Structures, social constructions and stories: The debate thus far

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WORKING DRAFT

Abstract

The aim of this paper is to step back, from the adoption of particular approaches to research, by asking wider questions about their practical uses and political significance. A critical (re)view of some approaches to research is provided. The specific focus of this paper is the relationship between research and disabled people. People with impairments whether they are physical, sensory or 'cognitive' have traditionally been oppressed by psychological research. This oppression is rooted in assumptions that view such impairments as violating individuals' very personhoods: so that 'having learning difficulties' (which used to be known as 'mental handicap') inevitably leads to consequent deficits in everyday living. However, recent developments in research thinking have challenged these individualistic assumptions and, in contrast, unearthed the ways in which people with impairments are disabled by societies that threaten to exclude them from mainstream activities. Two research approaches can be identified - narrative and discursive approaches to research - that promise much in terms of highlighting the social causes of disability. Yet, these approaches are in danger of ignoring a variety of phenomena that are crucial to an understanding of impairment and disability, thus recreating oppression so characteristic of traditional psychological understandings of disability. This paper therefore critically considers the strengths and weaknesses of these emerging new research paradigms, provides a practical example of combining the two, while also examining how researchers and professionals relate to incidents of resistance and consciousness raising put forward by disabled activists outside of the normal channels of research.

(1) Disability - Psychology's pathology

Psychological knowledge is seductive. Some would suggest that this is because it challenges commonsensical understandings of ourselves and others; contributing to the modernist project of rationalist intervention into the lives of needy individuals. Such interventions are increasingly being exposed as normalising and abusive actions where *the* object of contemporary knowledge – the human subject – is (re)constructed in ways that maintain the status quo and further enhance professional knowledge and related institutions ([Foucault, 1970 #117; Foucault, 1975 #301]). Disabled people know more than most about the (ab)uses of the psychology and related disciplines and institutions – what Rose (1985, 1999)

calls the psy-complex. People with impairments occupy a special(ised) and essential(ised) place in psychology. Impairments are constituted as objects, held by particular subjects, requiring a whole host of expert interventions and practices. A spectrum of treatments exists from cure to rehabilitation. All of these are tied to a conception of impairment as deficient and requiring correction. Disabled people are fundamentally the stuff of psychological knowledge.

Thankfully, two major developments have occurred in relation to knowledge – one inside psychology, the other outside – that hold the potential for challenging this psychological conception of disabled people. The first, *social constructionism*, has paved the way forward for the deconstruction of those phenomena that are considered to be natural. The recognition that sexuality, gender and race are culturally, historically and politically formed, particularly so through psychology's discourse and language, has started to enter the mainstream of psychological training (Burr, 1995; Gergen, ?????, Parker, 1999). It is interesting to note, however, that disability is usually ignored. The second, a more important development in knowledge about disability, outside of psychology, owes itself to the origination and development of the *international disabled people's movement* that has politicised 'disability' – the exclusion of people with impairments [Oliver, 1990 #89, Campbell, 1996 #304]. Disability studies around the globe, including the majority world, situates disability as a reality to be deconstructed and demolished through political and intellectual activity (Stone, 1999).

In this paper I want to critically and practically consider two approaches to research that invoke a *politicised* and *practical* vision of disability. I will demonstrate that while these research approaches have the potential for challenging psychology's individualisation and pathologisation of disabled people, they paradoxically threaten to re-create these very conditions. Finally, it is argued that much critical work on disability takes place outside of psychology and research and therefore raises necessary questions about the role of research in elaborating upon these incidents of activism on the part of disabled people.

(2) Narratives of disability - emphasising pathology?

One of the major ways in which oppressive discourses have been challenged has been through a turn to the accounts and narratives of the oppressed. Queer theory, feminism, critical race and disability studies have evaluated contingent discourses about their subject matter by turning to the stories of those very individuals that constitute their subject matter. These perspectives – gained through the use of various qualitative research methods and analyses – pitch analysis at the level of the individual, storied, experienced and insider accounts of individuals in a variety of (oppressed) groups. Hence, a turn to accounts of the 'reflexive' survivor of mental health systems not only exposed the abuses of people with mental health problems but also challenged the very understandings on which these abuses were based were justified. Therapeutic practices, of course, have a long history of drawing upon stories of 'clients' and 'patients'. Narrative and social constructionist forms of therapy take a particular view of such accounts (Parker, 1999). Generally, an individual's story should be seen as exposing a wider social and cultural background. As the biographical social scientist Daniel Bertaux, 1981 #9]. When we are told another's narrative we are also

thrown into a world of different interpretations that lie behind the narrative: from familial to cultural locations, from personal to political forces. Here then the therapist is involved in a dialogue and the swapping of stories – some more externalised in their style and content, some more individualised.

The turn to narrative in the social sciences and related practitioner contexts that grew so rapidly from the 1960s took seriously the accounts of individuals who for so long had been obscured behind pathological terms and deficient labels. In the field of 'intellectual disabilities / learning difficulties', for example, the work of researchers such as Bogdan and Taylor [1976 #12; Bogdan, 1982 #13] encouraged therapists, professionals and scholars of the field to rethink the arbitrary labels and educative tools that they used. These accounts demonstrated individuals that exist behind a label and encouraged readers to note how the significance of differences of all kind became downplayed from the empathic qualities of narrative (Nisbet, 1976). While narrative researchers draw upon a variety of epistemological and theoretical positions, all proponents share the view that (some) understandings can be gleaned through turning to those who have in some way been labelled. A turn to narrative is a celebration of the insider, specificity, indexicality and of lay-knowledge. The strengths of narrative accounts are tied into the inherent personal and constructive qualities of accounting for oneself alongside and with others. Moreover, much has been made of the opportunities for revisiting power relationships in the interactions between storytellers [Casement, 1985 #147]. This is not to say that storytelling is inherently an egalitarian activity, more that by illuminating an 'individual's psychology' via narratives are we able to consider the origins of such storied productions. Yet, while these strengths rightly appeal to generating understandings of social and psychological phenomena in complex ways, there are real problems with stories.

If we examine the British disability studies literature, a number of criticisms have been made. Disabled scholars such as Paul Hunt, Colin Barnes and Vic Finkelstein all perceive the threat of what has become known as the **sentimental biography**¹. Two connected issues have been identified. Firstly, storytelling may emphasise subjective experiences may over disabling barriers. Here accounts emphasise individuality but may ignore wider issues associated with the exclusion of people with impairments by society. Secondly, stories may re-emphasise sentimental *impairment-talk* into research. To understand this criticism it is necessary to turn to key distinctions made between impairment and disability in British disability studies literature. The ubiquitous 'Fundamental Principles' document published by the Union of the Physically Impaired Against Segregation in 1976 provided a bedrock for the development of disability studies in Britain – to develop empowering understandings of disability and impairment:

Impairment - lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.

Disability - the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and

¹ For an accessible introduction to some key debates in disability studies see Shakespeare (1999).

thus excludes them from mainstream social activities (UPIAS, 1976 pp3-4, Quoted in Oliver 1990, p11).

For Barnes (1999) there are real concerns that the subjective, experiential nature of the story encourages storytellers (including researchers and participants) to focus on the impacts of impairments upon day-to-day lives. While no one is denying that impairments are important and are crucial to the identities of disabled people (see Thomas, 1999), stories may slip into discussions of impairment that fail to recognise the significant influences of *disability* – the exclusion of people with impairments. British disability studies literature, through its strong links with disabled activists, has clearly articulated the ways in people with impairments are oppressed by a variety of material (Barnes, 1990), economic (Oliver, 1990, 1996), cultural (Shakespeare, 1999) and political inequalities (Barnes, 1991; Campbell and Oliver, 1996). Yet, just as these inequalities are exposed narratives begin to enjoy a place of reverence (Bowker, 1993). Hence, there is a danger that the phenomenological qualities of stories detract attention away from a variety of environmental deficiencies that need to be challenged through policy, politics and professionalisation. A turn to the insider threatens to undo the 'big idea' of the British Disabled People's Civil Rights movement (Hasler, 1993) - the social model of disability – that disability is a social problem not one situated and located in the impaired body. Instead, stories are in danger of tempting researchers and storytellers alike to construct accounts that are inherently interested in impairment and subjective elements of life.

Disability and wider concerns associated with the commonality of exclusion and resistance of disabled people are ignored. Hence, professionals and clients drawing upon narratives may be led into a focus on some assumed biologically derived notion of impairment encouraged through a particular adoption of storytelling. So any problems that are identified are considered in terms of impairment, of adjusting to this condition and ensuring that one does not allow one's impairment to get the better of oneself. Such notions of adjustment are typical of narrative research that sentimentally and unceremoniously tugs at the hearts of (pitiful) storyteller and (pitying) reader alike (Oliver, 1990). Furthermore, while narrative forms of therapy take a particularly discursive take on the use of stories, as we shall see below, there is a danger that storytelling is equated with some assumed, fixed notion of accounting for oneself as an impaired person. The challenge for researchers then is how can disability and impairment be researched in ways that maintain critical and politicised visions of exclusion, while avoiding tragic or sentimental conceptions of impairment. For some, a turn to discourse allows such a view to be maintained. We shall now turn to this.

(3) Discursive research and social constructions of disability - ignoring structure?

While stories may lapse into pseudo-biological accounts of impairment, proponents of discursive approaches to research argue that they are engaged in situating the socially constructed characters of both disability and impairment (Corker, 1999). A discursive stance – that draws on the work of poststructuralists such as Foucault and Derrida – constructs conceptions of disability and impairment that destabilise naturalised notions of ontology. Hence, while the biological character of impairment is in danger of lingering in the phenomenological backgrounds of a story, deconstruction has entered disability studies literature at just a time to challenge such lingering doubts. The work of Corker (1999),

Corker and French (1999), Hughes and Paterson (1996) have, to varying extents, considered the discursive construction of impairments in late capitalism – a society that had been given a number of other and additional monikers from network (Castells, 1999) to knowledge (Bell, ???) to postmodern society (Jameson, ????). Impairment is, therefore, up for grabs. Consequently, distinctions between impairment and disability are challenged: the very notion of inscribing impairment through the use of a variety of medicalised and biological objects is read as a discursive practice. Where once stood biological determinism now stands discursive determinism (Hughes and Paterson, 1996). Hence, any encounter with impairment is an encounter with an impaired body or mind that has a history and is party to a variety of specialist knowledge derived from a whole host of professionalised institutions which, in the main, imbue these bodies and minds with naturalised notions of deficit. Pathology is a ready partner to embodiment. But both are challenged and deconstructed through a turn to discourse. Hence impairment is itself part of disabling discourses.

To those critics who would assert that there are things, such as bodily or cognitive impairment, which are extra or beyond discourse, Judith Butler's response exemplifies discursive fundamentalism:

To concede the undeniability of ... 'materiality' is always to concede some version ... some formation of 'materiality'. Is the discourse in and through which that concession occurs ... not itself formative of the very phenomenon that it concedes? To claim that discourse is formative is not to claim that it originates, causes or concedes, rather, it is to claim that there is *no* reference to a pure body which is not at the same time a further formation of that body (Butler, 1990, p10, italics in the original)

Research driven by an adherence to the discursive world promises much for disabled people. The biggest challenge facing the social model of disability comes from those critics who would suggest that disabled people's exclusion cannot be put down purely to societal ills. As Shakespeare and Watson (1996) and Barnes (1998) note, the argument that the oppression of impaired people as solely down to a disabling society is still a sociological argument too far. Surely, some experiences of inability, incapacity and illness are typical to and the consequence of living with a biologically formed impairment? Well - no - as a turn to discourse challenges these very assumptions that view impairment as naturalised and, instead, probes institutional practices and knowledges that maintain the view of impairment-as-biological.

For example, the work of Clegg (????) who adopts a discursive approach to 'learning difficulties' in the field of clinical psychology, demonstrates the ways in which disempowering practices are based upon well-worn and used discourses of pathology associated with 'the learning disabled client'. Alternatives offered demand a rethink of the very concepts, language and meanings that construct 'clients' as particular subjects to be treated by a number of 'suitable' interventions. Professional intervention is thus deconstructed through the employment of discourse. Here we can insert the work of narrative therapists – see for examples Parker's edited collection (1999) – which utilise the work of Derrida and Foucault in their practices with clients. Psychological pathologies are externalised, historicised and discursively reformed through a turn to the wordy construction

of disorders. Alternative conceptions are (re)visited – irrationality instead of rationality – to consider as part of a dialogue those meanings that are seen to characterise one and not the other. Hence, 'non-walking' as an impairment can be reconsidered in social ways, unpicking those dominant understandings that place walking over non-walking and assume a more healthy existence for the former, a tragic one for the latter (see Oliver, 1996).

However, disabled scholars have identified problems with discourse and these are connected with questions of relevancy and history. A turn to discourse may ignore wider disabling barriers - particularly the material world - which can be viewed as existing in addition to discourse. The thesis that disability/impairment is an object with related subjects, whose very meaning is in need of deconstructing in a postmodern age, but a contemporary politics of disability may require a fundamentally more modernist approach at this particular historical stage of its development. For example, Barnes (1990, 1993) and Finkelstein and Stuart (1996) have drawn attention to the ways in which disabled people are still largely segregated from society through the provision of residential homes, day training centres and supported employment schemes. Turning to the cultural discourses that abound is all very well and good but the *fact* that disabled people are denied opportunities to contribute suggests that other more material barriers need to be addressed beforehand. Indeed, one of the dilemmas of those caught up in the 'turn to the text' is the assertion that maybe things are not as postmodern and discursive as academics often seem to think they are. While psychology has received some devastating attacks from social constructionists, questions remain about what is actually left behind following deconstruction. Indeed, some would argue that poststructuralist accounts mirror 'third way' politics of Blair and Bush government administrations - touching at the grey areas between agency and structure (see Goodley and Parker, 1999). Yet, around the globe disabled people consistently argue that real, material, structural conditions of exclusion create their disablement, their segregation from the world. What has discourse to offer such claims?

(4) Political stories and the activism of disabled people

The production of all knowledge needs itself to become increasingly a *socially distributed process* by taking much more seriously the experiential knowledge that oppressed groups produce about themselves, and research based upon the discourse of production that will have an increasingly important role to play in this. And who knows? This may eventually lead to the fusion of knowledge and research production into a single coherent activity in which we produce ourselves and our worlds in ways which will make us all truly human (Oliver, 1999, p191).

As we have seen above the use of stories may invite into the fray pseudo-biological notions of impairment. Meanwhile, discursive considerations may overlook other material conditions that are crucial to the societal inclusion of disabled people. So what way forward may we have as researchers for understanding disability in ways that do not enforce tragedy or irrelevancy? One way is to embrace the need for the use of *politicised narratives* that combine stories and actions of disabled people alongside the socio-political analyses of researchers and activists. Here impairments, subjectivities, experiences, disabilities, normality, ontology are wrapped together by a fundamentally social and political narrative structure. The issue here then is of accounting ethically – where this reflects some commitment to accounting for *and challenging* the conditions of disablement. Furthermore,

the role of researchers is in many ways extended beyond the typical channels that are usually prescribed. Take the following narrative drawn from my own experiences:

We are on our way to meet with the others from the *People First* group to play ten-pin bowling. I am driving. James and Colin chat in the back, Maria sits quietly in the front. We pull into the car park. It is full-to-bursting. Colin leans over from the back, and points out an empty space 'Look, we can park there, it is disabled space. Maria – you're disabled'. Maria leans on her stick and turns to face Colin – 'No, I'm not today – I haven't brought my disabled badge with me'.

This is a brief, light story that exemplifies subjects who have been labelled as 'having learning and physical disabilities' re/deconstructing meanings in ways that smack of convention and, in contrast, activism. The account allows us to see structural and material constraints upon personal narratives, situates resistance whilst also allowing for lived examples of deconstructing pathological norms. As researchers we engage in constructing versions of the world, but, a new epistemology for research practice 'must reject the discourse that sustains investigatory research and replace it with a discourse that suggests that research produces the world (Oliver, 1999, p188).

Indeed, the question is not about how researchers can take their personal marks off the work that they do but how research itself is a political and practical intervention into a variety of personal and social contexts. Combining stories and discourses allows us to start conceptualising disability and impairment in empowering ways though there needs to be wider questions about the commitment of researchers. In this sense, then, maybe researchers are, at times, in pursuit of politicised narratives that exist all around us, everyday, in and outside of what we normally consider to be research. Hence, it is a safe to say that we all always involved in practices that will have implications for ourselves and others – and that the doing of this research needs to be mindful of the social, cultural and material conditions that create the agents occupy our research environments. So what political narratives have you come across today?