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Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: identity and disability

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ABSTRACT *This paper focuses on issues of disabled people's notions of self-identity and is grounded in their accounts around their own self and identity. It starts with a brief description of what Hall (1996) describes as the two main schools of thought on identity. It then moves on to explore and discuss the self, and the embodied nature of self, and then explores the place of identity in disability studies. Disabled people's accounts around self-identification are then presented. The analysis of the data suggests that many of the informants do not see themselves as disabled and do not identify as disabled people. The political consequences of this are briefly examined. The views of those who identified as disabled are also explored.*

Theorising Identity

The concept of 'identity' has become both a contested and a prolific field of research and theory in recent years. Identity is also, as Shakespeare (1996) has argued, a major area of conflict between disability studies and mainstream social science. Hall (1996) has suggested that within the social sciences there are two historical and strategic approaches to the production of identities. The first model is based on the assumption that there is an essential, natural or intrinsic meaning to any identity. This identity is based on either a shared social experience, origin or structure. An example of this approach is found in the work of feminist theorists such as MacNay (1992), who promotes the notion of a female subject and, hence, a female identity to form the bedrock of feminist politics. Much of the writing on disability from within disability studies falls within this paradigm. The second model denies the existence of any identity based on a shared origin or experience. Identities exist only as opposites, they are multiple and temporal, and to propagate the concept of, for example, a male and female identity, or a

disabled and non-disabled identity serves only to strengthen essentialist arguments. Within Disability Studies this approach is found in the writings of, for example, Corker (1997, 1999), Liggett (1988) and Sheldrick & Price (1996).

To these writers, the project of Disability Studies and other emancipatory movements is to undermine any concept of identity or self. Within this paradigm disability or impairment cannot serve as a foundation as these are empty and constructed. Applying a category as a foundation or as fundamental to political claims can only result in political closure. Identity is constructed in relations of discourse and power. Fixed identities of disabled people are enforced through regulatory regimes (Liggett, 1988).

Whilst this approach appears to leave room for agency in that discursive practices are embodied in the performances of human actors, its insistence that identity is constructed through discourse serves to suggest a more deterministic process for identity formation. In Butler's (1990, 1993) work, a major influence on many who write from this paradigm, there 'need not be a "doer behind the deed" but that the "doer" is variably constructed in and through the deed' (1990, p. 142). The self is a performer, but there is no self behind this performance (Benhabib, 1992). Identity emerges solely through discursive means and there is no space for reflexivity. Discourse serves as a means of social control and symbolically inscribes with meaning and significance and through this identity emerges and is sustained. There is no possibility of escaping linguistic construction (Butler, 1993, p. 10). There is little room in this approach for an understanding of how identity forms, how selves are constructed by others and construct themselves. Such an understanding requires the presence of a self, a 'doer behind the deed' (Dunn, 1998).

Self

Self is an unformed, unfixed concept (Giddens, 1991) and is, as Mauss (1998) argues, constituted both as an evolving concept (which is social in origin) and as a universal sense (which is not social). This universal construct of the self is the product of the fact that 'there has never existed a human being who has not been aware not only of his body but also of his individuality, both physical and spiritual' (Mauss, 1998, p. 3). The universal self is a pre-requisite for the existence of a social self; the social self is embodied within the medium of the universal, biological self. Much of the sociological theorising of the self has tended to distinguish between these two concepts giving primacy to the social (Turner, 1996, p. 67). The role of the body in the creation of identities, the social ascription of role and its political implications have tended to be ignored. We act through our bodies upon our world and it is through our bodies that we experience and comprehend the world (Schutz, 1971)

The work of Mead, James and Connolly have been especially influential in this school of thought. It is premised on the notion of human individuality. Human beings are consciously aware of their own lives and it is through reflexivity that we become aware of a consciously constructed self (Dunn, 1998). The self, it is argued, arises as a result of self-objectification, the process of seeing oneself as others see

you. As Giddens puts it: 'Self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of his or her biography' (Giddens 1991, p. 53). [1] The self becomes constructed through discourse, it is produced in specific historical and institutional sites, it is the product of more or less rationalised schemes which shape our way of understanding; the self is an historical construction based on our biography (Taylor, 1989; Giddens, 1991). Self is the product of culture, providing individuals with an identity, so Taylor writes:

My self-definition is understood as an answer to the question Who I am. And this question finds its original sense in the interchange of speakers. I define who I am by defining where I speak from, in the family tree, in social space, in the geography of social statuses and functions, in my intimate relations to the ones I love, and also crucially in the space of moral and spiritual orientation within which my most important defining relations are lived out. (1989, p. 35)

Self is therefore seen as a universal human property, something that we must all possess and a characteristic that we must all develop (Lemert, 1994). Under the influence of Giddens and others, and in sharp contrast to the ideas of Butler discussed above, theorising on self within this school of thought has become colonised by reflexivity; who we are, who we choose to identify with, what we choose to do are more often experienced as matters of choice. We learn who we are not by concrete relationships within a physical community, but through abstract symbol systems. Group membership is no longer synonymous with identity formation. We are, according to Giddens (1991) able to choose our identity, and can ignore or reject identities fostered on us as a result of ascribed characteristics. We do this by the creation of narratives about the self and provided we can sustain these narratives we are able to maintain our sense of self (1991, p. 54).

Through this approach the problems associated with conflating identities into essential, fixed, pre-ordained, singular categories, for example the homogenisation of disabled people into a singular group and the ascription of a single identity, can be avoided. Our sense of self is constantly evolving. We constantly reconfigure ourselves through multiple identities, and time space and relationality are all important in identity formation. As Somers writes:

... it is through narrativity that we come to know, understand and make sense of the social world, and it is through narratives and narrativity that we constitute our social identity ... all of us come to be who we *are* (however ephemeral, multiple and changing) by being located or locating ourselves (usually unconsciously) in social narratives *rarely of our own making*. (1994, p. 606)

She further argues that what we do and how we do it are the result of cross-cutting relational story lines in which we locate ourselves. The notion of the self is therefore embedded in shifting networks or 'webs of interlocution' (Taylor, 1989). However, sociology, as Somers (1994) argues, with its focus on epistemology, the standards we

use, the way we understand the world and what we use to legitimate these foundations places little emphasis on ontology, on problem formation and on social being. Research is on action, rather than representations of being. Somers argues for a rejection of a decoupling of ontology and action, and an incorporation of social being and social identity into action, agency and behaviour. By so doing, social agency is brought to the fore and the notion of self and identity take on a political element as it involves 'refusing, diminishing or displacing identities others wish to recognise in individuals' (Calhoun, 1994, p. 21).

Somers is arguing for a focus on what she terms an ontological self, a sense in which the self becomes embodied, a mode of being in the body, of living the body. This is in contrast to what she sees as the epistemological self a sense of knowledge about the self derived from others, a disembodied self, a self away from the body, although the result of the body. Her call mirrors a growth in writings in which oppressed groups rewrite their past and present in a more positive, self assertive vein. For example, the Black American feminist writer Patricia Hill Collins, asserts that:

By insisting on self definition, Black women question not only what has been said about African American women but the credibility and intentions of those possessing the power to define. When Black women define ourselves, we clearly reject the assumption that those in positions granting them the authority to interpret our reality are entitled to do so (1990, pp. 106–107)

Disabled people share one important attribute; they are all made the subject of oppression (Barnes, 1991). Whether this acts as a categorical classification for disabled people as a social category or whether disabled people themselves identify in such a manner is not known. Do disabled people know who they are because of the fact that they have an impairment, because of the fact that they face discrimination or because of who they, ontologically, believe themselves to be? These are fundamental questions in any analysis of disability.

Identity, the Self and Disability Studies

Identity and notions of the self in disabled people have aroused a great deal of interest in medical sociology, especially amongst those who write in the interactionist tradition. For example, Goffman's (1968) analysis of 'spoiled identity', *Stigma* and Scott's (1969) *The Making of Blind Men* brought issues of impairment and identity into the sociological mainstream, and such writings have been influential in the work of, for example, Kelly, (1992, 1996) and Williams (1984). However, much of this work concentrates on the effect on identity and self of impairment, the emphasis being on the need for adjustment to loss, coping and mourning (Shakespeare, 1996). According to Gerhardt (1989), these writings fall into what she terms a 'negotiation model', and contrasts with those who write from a 'crises' model perspective. People who have an impairment or chronic condition, it is argued, suffer a loss of self and go through a process during which they negotiate their lives

in such a way as to be as ordinary as possible and so retain some contact with desired life-worlds.

However, in disability studies, identity and self have tended to be viewed through an analysis of oppressive social relations with the focus on changing society and empowering disabled people (see, for example, Barnes' [1990] analysis of the socialisation and identity formation of young disabled people).

Disability identity is important, as Shakespeare (1996) argues, because it is through identity that an understanding of the complex relationship between individuals, society and biology emerge. For those writing from a Disability Studies perspective, and those working within the Disabled People's Movement, identity as a disabled person is presented as something fixed, or stable. It is a shared experience based on common interests (Finkelstein, 1993; Campbell & Oliver, 1996).

In much of the writings on disability that have emerged from disability studies, identity is presented as unproblematic. So, for example, Oliver sees disabled people as identified through three key elements:

- the presence of an impairment;
- the experience of externally imposed restrictions;
- self-identification as a disabled person (1996, p. 5).

Identity for disabled people is therefore, according to Oliver, ahistorical, unsituated and decontextualised. Most writing about 'identity' tends to place emphasis on self-definition and/or social definition in terms of language. It is interesting that in both accounts it is assumed that disability identity exists prior to language, and is simply 'marked' or 'reflected' in how disabled people come to use language (Corker, 1999). This is not to deny the category 'disabled person', but to argue that such a classification must be historically situated, socially composite and seen as part of a multiple identity.

This is not to say, that the notion of a shared identity has not played a crucial role in the development of the Disabled People's Movement and the on-going political struggles. It has been, and hopefully will continue to be a powerful and creative force. Whether such a shared identity exists, however, has not been explored. There is an assumption in much of the writing on disability that what Somers (1994) would term an epistemological self, that is a self that is created through knowledge about the self built up from others opinions of the individual, predominate in constructions of the self. In the same way that Fraser & Nicholson (1990) argue against appeals to the unity of women to justify feminism and feminist politics, so there is a need to document experiences from a variety of disabled people. Knowledge is socially anchored in experience and that multiple social standpoints produce plurality of knowledges, each of which is partial (Collins, 1990). Through multiple oppressions, as Collins (1990) argues, Black women learn to rely on their own experience to survive. It may be argued that disabled people adopt similar strategies in their own constructions of their self, consequently, feelings and personal values carry broad political and social implications, and these feelings and personal values need to be explored. It is these that this paper now moves on to explore.

Data presented in this paper are drawn from an interview based study with 14 disabled men and 14 disabled women. These men and women were all volunteers, and were recruited through organisations of and for disabled people, housing associations and sports clubs. Each informant was interviewed twice over a 6-month period. The interviews were all tape recorded and transcribed for subsequent analysis. The data were analysed using standard protocols for qualitative analysis, as described by Loffland & Loffland (1995). All the informants have been given pseudonyms.

The Rejection of Impairment in Construction of Self-identity

Despite daily experiences of oppressive practices, only three of the participants incorporated disability within their identity. For the vast majority of the participants in the study, impairment was not seen as important to their sense of identity or self. This resistance to cultural perceptions of disability and a rejection of impairment as a central characteristic took a variety of forms. First, were those such as Arnie, who, through their accounts suggest that their physicality did not produce a difference between themselves and nondisabled people, challenging the universal 'biological' self:

NW: When you think of yourself, what image comes to mind?

Arnie: A normal person. The only difference is I'm in a wheelchair, and I try not to think of that as a difference.

NW: You don't think of that as a difference?

Arnie: No, I'm equally capable of competing with an able-bodied person.

NW: In what way?

Arnie: In jobs, in socialising, mixing with the opposite sex.

NW: How do you think your disability affects your view of yourself?

Arnie: It doesn't.

NW: It doesn't affect your view of yourself?

Arnie: I'm equally as intelligent as any able-bodied person and equally as capable of doing things as an able-bodied person.

For Arnie then, the presence of an impairment is not reported to affect his sense of self, he is as he describes a 'normal' person. Whilst he states that because he is in a wheelchair he is different, this difference is negated. For many who took this view, any differences between themselves and non-disabled people were simply the result of discrimination and prejudice. For example, Archie, after describing himself as normal, and noting that the only difference between himself and non-disabled people is that he uses a wheelchair, goes on to say:

I try and show them that I can do just as much as what they do, if not more, apart from the obvious things like, with them being able bodied, that

they can climb up stairs, and they've got better access to places because they can walk up stairs or they can climb up a hill or get a bus, or get on a bike or things like that. But I show them that that's the only difference, really, is the physical difference, cos they can use their legs and I can't. That's the only difference, is the access, because of society, that they don't really make enough access for people in wheelchairs. But apart from that ...

Physicality is therefore sidelined, self-identity rests in what Archie is able to do and not how he does it, and if it can't be done it is because of societal and environmental barriers, rather than the result of an impairment. He does not want to be othered on the basis of impairment, demanding a different way of defining normal and other. The sense of self is a sense of knowledge about the self, and whilst the self is, of course, embodied, in that it is through the body that Archie is able prove to others that his identity is not determined by his impairment, identity is disembodied. It is a self 'away' from the body. Importantly, though, there is no denial of impairment. Archie is therefore able to define who he is by what he becomes as a result of his actions. His self-identity is not immutable. He is allowed a dynamic analysis of what others think about him and he is able to transform the structure and content of what others say. Self can therefore become a struggle, as Archie confronts others, challenging their meaning. Self is thus a product of self-determination, autonomy and choice. It is his will that creates the self, but in interaction. In other words, the creation of the self becomes a symbolic work of constitution. It is Archie who decides what is symbolically important in his self-identity. By rejecting how others may see him and, through an interpersonal and social process challenging the narratives about him, he can adjust the ideas of others to fit with his own idea of his self-identity. By confronting 'disablist stereotypes', which he sees as negative and demeaning, he is able to present a picture of himself as an active, resistant agent. Self-identity becomes a political issue.

However, this political identity is not an ascription of identity on the basis of group membership. Identity politics, as writers such as Calhoun (1994) and Philipson (1991) describe is premised on the notion of a singular identity based on a set of ascribed characteristics through which individuals claim membership of a group distinct from the rest of society. Identity politics involves a preoccupation with group membership, a group that the members must see as clearly demarcated, with group boundaries a necessary definition of the self (Philipson, 1991). Self-identity and subsequently agency, for Archie is achieved through a practical demonstration of his skill and abilities and it is through this agency that he is able to reaffirm his own sense of biography and challenge identities ascribed to him on the basis of his impairment. Identity for these informants is more about the rejection of group boundaries than their reaffirmation and the presentation of the self involves a rejection of difference. Mark made this clear when he stated:

I don't tend to think of myself as disabled, you know I don't think, oh I'm in a wheelchair, disability's a major part of my life.

Identity is about establishing a sense of unity between themselves and non-disabled people. It is about overcoming the paradox of having a different body, one that is used by many people to ascribe characteristics, but at the same time rejecting this sense of bodily identity. It is also, however, not a self-identity posited on the post-modern values of diversity, heterogeneity, eccentricity and otherness as described by for example Butler (1990) or Young (1990). Archie demands that we think beyond the dualism disabled-non-disabled, his sense of self emerges through the product of a life narrative. It is a reflexive process.

This description of the self was performed by many of the participants. Joyce, for example, argued that she was not primarily a disabled person and that her identity was the product of relationships; relationships with people or with groups of people and the social roles that she performed within these relationships:

Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person. I see me as an ordinary person, sort of being a housewife, being an Auntie, just doing ordinary things that ordinary people do.

These relationships structure her self-identity. If this is accepted, then it has to be acknowledged that identity formation for disabled people is not a unique experience contingent on the presence of an impairment, as some writers seem to suggest [for example, the work of Charmaz (1983) and Bury (1991)], but is part of the experience of identity formation common to people as much research has shown (Mellucci, 1996).

Furthermore, for Joyce, being a disabled person was not only not seen as an insignificant part of herself. It was quotidian. Impairment is part of her everyday experience. She is just a person with an impairment. She feels normal. She is normal and the awareness of who she is, is not premised on who people think she is, but on what she feels herself to be.

For example, she described to me how annoyed she got when other, non-disabled people failed to see this:

That really gets my goat. You know, when you are trying to live a normal life and every time you achieve something they sort of pat you on your head and say 'Ain't that good?' and you don't need that. I mean to them it's wonderful because they have never had the experience but to you it's nothing out of the ordinary.

This idea of normality, of leading a normal life, of just getting on with things was present in many of the participants' responses. For example, Deidre talked about how people often told her that it must be hard for her to achieve things and said 'I don't find it too hard, I just get on with it'. Being impaired is a fact of life for many of the informants, it is an everyday condition and as such does not impinge on their sense of self.

For some of the informants, this was because they had always been that way; they had been born with an impairment and had no knowledge of life without an impairment. For example, John told me how he often used to try and imagine what

life would be like if he had not had an impairment, but could not. It is almost as if it is a phenomenological impossibility for him to imagine what life without an impairment would mean. John's image of himself was not as a disabled person, but as someone who was 'Going bald with a good sense of humour'. Throughout their lives, these particular informants had created a biography that incorporated their impairment into their sense of identity in such a way as to normalise the impairment. This is what Somers (1994) would term an ontological self. As Jane says:

When I was a wee girl I used to pray every night that just for one day I could walk. I would have danced the soles off my feet. And I could never accept this not being answered. Now I do, I realise it's not meant to be. Then, if any able-bodied person came into the children's home I'd always get round behind them to see where the key was. I couldn't understand how they could walk without crutches, sticks, callipers, so somebody had to wind them up in the morning, somewhere there had to be this key that turns. That's how I looked on it. But as I say, I don't know if I could accept being able-bodied and then struck down with a disability. Maybe you're lucky because you've known what it is to be able-bodied. Maybe I'm lucky that I've never known anything else, I don't know. But I just don't see myself as disabled—I'm in a wheelchair, big deal. The chair's my legs, I save a hell of a lot of money on shoe leather, I just don't see myself as disabled.

Here, Jane acknowledges not only that as a child she used to want to be non-disabled, but that the very idea of walking was something that she did not understand. She had had no experiences of what it would be to walk unaided, how it would feel to be nondisabled. Indeed, in the children's home that she grew up in, to be disabled was to be normal. As a child her self-identity is, according to this account, therefore not about a reconstruction of normality through the creation of an autobiography that accounts for and explains her own difference from others, but through an autobiography based on others difference from her. She is not trying to account for loss, illness or physical decay in her self, but to seek how it is that others can do what she cannot. Her experience as a disabled child among other disabled children is not unique. It is the difference of others from outside the home that forces her to confront her self. This confrontation initially set up a sense of loss of self-identity, and she became fixated on the difference and discovered what it was that she lacked. However, as her life developed the difference between herself and nondisabled people became normalised, there is nothing unusual for her to be a disabled woman. It is an unremarkable part of her sense of self, one so unremarkable that she does not incorporate it into her self-identity. As she puts it 'It's only bits of my body that don't work' and this has become habitual, but unimportant, part of her ontological self.

This analysis of what it is to have an impairment was not only confined to people born with an impairment. For example Drew argued:

I had a view of my body before I had my accident and I have a view of my

body now. I have a view that people have bodies. I know it is possible to change the body one has and the more money one has the easier that occurs. It's never been something that I have ever wanted to do. I don't, I've never believed as far as I can remember that it's really been important enough to me in that sense. I just think bodies are. I probably still in my mind's eye imagine that I'm 16 and the schoolboy athlete that I was. That's how my deep down personally I feel about myself. Not a nearly 40 year old, middle aged, slightly overweight man. I know, I'm not dismissing the fact that I'm a disabled person I know that my bodies a different shape than it was before I can see that there's no muscle there any more I'm not pretending that there hasn't been change. If change is the right word. For example change happens all the time in any case and for all I know I could wake up tomorrow and discover that all this research into spinal injury has produced a cure and will take me back 10 years, but of course it won't take me back 10 years. It will take me forward to wherever I go. I'm not spending time wanting that to happen or waiting for that to happen. I'm quite confident about myself as a human being here.

Impairment is not dismissed; indeed it is recognised. He is physically different from what he sees others to be and from what he feels his body should be. However, this difference is not internalised. He still, to a certain extent, feels that he is and has the body of the 16-year-old that had the accident. This is not to suggest that he does not recognise or accept difference in his behaviour or his abilities or the way that his impairment impacts on these abilities. For example, he argued:

Last week I got in my van ready to go somewhere and discovered I'd forgotten my wallet. That just makes me so bananas because it is such a tiny little thing and I know it's going to take me ages because I transferred in, got everything together, locked up the house, got into the van which usually I leave parked out on the green, transferred from my wheel chair and I was just about to drive off and I thought I forgot my wallet and that adds, leaving my wallet in the house, puts probably 20 minutes to half an hour on to my journey and that's just so frustrating because it is such a simple little thing that anyone else would say I forgot my wallet, take two minutes. I've to transfer, fiddle with my keys, get back up that hill which is just outwith my capabilities. It's something that annoys me intensely when it happens. It just means a lot of the time I've to get more thoughtful about what I'm doing.

These accounts mirror those given on the body by some of the informants. This is as would be expected given that the self and identity are, of course, always embodied. Giddens (1991) argues that 'Most people are absorbed in their bodies, and feel themselves to be a unified body and self' (p. 59), and following Lang proposes that unless this is maintained, the self becomes a false self. Dissociation results in a dislocation of the self and the creation of an unembodied self, 'in which the body appears as an object or instrument manipulated by the self from behind the

scenes' (p. 59). The analysis of data presented here would suggest that the separation of self and body for disabled people is part of their biographical narrative, and echoes the findings of Cunningham-Burley & Milburn (1998) on people in their middle years. Giddens it seems, in writing as a white, middle-class, heterosexual non-disabled male, as one whose body is not used as a signifier of difference, fails to accept that for many, whose bodies are not universally accepted, part of the biographical narrative appears to be about constructing a self that allows a separation or reconstruction of bodily image and self-identity.

For some of the participants with degenerative conditions, the medical conditions that arose as a consequence of their impairment had also become a normal part of their lives. So Moira, a woman with MS says:

Well I suppose this sounds ridiculous. I feel I'm lucky, because as my MS slowly gets worse, because it's been so slow, I don't know it's happening. And then by the time I suddenly think, I could do this a year ago I can't do it now, I'm so used to it that it doesn't really bother me.

Whilst at first, for these informants, their impairment, in contrast to those born with an impairment, can cause a loss of the self, with time their corporeal knowledge, their knowledge of their usual body functioning, the spatial and temporal knowledge that is founded upon this becomes altered and their current sense of bodily self is changed. Following Schultz & Luckman (1973, p. 106) it could be argued that their body image has been altered and that these bodily images are variable. Being disabled is not a major part of bodily experience and, consequently, has little impact on the sense of self. Tommy argued that 'I don't wake up and look and my wheelchair and think "Shit, I've got to spend another day in that", I just get up and get on with it'. This variability, however, is also contingent and situated. It is embedded within the structures that they find themselves.

The Reconstruction of Normality in Constructions of Self-identity

For others, self-identity as a 'normal' person is achieved not through a sidelining of impairment but through a restructuring of what is normality. For example, Javid:

Well if I look at it, my disability and everything, when I look at it in my mirror (you might have seen this mirror is complete right up to the bottom—it is specifically for that, for me to look into it and see my legs, day-to-day life and how this leaning tower of Pisa is leaning on one side, that's what I am) I feel that I'm looking at myself and I'm thinking this big thing is going to fall one day, everything has to come to an end, so I'm going to fall one day, and I'm getting big, I'm not getting small, and I look like, not a monster or anything, I look like a normal person, apart from my body structure is different.

This normalisation goes beyond describing himself as normal. It is different to the examples above in that Javid directly challenges the social construction of what it is to be normal and what is a normal body. His self-identity is not premised on notions

of roles or relationships, but on a reconstruction of normality. Like the informants described above he perceives himself as both different and at the same time normal but he overcomes the paradox that this implies in that he sees himself as both similar to other people and as different, but importantly, this difference has little or no consequence. Self-identity is the product of a conscious action, and it is through this reflexivity that he exhibits his bodily agency. His is not a docile body, he does not meekly adopt a passive and prescribed notion of self identity, and he is not trying to distance himself from his impairment or the value systems that are attached to having such an impairment. The difference of his body is not bracketed, but embraced.

Keiron, talked about how, in the past he would have seen himself as a disabled person first

It's a difficult one to answer, I mean, the answer I used to give was a hundred percent I would have said disabled straight away because that's all I'd been taught. I'd say more a person who happens to have a disability in the same way, if you like that, I was reading about Jacky Stewart yesterday, now he's an individual who happened to have a talent for driving cars, he also happened to have dyslexia but it still didn't detract from what he was, and what he is as an individual. So I think first and foremost I'm Keiron Brown the person, and I know how to concentrate on that side more than I did maybe 8 to 10 years ago when I'd just come away from a lot of the negative things.

Later he talked about what it meant to be normal:

Well what's normal? You could have, say for example, tomorrow I could be able to walk with no hassle at all, but what about that guy in Japan, the sort of average Joe who just decides, 'Oh I'm ok but I'll go into my bag and release this canister.' This guy can walk about and is perceived as a normal individual. What's normality? You see some of the things that happen, and some of the behaviour of some folk, I mean what's normal. I think that's a word that people use but they don't really understand a lot of the time.

Here, in a similar vein to Javid, Keiron questions the meaning of normality. In so doing he is not suggesting that by adopting a conceptualisation of difference and a challenge to normativity he can manufacture a self based on heterogeneity; far from it, Keiron does not see himself as different from other people.

The Political Consequences of the Rejection of Impairment as an Identifier

It could be argued that all of these views merely reproduce disablist practices. Through a denial of disability and impairment they are rejecting and distancing themselves from other disabled people (who ever these may be). By not self-identifying as disabled could be said to describe a state of self-alienation and inauthenticity. In the narratives of, for example, Keiron and Jane, the informants have moved in an almost exactly opposite way to that of gay and lesbian men, who

strive to move from the closet in which their gay identity is repressed and to come out and claim a gay identity (Seidman, 1998). This was as true for those who were active in the Disabled People's Movement as it was for those who were not. They tell a story of how, through their social experiences, they have moved from a position of difference, one in which their self-identity is dominated by social ascription, towards a position through which they resist this ascription and recover the self. The personal freedom that follows is not achieved through a demand for the recognition of difference, but through a wish to assimilate with the mainstream, to negate a difference that is seen as demeaning. Bauman (1992) makes this point eloquently when he argues:

... the only content of 'identity' allowed in the shifting 'nows' is the *right to choose* an identity the right to renounce an unfashionable or otherwise unappetizing identity, to don a currently recommended one, to distinguish oneself (oneselves) not necessarily by being autonomous, but by having—and practising and above all demonstrating—the right to be autonomous, in case one wished to be. The agonising hopelessness of the struggle for self identity so moulded derives from the fact that victory is impossible; or, rather, that victory, if won, would bring more agony instead of succour. What would one do with freedom to choose identity at will, where the will is not authoritatively guided? How would one know that freedom has been truly won, if the choice of identity were not authoritatively preset and fixed. (Bauman, 1992, p. 194)

For these informants being disabled is about living in a system in which people with an impairment are subordinated through relations that are contradictory to their own views of their self. This subordination is, however, challenged, they do not define themselves as other, they take choices and action despite this social constriction. These informants are creating an idea of themselves for themselves. They are not basing their ideas of self-identity on biomedical models that present disability as a tragedy. However, the construction is based, as Bauman (1992) argues, not on freedom or diversity, but under the guidance of cultural and bodily capital. Self-identifying as a disabled person it appears can challenge an individual's perception of themselves. The image of a disabled person as one who is weak and disempowered seems to be as potent an image to disabled people themselves as it is to others who purvey this image, given that many of the informants chose to distance themselves from such an identity.

Self-identity is not formed on the back of a call for difference. Being disabled, for many of these informants, is not about celebrating difference or diversity, pride in their identity is not formed through the individuals labelling themselves as different, as disabled, but it is about defining disability in their own terms, under their own terms of reference. They are not, as Shakespeare (1994) argues 'subverting stigma, taking a negative appellation and converting it into a badge of pride' (p. 253), but are reinforcing a stigmatised image of disability by denying that they are part of that. This has led writers such as Morris (1991), Corbin (1994) and Shakespeare (1996) to suggest that this struggle to attain 'normality' and eliminate

the existence of impairment adds further to the oppression of disabled people. Morris has suggested that disabled people are, in effect, stigmatising themselves and whilst she does not go so far as to suggest that such people are suffering from what Marxists would term false consciousness, it is implied. She argues that such an approach arises because disabled people have little or no contact with other disabled people who could act as support and strength:

One of the most important features of our experience of prejudice is that we generally experience it as isolated individuals. Many of us spend most of our lives in the company of non-disabled people, whether in our families, with our friends, in the workplace and so on. Most of the people we have dealings with, including our most intimate relationships, are not like us. It is therefore very difficult for us to recognise and challenge the values and judgements that are applied to us and our lives. Our ideas about disability are generally formed by those who are not disabled. (Morris, 1991, p. 37)

However, it could equally be argued that they are not reinforcing oppression, but trying to make difference *not* matter.

Some of the politically active informants, some of those who were recruited through organisations of disabled people, whilst rejecting an identity built on impairment, did identify with other disabled people when describing experiences of oppression. For example, Stella, in the following extract shows how such oppression forges a bond between herself and other disabled people.

If I am, if anyone is, denied access because of bad planning, bad design, through no fault of your own, inevitably you come away with—well, I come away with two things: I come away with a disappointment and a view of myself in one dimension as being lesser—in other words I have lesser access to certain things and therefore I must be a lesser person mustn't I? But the other thing that does for me because of the relationships I have, is to actually stimulate and challenge and say 'Let's change this' ... But what I would then do with that fact is to share it with other disabled people and do something about it.

In this way, a common identity emerges, but this notion of a shared response was not common. The question could also be asked as to who is being the more radical; those who reject disability as an identifier or those who embrace it?

The Incorporation of Impairment into Constructions of Self-Identity

In contrast to these informants, there were however a small number of people, all women, who described themselves in negative terms. For example Caroline says:

I think that I look terrible, I actually just believe that ... I think I'm just terrible. I just really wish I could ... when I go to my bed at night, I think, I wish I could just fall asleep and never face another day. It's probably just a coward's way out, but I wish something would just happen naturally that

I didn't have to face another day, you know? And then I wake up in the morning and it's another day to get used to.

or Eve who describes herself as '*a sad lonely character*'. For these women, at first glance, the presence of an impairment seems to impact on their sense of self. However, it could be argued that it is too simplistic to suggest that these two women describe themselves in such a manner because they have an impairment. Caroline talked freely about marital and other family problems, particularly concerning her daughter and Eve felt lonely and that all her friends had deserted her. She stated that 'I'm feeling so isolated here, the only thing I can do is feel down'.

She felt embarrassed about her impairment and described how difficult it was to maintain relationships:

Well, you are so much trouble to people. It does take patience to deal with somebody who is in a wheelchair—to go out with them. You would have to have a car that they can get into to with a boot that is big enough to take a wheelchair and things.

Like many of the informants, Eve talked about how difficult it is to go out with other people and how there is little spontaneity in her life because of the constant need to plan ahead. She described how, in contrast to the experiences of Moira above, her MS had recently led to a rapid deterioration

Eve: I would say the MS is very active. I am in a wheelchair, I can't walk and recently I have got very very shaky so that ... many things. I can't put my contact lenses in ... I am not feeling great. I haven't felt healthy for, well, the last few days—the MS has been very active.

NW: Does it come and go in phases?

Eve: No, everybody says that because MS can. I have never had remission not really, it has just been a gradual deterioration. Once it started, it has been getting worse. Over the last few months it has been getting worse quite rapidly.

Eve ascribed all her current problems as being the result of having MS. As she put it:

I just feel that before everything happened things were good and boyfriends were on the scene and marriage was on the scene and everything changed with MS.

Caroline and Eve were the only two participants who, when faced with, for example an inaccessible building, tended to blame themselves rather than the architect or builder. Their sense of what Antonovsky (1978) calls coherence is skewed towards a notion of self that should be able to control and manage things beyond which they could, in reality, be expected to control. There are boundaries to our ability to control things, and if we fail to recognise these boundaries and attribute blame to the self for things that are the responsibility of others then self-identity becomes damaged.

Conclusions

This paper has presented data from the informants accounts about their own sense of identity, who it is that they think they are and what are their images of themselves. It is clear, in many of these accounts, that the informants do not see themselves as disabled. That is, they do not claim an identity based on their impairment. To paraphrase Butler (1990, 325), they reject a description of themselves as ‘disabled people’ in the terms articulated by those who write in disability studies. An identity as a disabled person, in disability studies, is created through a regulatory regime that, inadvertently, constructs a ‘normal’ body and in endorsing the existence of such an identity, disability studies perpetuates the notion of difference between disabled and non-disabled people, reinforcing the dichotomy. A notion of the normal body is rejected by many of these informants. In this paper it was shown how some of the informants rejected physicality as an essential, biological, determinant of the self. Just because they had an impairment, they did not perceive themselves as different to other, non-disabled people. For others, self-identity is not about difference, but it is about what they can do. Other informants questioned the whole notion of normality, challenging the social construction of what it is to be normal and what is a normal body, challenging the very discursive practices that are used to identify them. By questioning what normality is, they question the very basis that others use to describe them as different. There appears to be little support for an identity politics built on the notion of a common group identity of disabled people. The representation of disabled people as other is rejected. However, whilst Butler’s theories are important here, in that they provide a theoretical basis for the rejection of a fixed identity as a ‘disabled person’ her analysis allows little room for agency. Identities, she contends are constructed through discourse, self-reflexivity is not recognised (Dunn, 1998).

The analysis presented suggests that having an impairment becomes part of the everyday experience; it is normal for them to have an impairment. Having an impairment is, for them, a fact of life. It is, ontologically, unimportant. It has become part of their being, their ontological existence, and their identities are self-constructed in such a way so as to negate impairment as an identifier. Awareness of the self is premised on a notion of what they feel themselves to be, not what others suggest they should be. It is not the product of discursive practices. Even though this acts at an individual level, the agency exhibited in this action is a very political action, in that they reject identities others may wish to enforce on them. These informants clearly live in a society which denigrates disabled people yet few of these informants have incorporated that into their sense of self and identity. This agency is in part, it seems, achieved through constructing a narrative identity that allows for a separation of body image and self-identity.

Oliver (1990, 1996) has claimed that the new disability politics that has emerged through the social model has seen a move away from self-help organisations *for* disabled people to self-organised, overtly political groupings *of* disabled people and controlled by disabled people. These, he suggests, constitute ‘a new social movement’ as described by Touraine (1981). However, as Touraine makes clear, for new social movements to be effective, participants must self identify as a member of

a collectivity. The accounts presented in this paper seem to suggest that, for many disabled people, such a collective is failing to coalesce.

Given the fact that all the informants described experiences of discrimination because they are disabled people, it is understandable that many of the informants choose not to identify as a disabled person. In the hierarchy of social values prevalent within British society, which accords little or no status to disabled people, describing oneself as disabled cannot be seen as a positive step. There is no social status to be gained for 'coming out' as disabled. Indeed, the very term 'coming out' may be inappropriate when used in conjunction with disabled people. The classic definition of 'coming out' is given by Simon & Gagnon as;

the point in time when there is self recognition as a homosexual, and the first major exploration of the homosexual community. (1967, p. 181)

For disabled people, there is no equivalent of the homosexual community. [2] Neither do disabled people share a common religion, common political beliefs, a common social class. There are differences along the lines of gender, age, ethnicity, sexuality, region, partnerships and health. All these serve to challenge the idea of a unanimity of a disability collective. There are no rules about what it takes to belong to 'the disabled community'. Whilst it could be argued that all disabled people share one essential characteristic; that is they have an impairment, the idea of a common identity based on the presence of that impairment, compelling as it may be, is not sustainable.

The analysis of data presented here would seem to suggest that a social movement which aims to represent disabled people, and bases its credibility on the fact that it does so, as many of the organisations of disabled people do, rests on an unreflexive acceptance of the distinction disabled/non-disabled. It is not that these informants are rejecting the social model of disability in favour of the medical model, they are merely downplaying the significance of their impairments as they seek to access a mainstream identity. This refusal by some of these informants is often portrayed as the result of 'internalised oppression' or 'false consciousness' by radicals within the disability movement (Shakespeare & Watson, 2001). Yet, surely all that these informants are trying to do is to challenge the idea of normality and refuse to be categorised on the basis of bodily difference.

There were, however, a small number of informants, who incorporated impairment into their sense of identity. Identity impacted on their sense of self. However, this may be the result of other, interactional factors. All these informants talked about problems in their lives, and it might well be that their other problems are focussed through their impairment. Indeed, given the discrimination that the informants felt throughout their day to day lives what is perhaps surprising, is not that there are some who describe themselves in the way that they do, but that there were so few.

NOTES

[1] There is a tendency to conflate identity, self and self-identity, often using the terms interchangeably (Lemert, 1994). For example, Strauss & Corbin (1987) refer to self as a matter of personal identity 'who I am over the course of my biography' (p. 252).

- [2] It could be argued that the only communities that disabled people share are those that have arisen as a result of disabling practices such as segregated schooling, housing policies, and Adult Training Centres. Further, the increasing number of disabled people now living outside of hospitals and homes run by organisations such as the Leonard Cheshire Foundation, the move to inclusive education and the increasing numbers of disabled people living in their own homes will, if anything, dilute what little sense of commonality there is that exists between disabled people.

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