

# ‘Learning Difficulties’, the Social Model of Disability and Impairment: challenging epistemologies

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## ABSTRACT

*Critical researchers enter into an investigation with their assumptions on the table, so no one is confused concerning the epistemological and political baggage they bring with them to the research site (Kincheloe & McLaren, 1998, p. 265).*

*A theory of disability as oppression ... recognises and, in the present context, emphasises the social origins of impairment. (Abberley, 1987, in Barton and Oliver, 1997, p176, my emphasis.)*

*Identification with the label of ‘learning difficulties’<sup>1</sup> has contradictory personal and political implications for people so-labelled. While this identification has allowed people to organise collectively through the self-advocacy movement, pervasive understandings of ‘learning difficulties’ that permeate many societal settings tend to be framed in ways that directly confirm a personal tragedy model of disability and impairment. This paper argues for a reconsideration of impairment in relation to ‘learning difficulties’, to challenge pervasive assumptions in relation to ‘learning difficulties’—at the level of epistemology—and to construct four inclusive epistemological foundations. The first, deconstructing impairment, draws upon a body of literature that has exposed the social nature of diagnostic criteria and destabilised naturalised notions of ‘learning difficulties’. The second, impairment, as storied, brings in the accounts of people with ‘learning difficulties’ that locate impairment in, and as, personal and social narratives. Thirdly, reculturising impairment highlights emergent resilient cultures of people with ‘learning difficulties’ that re-culturise impairment. Fourthly, epistemological impacts, grounds the analysis by calling for an attention to the ways in which assumptions about the origins of ‘learning difficulties’ impact upon the treatment of people so-labelled.*

## Introduction

Let’s develop a social model of impairment to stand alongside a social model of disability but let’s not pretend that either or both are social theory. (Oliver, 1996, p. 42.)

*The Turn to Impairment*

'Second wave' writers in disability studies are questioning the assumptions that underpin the social model of disability (Barnes, 1998). Significantly, this questioning movement has refocused epistemological attention onto *impairment* (e.g. French, 1993; Crow, 1996; Hughes & Paterson, 1997). Through appealing to sociological imagination and political commitment, these writers attempt to bring impairment back to the forefront of disability studies, away from its uncomfortable and counter-productive exile within quasi-medical discourses. Likewise, postmodern critiques (e.g. Corker, 1998; Corker & French, 1998) and their problematising of grand narratives, most obviously Marxism, offer localised, specific and discursively-orientated alternatives that take account of the discursively-embodied nature of impairment. Most notably, this turn to impairment challenges the widely accepted definitions provided by the UPIAS (1976) 'Fundamental Principles' document, which has been so influential in pointing ways forward for the social, political and theoretical emancipation of people with impairments (Oliver, 1990, 1996).

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 thus excludes them from mainstream social activities! (UPIAS, 1976, quoted in Oliver, 1990, p. 11).

While disability remains a social problem to be eradicated by societal change (through reconstruction of current systems and by deconstruction through revolutionising direct action), impairment's definitional links with medicalised discourses (as exemplified by UPIAS's definition) have become increasingly troubling. Thus, rather than viewing a turn to impairment as de-politicising, re-medicalising and 'watering down' the social model, more and more writers are arguing that a focus on impairment, alongside an alliance with the social model and disability movement, re-socialises impairment (see Williams, 1998). Such a turn is taking place alongside a current trend of post-modern and anti-foundationalist theorising about the body in the social sciences (Butler, 1990, 1993; Turner, 1992; Stam, 1998). For Hughes & Paterson (1997), frameworks such as phenomenology and post-structuralism provide theoretical routes for moving through and against Cartesian distinctions between biology and society, while alerting us to the impact of various institutionalised curative and rehabilitative social practices.

Yet, to see this 'turn to impairment' as a recent reaction to the current 'failings' of the social model of disability or the increasing influence of post-modern 'body theorising', ignores earlier writings within disability studies. In particular, the work of Paul Abberley, a 'first wave' writer and activist (Barnes, 1998), demonstrates a clearly articulated case for developing a social theory of *impairment* as a crucial component of a social theory of disability. Abberley noted 14 years ago that one of the general effects of the oppression of disabled people is that:

By preventing disadvantage as the consequence of a naturalised 'impairment' it legitimises the failure of welfare facilities and the distribution system in general to provide for social need, that is, it interprets the effects of social maldistribution as the consequences of individual deficiency. (1987, reproduced in Barton & Oliver, 1997 p. 175.)

Impairment remains a medical and psychological problem to be eradicated or rehabilitated. In contrast, Abberley recognises the need, in the present theoretical and political climate, to *emphasise* the social origins of impairment (p. 176). He goes on:

While the political implications of such an analysis are apparent [challenging societal assumptions of pathology], the conceptual consequences are also profound, since such a notion of disability as oppression allows us to organise together into a coherent conceptual whole ... isolated and disparate areas of social research.

In this bringing together of disparate social theories, there is a necessity to view impairment with ambivalence:

What is required is essentially an attitude of ambivalence towards impairment ... impairment must be identified as a bad thing, insofar as it is an undesirable consequence of a distorted social development, at the same time as it is held to be a positive attribute of the individual who is impaired. (p. 165)

This call for celebrating difference, whilst deconstructing the differences that are the consequence of oppression has obvious parallels with recent 'queer theorists' such as Judith Butler (1990, 1993), whose stance is one of 'using and refusing the body'. For Abberley, assumptions about impairment—our epistemological assumptions—play a crucial part in the development of disability theory.

### *The Status of 'Learning Difficulties' in 'the Turn'*

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, p. 10, italics in the original.)

A worrying omission in the 'turn to impairment' is the distinct lack of focus on 'learning difficulties'. Ann Louise Chappell's (1998) paper is conspicuous in absent literature that explicitly aligns itself with the social model and its relevance to the lives of people with 'learning difficulties' (though see Chappell *et al.*, 2000). While Chappell's analysis is to be welcomed, I will argue below that further consideration of the socially created nature of 'learning difficulties' is necessary. Specifically, I will

argue that a conception of impairment, as it relates to 'learning difficulties' and as part of the epistemological orientation of the social model, should be revisited. There are a number of key caveats on which this paper builds upon.

First, as part of a *social* model of disability, there is a need to work with and for an understanding of 'learning difficulties' as a fundamentally social, cultural, political, historical, discursive and relational phenomenon, rather than sensitively recognising the existence of an individual's 'naturalised impairment'.<sup>2</sup> Secondly, the experiences and expertise of people with 'learning difficulties', particularly those involved with the politicised new social movement of self-advocacy, constitute a body of knowledge that can be fruitfully drawn upon in reviewing notions of 'learning difficulties' (see Dowse, 1999; Goodley, 2000). Thirdly, a turn to impairment contributes to recent theoretical demands for building up a dialogue between the 'irrational' (impaired) and the 'rational' (non-impaired). As Foucauldian theorists have observed, the constitution of 'madness' (and other notions of 'psychological irrationality')—as an illness—at the end of the eighteenth century 'broke the dialogue' between reason and insanity (see, for example, Parker *et al.*, 1995). Contemporary conceptions are characterised by a reasoned, rational monologue *about* 'madness' that has been established only on the basis of such a silence (Foucault, 1967). Similarly, assuming a naturalised understanding of 'learning difficulties' breaks dialogue and leaves this 'psychological problem' the object of intervention by practitioners of the psy-complex where individuals and their individual *bio-problems* are the subjects and objects of study (Rose, 1989).

This paper questions how 'learning difficulties' is epistemologically formed and expands upon four foundations that initiate the development of a fundamentally social vision of 'learning difficulties' as it relates to impairment. In-fitting with Mike Oliver's (1996, p. 42) advice, this paper attempts to reconsider the *epistemological orientation* of the *social model* of disability, wherein impairment is considered as equally social as disability and therefore includes people with 'learning difficulties'. However, first, a point of reflection to ground this analysis:

People with 'learning difficulties' face discrimination in the disability movement. People without 'learning difficulties' use the medical model when dealing with us. *We are always asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as disabled people without 'learning difficulties'*. We want concentration on our access needs in the mainstream disability movement. (Simone Aspis of *London People First*, quoted in Campbell & Oliver, 1996, p. 97, my italics.)

My perspective on disability was fundamentally changed by literature of the social model. Crucially, this stance made two things very clear. First, that society creates disablement and is the arbiter of disciplinary powers that (re)produce pathological understandings of different bodies and minds. Secondly, that disabled activists point to the need for social change in which all social members—disabled and non-disabled—are to be involved. With such a clear social perspective then, it has become increasingly disconcerting to note how, as Simone Aspis points out, 'learning

difficulties' remains tacitly conceived of as a biological deficit. Indeed, Koegel (1986, p. 47) notes:

However much we pay lip service to the influence of socio-cultural factors, we *do* primarily see mental retardation as a biomedical phenomenon and *do*, as a result, tend to attribute incompetent behaviour exclusively to physiological causes. (Italics in the original.)

Why is this the case? Are we finally prepared, in this postmodern theoretical climate, to accept a personal tragedy perspective over a social model of disability, *in the case of certain impairments*? Obviously not, as disabled activists remind us of their daily experiences of oppression and resistance. However, whereas people with physical impairment are rightfully afforded a socio-historical position in the social model (Campbell & Oliver, 1996), as Aspis suggests, people with 'learning difficulties' are consistently underwritten. Thrown into the category of naturalised, irrational 'other'. Closed in, isolated and confined by a 'mental impairment' devoid of meaning and history, presocial, inert and physical. People with 'learning difficulties' are personal tragedies of their unchangeable 'organic impairments'. That these assumptions are so strongly held is particularly worrying in light of the concerted attempts by disability theorists and activists to expose the *social character of humanity* in relation to disablement. Are people with 'learning difficulties' really that non-human (a common view noted by Gillman *et al.*, 1997) that they can be ignored by disability theory, 'left out in the cold' as Chappell (1998) puts it, as an excluded category, marked 'the biological we cannot sociologise'? If so, this raises real concerns about the starting points of disability theory (and its impact upon politics and policy). Perhaps we are not really convinced that the social model of disability is a *viable epistemology* for approaching understandings of disability? For me, following the advice of the 'first wave' of disability theorists (Barnes, 1998), disability is a societal and political concern and, hence, so is 'learning difficulties'. Moreover, a turn to impairment as a social and political phenomenon necessitates on inclusion of 'learning difficulties'.

This paper asserts that social structures, practices and relationships continue to naturalise the subjectivities of people with 'learning difficulties', conceptualising them in terms of some *a priori* notion of 'mentally impaired'. However, there are alternatives. It is to these challenging epistemological foundations that I now turn.

## **Deconstructing Impairment**

Mental retardation is, in fact, a socio-political not a psychological construction. The myth, perpetuated by a society which refuses to recognise the true nature of its needed social reforms, has successfully camouflaged the politics of diagnosis and incarceration (Bogdan & Taylor, 1982, p. 15.)

Kinchelo & McLaren (1998) argue that critical research and social theory require constructing perceptions of the world anew, not just in random ways, but in a manner that undermines what appears to be natural and obvious. As early as 1956,

Dexter (see also Dexter, 1958) argued that ‘we need to see mental defectives [sic] in terms of the general theory of social problems’ (Dexter, 1956, pp. 10–11). Over the last 30 years a whole collection of social scientific literature has explored ‘learning difficulties’ as a social creation of a disabling society (Watson, 1996).<sup>3</sup> Furthermore, just as people with physical impairments have written about disability from their own perspectives, so the accounts of people with ‘learning difficulties’ have clarified the socially contested nature of disability.<sup>4</sup> However, while the social model of disability is not reserved for people with physical impairments, it may often seem that way (Ferguson, 1987). The absence of much of this literature in the writings of the social model (Chappell, 1998), ensures that Dingham’s quizzical statement in 1968 remains as relevant today:

What should concern us is the mystifying fact that so many social scientists ... do not regard mental retardation as a social and cultural phenomenon. I say mystifying, because nothing in the probabilistic world of social scientific reality is more certain than the assertion that mental retardation is a socio-cultural problem through and through. (p. 76)

### *Differences*

While Bogdan & Taylor (1982) draw a fundamentalist line under a sociological imagination in relation to the social core of ‘learning difficulties’, different positions can be observed in the literature:

If there is one firm conclusion to be made ... it is that *mild* mental retardation is as much or more a social and cultural phenomenon as it is a medical—genetic or cognitive—psychological one ... The definition of retardation, then, and some of the consequences of being thus labelled are concomitants of social life. (Levine & Langness, 1986, p. 191, my italics.)

This deviation highlights two things. First, that ‘learning difficulties’ can be understood as a social phenomenon—a creation of culture, politics and society (Morris, 1969; Korbin, 1986). To find its origins of we are encouraged to turn attention away from a focus on prescribed incompetence onto a society that excludes, discriminates and stigmatises people so-labelled (Mercer, 1973). However, a second point emerges, as Levine & Langness (1986) focus only on the social construct of ‘mild learning difficulties’. While Groce (1992, following Edgerton, 1967; Scheiner & Abrams 1980) estimates that 75–85% of all ‘retarded’ individuals are considered ‘mildly retarded’, this still leaves the disabilities of a number of individuals unaccounted for by sociological analysis. So what foundations are being laid here? Well, following Ferguson *et al.* (1992), Watson (1996) and Ferguson (1987), it would appear that where ‘naturalised impairment’ is ‘less’ then it is easier to begin formulating social theories of ‘learning difficulties’. This preoccupation with levels of ‘impairment’—Barnes and Oliver’s point about ‘impairment specific’ discourses—has wide implications for an understanding of disability as a social phenomenon (Shakespeare & Watson, 1997). The epistemological point being made is classically

Cartesian: some elements of humanity are open to sociological investigation ('mild learning difficulties'), while some are left in the realms of static, irreversible, individualised biology ('severe learning difficulties').

Based on such a distinction, the place of (some) people with 'learning difficulties' in the context of a social model of disability is decidedly shaky. For a more inclusive position, I would suggest that we need to enter into a dialogue about the *possible and perhaps necessarily exaggerated social origins* of the 'learning difficulties impairment' *per se*. One fruitful direction that we could follow is to revisit the diagnostic criteria that have been used to identify 'learning difficulties'. Ryan & Thomas (1980 and 1987) observed three commonly held criteria: low intelligence, social incompetence and maladaptive functioning. While these criteria are assumed to originate within the individual (as 'impairment effects', see Thomas, 1999), their historical, political and socio-cultural origins have been extensively exposed (see Levine & Langness, 1986). An awareness and acceptance of their external origins invites us to destabilise taken-for-granted embodied notions of 'impairment' and pushes us towards an understanding of people with 'learning difficulties' that recognises their resilience in the face of arbitrary 'scientific' categorisations that have historically denied their humanity altogether. *Impairment's alliance with 'the natural' is questioned and its social origins investigated*. Revisiting one dominant diagnostic criterion—'maladaptive functioning'—allows us to start developing one epistemological alternative.

### *The Creation of 'Maladaptive Functioning'*

Hot-topics for practitioners, particularly in psychology, are the 'challenging' or 'maladaptive behaviours' of people with 'learning difficulties',<sup>5</sup> which have been defined as:

Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities. (Emerson, 1995, pp. 4–5.)

Ideologically, such behaviour is seen as reflecting some underlying ('organic') individual deficiency, and these assumptions permit or sanction professional discourse and practice. For example, Goodwin (1992) notes how a paediatrician examined a child with 'hypnotonic spastic quadriplegia' (sic) and found vaginal injuries, anal scars and a sexually-transmitted disease. He reported, 'These symptoms could be due to an obscure syndrome'. Goodwin also recalls the case of a paediatrician belatedly and reluctantly reporting three boys who were having sexual intercourse with their retarded sister. His 'excuse' was 'Isn't it better to save three normal boys than one retarded girl?' Why do such interpretations abound? A naturalised view of impairment permits physical symptoms of child abuse to be understood either as indicators of some underlying (related) pathology (Breachin & Walmsley, 1989) or as inevitable life experiences. These examples of misdiagnosis—

professional abuse—are not simply examples of bad practice. They are interpretations logically based upon a view of maladaptive behaviour that locates causality of such behaviour in the ‘mentally retarded individual’. We are allowed to view behaviour, at convenient and conventional times, as an indicator of embodied impairment, precisely because the residue of thinking associated with impairment-as-natural remains:

At any given time for any given individual it may not be possible to differentiate between behaviour that is *a consequence of the retardation* and behaviour that is a consequence of behaving as one thinks the expectations of others define proper behaviour. (Kurtz, 1981, p. 14.)

However, we should not lose sight of how environments shape, define and create (views) of behaviour that are so often misread as correlates of ‘embodied impairment’. The socially constructed nature of impairment can be identified in many ways. First, *administrative constructions*. In 1973 the entire category of ‘Borderline Retardation’ was dropped from the Manual of Terminology of the American Association on Mental Deficiency (Ferguson *et al.*, 1992). People were cured overnight. Associated maladaptive behaviours had to be recategorised. Clinical practice had to look elsewhere for its subjects and objects of deficit. In Foucauldian terms, objects and subjects of an area of a discursive field were rephrased, re-ordered and manipulated. Secondly, *institutional constructions*. Oswin (1991) explored the bereavement experiences of people with ‘learning difficulties’. She found that often people were not told that a family member had died for fear that, ‘They were not up to such news’. Some of Oswin’s informants were not told until some years afterwards. Even when the loss of a family member was disclosed, any outward display of grief by people with ‘learning difficulties’ tended to be noted down by care assistants and psychologists as ‘challenging behaviour’: any alterations in behaviour following loss are usually attributed to the original diagnosis that person has already (French & Kuczaj, 1992, p. 108). Not only are ‘patients’ pathologised by the diagnostic classification itself, they are further pathologised when they do not fit criteria (Parker *et al.*, 1995, p. 3). A response of crying on hearing the death of a loved one may be seen as overly-emotional, passive and dependent, indicative of ‘retardation’. By contrast, lashing out in anger is likely to be viewed as challenging behaviour. A double bind exists, whatever the response, a diagnosis looms. Rusch *et al.* (1986) found that those institutionalised people with ‘learning difficulties’ defined as having challenging behaviour were most likely to be abused by staff and other inmates. It would appear that ‘maladaptive behaviour’ is an inevitable discourse of institutional contexts. Thirdly, *relational constructions*. Zetlin & Turner (1985, p575) examined the case reports of professionals. Many incidents of ‘problem behaviour’ were cited, including minor violations such as the regular use of marijuana and associated ‘uppers’, ‘and/or the daily consumption of a sizeable quantity of beer by two sample members’. ‘Unsocial behaviour’ becomes much more if the agent has the label of ‘learning difficulties’. As Martin Levine succinctly puts it:

If someone else whispers a lot during the play people might ignore it or get angry. If we whisper it is because we are retarded. It's like we have to be more normal than normal people (cited in Friedman-Lambert, 1987, p. 15.)

Moreover, an individualised view of maladaptive behaviour ignores the possibility that such behaviour constitutes rational and resistant reactions to maladaptive environments. While only a small proportion of people with the label of learning difficulties exhibit 'challenging behaviour' (Humphreys *et al.*, 1987, p. 9), professional practice must take into account the important psychological issues such as coping with chronic lack of self-esteem or *surviving within damaging social environments* (Clegg, 1993, p. 390). After all, people subjected to such environments are aware of the impacts, as 'Ed Murphy' notes about his girlfriend:

I don't think that retardation is holding her back so much as emotional problems. If she had confidence that would make the difference. I know she could build herself up (cited in Bogdan & Taylor, 1982, p. 74.)

Too often there is a tendency to view people with 'learning difficulties' in terms of their 'deficits' (Ryan & Thomas, 1980, p. 82; Booth & Booth, 1994). When allowed into the community perfection is demanded. Any deviation from the perfect path to community membership and 'they' may be recalled, incidents of maladaptive actions being cited. However, attending to the construction of (in)capacity in relational and social contexts negates the tendency to attach significance to the truth of individual impairment. Maladaptive behaviour may be testimony to the historical exclusion of people deemed inhuman, if it exists at all.

### **Impairment as Storied**

I may need help in some things, but I'm not retarded. I can take care of myself ... Everyone needs help. Some people need more. Even the ones in the outside—the normal people, have marriage counsellors and other people to help them (Martin Levine, a Canadian self-advocate, quoted in Friedman-Lambert 1987, p15).

A second epistemological component that I want to put forward embraces the 'turn to the text' in the social sciences. Bowker (1993) suggests that an age of biography is upon us. Accordingly, a current frame of reference in the social sciences is the epistemological notion that meaning and experience are constrained in texts (Potter & Wetherell, 1987; Burman & Parker, 1993; Parker & the Bolton Discourse Network, 1999). Various approaches study texts to throw light on personal and social life.<sup>6</sup> One of these approaches is narrative inquiry (Clandinin & Connelly, 1994).

Narrative inquiry is concerned with the storied nature of life (Bruner, 1986, 1987). Experiences are collated, cross-referenced and reflected upon in a storied manner (Clandinin & Connelly, 1994, p. 414). Some proponents of narrative inquiry would assert that stories are *the* central component of experience and reality

(Didion, 1979; Hoffman, 1993; Sarbin, 1986; Bruner, 1987). Narrative is seen as producing experience and vice versa. People impose structure and give meaning to their lives through the use of stories (Hoffman, 1993). People tell stories in order to live, both in the telling and doing of self (Didion, 1979, p. 11). Some would suggest that because human beings are storytellers (*Homo narrans*) and life is story put into practice (Gillman *et al.*, 1997, p. 680), so people are texts. Alternatively, other proponents use narrative as a medium through which to present and reflect upon some of the experiences and realities of people (Allport, 1947; Parker, 1963, 1990, 1994; Plummer, 1983, 1995; Langness & Levine, 1986). Here, reality and narrative are not necessarily seen as synonymous. Instead, because telling stories is a large part of what people do, storytelling is used as a method to lend some insight into the experiences and realities of narrators.

Using life stories addresses the 'disappearing individual' in the increasingly abstracted nature of social theory (Nicholson, 1928; Whittemore *et al.*, 1986). Indeed, stories challenge the death of the human subject so celebrated by contemporary postmodern social researchers (see Eagleton's 1983 chapter on post-structuralism). Stories allow personal insights into social worlds (Taylor & Bogdan, 1984; Smith, 1987), and theories of the social world, both 'lay' and 'academic', can be assessed from an individual standpoint (Langness & Levine, 1986). As Schutz (1964) observed, theories flounder when they fail to adequately immerse themselves in the worlds of those they attempt to understand. Yet, stories not only present subjective accounts of situations but also highlight social backgrounds. Bertaux-Wiame (1981, p. 260) suggests that stories allow readers to listen beyond the words of narrators and to tap into the speech of their social culture. Abstractions can be checked by stories (Bertaux, 1981). In this way then, stories oppose overly structuralist understandings of the social world (Allport, 1947).

A recent study (Goodley, 2000) draws in part upon the life stories of five people with 'learning difficulties': Lloyd Page, Patrick Burke, Joyce Kershaw, Anya Souza and Jackie Downer. Their accounts provide storied visions of impairment, while their long-term involvement with the self-advocacy movement, as with the Disability Rights Movement (Campbell & Oliver, 1996), suggests that certain *disability cultures* encourage social members to embrace particular definitions and understandings (see Finkelstein & Stuart, 1996).

### *Self-definition*

Can I speak now? You should see what I've got—I've got two arms and two legs, I'm not physically handicapped actually. (Anya Souza)

Life stories pick up on the self-defining aspect of self-advocacy group membership. Vincent (1998) uncovered similar opportunities for self-definition, or what she calls *the making of alternative frameworks of sense*, in African Caribbean parent groups. Definitions have been a key component of the self-organisation of disabled people, like the UPIAS (1976) document that separated definitions of impairment and disability.

Transforming personal and social consciousness is one of the key factors that separates new social movements from the old, more traditional social movements. (Campbell & Oliver, 1996, p. 105.)

Self-advocacy groups provide a context for re-evaluating old terms and coming up with new ones. This may be useful in view of the anxieties that parents face in explaining the label of 'learning difficulties' to their children (Todd & Shearn 1997). Narrators prefer the more dignified term of 'learning difficulties'—reflecting the *'People First'* organisation's chosen terminology:

We are people with 'learning difficulties', not what people used to call us, I won't say the word. (Joyce Kershaw—her story)

'Learning difficulties' is more dignified. (Jackie Downer)

Mental impairment? Now what the hell's that? Never heard of it. I've heard of learning disability. I think mental handicap is still being used but they shouldn't. (Patrick Burke)

The term 'learning difficulties' infers that people want to learn and posits a distributed notion of 'learning difficulty':

A man couldn't do woman's work ... I said, 'You want to come and see some of them working in the centre and I bet they'd have to teach you how to do it'. Come and try and do our work and you'll soon find out if you've got a learning difficulty or not. (Joyce Kershaw—my story)

Having knowledge about the label of 'learning difficulties' provides people with self-understandings that can be applied in every-day life (Roffman *et al.*, 1994), while highlighting the absurdity of genetically orientated notions of personhood and the associated assumptions of inability:

Who has 47 cells? I have. They haven't they've only got 46 ... My dad says I'm 'Up Syndrome' not 'Down Syndrome'. (Anya Souza)

Narrators recognise how labels prescribe 'difference' through the values that are attached to them. In addition, opinions expressed in the stories highlight the various ways in which labels are internalised. Jackie Downer separates herself from 'less able' people with 'learning difficulties', 'I'm lucky I'm not like people with severe 'learning difficulties'. Anya Souza dismisses the label, 'Would I say I have difficulties learning? No, I learnt well enough. I picked up things very quickly'. Joyce Kershaw contrasts having 'learning difficulties' with physical impairment:

'Learning disabilities'—I don't like that, disability makes you believe that we are in wheel chairs and we can't do anything for ourselves, when we can. We've got jobs now, we've got paid jobs. (My story)

Joyce's comments have parallels with those of a self-advocate cited in Sutcliffe & Simons (1993, p. 24), 'If you go for a job and you've got the label "disabled" they won't give you a chance'. The suggestion that people with 'learning difficulties' are not 'as handicapped' as physically impaired people, is controversial. Nevertheless, it

provides an interesting mirror image of prejudice expressed by some in the wider disability movement, 'I have to keep proving I'm not mentally disabled' (Elsa, in Campling, 1981, p. 85). Some readers could suggest that these narrators are hiding or minimising their impairments (see Barnes, 1996). Another interpretation is that self-advocacy groups remind members of what they can do as opposed to what they can't do:

It could be argued that whilst the disability movement has fought the colonisers of disability (e.g. the medical and allied professions) for the right to define disability on their own terms, the fight against the colonisers of learning difficulty is of a different order; it is a fight against the denial of humanity itself; hence, this group insistence on being perceived as *people first*. (Gillman *et al.*, 1997, p. 690, italics in original.)

Perhaps labels are unnecessary shorthand, 'You can't say you're "just handicapped" because you're labelling someone and that's not the way to talk to someone' (Anya Souza). The personal and political aspects of self-advocacy are highlighted in the ways in which narrators have considered the labels they were given.

### *A Storied Self*

Cohler (1991) asserts that biographical methods are a useful medium for documenting responses to adversity. Narrators often present stories in ways that accent resilience over adversity; so as to maintain a sense of coherence and personal integrity across the period of life that is being told. Consequently, narrators may recount past experiences in ways that emphasise their activity, intention and direction. This may be the case particularly for narrators who readily agree to tell their accounts and so have stories that they want to publicise. These incidents of 'bias' may not be a bad thing when the narrators are from a marginalised group. Too often people with 'learning difficulties' are submerged under the system, the therapeutic technique or the goals of the sponsored programme (Heckel, 1968). By contrast, their life stories can highlight the other sides to life that are often ignored by dominant institutions and practices (Gillman *et al.*, 1997).

The five stories referred to above can be seen as examples of a different narrative type to the 'problem saturated' descriptions offered by case histories and other formal documents (Gillman *et al.*, 1997, p689). Their accounts introduce the idea that narrators do have influence over and become active in their own lives. In this sense they are counter or alternative documents that contribute to a revision of official 'learning difficulties' documentation:

People with 'learning difficulties' might form a 'resistance movement'—perhaps through the already well established self-advocacy movement—in which the subjugated voices of people with 'learning difficulties' can be heard in the telling and 're-authoring' of their own stories. (Gillman *et al.*, 1997, p. 689.)

The five narratives highlight the everyday nature of resilience in spite of the

oppressive conditions outside of groups and present tales that give meaning to the term 'self-advocacy'. Formal and informal, low and high-level, individual and group, private and public aspects of self-advocacy are articulated. Even people with 'learning difficulties' can lead busy and varied lives. Moreover, the life stories challenge accounts of people with 'learning difficulties' that view behaviour in terms of an oversimplified linear relationship between some ill-defined (and ever-changing) state of 'retardation' as cause and retarded behaviour as effect (Levine & Langness, 1986, p. 192). Narratives remind us that people with 'learning difficulties' are not helpless, involuntary victims of genetic adversity, or the degenerated shells of individuals who 'might have been' (Whittemore *et al.*, 1986, p. 5).

### **Reculturising Impairment**

I may need help in some things, but I'm not retarded. I can take care of myself ... Everyone needs help. Some people need more. Even the ones in the outside—the normal people, have marriage counsellors and other people to help them. (Martin Levine, a Canadian self-advocate, quoted in Friedman-Lambert, 1987, p. 15.)

At the heart of a social model of disability has been its connection to and representation of the collective identity of the disability movement. In contextualising impairment in social and cultural collectives, the social model makes a key epistemological point: that people with physical impairments are, of course, social beings. This ontological point recognises the socially structured and shifting nature of impairment (Oliver, 1990) and initiates social theorising that unearths the socio-cultural, political and historical formations of oppression (Abberley, 1987), dependency (Barnes, 1990) and collective resistance to such disabling barriers (Campbell & Oliver, 1996). In contrast, tacit acceptance of naturalised impairment on the part of people with 'learning difficulties' ensures that their collective identity and cultures are ignored. This is hardly surprising in view of decades of institutionalisation:

The mentally handicapped tend to lead marginal existences, do not reside contiguously nor even necessarily interface with one another, do not consciously share any common identity nor a wish to do so, and cannot possibly share specific sets of knowledge and rules for action by which they can be identified ... There can be little doubt that retarded individuals are not also cultural animals like the rest of us (Levine & Langness, 1986, pp. 192–193.)

Levine & Langness conclude that people with 'learning difficulties' are deculturised, each existing as the quintessential unitary humanistic subjects—isolated, alone, lacking—'the other' (see Rose, 1989). Such assumptions will remain and guide a social theory of 'learning difficulties' unless we recognise a variety of social arenas occupied by people with the label of 'learning difficulties'. Two such arenas can be considered—parenting and self-advocacy—in order to establish an epistemological foundation based upon a notion of the social and cultural self.

*Parenting and Distributed Competence*

Booth & Booth's (1994, 1998) research on parents has turned the tables on dominant conceptions of the parent with 'learning difficulties'. Typical assumptions of professionals and service providers tend to view parenting skills in terms of the 'impairments' owned by each individual parent. Professionals approach the task of support with epistemological assumptions that promote deficit thinking: problems will arise in parenting because of the psychological deficits of the parents. In contrast, and in line with the social model's turn to the disabled person as *social being*, Booth & Booth unravel the (lack of) social networks surrounding the parents that contribute to what we might term 'fitness to parent'. In relation to parenting competence they argue:

Competence may more properly be seen as a distributed feature of parents' social network rather than as an individual attribute. The notion of what might be termed 'distributed competence' attests to the fact that parenting is mostly a shared activity and acknowledges the interdependencies that comprise the parenting task. (Booth & Booth, 1998, p. 206.)

Such a social move allows for a relational and interdependent stance in relation to assumptions about (in)competence and hence impairment. 'Fitness for parenting' is not an individualised quality, rather a product of social and relational networks.

*Self-advocacy and Passivity as Activity*

The rise of the self-advocacy movement, both nationally and internationally, constitutes another socio-cultural context inhabited by people with 'learning difficulties' (Williams & Shoultz, 1982). Recent research suggests that such contexts exhibit a variety of relational qualities in which notions of 'learning difficulties' as lacking can be revisited (Goodley, 2000). Specifically, the workings of self-advocacy groups raise questions about assumptions we may hold about 'severe learning difficulties' causally disabling social relationships. Take for example the following observational vignette from a self-advocacy group:

Rachel arrives at the meeting by minibus from the local 'Autistic Community'. She does not speak often. She spends her time quietly and apparently contentedly smelling her fingers and looking around the room. She doesn't appear to interact with any of her friends. At break-time Bill asked her if she would like a cup of coffee or tea. Erica, who lives with Rachel, replied, 'She likes coffee don't you Rachel?' Bill looked at Rachel, 'Coffee then?' (taken from Goodley, 2000.)

Dominant epistemological narratives would story the above vignette in terms of personal tragedy: Rachel being unable to contribute actively to the group as a consequence of her impairment (in this case Autism). However, looking at the event again, we can see how Rachel's solitary actions provided a catalyst for other self-advocates to act. Indeed, without Rachel's apparent 'inactivity', a chance for

inter-dependence would have been lost. If self-advocacy groups contribute to the development of collective self-empowerment and decision making of members (Simons, 1992), then Rachel was an essential cog in the mechanisms that brought about such a development.

In this sense, then, Rachel invites us to reconsider our assumptions about 'the inactive individual'. People with 'learning difficulties' are the object of assessment strategies that belittle, patronise, pathologise and objectify. Their (in)actions are understood as the behavioural consequence of some embodied 'impairment'. 'They' are split-off from culture, 'us', considered a homogeneous, infected group. However, in recognising the social relations of (dis)ablement, we review the collective resilience of people with 'learning difficulties' that seemingly emerge against the odds. Another story highlights this point further.

Elaine has been given the label of 'learning difficulties'. She attends a self-advocacy group in the North of England. In her personal files is penned, amongst other damaging assessments, a note by a clinical psychologist, 'Elaine will never be able to learn to cross the road'. The staff in her group home are legally obliged to follow such expert advice. Hence, before each meeting of the self-advocacy group, Elaine is ferried to the meeting room by taxi. The taxi makes an awkward U-turn in the road and parks so as to allow Elaine to get out of the car onto the pavement where other members wait and greet her. The door to the building where they meet is ten metres away. As soon as the taxi rounds the bend and disappears out of sight, Elaine walks across the road into the corner shop to pick up milk and biscuits for the coffee break.

Viewed in terms of an individualised assessment, Elaine is incompetent, a danger to herself, and an accident waiting to happen. On joining the self-advocacy group she is the 'shopping manager' (one of the officer positions voted in by the group), taking her responsibilities seriously and, yes, like us all when we cross the road, an accident waiting to happen. Above all, her resilience demands that we view people collectively and distributed; competent in certain circles, less in others. She demands that we start asking how we see people with the label of 'learning difficulties', while alerting us to the contexts (real or imagined) in which we do the seeing.

### **Epistemological Impacts**

When I first met Kim he was my son. A year later he was epileptic and developmentally delayed. At eighteen months he had special needs and he was a special child. He had a mild to moderate learning difficulty. He was mentally handicapped ... At nine he came out of segregated schooling and he slowly became my son again. Never again will he be anything else but Kim—a son, a brother, a friend, a pupil, a teacher, a person. (Murray, 1996, in Murray & Penman, 1996.)

*Let Our Children Be*—a powerful collection of stories by and about disabled children

compiled by Murray & Penman—poignantly captures the impacts of epistemologies of impairment upon children and their families. It is necessary that we take a brief look at the implications of epistemes in relation to the life worlds of people with ‘learning difficulties’. Assumptions about the origins of ‘learning difficulties’ have massive impacts upon the treatment of (and research *of*) people with ‘learning difficulties’. Two examples shed further light on what we do with the baggage that we bring to the table occupied by people with ‘learning difficulties’.

### *Assumptions that Underpin Support*

During a recent ethnography of self-advocacy groups in action, the support of advisors to self-advocates with ‘learning difficulties’ emerged as a crucial factor in the workings of the groups (see Goodley, 1998). In trying to make sense of this support, I played with the idea that interventions of support could be viewed as reflecting different discursive positions in relation to disability, namely the social model and the individual model of disability. One continuum of support specifically exemplifies this analysis: ‘Deficit’—v—‘Capacity’ interventions. At one end of this continuum, deficit, advisors lean towards presuming incompetence on the part of self-advocates (Booth & Booth 1992, p. 65). This is an intrinsic part of oppressive discourses that position disability in the realms of individual pathology, personal problem and individual incapability (see Booth & Booth, 1994). Koegel (1986) pessimistically observes that there is a tendency to assume incompetent behaviour on the part of people with ‘learning difficulties’ and to attribute this exclusively to physiological causes. For Safilios-Rothschild (1981), supporters who view incompetence in others, help to enhance their own rewards of ‘helping’ and ‘caring’. When someone is unable to do something, we will do it for him or her, we feel needed, but our control increases as a result. Take for example the following stories from the meetings of a self-advocacy group:

Cliff has reported to the group many times of being bullied by supervisors at work and staff in his group home. Tonight he mentioned it again. One day after work, the taxi did not turn up as had been ordered, and he told the group how he angrily reacted to this lack of punctuality by hitting a staff member. One of the staff advisors said to another, though loud enough so the group and Cliff could hear, that, ‘Cliff is always taking out his anger on others’. She told him that she would put him down for a place on the new ‘anger management course’ run at one of the Centres where she works.

Ken told the group that he had asked one of the staff members in his house if he could make a cup of tea. He had said yes but on boiling the kettle another member of staff came in and told Ken to stop. Ken said this was because they thought he might scald himself. The advisors suggested that he ask the staff in his home to show him how to make a cup of tea.

No one asked Cliff why he reacted like he did, or took into account the frustrations he had been feeling. The supporters might have considered what had made him feel

so angry and perhaps supported him in bringing up his grievances at his workplace and home. No one asked Ken if he had made a cup of tea before. There was a focus immediately on what he couldn't do, and ways and means of remedying these deficits. Ken's capabilities were not considered. When I asked him if he had made tea before he replied, 'Oh yes, I make it for the mother when I saw her at weekends'. Probing wider social reasons for someone's actions opens up numerous causes (Guskin, 1963; Koegel, 1986; Booth & Booth, 1992). Ken later told me that he had been in institutions for 22 years and was on the same ward with Cliff, who is some 10 years older, suggesting an even longer spell of incarceration. These life experiences may explain Cliff's anger and perhaps he just wanted someone to be on his side. Friedman-Lambert's (1987) profile of Martin Levine, a Canadian self-advocate, is relevant here. Levine recalls punching a fellow (non-disabled) employee at a work placement after being the butt of some hostile ridicule. As Friedman-Lambert tried to suggest some alternative ways by which Levine could have handled the situation, Levine replied, 'Come on Phil, what would you do?' (Friedman-Lambert, 1987, p16). In contrast, there were many occasions when advisors opposed pathological assumptions of inability, sometimes espoused by self-advocates, taking a capacity perspective (Booth & Booth 1994):

As the meeting went on a young Asian man stood outside peering through and knocking on the window. The members shouted at him to 'go away'. The advisor suggested that he was trying to get their attention because he wanted to join the group. One of the members exclaimed, 'He wouldn't understand'. The advisor replied, 'You don't know what he understands'.

This alerted members in the group to the notion that a person's abilities are not a mere reflection of some assumed 'impairment'. Moreover, the social bases of a person's 'problems', an important construction of the social model of disability, are reiterated:

One of the members, Denise, said that a particular user in the Centre was 'being a right pain'. The advisor reminded Denise, 'He has a lot of problems at home you know. You should bear that in mind'.

Virginia explained 'problem behaviour' as when people have a bad day or get upset and then might feel angry. Jarrord asked, 'What like hitting you?' 'That's right', replied Virginia.

Rudi admitted, 'It's not always easy to stick up for yourself against nasty people'. Paul [supporter] agreed, 'Yes some people don't listen do they?'

To reiterate the views of the Canadian self-advocate, Pat Worth, it is important that advisors reject a focus on supposed deficits and emphasise competence:

The major barrier is *attitude*. People see our disability only, they don't see our ability. We may have a handicap but we're not the handicap. (quoted in Yarmol, 1987, p. 28, italics in the original).

*Life as a Reflection of Syndrome*

Assumptions rely on objects. Indeed, perhaps one of the most important analytical contributions of poststructuralist writing has been the call to pinpoint and destabilise the objects that constitute given discourses. Fairclough's (1992) use of Foucault's method of archaeological enquiry is relevant here. This method aims, amongst other things, to unearth the 'historical *a priori*' (epistemes or discourses) that delimit in the totality of experience a field of knowledge (rationality, individualisation, etc.). Such 'historical *a priori*' define the mode of being of objects that appear in a field of knowledge, that is, the things that are 'known'. For psychology such objects include the 'brain' and the 'body', which when applied to people with 'learning difficulties' emerge as 'syndromes' and 'mental impairments'. These objects contribute to the seduction of psychological discourses and, when adopted, lead to particular assumptions about people with the label of 'learning difficulties'. Take, for example, the following vignette:

The special school's Christmas performance. Before an audience of family members, teachers, support staff and local dignitaries, students sang, danced and acted. Enter stage left, Hugh. A slight teenage lad, Hugh performed to piano accompaniment the classic Tom Jones number 'It's not unusual'. As his performance was greeted by enthusiastic applause, a teacher turned to me and shouted above the noise, 'It's his syndrome you know—it makes him so extroverted'.

Hugh's actions are discursively framed in terms of the available object of 'syndrome'. Following Butler (1993, p. 129), Hugh is understood as a set of naturalised violations or injuries to his very 'personhood'. This raises wider concerns about how people with 'learning difficulties' are implicitly understood by supporters, as well as conjuring up a number of mental images as to what possible signs and symptoms could be indicative of '“Tom Jones” syndrome': strangers throwing knickers at the afflicted as they walk down the street? Fortunately, these 'objects' do and can resist, as evident in the following stories taken from observational field notes of meeting of self-advocacy groups (from Goodley, 2000):

Karen had recently had a meeting with an educational psychologist because, she joked, 'I'm dumb in the head'. A supporter who works at the college suggested that this meeting be arranged because Karen 'was not joining in in class'. Karen disagreed—'No, I were bored'.

Virginia [an advisor] suggested that members in the group should be taught how to cook. At the back Karen piped up, 'I can cook already'.

Just as these self-advocates resisted assumptions of inability, incompetence or inappropriateness held by others, then so should an alternative epistemology of 'learning difficulties'.

## Defining Starting Points

From the above analysis it is possible to lay a number of key foundations of an epistemology of impairment:

- Impairment is social not the product of isolated individual pathologies.
- Sociologically imaginative approaches embrace notions of distributed competence, ability, intelligence, capacity and 'differently articulate'.
- The collective activism of people with 'learning difficulties' are incorporated into social theorising.
- Disability research is urged to recognise the social and cultural formations of (in)ability and, hence, work with the culture of people with 'learning difficulties' and their allies.
- There is a sensitivity to the social nature of all human beings (and their abilities).
- A critical approach is adopted in relation to the discursive and material formations of (ab)normality.
- Disciplinary powers of the psy-complex that perpetuate societal discourses of ab/normality and in/ability are challenged.

This paper sets out a socio-political, historical and culturally sensitive epistemology that permits subsequent theoretical developments. One such development might embrace poststructuralist ideas that challenge social—individual distinctions and thus open up spaces to re-culturise those things that are assumed to be natural (see, for example, Shakespeare, 1996; Corker & French, 1999; Goodley & Rapley, forthcoming). However, any theoretical foray into these spaces has to start from a fundamentally social and political position. It is no good theorising impairment in relation to learning difficulties if biological assumptions direct (aspects of) analysis. The only theory left would be one shot through with the ideology of individualism and pathology (see Priestley, 1998). The starting points outlined in this paper constitute a challenging epistemology that takes seriously the sociological core of living with the label of 'learning difficulties'. The aim now is to move from the social model of disability to mutually inclusive social theories of disability and impairment that are open and inclusive to people who have been labelled as having 'learning difficulties'.

## NOTES

- [1] The term 'learning difficulties' is chosen instead of other synonyms such as 'mental handicap', 'mental impairment' or 'learning disabilities', because it is the term preferred by many in the British self-advocacy movement. As one self-advocate puts it, 'If you put "people with learning difficulties" then they know that people want to learn and to be taught how to do things' (quoted in Sutcliffe & Simons 1993, p. 23).
- [2] See Baron *et al.* (1998) for a clear example of such a sensitivity to 'mental impairment'.
- [3] Examples include the following. Taking further Goffman's work (1961, 1963), Edgerton's (1967) ethnographic relationships with 'mentally handicapped' patients illustrated the stigmatisation of labelling and institutionalisation. Similarly, Morris' (1969) 'Put Away' and Braginsky & Braginsky's (1971) 'Hansels and Gretels' uncovered the experiences of adults

and children with learning difficulties in institutions. Bayley's (1973) exploration of mental handicap in the community, noted the social limitations of support and debilitating effects on community memberships (as did Mercer's 'Labelling the Mentally Retarded' that came out that same year). O'Donnell's (1976) assessment of resident rights highlighted the concerns that even the most institutionalised demand. Brechin *et al.* (1981) 'Handicap in a Social World', and Brechin & Walmsley's (1989) 'Making Connections', piece together the experiences of people with physical impairments and learning difficulties (see also Kurtz, 1981) While, the anthropological studies of Turner (1980). Groce (1992), Langness & Levine (1986), Koegel (1986), Whittemore *et al.* (1986), and Langness & Turner (1986), examine the cultural formations of retardation.

- [4] Examples include 'The World of Nigel Hunt' (Hunt, 1967), Ed Murphy's story by Bogdan & Taylor (1976, see also 1982), 'Tongue Tied' by Joey Deacon (1974), Kaufman's (1988) account of mother and disabled daughter, and Atkinson & Williams' (1990) anthology of prose, artwork and poetry. In addition, Korbin (1986) presents the life course of 'Sarah—a Down's syndrome child' to show the impact of social factors on development, and Lea (1988) refutes pathologising clinical definitions via the poetry of people defined by such criteria. Potts & Fido (1991; see also Fido & Potts 1989) collected the oral histories of a number of long-term residents in an English mental hospital, and Oswin (1991) uncovered people with learning difficulties' experiences of bereavement. Cheston (1994) provides the accounts of 'special education leavers', while Angrosino (1994) talks of how he collected life stories 'On the bus with Vonny Lee' and Booth & Booth's (1994) 'Parenting under Pressure' explores the personal stories of parents with learning difficulties. See Stanovich & Stanovich (1979) for bibliography of writings by people with learning difficulties.
- [5] See, for example, the many workshops, conferences and training programmes advertised in the *Bulletin of the British Psychological Society*, for an illustration of how fashionable challenging behaviour is amongst practitioners.
- [6] Approaches sensitive to text include interpretivism (e.g. Ferguson 1987; Ferguson *et al.*, 1992, post-structuralism (Burman & Parker 1993), social constructionism (Sarbin, 1986; Berger & Luckmann, 1987; Potter & Wetherell, 1987), ethnomethodology (Garfinkel 1967, 1968), ethogenics (Marsh *et al.*, 1978), grounded theory (Glaser & Strauss, 1967; Schatzman & Strauss, 1973) and critical discourse analysis (Fairclough, 1992; Parker and the Bolton Discourse Network (1999)), naturalistic inquiry (Guba & Lincoln, 1985).

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