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Title: Living with stigma and the self-perceptions of people with mild intellectual disabilities.

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Key words: Intellectual disability, stigma, self-concept, depression, anxiety, transition and ethnography.

Abstract

There is now overwhelming evidence concerning the awareness people with moderate to mild intellectual disabilities' have about the stigma they experience in their lives. However, there is still controversy about the potential impact of stigma on their self-perceptions. This paper will draw on findings from an ethnographic study to show that even when individuals have difficulty expressing their views verbally, their actions can provide evidence of how they struggle to establish or maintain positive social identities - sometimes at the cost of their mental health. The implications of these and other findings will be discussed in relation to social constructionist theories of self-perception. This in turn will be linked to a discussion about the kind of support that might be required by people with intellectual disabilities, and how stigma might increase vulnerability to emotional and inter-personal problems.

Living with stigma and the self-perceptions of people with mild intellectual disabilities.

Stigmatised treatment faced by people with intellectual disabilities can take many forms, from direct discrimination and abuse to the denial of everyday opportunities by loving but over-protective families (Jahoda, Cattermole & Markova, 1989; Cooney, Jahoda, Gumley & Knott, 2006; Beart, Hardy, & Buchan, 2005). Consequently there are subtly different ways in which stigma may impact on self-perception. Like other groups, the stigma people with intellectual disabilities encounter has a particular history. For example, fears about sexual promiscuity or a predatory nature can be traced back to the alarmist assertions of the eugenics movement (Jahoda, 1995). These negative images can coexist with commonly held beliefs about child-like innocence, which lead to rather different forms of discriminatory treatment. Sheerenberger (1983), in his wide ranging history of people with intellectual disabilities in the West, observed that an uneasy combination of pity and fear has underpinned the stigmatised treatment of people with intellectual disabilities. Thus stigma may be motivated by benevolence as well as hostility, born out of an effort to protect people thought to be vulnerable (Jackman, 1994; Glick & Fiske, 1995).

Whatever form discrimination takes, there has been consistent evidence that people with moderate to mild intellectual disabilities are aware of the stigmatised treatment that they experience (Reiss & Benson, 1984; Beart, Hardy, & Buchan, 2005). The kind of stigma that individuals face also depends on context. In Cooney et al's (2006) study those in mainstream school reported having a more difficult time compared to their special school peers, being subjected to name calling from non-disabled pupils and demeaning treatment by some teachers. The picture changes though when looking beyond the school gate, where it was found that both groups of children reported similar kinds of experiences. These ranged from being ignored or teased in the area where they lived to being unduly restricted by their parents.

From a symbolic interactionist perspective (Mead, 1934), one might expect that people brought up in circumstances where they are often treated in a discriminatory fashion would be likely to internalise the stigmatising views held by significant others and develop a negative perception of self. However, in a study exploring the views of people with intellectual disabilities leaving their family home or long-stay hospital in the UK, where they had lived most of their lives, this was not found (Jahoda & Markova, 2004). It should be emphasised that this was despite those in the hospital living in circumstances where the very language used and the clothes they wore defined them as ‘patients’. The great majority of participants in this study rejected a stigmatised view of self. This did not mean that they denied their disabilities or the particular difficulties arising from their impairments, but they refused to accept the negative stereotype of a disabled person such as being regarded as incapable of making choices in their lives. One man recalled making it clear that he should have a say over a proposed move to new accommodation, *‘I’m making my mind up myself, just the same as everyone else’*.

A sense of what was fair or just, at an emotional as well as a social level, seemed to play an important part in the hospital participants’ rejection of a stigmatised identity. In other words, people’s ability to differentiate between dehumanising treatment and an acknowledgement of their disability may derive from their shared sense of selfhood with non-disabled others, underpinned by shared values and goals. The participants’ accounts were nuanced and complex. For example, there was often a tension between their wish to differentiate themselves from others with disabilities to boost their own sense of self, and a wish to demonstrate solidarity with others who faced similar discrimination. Paradoxically, because the hospital participants were literally set apart and treated as patients, they had a sub-cultural status that helped them to reject the stigmatised treatment they faced. This fits with Branscombe, Schmitt, and Harvey’s (1999) notion of ‘rejection – identification’, which

proposes that experience of prejudice or discrimination can increase identification with the minority group, and that a sense of group cohesion can help to protect well-being. A similar finding was reported by Crabtree et al (2010), where membership of mental health support groups helped to promote a positive collective identity, even if this was not necessarily protective of individual self-esteem.

Individuals understand and deal with the stigma they face in a variety of ways. Finlay and Lyons (2000) interviewed people from day services for those with intellectual disabilities and found that the participants did not talk about themselves in relation to their intellectual disabilities, rather they used downward social comparisons to emphasise their positive identities. Their findings are consistent with those found for other stigmatised groups, where people tend to downplay their weaknesses and emphasise their strengths (Crocker & Major, 1989). This would constitute what social identity theory (Tajfel & Turner, 1979) designates as social creativity, but it can also be seen as a genuine disagreement with the dominant comparisons that dictate a stigmatized status. Whether people agree that they are part of a stigmatised group remains a matter of contention (Finlay & Lyons, 2000; Rapley, 2007) and will vary between individuals.

People might also make attempts to dissociate themselves from their stigmatized group or to become part of a higher status group through 'social mobility' (Tajfel & Turner, 1979). This might include attempting to hide difficulties with literacy and numeracy, and pass as someone without intellectual difficulties. However, Crocker and Quinn (2000) point out that the particular social circumstances of the stigmatized group, and how they relate to the society at large, is likely to mediate the impact of stigma. Leach et al (2010) have shown how Black Britons enjoy a positive collective identity that protects against potential discriminatory treatment. However, individuals with intellectual disabilities, unless living in congregate settings, are not a distinct sub-cultural group. They are most likely to live with

family in ordinary neighbourhoods. Therefore it may be more difficult for such individuals to avoid or reject discriminatory treatment, particularly when some of it comes from those they are close to who provide them with support that they need.

Goffman's (1963) original work on stigma did not focus on the impact of discrimination, it was concerned with how people negotiate their stigmatised social identities in their everyday lives. In turn, Robert Edgerton's (1967) anthropological study investigating the attempts of people with mild intellectual disabilities to build new social identities after being discharged from a long stay institution drew inspiration from Goffman. Edgerton found that his participants' lack of 'competence' made it difficult for them to achieve this goal without significant help from others. How people attempt to obtain social acceptance and status is a matter that will be considered in this paper with reference to extracts from case material drawn from a project concerning young people who have intellectual disabilities and mental health problems. Although there is a growing literature on the stigma associated with mental health (Dinos et al, 2004), this paper will focus on the impact of having an intellectual disability.

Crocker and Quinn (2000) have pointed to the methodological challenges of studying such real world phenomena in artificially created laboratory settings. Moreover questionnaire based studies, particularly when confined to relatively privileged social groups such as University students, can only provide limited insight into the lived experience of stigmatized individuals. The main drawback with much of the research concerning the impact of stigma on the self-perceptions of people with intellectual disabilities is that it has relied on one-off verbal accounts from structured or unstructured interviews. Generally, such data provides little sense of how people interact with their world, the dynamics of their everyday lives and how their experience contributes to their self-perceptions. There are even greater challenges attached to interview type research with people who have intellectual disabilities, given that

they may have limited expressive communication skills. Rapley (2004) has drawn on the analyses of small sections of dialogue to show how the communicative acts of individuals with intellectual disabilities can serve to resist being defined by others, particularly by professionals and those who assume a position of power. However, examining small sections of dialogue can miss the broader context of people's lives, and the real difficulties that people with intellectual disabilities can face when trying to achieve social acceptance or recognition in their own right.

In an attempt to build on previous research concerning stigma and people with intellectual disabilities this study made use of novel approaches, including video-diaries and photographs, to obtain insight into the experiences and feelings that they may hold but find difficult to express. This investigation set out to produce a series of case studies following the life history approach described by Langness (1981), which attempts to build a picture, over time, of individual lives in context. The aim was to provide understanding of 'aspects of behaviour and action' that can only be interpreted by examining the 'individual as whole, functioning within the larger socio-cultural context of his or her life' (Langness, 1981, pp. 85-86). To this end, at the conclusion of each of the case studies, summaries were produced for each individual, synthesising the material to address i) their experience of stigma, and ii) how they attempted to establish their identities as young adults at this period of transition towards adulthood.

Method

Two extracts from case studies will be outlined, drawn from a larger ethnographic project which followed up 17 young people with mild to moderate intellectual disabilities, in their late teens and early twenties. They all had significant problems of anxiety or depression, and were recruited from specialist mental health services and further education colleges which run courses for people with intellectual disabilities. These young people's emotional

difficulties were frequently a function of their social situation. Approval for the study was obtained from a local Health Service ethics panel in the central belt of Scotland.

Extracts from these two particular individuals were selected because they had contrasting experiences in dealing with stigma. While one of the participants had the autonomy to attempt to negotiate their own social status, the other remained trapped in a dependent relationship.

Procedure

The two participants described in this paper were visited regularly (a minimum of nine visits) over the course of six months to a year. A range of ethnographic approaches was used to tap into their experiences. Semi-structured interviews took place in a variety of contexts where the young people felt comfortable to talk to the researcher. In addition, interviews were carried out with their family and carers as well as others who were providing support such as social workers, teachers and health care professionals. Participants were also given disposable cameras to take photographs. The young people were given almost no direction about what sort of photographs they should take, but were just told that the pictures could be a helpful way of finding out more about their lives. The researcher would retrieve the camera when the film was full and return with the developed photographs to discuss them with the participant. Where possible, participants were also given video cameras to keep a video diary. The video was set up in a location in their houses where they felt able to record privately and talk about what they had done and how they were feeling. They were shown how to turn the video camera off and on. These innovative approaches provided other means for the participants to express their views, and helped to make the interviews more engaging. The participants greatly enjoyed using these media and the material that was generated offered an important picture of the young people's lives and their responses to unfolding events.

Pseudonyms are given to each of the participants to help maintain anonymity, although both the participants described in this paper gave permission for their materials to be used in the production of a DVD, primarily to help other young people and families who may be experiencing similar difficulties.

Case study extract 1

This participant, given the pseudonym of Gary, was interviewed on eight occasions, twice with his father, over an eighteen month period and he kept a video diary. Two of these interviews concerned sets of photographs Gary had taken. His clinical psychologist and community nurse were also interviewed. Gary first became involved in the study at twenty years of age.

Background obtained from interviews with Gary's father and professionals

Although he attended a special school for people with intellectual disabilities, Gary did well when he left school and for a short time he held down a job and had a flat of his own. Despite this promising start he struggled with the pressures of work and home life. He was bullied by other young people at work, whilst the help he was given by support services at home was insufficient to enable him maintain his flat. At the time he joined the study he was unemployed and had moved back into his father's house. His parents had separated when he was a child and he had limited contact with his mother. More recently his step-mother had separated from his father in very difficult circumstances. Gary would regularly drink alcohol to excess, and had been diagnosed by psychiatric services with clinically significant problems of depression and anxiety. Most worryingly, when in acute distress he had begun to walk out in front of cars and had only narrowly avoided being seriously hurt or killed on a number of occasions.

A sense of emptiness

In examining how Gary attempted to maintain or establish his social identity, the importance of context is shown by the photographs he took and the video diary he kept. A representative selection of the first set of photographs taken by Gary is shown in Figure 1. These are rather stark pictures of his house and the bare walls of his bedroom, along with pictures of his local shopping centre which he described going to on his own. When discussing the pictures with the researcher there was an overall sense of isolation and boredom. Asked about spending much of his time alone at home, when looking at the final photograph shown in Figure 1, he said that

‘In here (his house) it drives me nuts (crazy)’ and he linked this to his problems
‘Aye (yes). That’s why I’m going for the drink (alcohol)’.

The same sense of isolation came from the video diary that he kept. When speaking with either his family or the researcher he usually said very little and did not show much emotion. Nevertheless, a sense of frustration and anger was evident in his video recordings. He swore and complained that he ‘hated Mondays’ because it served as a reminder that he had nothing to do, ‘I don’t know what I’m going to do today, I’m sick of this’.

Seeking recognition

A contrasting set of photographs was given to the researcher on a later visit, four of which are shown in figure 2. Gary had got his father to take the first picture of him, dressed up for a Friday night out in his local town. There followed a series of photographs of Gary in a bar and club, apparently part of the crowd and with a variety of other young men and women. Yet when the researcher talked about the pictures with him, it became apparent that apart from one young woman he did not know any of the other people in the photographs. The final three photographs show him being taken to the accident and emergency unit of a local hospital by a policeman, after trying to throw himself in front of a car at the end of the

night. This followed an incident at the end of the evening when he had tried to speak to a girl, and this led to him being spat on by her boyfriend and his friends.

Further evidence of Gary's wish to promote a new identity was his father's description of Gary's wish to change his appearance:

'He wants to dye his hair constantly wants to dye it black the next time, he's gone to the sun beds to change the colour of his skin, he's getting new clothes to change the way he looks. He's wanting a complete change so I don't know what this is, God knows what this is.'

Whilst it may seem that this is fairly ordinary behaviour for a young person, his father's views have to be understood in the context of Gary's continual wish to make a fresh start in his life. When commenting on Gary's qualities and energy, his community nurse underlined what a difficult task it was for Gary to achieve the acceptance and social status that he desired.

'...he wants to be part of mainstream (society) but because of his disabilities he's unable to make that gap (sic) and he doesn't see himself as being disabled – he doesn't go to anything that's really obviously a disabled group. ... he's trying to be part of what everybody else does really.'

Case study extract 2.

This participant will be given the pseudonym of Sharon. Seven interviews were carried out with her over a six month period, she also took two sets of photographs and kept a video diary. Her mother and nurse therapist were also interviewed. Sharon was eighteen years old and living at home with her mother when she was recruited into the study. She attended a college course for people with intellectual disabilities.

Background information from interviews with Sharon's mother and professionals

She had been born with a hearing impairment and a hole in her palette, and her speech could be difficult to grasp at times. Following her referral for therapeutic help, aged 17, she had also begun having epileptic seizures. Sharon had been diagnosed with significant anxiety-related problems and mild depression, but what had brought her to the attention of specialist therapeutic services were aggressive outbursts with her mother. Sharon and her mother were receiving help from a nurse therapist.

Awareness of stigma

Sharon talked in the interviews about a keen sense of difference and her fear of people ‘looking at you as if you’re daft (stupid)’. Such views were rooted in past experience, and both Sharon and her mother described how she used to be sent out of her classroom to sit with younger children when she was in a mainstream primary school. She was subsequently moved to a school for children with intellectual disabilities which she said she had ‘loved’. Before leaving school, she was sent on work experience to a residential service for older people. She talked about being distressed when told to go and sit with the residents and watch television, rather than being given any work to do.

Sharon’s mother reported that her anxiety about going out was exacerbated by her epilepsy, but her nurse therapist also pointed to comments she had made about her sense of intellectual inferiority:

‘How come I’m different from my brothers and I’m stupid, and how come my nephew can count and I can’t and he’s seven.’

Negotiating adulthood

In the initial interviews Sharon expressed a reluctance to consider roles or tasks that might lead to failure, such as employment. She also pointed to the risks that her epilepsy posed to tackling independent tasks such as cooking, describing past accidents at home. However, her views became more inconsistent as the interviews progressed. For example,

Sharon said that she preferred college to school 'Because they treat you better, they treat you more like an 'adult'. She felt that in the future she might obtain employment and said the activity she enjoyed most at college was cooking. Nevertheless, she knew that she would not be allowed to cook at home or travel independently to the college.

Whilst Sharon got on well with the researcher, who was a young woman, she described herself as being 'shy' and said very little in interviews. And yet she talked, danced and sang when she recorded her video diary. She also spoke on the video diary about her reluctant acceptance of the serious limitations placed on her life, and this was clearly a matter of continuing regret. After watching a day time television programme she recorded the following views on camera:

'I'm just saying that I like 'ready, steady cook', one of my favourite programmes in the world...I don't think there's a better cooking programme than that anywhere. But I'm not allowed to cook, only do keep fit. I might burn myself and I have burnt myself before a couple of times. Feel stupid knowing you cannot do nothing, you cannot cook chips in the oven or can't put nothing on the gas. **You're** (sic) telling me that. Okay, I can use the microwave, I can make toast. But failing that I cannot go any further than that. Just the way it turns out, okay!'

Sharon's mother provided a distressing account of Sharon's first epileptic seizures, which had led to hospitalisation, and in this context her continuing anxiety about Sharon's safety was quite understandable. Yet such concerns were longstanding. Her mother said that she had rejected past offers of help when Sharon was younger because she felt; 'God, I've got to protect her'. Her mother's actions were borne out of a sense that her daughter remained her responsibility, and having always cared for and protected her she had a duty to continue doing so. Hence she seemed to view Sharon as child-like. For example, her concern that

Sharon would not accept the sanction of being told to go to her bedroom is not what one might ordinarily expect in a mother's relationship with her eighteen year old daughter. Other sources of conflict with her mother, raised by Sharon herself and her nurse therapist, were the fact that her mother continued to choose the clothes she wore each day and would not let her change her bedroom decoration.

Sharon found it very difficult to negotiate the move towards greater independence and adulthood. This seemed in part because of her lack of confidence, and may also have been due to prohibitions imposed by her mother because she viewed Sharon as incapable. Thus whilst Sharon seemed on the surface to accept her mother's authority on various matters such as her wish to travel independently, to work and to cook, she did not necessarily agree with her mother's judgements. As a result there was significant conflict about such matters, and Sharon faced considerable barriers to being the person she aspired to.

Discussion

Despite their emotional problems, these young people were not passive individuals shaped by external forces; rather they were actively trying to make sense of the world and establish their own identities within it. Central to this was dealing with stigma.

Goffman (1959) in his work concerning 'The Presentation of Self in Everyday Life' likens social interaction to dramatic performance. As people's social selves are given shape by others' responses, this means that the 'the very structures of the self' can be revealed in the way they prepare their performances for others. Hence Gary's wish to go out and be someone who is accepted and part of his peer group indicates his wish to break out of his stigmatised status as someone with an intellectual disability, who has led a rather isolated and lonely life. However, such a performance carries certain risks because it relies on obtaining acceptance or confirmation from one's audience. Risking potential failure, with subsequent feelings of embarrassment and shame, can be anxiety provoking. Sharon's sense of

powerlessness to actively challenge stigmatising conceptions held by others might have contributed to an understandable sense of injustice and anger.

There appeared to be a tension between the participants' apparent 'acceptance' of powerful external views that constrain their potential selves and a wish to contest such views. Social identity theory (Tajfel & Turner, 1979) and other theoretical approaches within the social stigma literature (e.g., Crocker & Quinn, 2000) may show the potential strategies people use to deal with stigma, but they do not describe what happens when these social negotiations prove unsuccessful or fraught. For example, at times Sharon seemed to accept her mother's view that she was incapable of cooking and at other times she complained about this. It would be mistaken to simply characterise all of her mother's actions as a form of benevolent stigma (Fiske, Xu, & Cuddy, 1999). There is a subtle difference between providing a level of support that is, in reality, required by Sharon due to her intellectual impairment and health problems, and an attempt to impose a child like status upon her. Therefore Sharon held in tension her close relationship with her mother and her wish to reject the imposed view of herself as someone lacking competence and destined to remain child-like.

The finding that these participants actively dispute others' views of them and try to shape their own identities is consistent with previous work in this area (Finlay & Lyons, 2000; Crocker & Major, 1989). This also fits with the results of the discourse analyses of micro texts described by Rapley (2004). Moreover, it was interesting that neither of the individuals described in this paper were particularly talkative, nor able or willing to provide elaborate accounts about their lives. The use of photographs and the video diaries provided revealing insights that would have been missed if there had been a sole reliance on interviews. Therefore, the lack of such verbal accounts should not necessarily be interpreted

as meaning that the participant does not hold a view about being treated in a stigmatised fashion or lacks self and other awareness.

In terms of working to improve the mental health of people with intellectual disabilities, the cases highlight the importance of social and inter-personal factors. Whilst the psychological treatment of choice for emotional problems presented by people with mild intellectual disabilities in the UK is Cognitive Behavioural Therapy (Beail, 2003), the difficulties these individuals faced were not merely with their cognitions, but dealing with real adversity. Hence interventions aimed at influencing people's self-perceptions in relation to stigma should be concerned with the realities of discrimination and social barriers, rather than just dealing with their interpretation of events. A young person like Sharon may need help to challenge or resist their stigmatised status, and have the scope to realise their potential and develop a sense of self-confidence. For Sharon this might mean being allowed to cook and travel independently. Yet from Gary's account it is apparent that one also has to recognise people's impairments. He had the autonomy to attempt to do as he wished, but what he required was the necessary support to achieve some of his goals successfully, and the resulting recognition from others to gain a sense of fulfilment. Group identification and the social support it offers has been shown to be a potentially important protective factor against the impact of discrimination on one's sense of self (Leach et al; 2009). However, people with intellectual disabilities are a socially marginalised group and often have impoverished social networks (Forrester-Jones, 2006). Indeed, after a range of psychiatric and psychological assessments and interventions it was this very kind of support commissioned from a voluntary organisation that ultimately had the greatest impact on his well-being. It may be difficult for someone like Gary to achieve a sense of belonging to any particular group, making social support crucial to achieving a positive sense of self.

Care needs to be taken when interpreting findings from two case studies. The rich data gathered from an ethnographic study of this nature highlights the complexity of people's lives, and there were many other factors about which we collected data, including family difficulties, physical health problems and economic hardship. It is also the case that other participants fared better in their attempts to gain social status or success. With support, some developed social lives based around college friends or attained greater autonomy, allowing them to have regular social outings on their own. It should also be emphasised that these young people were doubly disadvantaged, having both intellectual disabilities and significant emotional problems. However, it is not an easy task for stigmatised individuals with limited cognitive abilities, social status and autonomy to influence how others perceive them. On the other hand, there remains a broader and shared social responsibility to challenge the stigma people with intellectual disabilities face.

Conclusion

This study examined the experience of young people with intellectual disabilities who had additional mental health problems. Future research might usefully explore how people with intellectual disabilities ordinarily manage to negotiate preferred identities. Using a variety of data collection strategies was a novel aspect of this study, and proved essential to gaining insight into the meaning of stigma for these participants and to finding out how they dealt with it. The absence of such in-depth longitudinal work in the mainstream social psychological literature is also a matter of concern. While experimental control or reliance on formal interviews and questionnaires offer rigor, it may not be possible to reveal subtle social processes that occur in real life. The tension between the acceptance and rejection of social stigma was not something that the two participants with intellectual disabilities in this study were able to verbalise easily, but using innovative methods a richer picture emerged over time.

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Figure 1. A representative sample of three photographs from Gary's first film.



Figure 2. A representative sample of four photographs from Gary's night out.

