



'I won't think of meself as a learning disability. But I have': social identity and self-advocacy

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Summary

In this paper the small body of research which looks at how people labelled as having learning disabilities view this social identity is considered. The author argues that this research has implications for our assumptions about self-advocacy groups for people with learning disabilities.

Keywords *Identity, learning disability, self-advocacy*

Introduction

The number of self-advocacy groups for people with learning disabilities in Britain has grown substantially over the last 25 years. Simons (1992) estimated that around 500 such groups existed. With the Government White paper 'Valuing People' pledging 1.3 million a year for the next 3 years to develop self-advocacy services for people with learning disabilities, this growth is likely to continue (White Paper 2001).

This paper considers the possible implications for self-advocacy groups of findings from a relatively small amount of research into how people with learning disabilities understand and define the label of learning disabilities and how salient they find this identity. It is argued that many people with learning disabilities do not see 'learning disabilities' as a salient identity, and that many adults with learning disabilities will struggle to define what 'learning disabilities' means and who it includes, and this has important implications for advocacy groups for people with learning disabilities.

The basis for collective action

It can be argued that awareness and understanding of the social identity of having learning disabilities is central to advocacy groups' existence (Finlay & Lyons 1998). Members' understanding of the categorization of learning disabilities has implications for collective action (Finlay &

Lyons 1998). In order to challenge the way they are treated, people with learning disabilities need to identify with one another as people labelled by society. Corbett (1997) compares the process of 'coming out' as disabled to coming out as gay as it is saying 'This is who I am and I align myself with this group of people'. This does not mean that people have to accept this label but that collective action stems from aligning oneself with others labelled in the same way (Rose & Kiger 1995), and by going forward to challenge the meanings of such labels.

Self-advocacy starts from the premise that people labelled as having learning disabilities will group together to speak up for their own and others rights. However, there is evidence that many people with learning disabilities do not see the categorization of learning disabilities as salient to themselves.

Before the relevant literature is reviewed, a brief definition of the diagnostic criteria for receiving the label of learning disabilities is given.

Being categorized as having learning disabilities

People with learning disabilities are defined as such by others because they differ from a culturally defined idea of 'normal' intellectual functioning (Manion & Bersani 1987). There are clear diagnostic criteria for including someone in this category. The Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition (American Psychiatric Association

1994) states that 'mental retardation' is defined by having an IQ below 70, combined with 'deficits or impairments in present adaptive functioning...in at least two of the following areas: Communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety' (p. 46). Additionally, if these criteria are met it is necessary that they are evident before 18 years of age.

In Gillman *et al.*'s (2000) critique of the process of classifying someone as having a learning disability, they ask 'who has the power to name?', and conclude that '...the disabled identities of people with learning difficulties remain largely "embodied" and with the definition control of professionals' (p. 1). It is a property of this identity that it is unusual for the classification of learning disabilities to be sought by the person to whom it's given (Davies, 1998).

A second property of being classified as having a learning disability is the permanence of this identity. Harris (1995) believes that having a learning disability is to own an identity that is hard to leave.

The salience of the identity of learning disabilities

Within the comparatively small body of research which considers how people view their identity of having learning disabilities, there has been a consistent finding that a high number of participants do not feel it to be applicable to themselves (e.g. Cunningham *et al.* 2000; Davies & Jenkins 1997; Jahoda *et al.* 1989) Often it has been assumed that people who join self-advocacy groups actively identify themselves as people with learning disabilities (Walmsley & Downer 1997), but there is very little research to verify this. Aspis (1998) has queried this assumption arguing that at least for the groups that exist within day centres, people may identify at the level of service users instead. In one of the few studies to ask self-advocates about their learning disabilities identity, Simons (1992) has found varying levels of acceptance of the identity of having learning disabilities amongst the 54 self-advocates he interviewed

The literature suggests that this lack of salience of the label of learning disabilities amongst many of the people to whom it's given can be explained by (a) people with learning disabilities not having access to the meanings of and discussions about 'learning disabilities' as a categorization, and (b) the emotional impact of this label. These are considered below.

Difficulties in defining the term 'learning disabilities'

Research by Davies & Jenkins (1997) found that when the 60 young adults they interviewed were asked to define the

terms 'learning disabilities' and 'mental handicap' (both terms were being used in services at the time), then 42% didn't know what the terms meant, 30% gave a definition that excluded themselves, and of the 28% who gave a definition which included themselves 13% gave only a partial or vague answer.

In my own research I interviewed eight adults with learning disabilities who belonged to a self-advocacy group. The study used grounded theory to generate a model of the impact of self-advocacy group membership on interviewees' sense of self (Beart *et al.* 2004). Although it was not the main focus of the research I became interested in the level at which participants identified with the group. During the interviews I found that while all the participants identified themselves as belonging to a group for people with learning disabilities, half didn't feel this label was salient for them and all of them struggled to define the meaning of this label.

It also emerged from the interviews that the participants hadn't joined the self-advocacy group because they identified with it being for people with learning disabilities. Most described not being sure what the group was for but thought they would take a look since they had been invited. They went on to describe a positive change in their self-concept and a re-evaluation of their past through their membership, which then led to their seeing collective action and speaking up for people with learning disabilities as important.

There is of course more than one way of understanding what the label of learning disabilities means than explicitly stating that one identifies with the label. Rapley (2004) uses discourse analysis to argue that the identity of 'learning disabilities' is fluid and dynamic and something that is negotiated through interactions with others. Rapley argues that other researchers have mistakenly assumed that this identity is a static characteristic, and that when their participants do not explicitly state they have a learning difficulty they assume the participants do not know.

It is important to clarify that I am not saying that the participants I spoke with did not know what having a learning disability meant in terms of lived experiences, or that they could not express the personal meaning of this label since they clearly did both during our interviews. I was however interested that they did not appear to have access to or use in any way the diagnostic description which still dominates our services.

One reason participants talked about for the difficulty in defining learning disabilities was the different (often complicated) terminology for learning disabilities. The extracts below from interviews with two self-advocates highlight the different labels used in reference to people with learning disabilities.

There is learning difficulties and learning disabilities.
At the house where I live it's for mentally handicapped.
When I come here it's people who have learning

disabilities. At home it's all people with mental handicap, people with Down's syndrome.

It's for people with learning difficulties ... For learning disabilities, mentally handicapped, autism

Davies & Jenkins (1997) have drawn an important distinction between understanding one's own social identity of having a learning disability at a verbal level, and understanding it at an emotional level. They argue that while people with learning disabilities experience discrimination and their own difference in their day-to-day lives, they 'do not have access to the cultural discourse about them' (p. 107). In this case participants did not appear to have access to the definitions that services are built around.

The emotional impact of the label of learning disabilities

The second reason that self-advocates may not see the identity of learning disabilities as salient is that being given this label can be an emotionally painful experience. Sinason (1992) puts forward the theory that from a very young age the child with learning disabilities experiences a variety of largely negative feelings from others. 'Strangers stare unashamedly, some people giggle, some become sentimental. The child and the parent have to deal with instant celebrity without any of the positive rewards that can bring. Sometimes there is a turning away, a fear and a hostility, a sometimes spoken wish that such sights should be hidden from public view' (p. 41).

The people I interviewed in my own research also highlighted the painful feelings that can be associated with saying I belong to a group for people with learning disabilities.

I won't think of meself as a learning disability. But I have.

When asked people's likely reaction if they were asked 'do you have learning disabilities/difficulties?' one interviewee explained the difficulty in talking about this identity.

It would upset them and they would feel scared, excluded...People think they have a learning difficulty. They're scared to say to people.

Implications for self-advocacy groups

The small body of research discussed above challenges some of the assumptions around members of self-advocacy groups. First, it should not be assumed that by belonging to a self-advocacy group for people with learning disabilities people see the label as salient to themselves. For many people, on an emotional level this

ascribed social identity remains a difficult one to acknowledge, and discuss.

Secondly, people may only come to see collective action as important after joining the group, as their knowledge of the label they have been given grows. It should not therefore be assumed that all people who join a self-advocacy group align themselves with the cause of others labelled in the same way.

Thirdly, research shows that the terminology surrounding the identity of learning disabilities is often confusing. However, services are still based around this jargon laden diagnostic criteria rather than a social model of disabilities, and the power to label still largely lies in the hands of professionals such as myself. Perhaps part of the way forward is for professionals to be prepared to engage in open and honest discussion with self-advocacy groups when these groups question the labels they have been given. Such discussions will hopefully provide an important step in self-advocates challenging and re-defining this identity in their own terms, as a social construct rather than a medicalized condition, and in developing a shared language that is empowering rather than confusing.

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