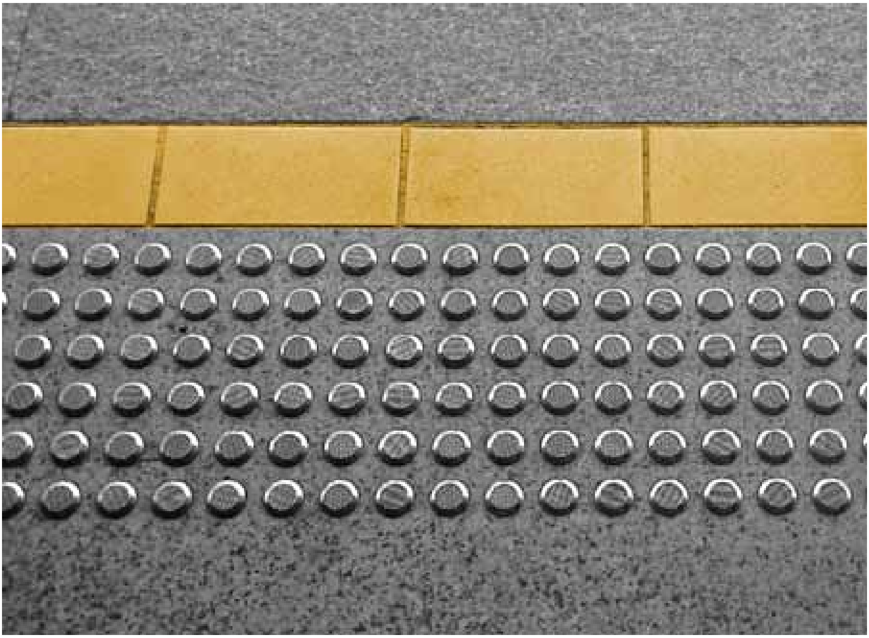

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Everybody will have an impairment

Interview with Prof. Nick Watson, Director of the Strathclyde Centre for Disability Research, University of Glasgow

Conducted on March 3rd 2011, by Elisabeth Badenhoop

B: What is the tradition of sociology in Glasgow? How come there is such a strong Marxist and feminist influence in the department?

W: There is a long tradition of the sociology department in Glasgow since its emergence from the politics department in the 1960s. In this tradition there is an element of materialism if we think for example of Bob Miles' (Robert Miles, E.B.) work on racism, John Eldrige's work on the media, Bridget Fowler's work on cultural theory and David Evans' work on sexuality. But there is also, to a lesser extent, a poststructuralist element with Howard Ferguson's work on phenomenology and David Frisbee's work on Simmel.
Compared to French sociology we are much more materialist. Bruno Latour for instance was very critical of our, what he saw as, British empiricism during a seminar a couple of years ago. But as a department, there is a strong feminist and materialist understanding with teachers such as Bridget Fowler, Satnam Virdee and Andrew Smith.

B: How does this resonate to the rest of British sociology, is the Glasgow tradition in any way representative?

W: Glasgow is much like many other departments, we all have our own little differences but we are generally like the rest.

B: Please tell us about the relationship of sociology and Disability Studies. How well integrated are Disability Studies in sociology here in Glasgow?

W: The history of this centre started from a bequest. The university was given a large sum of money to set up this centre in the late 1990s. It was originally a stand-alone centre, and then became re-organised in the department of sociology when I started here in 2004. Disability Studies are integrated in sociology only now but in the past and until recently they were separate. In contrast to other equality groups such as gender, ethnicity and sexual orientation, they are not as embedded within the mainstream sociology. Take for example Judith Butler, who would describe people of colour, gender, and different sexuality but not mention disability. Disability is not described in the same way. So part of the role of this centre has been to try and mainstream disability within sociology and I still think there are some of my colleagues who do not consider disability as much of an equality issue.

B: Anne Waldschmidt is one of the pioneer Disability Studies writers in Germany and now holds the first chair of "Soziologie und Politik der Rehabilitation, Disability Studies" at the University of Köln, which she created herself in 2009. Waldschmidt (2010) recently stated in an interview that Disability Studies in Germany have still a rather marginal status nowadays and are mainly situated in special education. How well established are Disability Studies in the UK nowadays?

W: I think Disability Studies here in the UK have grown out of their original marginal status in special education. Some influential people in the UK disability movement, Len Barton for example, still have this background of special education. But there is also a whole group of Disability Studies writers who came out of special education and argue against it, such as Sheila Riddell and Michele Moore. In contrast to the other European countries, the U.K. and U.S. Disability Studies have emerged through an activist movement and network. My reading of German Disability Studies might be wrong but my impression is that although their protagonists are politically engaged, they come from an academic background.

B: So how did Disability Studies emerge in the UK?

W: Admittedly, this is not a nuanced history but a crude history. It all emerged in the 1970s, when an organisation called the Union of Physically Impaired Against Segregation (UPIAS) published the Fundamental Principles of Disability in 1976 around which a group of activists formed and used the idea to develop what became known as the 'social model' of disability. Vic Finkelstein was very influential in that. He was an academic who started the Open University course on disabled people's handicaps in the community. Finkelstein started publishing his work (cf. Finkelstein 1980). And then Mike Oliver, another disabled academic who did his Ph.D. in sociology in London, coined the term 'social model' in his book called Social work with Disabled People (Oliver 1983). More academics became involved such as Len Barton and Colin Barnes from Leeds, another Ph.D. student in sociology who, in the 'Cabbage Syndrome', did an ethnography of young people in a day centre (Barnes 1990). Writers such as Jenny Morris and Liz Crow brought in a feminist perspective in Disability Studies. Around all these people a group emerged.

Len Barton and Mike Oliver for example started to organise a series of seminars from the early 1990s which grew larger jumping from 20 participants in the first seminar to over 400 in last year's meeting of what is now known as the Disability Studies Association in Lancaster. This has coincided with several factors, for instance, the increased recognition that disability is an equality issue not only in the UK but also in Europe.

B: The social model has been foundational in the Disability Studies. What are its benefits?

W: The social model is what defined Disability Studies. It is what separated Disability Studies out from medical sociology, which concentrated on impairment whereas Disability Studies focused on the way in which society is organised and the barriers society puts in place for disabled people. Vic Finkelstein called this "sterile effects", for instance, why is it that people can't go into buildings etc. So it was that shift that set Disability Studies apart from traditional medical sociology. Put simply, rather than focus on what is wrong with the individual, the social model focuses on what's wrong with society.

B: In German Disability Studies the social model is still prevalent. Yet it has been criticised by postcolonial, queer and/or feminist writers (cf. Morris 1991, Crow 1996, Vernon 1996, Raab 2007, McRuer 2010). You and Tom Shakespeare have once called the social model an "outdated ideology" (Shakespeare/Watson 2001). What are the problems of the social model? Has social constructionism come to a dead end?

W: I don't think it's the social constructionist element, rather it's the materialist element of the social model that has been forgotten. The social model demands that you separate impairment and disability, which I think you can't separate, the two are linked. There is a materialist side to the social model. Carol Thomas (1999) has done some interesting work on the social model to meet some of its challenges from a materialist position. She came up with three effects of disability: "disablism", that is the material barriers; "psycho-emotional disablism", the individual emotional damage that is created by the way the society treats you, the denial of rights; for example, how every time you go out in the street people stare at you and how that psycho-emotionally damages you; and "impairment effects". Early Disability Studies or as she says "hardliners" of the social model say impairment has nothing to do with disability and disability is only about the social barriers. Thomas argues this is not what the social model is all about but what it has become. She says we need a more nuanced understanding.

I have a lot of sympathy with her argument but I also see the danger of focusing on which of the three we are dealing with. Think of speech impairment for example. If you are in a disabling condition, a position where you are being disabled or disadvantaged because you have a speech impairment, it makes you feel angst and your speech impairment gets worse. So it is very hard to separate the two out. Or take for example the mental health problem; if you have depression and go out and people treat you badly, bad treatment can make the condition get worse. Is it a cause or an effect? It is very difficult to unpack these things, they all happen at the same time. I don't think they need separating out. At the moment we are doing research on motor neurone disease and it is already clear that the actual impairment has a huge effect on the people. They have breathing difficulties that they are so afraid, they have a constant fear of choking. It is the impairment itself, which creates the psycho-emotional damage. They cannot be left alone for three minutes because they are scared of choking.

So there are real problems with the social model, and I would prefer a critical realist approach. Dan Goodley has done quite some interesting work on postmodern writers such as Deleuze and Guattari developing what he calls a "rhizomatic approach" to disability (cf. Goodley 2007, 2011). A lot of his writing is about denying categories such as impairment arguing it is a social construction. I am not sure that gets us anywhere. Clearly there are some real things out there, for example spinal cord injury is the result of a damage to the spinal cord and it has real, hard effects – these are not imagined, socially constructed. Be it multiple sclerosis or a mental health problem, you need actual help, you can't ignore these things, these are hard facts, which are found throughout all cultures. We have to accept this reality and work with it. This does not mean, however, that we devalue people but we have to accept their difference. This notion of real difference is there, for example there are certain groups of disabled people with profound learning disability who will never work and you can't sit back and say that is socially constructed, that the disadvantage they are experiencing is solely the result of society, that they are labelled. These are real experiences but because they are real we are not saying people should not experience these differences.

B: "Difference" is a key notion in all the equality groups. From a critical realist perspective you have argued that all people have (or will have) an impairment sooner or later in their life, so the differentiation of abled/disabled is redundant. Also in other disciplines such as gender studies, critical racial studies etc. we encounter the 'problem of reification': How can we research inequalities without reproducing the very categories that we actually contest? How do you tackle the problem of reification in your own writing?

W: It is very difficult. I think one of the differences between discrimination of disabled people and discrimination of gender, sexual orientation or ethnicity is that with disability you have to take positive action. This means, that you have to put in ramps, put in hearing systems to make information possible in different formats whereas for the other groups you just have to remove attitudes. Think of the debate between Nancy Fraser and Axel Honneth about redistribution versus recognition (cf. Fraser 2000, Honneth 2004). Take the case of sexual orientation, if you recognise that people of different sexual orientations are entitled to equal treatment, then that's all you have to do, you don't have to make positive steps, whereas to include somebody who is blind or deaf you have to provide reading and hearing sign language interpreting. There are needs and we have to acknowledge that there are different needs and that disabled people need a different level of support.

The other problem with disability is that unlike the other equality groups, there is nothing intrinsically "wrong" with being a woman or with being someone of a different minority. Actually, "wrong" is the wrong word. Materialist Disability Studies writer Paul Abberley (1987) uses the word "real inferiority", which I don't like but there are real consequences of impairment. We advise people to wear seat belts, not to get injured in car accidents. We advise women to take folic acid during pregnancy because of the risk of spinal bifida. This does not mean that we devalue people who have spinal bifida. We encourage people to adopt safe sex practice because HIV is a chronic condition. The social model cannot handle cure. People who have chronic heart disease, which means that they can't walk, can have a heart bypass and walk again. Nobody of the disability movement would say they shouldn't do that. And yet, Disability Studies have a very difficult relationship with cure.

B: "Intersectionality" has advanced to a "buzzword" in the social sciences and especially in gender studies (Davis 2008). What has been its reception in Disability Studies?

W: I think intersectionality is very important for Disability Studies. There is a danger that we reify disabled people on the grounds that they have an impairment and we ignore the fact that they have multiple identities. For many disabled people having an impairment actually is not a major identifier, their family role, sexual orientation or ethnic background etc. are just as important. The notion of intersectionality allows us to bring all of this together. Of course, there is a danger of disaggregation that you might end up with small groups where you would have for instance only gay black disabled men in one group. Whereas the disability movement was originally about all disabled people just like feminism was about all women, they are both now so much disaggregated.

One aspect about disability that singles it out from the other equality groups is the fact that disability is something we will all experience. For instance, you don't wake up and have a different gender the next day, whereas you can wake up and find yourself having acquired an impairment. This is why in America they use the term "temporarily abled". That is the great thing about intersectionality, it introduces disability to a wider audience. Disability is the one thing that combines all equality groups, it is something that, in the end, everybody will experience. All of us will experience some period of disability. So intersectionality shows that disability happens across all equality strands.

There is another aspect of this argument. You may opt to reassess your sexual orientation in your later life, but disability is not like that, it is fate. If it hits you, it hits you; there is no other equality group that has that.

B: You have already mentioned the women's movement. Disability Studies and feminism have had a difficult relationship. Maybe you want to comment on that.

W: In the 1990s, in particular in the UK, the women's movement and Disability Studies have had quite an uncomfortable relationship because the women's movement wrote about the drudgery of care and the fact that women's identities were oppressed in their role as carers, the burden this meant, and how this could limit their opportunities. Some feminist Disability Studies writers such as Jenny Morris shifted the focus to the cared for who are mostly women since they tend to live longer and will experience impairments in their later life. So there was a very uncomfortable relationship about that. To a certain extent it is resolved.

There is a great book by Lynch et al. (2009) on "affective equality". She writes about people who make decisions to care for other people. Often it's not a rational but an affective decision, taken out of love. Surely there are times when care becomes difficult, but often it is done out of love. Thus, caring for somebody has a positive side. A lot of people actually choose to care for people, which is shown in the caring stories we found out in our work on motor neurone disease. As well as people with motor neurone disease, we interviewed partners of people who had died of motor neurone disease. None of them said that they were glad that their partners were dead. Some of them said that providing that care for their partner was the most intensely loving time in their lives. The feminist ethics of care does not take that into account. Nobody is independent, we are all interdependent. We like to care for people and we like to be cared for.

Elisabeth Badenhoop: Care is again a perfect example, which could best be approached with an intersectional analysis, since it is not only about women, it is about migrant women, too…

W: I talked to somebody who was interviewing a group of Zimbabweans who said they worked for the BBC, the 'British Bumcleaning Corporation' because they came over and worked in care. If you look at care homes in the UK, a lot of them are staffed by migrant workers.

B: Some of the Disability Studies writers argue that only disabled people can do research on disability (cf. Barnes 1992, Stone/Priestley 1996). This position presupposes an essentialist understanding of disability. The problem of essentialism, of authorship and experience, was not only a problem in Disability Studies but has been critically discussed within Black Feminism (cf. Mirza 1997, Collins 2000, Yuval-Davis 2006). To come back to that very simple question, who can do disability studies?

W: You are quite right, it assumes that all disabled people are homogeneous, which is simplistic nonsense or at best, said out of self-interest. Anybody can do Disability Studies, as long as they are good academic researchers. Why should I as middle-aged white academic who acquired a disability in my 30s know anything about the life of somebody with a working class background and profound learning disabilities? We have nothing in common apart from the fact that we both have impairments, which are not the same. I think there is a danger in Barnes' statement. Of course I think everybody can do Disability Studies.

B: What are still 'blank areas' in Disability Studies; which topics have not yet been fully covered?

W: There are several areas. What we haven't looked at, yet, is this notion of chronic illness and especially chronic illness that is enduring. I mean, where does chronic illness end and impairment begin? This is a difficult relationship to unravel. We are also only just starting on mental health. Mental health is particularly difficult. For some people with a mental health problem, the problem itself actually creates exclusion. For example, somebody who has agoraphobia (a fear of going outside) or a fear of social inclusion, the inclusion itself is a real problem for them. Another issue we have not really analysed is the role of medicine. We are still uncomfortable with examining the role of medicine in the lives of disabled people. Simplistically, a lot of the Disability Studies' writing on medicine still portrays medicine as some sort of oppressive regime; yet, some of us are alive because of medicine.

B: What about cultural representation, how has that been covered?

W: There is quite a lot of work already done on cultural representation, going back to the 1960s where people have written about cultural representation of disabled people, especially in North America. I am thinking of people such as Rosemarie Garland-Thomson, Lennard Davis, David T. Mitchell and Sharon L. Snyder. I am not saying that we don't need more of it but it's not precisely a gap in the canon of Disability Studies writings, there are more urgent themes such as the relationship between disability and mental health or the notion of chronic illness. Oliver (2009) for example still writes that rehabilitation is an oppressive regime because it is trying to make people walk but this is too simplistic, we still need to unpack that further.

B: You mentioned already the rather sympathetic expression of 'temporarily able-bodied' in American English. Which terms have become widely accepted in everyday language in Britain to speak about disability?

W: „Temporarily able-bodied' is a euphemism and I find it a bit irritating but it's all right to use. In the UK we use the word 'disabled person' solely because we think it's a person who is disabled, whereas in America and Australia they would use the term 'person with disability' because they like to think that they put the person first. These are two different approaches; you can tell where somebody is from, where they stand politically. Take for example the word 'carer', a person from the UK Disability Movement would say 'personal assistant' because it is not about providing care, it is about providing personal assistance and support. In fact, the role of the independent living movement was central to the founding of the disability movement and the modern disability movement both in the USA and the UK. They shifted the focus from the ability to, for example, wash yourself to the power to decide who washes you.

B: What improvements has the UK Single Equality Act 2010 brought to disabled people and what are its limitations?

W: We do not really know yet. What the Single Equality Act 2010 did was to incorporate the Disability Discrimination Act 1995 together with all other UK anti-discrimination legislation into one single piece of law. If you look at the equality measurement framework, which has been published by the Equality and Human Rights Commission you get one equality review, which indicates how fair is Britain today to disabled people. Compared to 1990, when Barnes wrote about disability discrimination and cited diverse examples of the disadvantages that disabled people face, today

there are still lots of disabled children who are being excluded from or bullied at school, however there are also new things emerging, for example there is data on disabled people reaching higher education, which is a huge improvement compared to the 1990s.
But I think we are entering really rough times. The think tank DEMOS has recently predicted that by 2014, 9.4 billion per year will be taken from disabled people in terms of budget cutbacks. Disabled people are right at the forefront of these austerity measures that this new government are introducing. So there is a real danger that we are witnessing a step back from the massive advances we made in the delivery of social care and access to services during the last 15 years or so.

B: The UK society is currently experiencing most severe financial cuts. There is talk about introducing tuition fees at undergraduate level in Scotland now, too. How is the Strathclyde Centre for Disability Research going to be affected by the cuts?

W: It will be a lot harder to get research grants. We do a lot of research for voluntary sector organisations and obviously they will have to fund a lot more frontline work now themselves. The two studies we are conducting at the moment, the one on motor neurone disease and the other on growing old with cerebral palsy, are both funded by voluntary sector organisations and I am concerned that in the future getting this sort of funding will be difficult because they will have to provide a lot more frontline support rather than provide support for research. Also, the government research budgets have been hit and the last thing any government would want to hear at a time of financial cutbacks is a group of academics to tell them that they are not providing enough care and support. In this way, there is a danger that our research funding will be hit like that. And obviously, students' tuition fees are a big problem and we do not know yet what effect this will have.

B: At Glasgow University, we are just witnessing that whole subject areas such as anthropology, social work, and modern languages are cut, which has provoked a broad movement of resistance by both teachers and students. Would you like to comment on how successful you think the protests will be?

W: I think the university handled it dreadfully. I hope that the protests will be successful. In the past, in other universities where they tried to do this they encountered so much protest, for instance at King's College or in Leeds University, that they pulled back in the end. I hope the same will happen here, too.

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More information on the Strathclyde Centre for Disability Research can be found on the website: http://www.gla.ac.uk/schools/socialpolitical/research/sociology/strathclydecentrefordisabilityresearch/

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