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Coping with social stigma: people with intellectual disabilities moving from institutions and family home

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Abstract

Background Social stigma and its impact on the life opportunities and emotional well-being of people with intellectual disabilities (IDs) are a subject of both practical and theoretical importance. The disability movement and evolving theories of self, now point to individuals' ability to develop positive identities and to challenge stigmatizing views and social norms.

Method This paper presents findings from a phenomenological study of 10 individuals making the transition from their family home to live more independently and 18 individuals moving from a long-stay hospital to live in community housing. It builds on an earlier data set obtained from people living at home with their families and examines: (1) people's awareness of stigma, and (2) their modes of adaptation to stigma.

Results The participants all believed that they faced stigmatized treatment and were aware of the stigma associated with ID. They presented a range of views about self in relation to disability and stigma. These views included regarding themselves as part of a minority group who reject prejudice, and attempts to distance themselves from stigmatizing services and from other individuals with IDs.

Conclusions The findings are discussed in relation to theories of self and the importance of considering psychosocial factors is stressed in clinical work with people who have IDs.

Keywords identity, intellectual disability, self-worth, social comparison, stigma

Introduction

Mental health problems have a higher prevalence in the intellectually disabled than in the non-disabled population (Prosser 1999). Dykens (1999) has pointed to a number of possible vulnerability factors, including social deprivation, and experience of failure. While social and other adaptive problems might be the reason for people being marginalized and experiencing frequent failure, a distinction has to be made between people's actual disabilities and the social barriers and discrimination arising from stigma. Stigma arises when a person differs from dominant social norms on a particular dimension, and is negatively evaluated by others. Consequently, the person's whole identity is defined by that dimension and the person is dehumanized, to a degree, by

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those who hold such views (Goffman 1963; Crocker & Quinn 2000). Stigma may have a significant impact on the lives of such individuals. Mead (1934) proposed that a key mechanism in the development of self-concept is that of becoming an object to oneself, reflecting upon how one is treated by significant others. This is also referred to as the 'looking glass' theory (Cooley 1956) because one comes to see oneself in the evaluative behaviour of others. Becoming aware that one is stigmatized is liable to threaten a person's sense of adequacy and well-being. In turn, according to Cognitive Behavioural Therapy, such negative self-evaluations could give rise to emotional problems such as depression and anxiety (Blackburn & Twaddle 1996).

Since Goffman's (1963) account of stigma there have been subtle shifts in the understanding of this issue that reflect wider social changes. In the past it was thought that acceptance was mainly achieved through conformity. In his classic study of people with intellectual disabilities (IDs) leaving long-stay hospital, Edgerton (1967) demonstrated how an awareness of their stigmatized status resulted in attempts to overcome this spoiled identity and to 'pass' as normal. However, the growth of minority pressure groups has demonstrated that stigmatized individuals or groups, or those concerned with their welfare, can achieve acceptance through social and political action to change social norms (Jahoda 1995). Once again, action can be taken both individually and collectively to counter stigma. Thus, people might complain to the police about being bullied by local children or campaign for better employment opportunities. Studies concerning stigma and the self-concept have also shown how people with IDs can maintain positive identities by placing value on non-stigmatizing personal characteristics (Crocker & Major 1989). Downward social comparison through comparing themselves positively with other disabled individuals (Dagnan & Sandhu 1999), or denigrating other marginalized or low status groups (Finlay & Lyons 2000) is another way of maintaining a positive sense of self.

Crocker & Quinn (2000) present a more sophisticated model of stigma and its impact on individuals' views of self than Goffman (1963). In essence they argue that a number of social factors and mediating psychological processes are likely to influence the meaning of stigmatizing experience for the individual. For instance, being treated in a prejudiced fashion by a person one expects to be understanding and helpful might have a greater emotional impact than being so treated by an individual one expects to be prejudiced (Crocker *et al.* 1991). Situational factors may lead to a heightened awareness of stigma. For example, past experience of social rejection in certain circumstances might amplify awareness of stigma in these settings (Pert *et al.* 1999). However, Crocker and Quinn (2000) argued that the negative impact of stigma is not merely the result of direct social experience. They pointed out that the social representations of particular groups can be stigmatized, and that these social representations are often well understood by members of stigmatized groups themselves. Therefore, the number of positive social roles that individuals have, such as employee, church member or self-advocate, has also been suggested to act as a buffer against the emotional damage of stigma (Dagnan & Sandhu 1999). Individuals may also be able to challenge negative stereotypes imposed by others and gain acknowledgement for areas of personal strength. Crocker and Quinn's model highlights the contextual and dynamic nature of stigma, and the fact that people may hold a range of beliefs about self in relation to disability and stigma.

In order to understand the psychological impact of stigma on people with IDs, and how they actively interpret and manage their identities, it is necessary to examine their beliefs about self in relation to others and their social circumstances. Consequently, this exploratory study attempts to provide some insight into the dynamic relationship between people's self-perceptions and stigma, by examining the views of individuals at a time of change in their lives. It presents findings from one group of participants with mild IDs who were about to leave, or had just left, their family home and another group leaving long-stay hospital to live more independently. Two main questions are addressed. As this study is concerned with individuals' reactions to stigma, the first question is whether or not the participants believe they face prejudice or discrimination. The next question is how they adapt to their social circumstances, and the views of self they hold or wish to present in relation to stigma. The two groups will be examined separately, not to make comparisons, but simply to take account of the family and institutional contexts.

Method

Participants

The 28 people with mild ID who participated in this study, came from different environments: (1) The Housing group included 10 people who left their family homes to live in one of four housing projects provided by a voluntary organization for people with IDs in Scotland. The housing association provision consisted of a core house offering hostel-like accommodation for six individuals. In addition, there were small single person flats for a further six people. The staff also provided support to a number of satellite flats. The stated role of staff was to facilitate an ordinary home life for the tenants, while at the same time encouraging them to be as independent as possible. However, it was recognized that the hostel-type accommodation was somewhat incompatible with an ordinary life. (2) The Hospital group consisted of 18 people who were living in a hospital at the beginning of the study. As the participants were being considered for discharge they had been moved to a rehabilitation unit. The hospital would fit Goffman's (1961) description of a 'total institution' in which individuals' lives are closely controlled. It was one of the first institutions for people with IDs to be established in Britain, and was situated on the outskirts of a Scottish town. There were still over nine hundred residents in the hospital when the study was carried out.

Two criteria were applied to the selection of the participants: firstly, that they should have no severe communication difficulties; secondly, they had to be considered by their respective staff groups to have the potential to live in settings requiring only limited staff support, and to be able to shop, cook and wash clothes for themselves. The potential of the hospital participants for this form of living was assessed by a hospital multidisciplinary team on the basis of the Wessex scale (Kushlick *et al.* 1973). The hospital participants were selected from among the residents in a rehabilitation unit over a 2-month period. The Housing group met the above criteria by having been accepted to live in a setting which offered only limited staff support and demanded that their tenants should acquire the self-help skills outlined above. They were selected from people who moved from their parental homes during a 4-month period, to live as tenants in accommodation run by a voluntary organization. Sociodemographic characteristics of the Housing and Hospital groups are shown in Table 1.

Table 1 Sociodemographic characteristics of the participants

Characteristic	Hospital group	Housing group
Number	18	10
Sex		
Male	15	3
Female	3	7
Age range	20–55	20–40
Mean age	37	32
Physical disabilities or speech problems	4	2
Spent majority of life in hospital	11	0

Procedure and interviews

Semi-structured interviews were carried out with the participants. Prior to the interviews, about 12 hours were spent by researchers gaining the confidence of each participant and an undertaking was given to maintain strict confidentiality. The interviewer attempted to spend time with the participants at home, at the hospital or day placement, and to accompany them to a club or other leisure activity. In addition to building a relationship of trust, the researcher obtained insight into the wider context of the participants' lives, providing a greater understanding of what the participants were talking about in interviews and facilitating the flow of dialogue.

At least two interviews were carried out with each participant, lasting in total between 2 and 3 hours. Approximately 45 hours of interviews were tape-recorded and transcribed verbatim. The intensive nature of the work limited the size and scope of the study. The interviewer had a list of topics to cover, while attempting to promote a dialogue and allowing the participants to raise issues which *they* saw as important. The interviews covered two areas (1) the participants' awareness and experience of stigma associated with their disability; and (2) how they responded to stigma.

Strategies for opening up sensitive topics for discussion were piloted for the interviews. The topics of stigma and of disability were always approached indirectly. The interviewer did not use the words ‘handicap’ or ‘disability’, nor assume that the participants felt stigmatized in any way.

Analysis

The first step was a content analysis of the interviews to identify the participants’ reported experience of prejudice and discrimination and their awareness of stigma. The participants’ interview transcripts were then analysed qualitatively, drawing on the methods employed by Edgerton (1967, 1984). This involved producing a summary of the views each participant expressed about disability and stigma. The summaries were then examined in order to establish the main themes which emerged in respect to how people managed their identities in the face of stigma.

Results and discussion

At the outset, participants’ experiences of discrimination and prejudice will be outlined. The second section of the results goes on to examine how the Hospital and Housing groups responded to stigma.

Section A: experience of stigma

Table 2 shows that most Hospital and Housing participants were acutely aware of the discriminatory treatment they faced in their lives and the stigma associated with being known to use specialized services. All participants mentioned at least one area of concern with reference to services or their social acceptance in the wider community. Indeed there were a number of common themes raised by the Hospital and Housing groups, in terms of their experience of social rejection, discrimination and prejudice.

Section B: presentation of self

There were several dominant themes which emerged from the participants’ interviews in relation to how the participants responded to stigma, or the views of self they wished to present at this time of change.

Hospital group

Counter-culture and a sense of personhood

A key theme which emerged from the Hospital participants’ interviews was their sense of themselves in relation to the institutional context in which they found themselves. Over and above complaints about particular practices and lack of freedom, privacy and respect, there was an awareness of their position as residents within the hospital. They felt themselves cut off from the wider social world, where people were referred to as ‘outsiders’. These common resentments fostered a counter-culture, which clearly opposed the status afforded by the hospital. Thus the Hospital participants who emphasized the common humanity of all those with IDs did so with reference to a particular institutional framework. As one man commented:

> They’ll no listen to you, what the residents in this hospital says. No look at our point of view. Staff help staff, residents haven’t got a say in anything. Residents will never have a say, no in a hospital like this.

However, the very institution which set people apart as ‘patients’ provided a common language for them to reject such treatment. Such a view was put by one man in the following terms:

> In this hospital you’re classed as patients, residents, high-grade and low-grade and all this. I never kenned I was a patient. I thought how was you to get treated just the same as anybody else outside. It should all be stopped – classed as patients . . . we’re no dogs or animals or that. We’re just the same as anybody else. They should stop all this.

Distancing self from stigma

When the hospital participants described their social environment, they did not merely resent the discriminatory treatment which they experienced within the hospital, but they were also acutely aware of the stigma associated with the hospital in the wider community. Hence the Hospital participants who viewed themselves as superior to their peers with IDs wished to dissociate themselves from the institution. Leaving hospital was not seen as a means to an end. To achieve acceptance in the wider community, the par-

Table 2 Hospital & housing participant's perceptions of their social environment and the experience of stigma

	Number of participants who expressed views (out of 18)	**Typical Views Expressed**
Hospital group		
Staff treatment		
Resented authoritarian attitude of the staff	15	You hadn't got a chance. You had to stick to the rules of the staff. 'Cause when you're down in the ward, the staff are in charge of you. You cannae say to them. – I want to do my own things. – You wouldnae get a chance to run your own life. They wouldnae let you.
Rules and hospital hierarchy		
Complained of the humiliation of public bathing	13	I don't like the way they (hospital staff) tell you, wash your hair and that, because that's my business. We don't like to tell them to go and do things, because I know that's cheeky. You see we're no kids. It's different with kids. We're grown-up . . . I just want to be happy. I'm not wanting to miss my life. I don't want to miss the world. I want to get my freedom, my age you know . . .
Complaints about lack of privacy and of opportunity for peace and quiet	9	
Felt hospital environment was unjustifiably restrictive	15	
Social segregation and the stigma associated with the hospital		
Physical separation made it difficult to get to know people outside	16	It upsets us you know, inside. Hurts me, it feels like breaking heart. If they were in hospital, what we are, if we were outside, we wouldnae call them names. You feel alright in a way. But if I was likes of going out, people might come up and say to you. – Where do you come from? – and you hate telling them, you've got to try and keep it to yourself. Then they take a look at your clothes tag and they say – Oh is that where you're from? – See that's what I mean, that's what I hate.
Experience of cheek, abuse or rejection because a hospital resident	15	
Complained of hospital tags on clothes	7	
Complained of being taken out by uniformed nurses	7	
Did not want to live in vicinity of the hospital	17	
Not wanting people from outside to know that they came from the hospital	6	
Housing group		
Adult training centre (out of 9 participants who attended the ATC)		
Felt could not obtain work because 'disabled'	2	(Talking about work) – I would like to do what other people are doing. It's because I can't do them, that's why I get a wee bit upset, seeing people doing things that I would like to do. Like being normal people. That's what upsets me a bit . . .

Table 2 *Continued*

	Number of participants who expressed views (out of 18)	Typical Views Expressed
Worried they would be victimized in open-employment	2	
Adult training centre staff		
Felt treated them like children, not taken seriously	7	Well, it was mainly the idea that folk would see me as really handicapped and a lunatic and all that kind of thing because I came to xxx Centre.
Awareness of stigma associated with ATC	7	Like adults, Mrs . . . just treats us like adults. No children, no like in a primary school. She says, – You're not at a primary school, you must act like an adult, not like a child. – . . . I feel like getting called adults instead of children.
Thought they could not obtain jobs because employers would discriminate against people with a learning disability	5	
Home life		
Felt some of hostel rules demeaning	3	As if I was a bairn, at my age, 30 odds. I dinnae need to be telt to have a bath. My mother says, 'they're right' and I'm 'wrong' . . . I was embarrassed. I couldnae say a thing.
Wished to have more social contact with staff	4	
Felt stigma attached to hostel and flats because of design of buildings	2	
Social life and networks		
Felt cut-off from or rejected by non-disabled peers	7	Even with pals, I never got a pal in my life. There's fellows I knew at school, that's all they are, but they were never my pals, they wouldnae mix with me. Put it bluntly, I was never good enough for them. I used to just say – well, if I'm no good enough for them, that's it, finished.
Had experienced teasing/abuse from non-disabled peers	8	
Lack of social confidence because of limited social experience and having few friends	2	
Specific instances of discriminatory treatment that emphasized their feeling of social marginality	5	
Would like to go out more and make more friends, particularly with non-disabled others	8	

ticipants believed they would also have to make a deliberate effort to break away from their stigmatized past. As one man, interviewed several weeks after he had left hospital, stated:

> When I left there, I left all that behind me. That's the way I felt. I said to myself, when I leave the hospital, I'll forget all about the hospital. I don't even tell people I've been there. If you start telling people, they'll start telling everybody else and all of them will start making a fool of you.

Another man stated:

> You dinnae want the boys (from the hospital) coming down to your house. I dinnae anyway . . . What happens if you've got visitors or mum and dad's come through. I just wouldnae let hospital boys come down to my house . . . I want normal boys. They're no normal in here.

There was a tension manifest in a number of the participants' interviews between a wish to assert a sense of camaraderie with a group of fellow oppressed individuals and a wish to maintain their superiority to their peers. Indeed, a number of participants cited the support of professional staff in the hospital who had told them that they should have never have been admitted:

> She (the doctor) knew I should never have been in . . . You should have seen some of the boys . . . cause the boys in there, they're all stupid, their minds away, right. They'll be there the rest of their days, 'til they kick the bucket.

Yet the hierarchical nature of the institution should also be taken into account when considering the superior attitude adopted by a large number of hospital participants. Perhaps the most distinctive terminology used by residents and staff described characteristics which identified their position within the hospital. For example, 'high-grade' and 'low-grade' were used as a classification of ability and as a term of abuse. Being given particular jobs in the hospital or being part of the rehabilitation programme were also markers of status. Depending upon their assessment and the success of their training, the residents then progressed quite literally down the road to staffed houses, just inside the back gate of the hospital. Thus right up to the point of departure, their social status was determined by their place in the hierarchy. Concern with status was evident from this man's account of his new label of 'resident' in a hostel:

> It's residents no patients . . . Because I'm big, I'm no a patient . . . That's wee boys patients . . . I'm a grown man now . . . I'm no a child anymore.

As indicated above, there was an emphasis on increasing competence as a criterion for success in the rehabilitation programme. Yet it was noteworthy that in only two of the participants' accounts the notion of agency, or greater self-determination through the acquisition of new skills, was the dominant theme. As one man who emphasized his abilities stated:

> There was nothing wrong with me. But the staff and the doctor thought I was a bit of a nutcase, that I couldnae look after myself. But I proved them wrong. I am happy the way I am, doing everything.

Even those who regarded themselves as superior to their peers in the hospital, acknowledged particular problems they had with learning. One man explained:

> There's a lot of things I'm no very good at. I guarantee everybody that works here, and all over, they all got things that they're not very good at doing, everyone.

Rather than maintaining a positive view of self through proving their competence, the immediate goals upon leaving the institution were concerned with developing a new identity.

A number of participants felt that moving out of the hospital did not merely afford them a different lifestyle but, in a sense, also gave them the opportunity to become a different kind of person. In so far as they were no longer expected to conform to the role of a patient there was some justification in the belief that they were able to adopt a new persona. Several weeks before leaving the hospital, one man expressed his aspiration as follows:

> Well, I don't mind being called a patient but I'd like to be an outsider for a change, you ken. I'm still a patient here, but I wouldn't mind being outside and being called an 'outsider' for a

> change, instead of a patient. But if you're somebody like outsider, you'd be whatever you'd want to . . .

Housing group

Agency: a demonstrable achievement

Participants cited the part that they had played in the move to their new house, and their aspirations for their future lives, as evidence of their competence and the injustice of past stigmatized treatment. They attached importance not merely to their changing lifestyles, but to the fact that their parents or relatives had come to recognize their ability to live more independently. One man described how he had always found it hurtful being overprotected and had never accepted the underlying implication that he was a vulnerable individual and less able to reach his own decisions. He made this point when he described the discussion he had with his (non-intellectually disabled) brother about moving to live in the housing association accommodation:

> It's no you that's making my mind up for me, I'm making my own mind up for me. I'm making my mind up myself, just the same as everyone else, I only take epileptic fits but I've got a mind of my own.

The past battles described were not always won, and in some instances the participants were left with ambivalent views towards their parents or relatives. One woman had achieved greater independence over a period of years, culminating in her move from home. She expressed satisfaction at her mother's shift from being very overprotective to becoming somewhat supportive of her independent lifestyle, and of the fact that she was living with her 'boyfriend'. However, she had spent her late adolescence and early adulthood in a long-stay institution and she remained angry that her mother had sanctioned her sterilization, which was carried-out against her will before leaving. There were still instances where she expressed resentment about her mother's attitude towards her:

> I say (to mother) – I'm no a wean (a child), I'm an adult. I'm entitled to dae what I want, I'm entitled to go out when I want and come in when I want. I'm no a wee wean, don't treat me like one – But she still does – You're still my wee lassie, she says. I say – But I'm no a wee lassie. Don't treat me like one.

A lack of recognition by significant others

In several instances, parents' refusal to recognize individuals' potential for change could leave them feeling vulnerable. Even where they felt that they had proved a point to their family by their move, they were aware that they were forced to face the future without a key source of social support. In terms of their attempts to promote a positive identity, these participants were reticent about past achievements and focused more on future possibilities. Yet they remained fearful that their attempts to build a positive identity might be undermined. For example, one woman talked optimistically about her wish to marry her fiancé and have children. She went on to speculate what these children would think when they grew up and 'learned more about their mother and father': a sad acknowledgement that while she could dismiss the consequences of being seen as a disabled person, this did not diminish her dread that her own children would come to share such views. Another woman expressed her frustration at her mother's failure to recognize her progress:

> My mum says I'm no right, I won't be able to cope. But since I moved in here I've been coping great. I've been doing well in here.

Remaining in stigmatized services – a relative view of self

A number of participants wished to emphasize their achievement in leaving home to counteract their stigmatized status. Nevertheless, they were moving to residential services for people with IDs and most continued to attend segregated day services. Given their awareness of the stigma associated with the day services in particular, this presented some difficulties in promoting a positive identity, as one woman stated:

> It's just the thought of going to a Centre, to get classed as disability, when I'm no. That's all in the past, now I dinnae bother.

The reputation of the Day Centres caused greatest concern. A participant described her fear of being asked where she worked in the following manner:

> I remember one time someone says to me – Where do you work? – I says – xxx (Centre). They goes – Is that the luny place? – I says – that's no the luny place. Cheek! It's a bit of a nutter place right enough, but it's no a luny place; (makes you feel) rotten if someone says that to you.

In common with the hospital group, some housing participants rejected the stigma faced by all people with IDs, including those less able than themselves. This meant that they felt on a par with non-disabled individuals and staff members in services. For example, one man who held these views had applied for a staff member's job in his day service. In other instances participants were keen to describe themselves as better than less able individuals, or to people with physical disabilities. One woman thought that people would regard her as superior to others at the Day Service she attended:

> They all think, why should I go to the Centre ken, because I'm no handicapped like their wee yins (ones). Well, I feel that anyhow.

However, this elitist view was rarely presented consistently. Their experience of prejudice and discrimination meant that they shared the same problems obtaining social acceptance as other disabled individuals. For example, even though the woman quoted above emphasized her wish to distance herself from less able individuals, she acknowledged that she herself could not escape from the prejudice they faced. Thus she could not prevent herself from empathizing with their predicament. She described an instance where her nephew had laughed at a disabled person and she had rebuked him:

> I said – that's not very nice. You could end up like that one day – they just laughed at me. You just can't get through to kids, explain what it's all about.

On occasion, the move to the residential service meant that participants had to accept a compromise between the public persona they wished to present and the gains from their new lifestyle. One woman had refused to obtain a disabled bus pass because she did not wish to be seen by others as 'stupid'. Despite being critical of certain staff practices she actually enjoyed the camaraderie and friendship in the group living situation to which she had moved.

This seemed to produce a conflict between her wish to maintain a non-disabled identity and a pragmatic readiness to accept her circumstances. By accepting that her move to the flat had been a positive step in her life she was shifting to a position where her public label was less important than her personal sense of satisfaction with her life.

A number of participants who wished to emphasize their relative superiority to other disabled individuals remained fearful of mainstream settings. Although they wanted to break away from segregated services, they remained anxious that any personal failings that were exposed could lead to ridicule and rejection by non-disabled others. After expressing his wish to move on from segregated services one man went on to describe his fear of rejection:

> No, well there were a couple of folk who thought I was stupid and that, but my dad always stuck up for me when I was younger. . . . I sometimes wish that I was accepted more by boys about my own age and all that. I would like to be able to participate with folk that aren't handicapped, but I'm scared for the reason that they'll be put off me because I go to xxx Centre and all that kind of thing.

Concluding discussion

In common with previously published studies (Flynn & Knussen 1986; Jahoda *et al.* 1988; Rapley *et al.* 1998), stigma was something with which the participants had to cope in their everyday lives. Thus, a lack of social acceptance was an area of major concern for these individuals. It was striking that despite the very different backgrounds of the Hospital and Housing groups, there was considerable common ground in terms of the experiences they highlighted in relation to stigmatized treatment. While some Hospital participants may have proposed 'denying' their past association with the institution as a means of presenting a new self to the wider world, they were not denying their disability or experience of stigma to the interviewer. Rather, they wished to live down their stigmatized identities in community settings.

In line with previous findings (Finlay & Lyons 2000), there was evidence that downward social comparison played a part in both the Hospital and Housing groups' rejection of a globally disabled identity. Although social comparison may have played an important part in determining some participants' self perceptions, it has to be understood in the context of their wider social awareness. Participants often recognized that the nature of their self-presentations would change in different social circumstances and according to their social goals, leading to contradictory beliefs. This was evident in the fact that a number of participants expressed both an empathy with their peers and a wish to escape from prejudice and discrimination by distancing themselves from their peers. Stigma infused many of the other participants' struggles to retain a positive view of self with inner tension. This was difficult to detect, because the participants' sensitivity to such treatment tended to be hidden by an outward acceptance of their social circumstances. Often a sense of powerlessness was underlying such an apparent acceptance, that masked emotions of anger, frustration and hurt, which were expressed during the interviews. These feelings were particularly apparent when participants knew that their achievements *per se* were not enough to achieve acceptance of their new identities by significant others in their lives. Other individuals were anxious lest greater involvement in non-segregated settings might lead to the experience of failure or discrimination. It is therefore unwise to take people's acceptance of their social circumstances at face value.

The participants' sense of self was not merely a 'reflection' of how they were treated or perceived by significant others (Cooley 1956). An awareness of their position in wider society, beyond the restraints of the hospital or their limited community experience, seemed to allow them to differentiate between treatment that was justified by their actual disability, and prejudice and discrimination. This finding is consistent with Crocker & Quinn's (2000) view that stigmatized groups are aware of their negative social representations. The ability to arrive at a broader social understanding of self may be explained by the notion of a 'generalised other'. Mead (1934) proposed that during the process of socialization individuals internalize a representation of a typical ('generalised other') person. The anticipated reaction of this 'typical other' provides individuals with a template against which to judge their own and other people's actions. Consequently, individuals are able to determine whether other people are treating them reasonably or not. Whether such an explanation has value is debatable, but how people with IDs develop quite sophisticated social understanding despite impoverished social opportunity requires further investigation.

The notion of the 'generalised other' suggests that being socialized to accept the same social rules and codes of conduct as their non-disabled peers may have helped the Hospital and Housing participants to reject a stigmatized identity. Yet the main difference between the accounts of the Hospital and Housing participants was the Hospital group's sense of being part of a counter-culture. The Housing participants were loath to be critical of significant others in their lives, such as their parents, even when they felt treated in a discriminatory fashion compared with their siblings or peers. Parental support and recognition of their achievements remained vital to their sense of self. However, the hospital group had no hesitation about being critical of the institution and largely believed that they shared a common and unjustified fate with the other residents. Harris (1989) pointed out that a sense of personhood could be affirmed in apparently dehumanizing circumstances 'where low status subsocieties have their own social order encapsulated in the wider one.'

Markova (1987) argued that to develop or maintain a social identity is an active process. Opportunities for personal development, such as a move to independent living made by a number of participants in this study, or richer social experience, could help to consolidate a positive sense of self. This finding supports current social policy initiatives, emphasizing the mental health benefits of greater social inclusion in areas such as employment (Riddell *et al.* 1999). Yet individual achievement as such may prove insufficient where people continue to be subject to prejudice and discrimination, or develop greater sensitivity towards threat to self (Pert *et al.* 1999). Factors that increase the resilience of people with learning disabilities to the impact of social stigma remains a vital area for future research.

The notion that people's perceptions of events and emotional reactions are driven by their core beliefs about self is a key assumption in cognitive approaches to understanding and treating serious emotional and interpersonal problems (Blackburn & Twaddle 1996). In keeping with recent research (Dagnan & Sandhu

1999), this exploratory study highlights that views about self in relation to disability and stigma can be a core element of these individuals' self-concepts. In turn, this may influence how they interpret situations and the self-evaluations that they make, with subsequent emotional and behavioural sequelae. Consequently, the nature of people's beliefs should be taken seriously when clinical psychologists are assessing, formulating and treating serious emotional and interpersonal problems faced by people with IDs. Such a view echoes other recent calls to address the social consequences of people's disabilities (Craig *et al.* 2002). This may be central aspect of their experience, which people with IDs themselves cannot ignore.

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