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Stigma of mental illness and ways of diminishing it

Peter Byrne

Stigma is defined as a sign of disgrace or discredit, which sets a person apart from others. The stigma of mental illness, although more often related to context than to a person's appearance, remains a powerful negative attribute in all social relations. Sociological interest in psychiatric stigma was given added vigour with the publication of *Stigma – Notes on the Management of Spoiled Identity* (Goffman, 1963). More recently, psychiatrists have begun to re-examine the consequences of stigma for their patients. In 1989, the American Psychiatric Association's annual meeting's theme 'overcoming stigma' was subsequently published as a collection of articles (Fink & Tasman, 1992), and last year saw the launch of the Royal College of Psychiatrists' five-year *Changing Minds* anti-stigma campaign.

What stigma means

Beyond any definition, stigma has become a marker for adverse experiences (see Box 1). First among these is a sense of shame. Mental illness, despite centuries of learning and the 'Decade of the Brain', is still perceived as an indulgence, a sign of weakness. Self-stigmatisation has been described, and there are numerous personal accounts of psychiatric illness, where shame overrides even the most extreme of symptoms. In two identical UK public opinion surveys, little change was recorded over 10 years, with over 80% endorsing the statement that "most people are embarrassed by mentally ill people", and about 30% agreeing "I am embarrassed by mentally ill persons" (Huxley, 1993).

The adaptive response to private and public shame is secrecy. Commenting on the barriers to the management of depression, Docherty (1997) cites both patients' shame in admitting to, and physicians' reluctance to enquire about, depressive symptoms. Family and friends may endure a stigma by association, the so-called "courtesy stigma" (Goffman, 1963). In one study of 156 parents and spouses of first-admission patients, half reported making efforts to conceal the illness from others (Phelan *et al*, 1998). Professionals are no different in this regard, and hide psychiatric illness in themselves or a family member. Secrecy acts as an obstacle to the presentation and treatment of mental illness at all stages. So, unlike physical illness, when social resources are mobilised, people with mental disorders are removed from potential supports. Poorer outcomes in chronic mental disorders are likely when patients' social networks are reduced (Brugha *et al*, 1993).

The question arises as to just what all this shame and secrecy is about. Negative cultural sanction and

Box 1. The experience of stigma

Shame
Blame
Secrecy
The "black sheep of the family" role
Isolation
Social exclusion
Stereotypes
Discrimination

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myths combine to ensure scapegoating in the wider community (see Box 1). The reality of discriminatory practices supplies a very real incentive to keep mental health problems a secret. Patients who pursue the secrecy strategy and withdraw have a more insular support network. Discrimination occurs across every aspect of social and economic existence (Fink & Tasman, 1992; Heller *et al*, 1996; Read & Reynolds, 1997; Byrne, 1997; Thompson & Thompson, 1997). A civilisation should be judged by how it treats its mentally ill: discrimination is also about the conditions in which our patients live, mental health budgets and the priority which we allow these services to achieve. By way of summary, Gullekson (in Fink & Tasman, 1992) writes about her brother's schizophrenia:

> "For me stigma means fear, resulting in a lack of confidence. Stigma is loss, resulting in unresolved mourning issues. Stigma is not having access to resources… Stigma is being invisible or being reviled, resulting in conflict. Stigma is lowered family esteem and intense shame, resulting in decreased self-worth. Stigma is secrecy… Stigma is anger, resulting in distance. Most importantly, stigma is hopelessness, resulting in helplessness."

Stereotypes

Goffman (1963) commented that the difference between a *normal* and a *stigmatised* person was a question of perspective, not reality. Stigma (like beauty) is in the eye of the beholder, and a body of evidence supports the concept of stereotypes of mental illness (Townsend, 1979; Philo, 1996; Byrne, 1997). Stereotypes are about selective perceptions that place people in categories, exaggerating differences between groups ('them and us') in order to obscure differences within groups (Townsend, 1979). As with racial prejudice, stereotypes make people easier to dismiss, and in so doing, the stigmatiser maintains social distance. The media perpetuate stigma, giving the public narrowly focused stories based around stereotypes. On a more positive note, the media are a useful location to begin the search for negative representations and adverse attitudes to mental illness, and ultimately the media will be the means of any campaign that aims to challenge and replace the stereotypes.

Philo (1996) measured violence as the central element in television representations in 66% of items about mental illness, an interesting figure in that it corresponds with the Royal College of Psychiatrists' 1998 survey, where 70% believed that people with schizophrenia are violent and unpredictable. At the other extreme, people with mental illness are frequently portrayed as victims, pathetic characters, or "the deserving mad" (Byrne, 1997). This parallels the experience of physical disability, where sympathy is a pretext for social distance – the "Does he take sugar?" strategy. The Royal College of Psychiatrists' survey also recorded consistently high responses (ranging from 50–79%) in relation to six common mental disorders, when the public was asked whether the *sufferer* was "hard to talk to". Most clinicians would instinctively encourage empathy not sympathy for their patients.

In cinema and television, mental illness is the substrate for comedy, more usually laughing *at* than laughing *with* the characters (Byrne, 1997). As part of the 'them and us' strategy, mental disorders have also been conferred with highly charged negative connotations of self-infliction, an excuse for laziness and criminality. Hyler *et al* (1991) have written about a number of Hollywood films where the representations of mental illness are of "overprivileged, oversexed narcissistic parasites". But 'pull yourself together' attitudes are not confined to fictional screen representations, with one Northern Ireland general practitioner writing:

> "Yet they ('neurotic patients') take up far too much of our time and energy – people complaining, miserable, depressed, neurotically whining about how unhappy they are, pouring out all their problems in the surgery and dumping them on my doorstep. It would be really unbearable if I was actually listening to them" (Farrell, 1999).

The process of stigmatisation

The history of stigma, culturally determined, is described elsewhere (Section 2 of Fink & Tasman, 1992; Warner in Heller *et al*, 1996). Some social scientists believed stigma was a function of labelling by psychiatrists, citing benign public attitudes of self-report studies and the observation that many patients were unaware of stigma: this is not supported by the evidence (Link *et al* in Fink &

Box 2. Stereotypes of mental illness

Psychokiller / maniac
Indulgent, libidinous
Pathetic sad characters
Figures of fun
Dishonest excuse: hiding behind 'psycho-babble' or doctors

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Tasman, 1992). Mental illness stigma existed long before psychiatry, although in many instances the institution of psychiatry has not helped to reduce either stereotyping or discriminatory practices. Further, the ubiquity of stigma and the lack of language to describe its discourse have served to delay its passing: racism, fatism, ageism, religious bigotry, sexism and homophobia are all recognised descriptions for prejudiced beliefs, but there is no word for prejudice against mental illness. One possible remedy to this would be the introduction of the term 'psychophobic' to describe any individual who continues to hold prejudicial attitudes about mental illness regardless of rational contrary evidence. Despite inevitable objections from some, the rise of 'politically correct' language has been a key factor in the success of campaigns opposing discrimination based on gender, age, religion, colour, size and physical disability (Thompson & Thompson, 1997).

Negative attitudes to people with mental illness start at playschool and endure into early adulthood: one cohort confirmed the same prejudices on re-examination eight years later (Weiss, 1994). Green *et al* (1987) measured consistently negative public attitudes at five separate points over 22 years. These studies, and that quoted above from Huxley (1993), directly contradict a recent claim (stated but unreferenced) that "public perception of psychiatric disorders will change: improved understanding of the causes and mechanisms of disease is likely to reduce stigma" (McGuffin & Martin, 1999). Accepting the low value most cultures attach to mental disorders, are there any qualities in stigmatisers that could be altered to reduce overall levels of stigma? Adorno *et al* (1950) have hypothesised about the likely make-up of prejudiced people: they have an intolerance of ambiguity, rigid authoritarian beliefs and a hostility towards other groups (ethnocentricity). Other studies of the attributes of those who are more likely to produce negative evaluations of stigmatised people found no relation to "conventionalism", but did report an association with a "cynical world view" (Crandall & Cohen, 1994).

Knowing someone who has a mental illness is not associated with more enlightened attitudes (Wolff *et al*, 1996*a*), but Huxley (1993) identifies that the key factor is direct contact with people who have had "helpful treatment for episodes of mental illness". The challenge, listed in the third section of Box 3, is to confront the stigmatiser with his or her irrational beliefs, in addition to enabling direct contact with "one of them". This may seem an unrealistic aim, if the prototype stigmatiser conjures up images of shaven-headed boot-boys, but any list of stigmatisers includes landlords, employers, insurers, welfare administrators, housing officers, universities, health care professionals, lawyers, prison workers and teachers.

Levels of intervention

The starting point for all target groups and at every level is education: to date, the *Changing Minds* campaign has succeeded in its requests to medical journals to publish articles on stigma. These articles, including the excellent *Lancet* series (*Lancet*, 1998) have provoked discussion within professional circles, and beyond. *Psychiatric Services* and the UK-based *Journal of Mental Health* have been major forums for research and debate on this subject, and more

Box 3. Factors which influence the prejudice of stigmatisers

Factor type	*Example*	*Likely to increase prejudice*
Attribute of stigmatised	**Gender**	**Male gender**
	Appearance	**Unkempt appearance**
	Behaviour	**Acute illness episode**
	Financial circumstances	**Homelessness**
Assumptions about the individual's disorder	**Perceived focus of illness**	**Many deficits**
	Perceived responsibility	**Not responsible for actions**
	Perceived severity	**History of hospital admission**
Knowledge base about particular disorder	**Perceived origin**	**Self-inflicted**
	Perceived course	**Incurable/'chronic'**
	Perceived treatments	**'Needs drugs' to stay well**
	Perceived danger	**Criminality or violence**

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recently the *Psychiatric Bulletin* has featured a number of key articles. Other professions – nursing, occupational therapy and social work – have been writing about these issues for far longer and in greater depth than psychiatrists. Publications in the lay press circulate the arguments to a wider audience. The Internet is already a highly effective means of distributing information and specific anti-stigma initiatives, and readers can access details of *Changing Minds* and other campaigns through www.rcpsych.ac.uk. and www.irishpsychiatry.com. Stigma and its sequelae should achieve a prominent place on the curriculum of all health service professionals and their students. The latter group will be the decision-makers of the next millennium and will either initiate further social psychiatry research or make the same mistakes as their predecessors.

Wolff *et al* (1996*a*,*b*) have provided a practical working model for interventions aimed at various target groups (see Box 4). One aspect of this is to listen to the concerns of the people whose attitudes you wish to change. Young couples with children have specific fears that need to be addressed, and in this group, reductions in levels of fear can be achieved with educational interventions (Wolff *et al*, 1996*a*). Other settings, for example schools, workplaces and welfare services, will require different information packages tailored to their needs. The content of these interventions should include the components of established psychoeducation modules, the stigma–discrimination paradigm (a prototype presentation is available at www.rcpsych.ac.uk) and information specific to the needs of the target group.

Mental health professionals need to move beyond teaching psychoeducation in isolation (at the clinic) to full participation in planned programmes of public education (see Box 5). Every intervention must convince its target group of the importance of stigma/discrimination, challenge stereotypes in ourselves and others, and pursue the ongoing task of unravelling the nature of prejudice. These three separate tasks are summarised in the *Changing Minds* slogan: "Stop, think, understand".

Closing the knowledge gap is only part of the answer. Stigmatisers, as a rule, are unlikely to volunteer to attend educational packages. Even assuming the message reaches all targets, education alone cannot change centuries of folklore and prejudice. The 'carrot' of education must be accompanied by the 'stick' of challenges to media misrepresentations, positive discrimination in the workplace, test cases in the courts, and legal sanction through (for example) the Disability Rights Commission. In this regard, lessons can be learned from AIDS foundations and the gay community, who met the challenge of initial public antipathy to AIDS, and who have now achieved the dual goals of health promotion and major reductions in discriminatory practices (Thompson & Thompson, 1997).

Changing psychiatry first

Ask yourself the following questions: could you give a talk about stigma next week? What have you done to reduce stigma and discrimination against your patients? Is stigma on the undergraduate curriculum of your university, or something about which your trainees have formal teaching? It is not just that psychiatry has a shameful history in its contributions to modern-day misconceptions about mental illness (see Box 6), but that it has also failed to address its current deficiencies. None of the standard British psychiatry textbooks cites "stigma" in their indices. There is a dearth of *psychiatric* research on stigma and discrimination, and a perennial resistance to rocking the stigma boat. Wolff *et al* (1996*a*) described their failure to achieve ethical approval for their study in London, and also described staff preconceptions that it would draw attention to the patients' problems, making integration locally more difficult.

Many psychiatrists share the stereotypes described above. Lewis & Appleby (1988) reported that

Box 4. Key suggestions for educational interventions: after Wolff *et al* (1996*a*)

- **Specific target groups, with prior identification of their attitudes**
- **No evidence of community backlash**
- **Flexible public education packages**
- **Small groups work better**
- **Several interventions over time exceed the sum of their parts**
- **Continuing contact with the group (keyworker) maintains momentum**

Box 5. From psychoeducation to public education

Patient	**Person**
Family	**Target group**
Network	**Community**
Advocate group	**Society**

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psychiatrists reacted to vignettes differently if the person had been given the diagnosis of a personality disorder: once labelled, primary diagnoses differed and value judgements (e.g. "manipulative", "does not merit NHS time", "unlikely to improve", "likely to annoy") appeared more frequently. Antipathies to psychiatry and psychiatrists are widespread among the medical profession, but perhaps the real issue is that the majority of psychiatrists fail to challenge these prejudices. This failure to respond, be it acquiescence or resignation, cannot continue. The impetus to challenge ageism did not come from medical gerontology, but was later championed by that speciality. Radical action within and outside psychiatry is now required.

Dubin & Fink (in Fink & Tasman, 1992) describe how psychiatrists perpetuate many concepts underlying biased and stigmatising attitudes, and suggest that the way in which psychiatry is structured maintains the status quo. Eisenberg (1995) has criticised the highly charged 'either/or' discourse that mental diseases are either biological/'no one's fault' or psychological/'caused by' parents, spouses or patients. Silence on these issues is no longer tenable: for all aspects of stigma and discriminatory practices, psychiatrists need to complain more often and more effectively – media coverage is a good starting point (Hart & Philipson, 1999). For psychiatrists, the debate goes beyond stigma. It includes the quality and structure of existing services, and the barriers that deny access to them (Thompson & Thompson, 1997). Compliance is one example where both a concept, and the theories underlying it, are in need of a radical change in mind set. Brandon (in Read & Reynolds, 1996) has provided a number of suggestions for change among psychiatrists, principally abandoning the 'them and us' mentality. Crepaz-Keay (in Read & Reynolds, 1996) sums up the (stereotypical) psychiatrist's reactions to advocates: "But *you're* not like *my* clients" or "Who do *you* represent?".

Box 6. A history of dumb ideas in psychiatry

Moon (lunatic) and womb (hysteria) theories
Technique of persuasion
Epileptic personalities
Mental and moral defectives
Eugenics (Ernst Rubin)
Insulin coma treatment
Frontal lobotomy
Momism, schizophrenogenic mothers, Schism & Schew families
Treatments for homosexuality

Practical stigma management

If every psychiatrist left rehabilitation to the rehabilitation team, there would be no rehabilitation. Equally, if every psychiatrist leaves 'the stigma issue' to the *Changing Minds* campaign, there will be no enduring change. Psychiatrists should address stigma as a separate and important marker in its own right. Because of the nature of stigma, patients are unlikely to bring it directly to the attention of the mental health team. Clinicians should ask about the nature of adverse experiences, discrimination, the extent of social networks, self-image, etc., and incorporate these issues into the treatment plan. Acknowledging the existence of prejudice is an essential first step, and is no more 'dangerous' than enquiry into suicidal ideation. There may be a specific focus of adverse experiences (bullying at work or school, family difficulties), or ways in which the patient can alter others' reactions to him- or herself (see Box 3). The patient needs to construct these stigmatising experiences as part of a generalised prejudice in society, allowing the possibility of overcoming his or her own difficulties. Alongside this, the clinician will gain in adding to his or her existing knowledge of the patient's social context and learning more about stigma.

Schizophrenia presents unique challenges. Lack of insight is always problematic, but an affective component can be associated with denial of symptoms or rejection of treatment at key points in the illness. The life events model contains many events that could be precipitated by stigma-led experiences: losing a job, a home or a friendship. It is about humiliating and devaluating experiences, and these play an important part in relapses of depression. Equally, the central roles of vulnerability, destabilisation and restitution factors have a bearing on outcome. Pessimism in the profession may also negatively affect patient perceptions here: for years, the chronic social breakdown syndrome of long-stay patients was seen as an integral part of schizophrenia (Eisenberg, 1995). Given that at least 50% of people with schizophrenia have significant social skills deficits, any programme must include improving interpersonal skills. A symptom-focused approach that includes stigma management can be incorporated into an existing cognitive–behavioural model of treatment (Enright, 1997). A comprehensive list of social obstacles to successful de-institutionalisation has also been described (Farina *et al*, in Fink & Tasman, 1992).

With the possible exception of some patients with Alzheimer's dementia, patients need to know their diagnosis and what the problems are and are likely

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to be. Just as adverse public attitudes endure over time, the adverse effect of stigma on individuals' well-being persists from entry into treatment up until a year after successful treatment (Link *et al*, 1997). Cognitive–behavioural therapy (CBT) is now of proven efficacy across the spectrum of mental disorders (Enright, 1997): its core strategy is disseminating information about the illness. Holmes & River (1998) have outlined a CBT approach to combating stigma in individuals. Their article is one of seven similar articles in the Winter 1998 (vol. 5) issue of *Cognitive Behavioural Practice*.

The next step in management is to transform the person from patient to advocate. Part of coping with stigma is fighting stigma. A recent Royal College of Psychiatrists' Council Report lists many different kinds of advocacy: self, peer-group, legal, carer and citizen (Royal College of Psychiatrists, 1999). In joining an advocate group, the dangers of a 'them and us' situation arise. Certainly, not everyone who experiences mental illness needs the companionship and validation of others who have had similar experiences. But if the advocate group includes contacts with partners, friends and families, along with community groups, civil rights activists, campaigners, even (*sic*) mental health professionals, then it will be a valuable experience. The College, in the same report, issues a formal policy directive on advocacy, broadly welcoming it, and recommending early exposure to it for its trainees. Fisher (1994) identifies empowerment as essential to recovery from chronic disability. The relationship between psychiatry and the advocacy movement is not a one-way street. In the past three years, these are the learning experiences that the author has encountered at advocates' meetings:

- an architect objecting to her work colleagues' constant references to a psychiatric unit they were designing as a "nut house" or "psycho depot"
- an insurance executive, with a remote history of mental illness, challenging the loading of his insurance policy – by his own firm
- a nurse, following an episode of depression, insisting on returning to the intensive care unit and not, as suggested, to a convalescence ward
- a medical student challenging the Dean to show the same flexibility with mental illness as he had previously shown with physical disability
- a teacher with bipolar disorder encouraging the schools' board to include information on this illness on the curriculum
- a footballer insisting his team play the local psychiatric unit
- a newsagent offering to keep newspaper cuttings to facilitate a local initiative on negative media coverage of mental health issues
- a parent's description of services as "supermarket psychiatry"
- a man who had recovered from an episode of depression, objecting to a public education campaign that would include schizophrenia and depression together: "Why drag depression down to the level of the gutter?"
- a consultant psychiatrist, on hearing an articulate account of schizophrenia from a woman living with the illness, "Then she couldn't be schizophrenic".

Future directions

It is difficult to predict the progress over time of a variety of existing anti-stigma initiatives. Media coverage of these interventions will be essential to disseminate positive mental health messages, while challenging current misrepresentations. Regardless of the means (education, legal remedies, health service changes), the end is to promote social inclusion and reduce discrimination. The nature of that discrimination will change as the practices of discrimination are successfully challenged: the task is to identify prejudice in whatever context. Examination of the achievements of other anti-discrimination movements leaves mental illness stigma as one of the last prejudices. A prerequisite must be to continue listing discriminatory practices from different perspectives. In some instances, for example the current practice of psychiatric assessment of candidates for organ transplantation, psychiatrists are already part of the discriminatory culture, and must rely on others to highlight injustice. Double discrimination, the coincidence of mental illness and ethnic minority status, is another area where psychiatry on its own will not effect change (Browne in Heller *et al*, 1996). Psychiatry in these and other areas must collaborate with other fields in identifying problems and effecting enduring solutions.

All available evidence confirms the value of local initiatives, and that means *your* active participation. Which would be worse – the widespread reduction of prejudice against people with mental illness without the participation of our speciality, or the maintenance, through disinterest, of the status quo?

Please send new ideas for combating stigma to: Liz Cowan, Changing Minds Campaign Administrator, Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG.

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Multiple choice questions

1. With regard to an individual's experience of stigma:
   a he or she can do little to change the reactions of prejudiced people
   b most psychiatric patients will complain directly to their doctors of the effects of stigma on their lives
   c the experience of self-stigmatisation can be similar to negative automatic thoughts or the negative cognitions described in depression
   d patients with either alcohol problems or eating disorders are each more likely to be blamed for their conditions than other patient groups
   e courtesy stigma refers to strangers feeling pity for an individual.

2. The following statements are true about people who hold prejudiced attitudes:
   a knowing someone with mental illness is associated with more benign attitudes to people with mental illness
   b people who do not blame the individual with mental illness are more likely to get involved in anti-stigma initiatives
   c women show more benign behaviours to the stigmatised than men
   d parents with young children tend to show a greater understanding of the links between mental illness and violence
   e direct contact with someone who has acute psychosis helps generate greater understanding later on

3. Regarding research on the effects of stigma:
   a the majority of research has been carried out by psychiatrists
   b there has been a marked increase in stigma-related publications over the past 10 years
   c stigma management is a concept first devised by social workers
   d telling people they have schizophrenia is associated with an increase in suicidal behaviour
   e teaching patients about the nature of bipolar disorder reduces the number of manic relapses and improves social functioning overall.

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4. With respect to stigma and the course of the illness and its treatment:
   a social isolation is associated with a longer duration of depression
   b general practitioners do not perceive themselves as being involved in the care of their patients with serious mental illness, particularly if they are Black African, Black Caribbean, or male
   c studies of people who had contact with psychiatric institutions (USA), compared to controls, show median ages of death of 66 and 76 respectively
   d measuring the attitudes of health professionals, patients with anorexia were seen as significantly "less likeable" than patients with schizophrenia, and as being responsible for their illness
   e since the publication of Goffman's *Stigma* in 1963, psychiatrists have been at the forefront in campaigns to identify and abolish stigma.

5. Research on community attitudes to mental illness (Green *et al*, 1987) show:
   a little or no change over 22 years in negative attitudes to mental illness
   b attitudes to people with individual mental illnesses have shown more understanding as knowledge increased, alongside phased community care
   c 'psychiatrists' are held in equally high esteem to 'doctors'
   d to be an 'ex-mental patient' carries a number of low positive ratings
   e stereotypical beliefs, such as "dangerous", "worthless", "weak" and "foolish", have persisted to the same degree over 22 years.

MCQ answers

1	2	3	4	5
a F	a F	a F	a T	a T
b F	b T	b T	b T	b F
c T	c T	c T	c T	c F
d T	d F	d F	d T	d T
e F	e F	e T	e F	e T

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