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British Journal of Learning Disabilities

Running head: managing relative abilities

Resisting having learning disabilities by managing relative abilities

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Accessible summary

- People who attended a community centre for people with learning disabilities talked to researchers for the study about the centre, their school and personal experiences
- The researchers were interested in what the people in the study said about learning disabilities
- This study found that people who attended the centre compared their abilities to those of others around them to make sense of who they are
- People in the study presented themselves positively by describing their abilities in comparison to other people.

Abstract

Previous research has shown that identities and the attributes from which identities are inferred are negotiated within social interaction and language. The identity of having learning disabilities commonly is associated with ascriptions of lesser abilities than other people, and in turn might be inferred from such abilities. This study examines how individuals potentially ascribed with an identity of having learning disabilities discursively manage the ascription of abilities and disabilities relative to other people. Semi-structured interviews were carried out with eight individuals categorised as having learning disabilities. Interview transcripts were coded for all references to relative abilities and analysed using discourse analysis. The participants displayed three orientations towards abilities, namely (a) ascribing deficits to 'others', (b) resisting comparisons of deficit, and (c) claiming 'normal' attributes. For the participants, these negotiations of relative abilities provide ways of managing specific aspects of identities associated with learning disabilities.

Introduction

Increasingly within the field of learning disabilities research there is a recognition that the identification of an individual as having learning disabilities (US terminology: mental retardation) comprises the social construction of identity and that such an identity therefore is negotiable (Rapley et al., 1998). This approach is something of a move away from the individual deficit approach within which, the definition of 'deficit' usually evolves from comparison of relative ability against a 'norm'. For example, DSM-IV defines learning disabilities using a combination of IQ score-discrepancy and below age- and grade-level measures (Kendall, 2000). A considerable drawback of such an approach is that it presents the learning-disabled identity as one which is static and immutable and tells us little about how such an identity is managed in everyday social situations. The shift in focus to a social constructionist approach, by contrast, opens up for examination issues of how an identity of having learning difficulties becomes assigned to particular individuals and of the actions of professionals, parents and individuals themselves in the construction of the identity.

According to the individual deficit view, the identity of having learning disabilities is treated primarily as a matter of application of a recognisable category. Given the highly stigmatising potential of a category that is associated with deficit, it is hardly surprising that few individuals seek the identity for themselves. Instead the identity commonly is assigned and controlled by professionals (Gillman et al., 2000; Oliver and Barnes, 1983) and is based on 'socially constructed criteria based on IQ and social functioning which identifies [individuals with learning difficulties] as needing special services' (Beart et al., 2005 p.18). Often, parents may be involved in the assignation of this identity to their children, with the possibility of access to special services being viewed as beneficial in the management of everyday life (Todd & Shearn, 1997). Several studies (Todd & Shearn, 1995;1997), however, have reported that individuals identified as having learning disabilities will deny or make no

reference to the label. It has been suggested that this denial allows individuals to distance themselves from a highly stigmatising and powerful label which overrides alternative identities (Burns, 2000; Walmsley and Downer, 1995; 1997) and potentially leads to negative consequences such as reduced opportunities (Valuing People: White Paper 2001) and poor mental health (Olney et al., 2004). Furthermore, parents and service providers are often complicit in their children's refusal to accept the label (Szivos and Griffiths, 1990; Todd and Shearn, 1997). Collusive denial between parent and child thus becomes seen as a means of allowing individuals with learning disabilities to live in a 'protective capsule' (Goffman, (1968) whilst remaining ignorant of their evident difficulties.

To view identity as a self-evident categorisation, and individual denial as evidence of invisibility of such categorisation, is however to ignore the ways in which individual identities are managed and negotiated in everyday life. Walmsley and Downer (1997), for example, argue that many researchers have neglected to consider that people labelled with learning disabilities might have alternative identities that are more meaningful to them as individuals, such as identities derived from ethnicity or sexuality. The proposed category of people with learning disabilities thus may comprise individuals with a heterogeneous and diverse range of difficulties, abilities and identity concerns (Smith, 2002). In the words of Jackie Downer, a self-advocate for people with learning disabilities, 'I'm so used to saying 'my needs, tough luck about the others'. They're somewhere else. I think it can work but it takes time. And we, as people with learning difficulties, we got no time (Walmsley and Downer, 1997, p. 44). Similarly, Finlay and Lyons (2005) argue that explaining label negotiation as a maladaptive coping response denies the opportunity to examine the lived experience of those labelled as having learning disabilities and thus neutralises the power to question how this label is constructed.

An alternative approach to equating denial of the label with a lack of awareness, comes from research that looks at how individuals' own concerns with identity impact upon their acceptance or rejection of the label. For example, Davies and Jenkins (1997) found that being categorised in terms of having deficits came to shape young people's experiences of self-identity across a range of social relationships. These young people did not, however, incorporate this categorisation into their self-identities in their discourse with other people. In circumstances such as these, non-identification with the label provides one way of dealing with contested categorisations that conflict with individual experiences (Goodley, 2001). It is therefore unsurprising that individuals rarely claim the identity of 'learning disabilities' for themselves, although more often accepting such categorisation when put to them directly by other people (Finlay & Lyons, 1998). Even when directly confronted with the identity individuals can manage the potential ascription of this identity in various ways, including avowal or disavowal of the identity (Rapley, Kiernan & Antaki 1998). Such findings suggest that individuals negotiate identity according to context, rather than being unaware of their 'status'.

While the category of having learning disabilities has received considerable interest from researchers in recent years, rather less attention has been given to the implicit properties of the category. As numerous writers (e.g. Hester & Eglin, 1997; McKinlay & McVittie, 2007; Widdicombe & Wooffitt, 1995) have noted, the membership of any social category is associated with a range of attributes that can be inferred from membership. At the same time, such attributes in themselves infer category membership: categories and category-bound attributes are thus mutually constitutive in meaning. In the case of the identity of having learning disabilities, as noted above, categorisation usually proceeds on the basis of 'deficit'

and raises the inference that an individual with learning disabilities will have deficits when compared against the 'norm'. Conversely, a deficit in abilities when compared to the norm infers an individual identity of having learning disabilities. Recent work has examined how individuals manage the categorisation itself in terms of negotiating identity; the question of how they negotiate their relative abilities remains to be explored. It is to that issue that we turn in the present study.

Method

The study was conducted in Edinburgh, United Kingdom at a local authority community centre which provided leisure facilities / activities for individuals classed as having learning disabilities. The majority of users had been made aware of the centre and its facilities / activities by general practitioners, community nurses or social workers. Recruitment of participants and interviewing were conducted within the centre, with the consent of the centre manager. Institutional ethical approval was granted for the study. Two part-time (female) volunteers who had worked at the centre for approximately two years conducted recruitment and interviewing. Their previous contacts with users of the centre served to make discussions about the study and subsequent interviews more naturalistic encounters than might have occurred otherwise. In facilitating the establishment of easy rapport in the interview setting, existing familiarity between interviewers and interviewees allowed participants to talk openly about their experiences.

Eight participants who had used the centre regularly over periods of time varying between one year and ten years were recruited to take part in interviews. Further demographics are reported in Figure 1. We do not include details of any standardised assessment scores or ratings of the participants' abilities. This omission is intentional, as to seek any such

information in the course of the participants' attendance at a leisure-based centre would have been inappropriate and would have had a negative impact upon the rapport existing between the volunteers and the participants which might have affected not just the study itself but the quality of future interaction within the centre.

Semi-structured interviews were conducted, based on topics that included the interviewees' attendance at the centre, their education, friendships and personal experiences. In line with the focus of the study on how individuals described their abilities relative to others, participants were not directly asked whether or not they identified with the category of having learning disabilities. Rather, participants were encouraged to describe their experiences in their own terms in order to allow sensitivity to the accounts themselves (for a discussion see Flick, 2006). All interviews were tape-recorded with consent and transcribed¹. Participant numbers were substituted for names and the transcripts were rendered fully anonymous.

All passages within the transcripts containing references either by interviewers or interviewees to relative abilities were selected for further analysis. Analysis was conducted using discourse analysis where the focus of interest is on participants' discourse in its own right. 'Discursive researchers do not view discourse merely as a medium through which the researcher can discover something about research participants' inner, mental worlds. Instead, discourse is viewed as a phenomenon which has its own properties, properties which have an impact on people and their social interaction' (McKinlay & McVittie, 2008, p. 8). Discourse analysis accordingly looks to account both for consistency and variation found in naturally occurring talk and emphasises the action orientation of discourse. In talk, external phenomena, inner psychological states and identities can be and are described in a number of

¹ (.) indicates audible pause (not timed), . . . indicates material omitted, :: indicate extended vowel sound, e.g. e::m, that indicates words or syllables given particular emphasis.

different ways; the versions that individuals produce are used to perform particular actions in the specific (linguistic) context of their use. Discourse analysis thus becomes the study of ‘discourse as *texts and talk in social practices*. That is, the focus is not on language as an abstract entity . . . Instead, it is the medium for interaction; analysis of discourse becomes, then, analysis of what people do’ (Potter, 2004: 203, original emphasis). The task for the discourse analyst is to show how participants’ descriptions are constructed and the functions that their descriptions serve.

Applying this approach in the present study, all passages selected from the transcripts were subjected to fine-grained analysis. Initial stages of analysis examined the ways in which these descriptions were constructed. Thereafter the primary focus of analysis was on identification of the functions that these descriptions served for the participants, and on how they presented the participants’ abilities in relation to other people and within the broader community. In accordance with recognized discourse analytic procedures, we reproduce below data extracts upon which the fine-grained analysis is based. The reader is thus in a position to evaluate the coherence and quality of the analysis that is provided.

Findings

In the interviews, the participants’ descriptions oriented to relative abilities in three ways. These ways, namely (a) ascribing deficits to ‘others’, (b) resisting comparisons of deficit, and (c) claiming ‘normal’ attributes, we consider in turn below.

(a) ascribing deficits to ‘others’

This first set of references to abilities was found where the interviewees themselves introduced such references, following a question by the interviewer that asked about their own experiences:

Extract 1(P1)

- 1 I: What type of school do you go to?
2 P1: It's a special school (.) for people with special needs (.) like if they're disabled
3 or if they've got a reading problem or English or anything like that.

Extract 2 (P8)

- 1 I: What about your time at school?
2 P8: You see (.) there was one or two who were quite (.) you know couldn't sort of
3 get things right and of course you can't really help them at school understand
4 (.) well you know say you were very good at doing your sums . . . there was
5 one person who was very bad at writing very bad you know he's (.) quite
6 honestly his hand couldn't really touch the paper and (.) he was frightened to
7 write in case he marked the paper or something like that.

Instead of making reference to their own abilities and experiences, the interviewees introduce references to other pupils at the schools that they attend(ed). The interviewees ascribe to these pupils a range of features that are negative and which mark out those concerned as being different from usual educational expectations.

Interviewees emphasise the differences between themselves and the individuals that they are describing by making use of common discursive devices that lend rhetorical weight to their claims. In Extract 1, the use of a list 'if they're disabled or if they've got a reading problem or English or anything like that' suggests that the instances that are described are not exhaustive

but instead reflect a larger class of possibilities (Jefferson, 1991). It thus emphasises the extent of the differences between P1 and the others who are being described. Similarly, much of Extract 2 refers to features that differentiate P8 from those being described. This adds weight to the claim that at school the participant was the giver rather than the receiver of help and that it was other pupils who had disabilities.

What these comparisons achieve is to normalise the interviewees' abilities. All participants had attended schools that were commonly regarded as providing special needs education. As such, this very attendance potentially makes relevant the matter of relative abilities of those who attended these schools. By discursively introducing other people and ascribing deficits to them, the interviewees distance themselves from potential ascription of negative attributes and the identities that might be inferred from such attributes.

(b) resisting comparisons of deficit

Although the interviewees introduced their own comparisons, they consistently avoided taking up any comparisons referring to disabilities that were proposed by the interviewers:

Extract 3 (P7)

- 1 I: What about people with learning disabilities compared to (.) physical
2 disabilities?
3 P7: I'm not su- (.) I don't know (.) I don't know that.

Extract 4 (P2)

- 1 I: What do you think about how (.) people with learning disabilities are treated
2 compared with people with physical disabilities?

3 P2: One of my youngest cousins actually (.) she is in a wheelchair (.) yeah I dunno
4 actually (.) I should imagine it'd be pretty hard for them to get on actually (.)
5 'cause of erm the disability they have actually erm (.) I'm sure that'd be pretty
6 hard.

In Extract 3, P7 gives a short and non-committal response, repeatedly disclaiming the necessary knowledge. In Extract 4, P2 takes up the second category in the question, namely 'people with physical disabilities'. P2 refers to personal experience in that a relative is stated to have such difficulties. However P2 provides the remainder of the description at lines 4 to 6 on the basis of imagined consideration of the difficulties faced by such individuals rather than on the basis of personal knowledge.

These responses function to distance the interviewees from the comparison that is potentially on offer. Their references to lack of knowledge suggest and are consistent with identities that are somewhat different from those that might be inferred from references to disabilities as suggested in the question asked.

(c) claiming 'normal' attributes

When participants described the experiences of people with learning disabilities, without any inference of first-hand knowledge, their responses displayed a third orientation to relative abilities, as seen in the following extracts:

Extract 5 (P3)

1 I: How do you think people with learning disabilities are treated in everyday life
2 (.) say if they go into a shop?
3 P3: Someone would give them a hand (.) someone would give them a hand.
4 I: if they were on their own?

5 P3: They'd be treated bad I think (.) by the shopkeeper 'cause it's not actually
6 their kind of people (.) don't know how to count money and that (.) we should
7 just help them.

Extract 6 (P4)

1 I: So how are people with learning disabilities treated in everyday life (.) for
2 instance shopping?

3 P4: Depends on the shop assistant (.) I mean you could be a good assistant (.) you
4 could be a bad assistant (.) I mean 'oh eh here's a handicapped person what do
5 you want' (.) y' know . . . There's nothing wrong with the person (.) it's just
6 that they don't have the same style as a normal person like me and yourself.

A first point to note is that each interviewee explicitly refers to members of the potential category in terms of 'otherness'. Thus, in Extract 5, the speaker refers to 'them' and 'they' (lines 3, 6 and 8), while in Extract 6 the suggested description is reformulated to one of 'a handicapped person' (lines 4 to 5) and the more generic 'the person' (line 6).

Secondly, each speaker avoids aligning himself or herself with the category and instead explicitly aligns with features of a contrast group. Thus in Extract 5 (line 8), we see the interviewee constructed as a person who helps these individuals rather than as someone requiring help, a claim that is backed up by a display of awareness of the difficulties faced by people with learning disabilities (lines 6 to 7). We find a similar display of awareness in Extract 6 (lines 3 to 5), made more persuasive through an example of the intolerance of a hypothetical shop assistant. Thereafter the interviewee explicitly introduces the attribute of being 'normal' (line 6) in aligning with the identity of the interviewer (line 7), and claiming an identity of 'normality'.

By adopting the footing of helper / witness to the difficulties of category members, the speakers are able to provide knowledge-based accounts of the experiences of those with learning disabilities while simultaneously distancing themselves from any attributes that might infer membership of that category.

This and the other two orientations to relative abilities identified here thus provide the participants with a range of ways of negotiating identities other than those that might be readily ascribed to them, such as being someone with learning disabilities, who might require help. The six data extracts analysed here come from different participants, indicating the frequency of management of identities within the present sample and that all of the participants drew upon at least one of these forms during the course of the interviews. These frequencies of occurrence suggest that, for the present participants at least, the roles of other people and relational aspects of their experiences provide a major element within negotiations of their own abilities. By invoking attributes similar to those of other individuals, while avoiding attributes that might suggest lesser abilities, the participants resist any inference that might lead to them being ascribed an identity of having learning disabilities.

Discussion

These findings come of course from a relatively small-scale study and the participants cannot necessarily be regarded as representative of all to whom these identities might be relevant. Nonetheless, what these findings show are at least some of the ways available for people who might be categorised as having learning disabilities to disavow this identity during social interaction. The findings are consistent with those of other writers such as Oliver (1992; 1996) and Gillman Heyman, & Swain, (2000), who have argued that identities of being

people with 'learning disabilities' should be examined for their use and effects instead of being accepted a priori as unproblematic.

The term 'learning disabilities' is applied to wide range of individuals with diverse abilities or problems and who do not readily comprise a homogenous social group (Smith, 2002). It is perhaps unsurprising then, that people potentially labelled as having learning disabilities will dispute that label when comparing themselves to others who might be substantially more physically or cognitively impaired than themselves. As seen above, references to others can be drawn upon to distance participants from ascriptions of requiring special needs education, and further to distance them from the unwanted identity itself through careful reworking of the abilities of themselves relative to others. .

What the present findings show is for individuals the relevant issue is not simply that of category membership itself but also the attributes of relative abilities that might give rise to such membership. Just as the notion of 'deficit' and assessment of relative ability against a 'norm' has been a longstanding primary concern for many researchers (e.g. Schalock & Luckasson, 2004; Shaw, et al., 1995) so the matter of relative ability equally is a central element of identity for individuals who might be categorised as having learning disabilities. The concept of normality is based around relational comparison either to an abstract norm such as IQ, or a more context-based norm of abilities to carry out everyday tasks. It is not surprising that abstract conceptual comparisons of ability are of little relevance to people with learning disabilities (as is equally the case with individuals deemed to be 'normal'). What is of more relevance is perhaps relational comparison to others in specific everyday contexts.

Resisting ascription of the identity of having learning disabilities accordingly requires first, attention to membership of the category itself and second, attention to all factors on which the identity might be based. Rather than being treated however as straightforward descriptions or evidence of relative abilities, these too can more usefully be viewed as topics that individuals negotiate on an everyday basis in making sense of their lives and experiences.

These findings demonstrate further the importance of understanding identities associated with intellectual disabilities from the perspective of the individuals concerned. Moreover, the relevant identities need to be viewed not just as the acceptance of or resistance to the application of a category description. Rather issues of identity permeate much of the talk of those concerned, occurring in their descriptions of themselves, their own experiences and the ways in which they should be regarded in relation to other people. In this way, issues of how individuals are and can be identified should be viewed not as categorisation on the basis of externally recognised criteria but rather as practical concerns and ongoing negotiations of those to whom any such identifications are most immediately salient. The identity of having learning disabilities and the attendant features of such an identity are, like other identities, a 'participants' resource' (Widdicombe, 1998).

These issues of identity impact upon a range of professionals and others who interact with individuals to whom the identity of having learning disabilities might be ascribed. First, the negotiation of identity evident in the transcripts of this study has implications for the field of intellectual disability research. Instead of assuming that the learning-disabled identity is 'given', researchers should perhaps be aware that well-meaning attempts to extract information on disability-related issues might be perceived by the participants as raising issues of ascription of and resistance to problematic identities and category attributes. Any

such attempt therefore may well become a 'contested examination of the adequacy of people's understanding of others' categorization of them as [impaired actors]' (Rapley et al., 1998, p.809). Second, the present findings indicate the need for awareness and sensitivity on the part of educational practitioners and others who have regular contact with individuals for whom such issues arise. Identities are relevant in ways in which individuals respond to many questions. The descriptions or lack of descriptions that they provide on such matters should not be taken as suggesting a lack of knowledge or ability; instead these discursive forms can be seen as action in their own right, as part of the everyday negotiation of identities for individuals.

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Figure 1: Age, gender, occupational status and living arrangements of participants

Participant	age (years)	gender	occupational status	living arrangements
1	17	female	in special needs education	with parents
2	22	male	employment	with mother
3	22	female	supported employment	with parents
4	54	male	supported employment	supported accommodation
5	44	female	supported employment	with mother
6	42	female	unemployed, previously in supported employment	supported accommodation
7	22	male	training centre / job placement	supported accommodation
8	31	male	attending training centre	supported accommodation