, with a particular interest in sociology of the body. He talked to ordinary disabled people about health and disability. He discovered what some of us already suspected. Outside the disability movement, most people had much more nuanced and complex views of what disability was and how it affected them. They did not tend to take the radical social model view. But at the same time, they did not see themselves as different or unhealthy, even if they had complex conditions which most non-disabled people would regard as very much disabling. Nick’s respondents were able to distinguish their overall quality of life – which was good – and their state of health. But he was also able to trace how views of disability changed for the better, once people became involved with other disabled people.

How does this change the world? I think it means we are listening to what disabled people say, not to what we think they say, or should say. I think it means challenging understandings of health and illness so that medical professionals can take a wider view. I think it contributes to understanding the diversity of disability, and the implications for services and other responses.

Alan Roulstone's work on technology and employment

Alan was a colleague of mine at Sunderland University, just after he had finished his PhD. That research was about new technology. He came to the conclusion that a social model of technology was needed. In other words, computing and other assistive technologies did not simply provide a technical fix, thus solving all the problems of disabled workers. The most important questions were about economic access and social power, rather than about technical issues. Since then, Alan has explored a range of policy questions, mainly around employment. In particular, he has evaluated the impact of government innovations, such as the New Deal for Disabled People, which the Labour government brought in in 2001, to address the exclusion of disabled people from work and their dependence on benefits. While I do not always agree with Alan's analysis, what I value is that he consistently provides or analyses solid evidence, to try and get at what is going on in the field of work.

How does this change the world? I think by clarifying what is going wrong with government policy, and suggesting improvements. It's back to the emphasis of Colin Barnes' book about discrimination. These types of studies, together with the Zarb study, are also similar to the emphasis of much disability research in the Nordic countries, which often explores the role of the welfare state, and its impact in the lives of disabled people.

Teaching programmes

I want to say a few words about the teaching of disability studies. I assume that in Japan, as in many other countries, there is potential to develop disability studies courses in universities, and I welcome that. But I want to highlight what I think, at their best, the features of these courses might be, points I have adapted from United States Society of Disability Studies recommendations:

- They should be multidisciplinary: humanities, sciences, and social sciences.
- They should challenge view of disability as individual deficit remedied solely through medical intervention or rehabilitation: should examine social, political, cultural, and economic factors.

- They should study national and international perspectives, policies, literature, culture, and history to place current ideas of disability within their broadest possible context.
- They should actively encourage participation by disabled students and faculty, and should ensure physical and intellectual access.
- They should make it a priority to have leadership positions held by disabled people, while welcoming contributions from anyone

I add these points to a talk about disability resesearch because I am clear that teaching is just as important as research, not just because only through teaching can we develop the next generation of disability studies researchers, but because it is particularly through teaching that we can empower people with disabilities to understand the world they live in. It is also through teaching that we can challenge and inspire many different professionals who work with disabled people – teachers, doctors, social workers for example – to take a more progressive and supportive approach.

Conclusion

I said that research should make a difference, most of the time. I say this because I do not want to rule out researching things for the sake of it. I am interested in artistic and literary representations of disability, and enjoy writing about those things. I hope that the papers I produce on the subject are interesting and fun, but I cannot pretend that they are likely to change the world.

So I am really talking about balance, the balance between empirical work and theoretical work, or the balance between basic research and applied research. You may place the balance somewhere different to me. But I hope you accept that disability studies is distinguished by its emphasis on making a difference in the world. People with disabilities are amongst the poorest and most socially excluded of the population, and we who are privileged to be academics have a moral duty, I believe, to do what we can to alleviate that disadvantage through the research and teaching which we do, rather than only to build our own careers, our reputations or our pension funds.

Now, those of us working in disability studies are following a path that is well trodden. There are other fields of enquiry which have had close connections to practice. There are other researchers who have set out to change the world. For example, Marxist research on class and inequality, or feminist research about gender oppression, or lesbian and gay research about homophobia, or Black Consciousness writings. But in each of these cases, the early radical emphasis has given way to a more abstract and esoteric exploration. I remember Theresa Brennan, a feminist theorist, talking about how often this was a reaction to defeat. After the failure of the European revolutionary movements of 1918-1920, Marxist research turned to theory, rather than practice. Perhaps after the challenges of the late sixties and the seventies, women's liberation writers turned to cultural feminism. Lesbian and gay research also turned its gaze on culture and began to talk more about theory than practice. When early promise gives way to disappointment, perhaps it is natural to try and explain why. Moreover, it is hard work being an activist, and the life of the academic looks rather tempting.

You will realize that I am concerned that disability studies does not suffer the same fate. I note that in the United States, disability studies is now dominated by the humanities, rather than by the social sciences. I note that my colleagues in the US are concerned with establishing disability studies as a discipline, alongside gay and lesbian studies, post-colonial studies and gender studies. I worry that while the talk may remain radical, the content becomes more abstract and less accessible to the constituencies whom the research was originally meant to serve. Perhaps the answer to this problem is to worry less about having a separate discipline, and more about mainstreaming. Let us encourage mainstream historians to think about disability, let us encourage mainstream literary scholars to think about disability, let us think about mainstream philosophers and anthropologists to think about disability. That way, those of us who are concerned with disability studies changing the world can concentrate on that endeavour, reserving the right to dabble in the more academic questions when we need a change from grim reality.

Thank you for listening.