

Ruth Bailey. Paper given at Disability Studies Association, 18th September 2006.

HANDLING ACCESS IN A HEALTH CARE CONTEXT

IRIS' STORY

Introduction

Disabled people have great difficulty in parking when using either of Edinburgh's main hospitals. That's a headline from the preliminary findings of my PhD research on disabled people's health care encounters. However, as important as I think it is to highlight disabled people access needs, especially to health care providers, in this setting I want to focus on understanding the *experiences* of encountering disabling barriers. In particular I want to explore how disabled people handle access issues and if this can inform theoretical debates about access.

Why focus on access handling?

There are two reasons.

The first is a matter of expediency. Having completed the last of my 50 interviews less than a month ago, my analysis has barely begun. However, at the end of last year I used autoethnographic methods to write a paper exploring my own experience of access issues. That provides the theoretical framework for this paper.

The second reason for this focus is my theoretical interests. The social model of disability has succeeded in politicising space. The principle that, as Shakespeare and Watson put it, 'we are disabled by society not by our bodies' is well established including in statute. Of course I'm thinking here of the Disability Discrimination Act (DDA)

Aside from the political project of barrier removal, several commentators, for example Imrie (1996), have noted the paucity of detail about the interaction between disabled people and the multiple spaces we use. It is this detail which interests me. By looking at the experience of one of my interviewees, lets call her Iris, I hope to shed light both on some of the particularities of

access in a health care context and to reflect upon 'the fit' between experience and theory around access and disabling barriers.

Method

At this point, however, I want to say a little about the study in which Iris took part. Disabled people's health care encounters is my PhD research, which is funded by an Edinburgh based disability organisation. It aims to learn about disabled people experiences of using health care services and to trace the factors which influence these.

To achieve this, data has been collected from 27 disabled people using qualitative interviewing methods. Of these 27, 21 have been interviewed twice. The second interview wasn't part of my original research design. It came about following 5 pilot interviews - and my having 2 extended stays in hospital. Reflecting upon both of these led me to the belief that to capture the lived experience of disability one needed to pay attention to the details. Hence the second interview, which allowed me to follow up on issues in greater depth and detail. More pragmatically, it allowed me to finish the first interview after an hour, necessary as a way of managing my fatigue. (The detail of embodiment even influences research design.)

This paper is an opportunity to test if a second interview facilitates the sort of fine grained analysis that is possible when using one's own experience. Of course the comparison isn't fair. When analysing others' experience one has so much less to work with. Interpretations have to be far more speculative and circumspect. This is my plea to you is to treat this paper as feeling my way and the beginning of a work in progress.

Theory

Before looking at Iris's experience I want to briefly outline where I am coming from theoretically.

I feel Disability Studies is the appropriate home for my work. However its founders, Oliver and Finkelstein may not agree. They reject the value of research based upon individual experience. As materialists and Marxists respectively, they see disability and disabling barriers as being created by the social and economic

forces of production in capitalist society. From this perspective, disabling barriers are objects 'out there', existing independently of any disabled person. An access encounter is an isolated moment in time where a disabled person confronts a barrier and her intentions are thwarted.

For me, the problem here is the lack of theoretical space to explore agency: what happens in the moment of the access encounter, are some people able to negotiate around barriers more easily than others, and if so why? The social model is silent on these points. As such it risks casting disabled people as victims of barriers just as the medical model casts disabled people as victim of their body. The great irony here is that in the campaign for civil rights, for barrier removal, a key tactic was to handle a barrier in the most visible and media eye-catching way – for example by handcuffing oneself to a bus.

The theoretical modifications to social model proposed by Thomas do provide some scope for looking at agency. She takes the original social model definition of disability, the imposition of restriction upon people with impairments, and recasts it '*as a social relationship between people*'. (Thomas, 1999 p40-41). Doing so highlights that within a materialist context social relations emerge through which disability – and disablism - is constructed and experienced anew. From this viewpoint it becomes possible to argue that access is contingent not only upon the materialist features of a particular environment, but also on the relationships which arise at the moment of the access encounter.

Looking at how access is handled is to tread dangerous ground. It risks undercutting the demand for universal access because it could be taken as implying "that we can manage" with something less. Yet the argument I want to make is actually the opposite. By illustrating the costs of managing substandard access, I hope to add weight to the argument for barrier removal. Further, by capturing the everyday experience of dealing with poor access the relevance of the social model can be extended beyond the political few. As Watson and Shakespeare (2001) point out, if we fail to address the experiences and concerns of individual disabled people, we risk alienating them from the disability movement.

I want to turn now to Iris's story of access handling.

Iris's Story

Iris told me that she has a spinal injury, is a wheelchair user and has twenty four hour Personal Assistants. She uses a number of health services including district nurses and the local hospital and the spinal injuries unit which monitor her kidney and bladder problems. It has been while attending these monitoring appointments that Iris encountered most access problems. These problems centred upon needing a hoist and using the non emergency ambulance service.

I will now look at how Iris handled each of these.

Hoist – whose responsibility

To plan or not to plan?

In the context of the NHS, Iris has developed quite a nuanced judgement about when she has to be proactive and plan ahead to ensure her access needs are met:

“ With the NHS ... I don't ask questions like if they have a ramp because I always assume that there will be a way in ...but might not (have) other specialist things that I might need... if it is bigger or... when I go to the clinic at Eden Hall in Mussleborough, that is the clinic for spinal injured patients ...they're always going to have a hoist somewhere lurking behind, but as I say the place at Leith which is smaller...”

Here Iris is making the assumption that most NHS premises would be wheelchair accessible but believes a hoist to be 'specialist' equipment. As such she feels its availability depends upon the type and purpose of the NHS facility. On the strength of this, when it came to the appointment at the Leith clinic

‘I tried to phone...if it is somewhere that I haven't been before I tend to not trust them so I phone up and say “have you got a hoist for me?”’.

Despite doing this, when Iris arrived at the clinic:

“I could see that they weren’t expecting me to be in a wheelchair... they didn’t make a big fuss, somebody just went whooshing off to find a hoist”.

This account raises a number of questions.

“They weren’t expecting me”

First, how should we interpret Iris’ handling of the situation? Making the advanced phone call, planning ahead, probably marks Iris out from other patients. It’s as if Iris has an extra layer of things to deal with: will they have a hoist for me, shall I ring? Most people probably don’t give a second thought as to these things.

It’s this, I think, which links Iris’s tactic of ringing ahead and the sentiments expressed in the phrase “they weren’t expecting me to be in a wheelchair...”. This was a constant refrain during this part of the interview. It can be interpreted in contrary ways.

On the one hand, the phrase could be seen as a shorthand way of referring to her access needs. With this sense, the tactic of ringing ahead is a pragmatic one, a way of ensuring her needs are met with the least amount of hassle. On the other hand, the phrase suggests that wheelchair using patients are unexpected, even in the NHS. I find this quite ironic, although I haven’t quite worked out why. In this alternative sense, ringing ahead is a means of announcing one’s existence to the world. This is emotionally charged – but it also avoids that awkward moment of first meeting when you notice others register that you are not what they expected. If that’s what Iris feared then her comment ‘they didn’t make a big fuss’ was a mark of relief.

A pertinent question here is whether handling an access matter should be interpreted as an act of resistance. Ringing ahead could be seen as colluding with the idea disabled people can’t just turn up and expect their needs to be catered for. But it is also a means of taking control, of refusing to leave one’s health care encounter down to the vagaries of a small clinic. As Iris said, she ‘didn’t trust them’. Perhaps both these readings involve resistance because they engage with the issue and challenge the status quo of excluding spaces. Theoretically, both involve the back and forth of relationship which fits with Thomas’ social-relationship approach.

Providing a hoist – whose responsibility

The second question raised by Iris' account is who should be responsible for ensuring a hoist is available. Certainly, Iris sees it as her responsibility. When I asked her if this should be the case she replied thus:

“Well in an ideal world you wouldn't have to do that [phone ahead], in an ideal world somebody would say to me don't worry X Leith will have the facilities for you...but we don't live in an ideal world...”

It may not be an ideal world but it is a world in which the DDA is on the statute book. This places an obligation upon services providers such as the NHS to anticipate disabled people's access needs and to make reasonable adjustments if need be. But what sorts of needs can be anticipated and in what circumstances? Ultimately this will be decided by case law, assuming that there are disabled people prepared and enabled to make a claim through the courts.

Can all access needs be met?

However, on a day to day basis, disabled people have to consider which services providers have taken responsibility for which needs - and plan accordingly. This is what Iris was doing in the quote we looked at earlier explaining when she would phone ahead. This suggests – and I think rightly – that access is dependent on context, in this example type of NHS premises. It is also dependent on embodiment, as indicated by the Iris' phrase 'other specialist things that I might need'... I use the term embodiment rather than impairment here because it conveys more than a biological condition. It includes how a condition is manifested and managed as well as subjectivity and the social. These are all components – but decidedly *not* determinants - of access need.

I want to take a little detour here to get to grips with this issue what needs can be anticipated and the assumptions which disabled people can make about who is responsible for what. I want to do this by suggesting there are two types of access needs. Macro needs which can be anticipated and micro needs which can also be anticipated – but only indirectly.

Macro needs are those where a single adjustment can facilitate access for a whole group of people. I'm thinking here of the provision of a text phone to enable deaf patients to call the GP surgery or a hospital providing its leaflets in a range of different formats. However, as hinted at above, some barriers emerge in a particular space, being used for a particular purpose involving a person with a particular embodiment. Such micro needs require adjustments which will be dependent upon the combination of these elements. Anticipating them is problematic because they are in part 'person specific'.

Micro needs are perhaps particularly likely to emerge in health care settings. This is because, for example, diagnostic procedures require bodies to be positioned or behave in unusual ways. Drawing on my own experience, I want to highlight one such need.

Once, I was admitted to hospital and allocated a bed which didn't have the features I needed. The context part of the equation is that had I been a visitor or a member of staff in that ward, chances are I wouldn't have noticed the bed let alone labelled it an access problem. Similarly, had my embodiment been different it would not have been an access problem. I handled the problem by raising the matter with the nursing staff. They responded immediately and swapped my bed for an accessible one.

Now I don't think the staff could have anticipated my needs: indeed I didn't anticipate them. However, they took responsibility for dealing with them as soon as I raised them. It is this ability to respond 'in the moment' which is key. It may not be possible to anticipate the specific nature of micro needs, but the need to be sensitive and responsive can be. Hence micro needs can be anticipated indirectly. To facilitate this, NHS staff need to be encouraged to develop and build upon these responsiveness. If it doesn't, there is a risk that the DDA will only meet the 'macro needs' or, as one of my respondents put it, those of a 'fit, male paraplegic.'

Moving on, I want to explore the other access issue which Iris told me about, the problems with the ambulance service. She told me that on the last occasion she used the service the ambulance men

“were in two minds as to whether to pick me up because they didn't know whether I would be able to get taken home again

...if you want to get a wheelchair into the house you've got to have two people on the ambulance run, as opposed to only one and sometimes they run with only one.

Here a number of access problems are compounded - inaccessible housing, lack of accessible transport and finally requiring a double crew where a wheelchair user needs lifting into the house. Yet the focus of attention is the wheelchair, the symptom, rather than the cause.

What we don't know here – the detail I omitted to ask for – is how Iris handled this situation. Did the ambulance men consult Iris about whether they should take her, what was said, how did she feel? What she did express was irritation at what she felt was the root problem: a breakdown in communication between the department booking the transport, who said they told the ambulance service Iris was a wheelchair user, and the ambulance service who said they weren't told.

Ultimately Iris handled this situation by opting out.

I have to admit that I've decided that because I live near the [hospital] I'll just take a taxi. Again that's not fair on people who don't live nearby and who can't take taxis. That's maybe harsh on them.

She acknowledges that this solution was possible due to her economic position. This highlights another component of access relationships. Social and economic position of those involved, together with other issues of social identity such as class, race and gender, influence the range of handling options available. Again, because the social model omits space for agency means that these issues get overlooked.

Iris went on to speculate that if she needed to attend Edinburgh's other hospital, taking a taxi wouldn't be an option. Located on the edge of town a round trip would cost £30. One would like to think that Tessa Jowell (Health Secretary) and the like would take account of this when thinking about the wisdom of consolidating services into regional centres. But I'm not holding my breath...

Finally, I want to explore briefly the emotional element to handling access issues. Iris' injury had happened quite recently and I

imagined – or rather assumed – she would have gone through the process of learning to deal with access issue. But there wasn't much evidence of this – although it is hinted at here.

I kind of find that the way to cope with that is Don't get wound up it's not going to do you any good.

This sounds like an injunction to self. It's as if she had worked out intellectually the best way to handle things ...not getting wound up...and was now working on putting this into practice. This suggests that another element of access encounters is learning the best way of handling self. Thomas's concept of psycho-emotional effects is pertinent here. It acknowledges that disabling barriers have emotional and psychological costs. Barriers not only restrict what disabled people can do but also who they can be. But here Iris is being pre-emptive and engaging rather than reactive and passive as the concept suggests. Having to be proactive also has emotional costs.

On a number of occasions, Iris would describe an access barrier, and then immediately play it down. For example, a nurse told Iris' PA to wait outside while hospital staff hoisted her. The staff made a real pig's ear of it and had to ask the pa to help. Iris put this down to 'it's just people' and the nurse being 'sniffy'. When I asked a final question about access problems she said.

“But apart from those little things (ie the lack of a hoist) and the ambulance service that I've told you about, apart from those I've not had access problems”

It's hard to really know what's going on here. Taken at face value, it suggests that access barriers are no big deal. Perhaps the lack of a hoist when you've asked for it is a little thing and not as oppressive as social model analysis suggests. Or perhaps we need to go in to psychological waters – which makes me very nervous – and say this downplaying is actually denial. Perhaps Iris has yet 'to come to terms' with what has happened, how truly awful things are? Or is it a case of false consciousness. In which case is my role as researcher to impose the correct, ie social model, interpretation?

Yet another reading is possible. Has Iris become so used to handling access issues that she takes doing so for granted? The

case for this interpretation is strengthened insofar as a number of respondents adopted a similar stance. For example, Joel said he had never had any access problems with the NHS and then went on to describe writing complaint letters about the height of the mirrors in the accessible toilets and insisting an ambulance driver contact his controller after refusing to take Joel's chair! This

adds to my early argument that having to deal with access issues is an extra dimension to daily life.

It is this last reading that interests me most. Viewed in the context of this exploration of access handling, it suggests something of a paradox. On the one hand, this paper made an attempt to elaborate the fourth dimension, what has to be done to engage with society and refuse to be marginalised and excluded. Yet so much of this is hidden: it is hidden from non disabled people, hidden within the social model and, finally it seems, hidden from ourselves. We rarely stop to count the costs of living in a disabling world.

As I have been writing this, I've kept asking myself, won't everyone know about all this, aren't all these fine details about ringing a clinic in Leith boring? And another question, what's the point? My response to the first, is well, yes, maybe the detail has been boring, especially if you've come here on the strength of my abstract, which promised early findings about disabled people health encounters. But that's exactly what it's like having to handle access issues. You get so bog down in the means of getting in, or getting there, that the reason why you're trying to do becomes obscured.

With regard the second, for me my hope is that by looking at access handling a small part of disabled people lived experience is revealed. Along the way, I have tried to highlight some of the conceptual characteristics of disabling barriers which I want to go on to use to engage with currently theoretical thinking on access, for example the work of Hughes & Patterson (1999), Freund (2001), Imrie (1996) and Gleeson.

References

Freund, Peter (2001) Bodies, Disability and Spaces: the social model and disabling spatial organisations, *Disability & Society*, 16, 5, 689-706.

Gleeson, Brenden (1997), *Disability studies: a historical materialist view*, *Disability & Society*, 12, 2 179-202

Hughes, Bill (2000) Medicine and the aesthetic of invalidation of disabled people, *Disability and society*, 15, 4, 555-568.

Hughes, B & Patterson K (1999) Disability studies and phenomenology: the carnal politics of everyday life, *Disability & Society*, 14, 5, 597-610.

Imrie, R. (1996) *Disability and the city : international perspectives* . London: Chapman

Imrie, Robert and M. Kumar (1998) Focusing on Disability and Access in the Built Environment, *Disability & Society*, 13, 3, 357-374.

Shakespeare, Tom and N. Watson (2001) The social model of disability: an outdated ideology?, *Exploring theories and expanding methodologies*, 2, 9-28.

Thomas, C. (1999) *Female Forms*. Buckinghamshire: Open University Press.