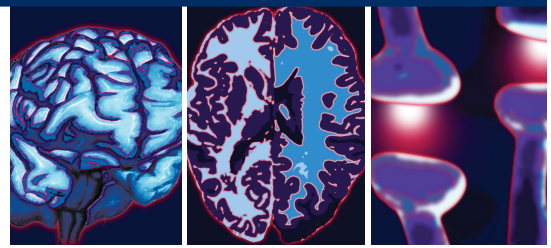


SPECIAL REPORT



Prejudice, discrimination and social exclusion: reducing the barriers to recovery for people diagnosed with mental health problems in the UK

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Practice points

- We should focus on positive attributes, strengths and skills rather than problems, diagnosis and dysfunctions when working with those with mental health problems.
- We need to work with communities to create opportunities for face-to-face contact between people with and without disabilities on an equal basis.
- People need to be helped to access opportunities within their communities to achieve their personal goals and aspirations.
- People should be made aware of their rights to reasonable adjustments under the Equality Act.

SUMMARY If people with mental health problems are to recover valued lives then they need support to become contributing members of society. This article demonstrates the ongoing existence and impact of exclusion in impeding recovery and explores the mechanisms underpinning inclusion for both individuals and their communities. The significance of tackling lack of knowledge, negative attitudes and rejecting behavior are described and approaches to decrease these are discussed. Future directions are considered with recommendations for changes in the educational messages used, the facilitation of contact in community settings, the measurement of outcomes in terms of positive social achievements and reference to the United Nations Convention on the Rights of Disabled People, the UK Equality Act and the forthcoming UK Disability Strategy.

“Out of the blue your job has gone, with it any financial security you may have had. At a stroke, you have no purpose in life, and no contact with other people. You find yourself totally isolated from the rest of the world. No one telephones you. Much less writes. No-one seems to care if you’re alive or dead” summarizes Bird [1].

To be diagnosed with mental health problems is a devastating and life changing event [2,3]. Not only do you have to cope with strange and sometimes frightening experiences, but also with all that these mean in our society in terms of loss of role, status and identity. The prejudice and discrimination that surround a diagnosis of mental

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health problems ensures that many people with such diagnoses continue to be excluded in all facets of economic, social and civic life [2,4–7]. Recent UK data demonstrate that the vast majority of people with mental health conditions (91%) report experiencing discrimination in at least one area of their lives [8] – the most common manifestations taking the form of being shunned and feeling avoided by others.

Too many people continue to believe that people with mental health conditions cannot be trusted (e.g., as babysitters or holders of public office) [9] and social isolation remains rife [10]. However, it is in the area of employment that discrimination and exclusion are most marked [10]. The largest proportion of people applying for ‘out-of-work’ benefits for disabled people (43%) have a mental health condition. While unemployment rates among all disabled people have risen steadily over the last decade, since 2000, the employment rate for those with a mental health condition has remained stable. In 2012, the employment rate stood at 14% [1], some 32.3% less than that of all disabled people and 60.4% less than that of non-disabled people. The poverty and reduced social networks as a result of unemployment serve to further increase exclusion.

A number of beliefs about the person with a mental health condition underpin the prejudice and discrimination that lead to exclusion [11,12], including:

- Personally weak or to blame for their illness;
- Dangerous or likely to become violent;
- Unpredictable or difficult to interact with;
- Unlikely to recover even with treatment.

To these, the belief of a biological basis for the condition (see below) and a discontinuity (rather than continuum) with normal experience have been added [13].

Different diagnoses may attract different degrees of prejudice and exclusion. For example, a number of studies have demonstrated that people prefer greater social distance from those with a diagnosis of schizophrenia than those with a diagnosis of depression [13], and those with ‘serious’ mental health conditions have lower employment rates than those with ‘common’ mental health conditions such as depression [10]. However, employment rates among those with such conditions remain far higher than those of other disabled people [10]. Lasalvia *et al.* showed that the

majority of people with depression reported experiencing discrimination in at least one domain of life [14]. However, it may be the case that different beliefs underpin discrimination against people with different diagnoses. For example, Norman *et al.* found that both students and business people desired a greater social distance from people with schizophrenia [13]. In comparison with depression, participants were significantly more likely to perceive a discontinuity between schizophrenia and ‘normal’ experience, and that schizophrenia was more likely to result in socially inappropriate behavior. Conversely, in comparison with schizophrenia, participants were significantly more likely to believe people with depression to be personally responsible for their illness. Their results were mixed in relation to perceived danger (students perceived those with schizophrenia as more dangerous; among business people there was no difference in perceived dangerousness between schizophrenia and depression). Thus, it may be the nature of beliefs underpinning discrimination that differs with diagnosis.

While there may be differences in the degree and nature of the challenge, everyone diagnosed with mental health problems faces the challenge of recovering a meaningful, valued and satisfying life within and beyond the problems they experience. Assisting people to achieve this is one of the key planks of the English mental health strategy [15] and requires the opportunity to do the things you value and be a contributing member (rather than a ‘burden’) in your community [2,3,16,17]. This cannot be accomplished by treatment alone. Neither medication nor therapy constitute a cure for prejudice and discrimination, and improvements in treatment and its availability over recent decades have not seen a commensurate decrease in exclusion; indeed, there is some evidence that employment rates have actually fallen [18,19]. Stigma, discrimination and exclusion are major barriers to recovery; their consequences for the self-esteem, social functioning, depression, life satisfaction and employment of people have been widely documented [3,5,6,20–22]. To promote social inclusion it is necessary to move beyond treating individuals towards creating communities that can accommodate people with mental health problems. If this is to be achieved, an understanding of the underpinning mechanisms is important.

Understanding discrimination & exclusion

Sayce defines social exclusion as [4]: “the interlocking and mutually compounding problems of

impairment, discrimination, diminished social role, lack of economic and social participation and disability. Among the factors at play are lack of status, joblessness, lack of opportunities to establish a family, small or nonexistent social networks, compounding race and other discriminations, repeated rejection and consequent loss of hope and expectation.”

It has become commonplace to talk of the ‘stigma’ of mental illness [101], but there has been controversy about the use of this term [2,4,6,23,24]. Sayce has described how the terms used lead to different understandings of where responsibility for the problem lies and, as a consequence, different prescriptions for action [25]. Most definitions of stigma focus on characteristics of an individual that are devalued [26–29]. This leads to a focus on the impact of stigma rather than the mechanisms that result in the disadvantages. Sayce [4,25] and Corrigan *et al.* [30] draw on understandings of other types of discrimination, such as racism, and emphasize the importance of shifting the focus from individual/psychological explanations to a consideration of the structural and institutional discrimination that restricts opportunities.

Cognisant of these critiques, Link and Phelan conceptualize stigma in structural terms and explore the mechanisms via which undesirable characteristics come to be linked to labeled individuals and result in the limitation of opportunity and exclusion [24]. They describe exclusion as arising when four inter-related components converge. The process necessarily begins with distinguishing and labeling human differences. This alone does not result in exclusion and the denial of rights; most human differences, such as the color of one’s car or the length of one’s forearm, are ignored. The second component involves dominant cultural beliefs linking undesirable attributes – negative stereotypes – to labeled persons. The label ‘mental illness’ has been variously associated with characteristics such as dangerousness, incompetence and unpredictability. In the third component, labeled individuals are placed in distinct categories: ‘they’ are separated from ‘us’. In the fourth component, ‘they’ (labeled people) experience loss of status, discrimination and exclusion.

Three types of discrimination can be identified [31]:

- Individual discrimination occurs when, for example, people are turned down for a job or shunned/taunted because they are believed to be mentally ill;
- Structural discrimination (akin to institutional racism) occurs when a set of institutional practices work to the disadvantage of people with mental health problems. For example, people diagnosed with mental health problems are likely to have difficulties getting/keeping jobs and be unemployed for protracted periods of time. Thus, they may lack the ‘good work history’, references and personal recommendations necessary to get a job, thereby further decreasing their chance of employment;
- Discrimination can result from the ‘stigmatized’ person’s beliefs and behaviors. As a consequence of individual and structural discrimination, people are likely to lose confidence in their abilities/possibilities and give up applying for jobs and trying to engage in other facets of social and civic life.

Sayce [4], Corrigan [30] and Link and Phelan [24] all emphasize that discrimination and exclusion are entirely contingent on access to social, economic and political power. It is such power that [24] “allows the identification of difference, the construction of stereotypes, the separation of labeled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination ... we apply the term stigma when elements of labeling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows them to unfold.”

Reducing discrimination & exclusion

Thornicroft has argued that underpinning the exclusion experienced by people with mental health conditions experience lie three key elements: problems of knowledge (ignorance), problems of attitudes (prejudice) and problems of behavior (discrimination) [6]. However, it is becoming increasingly evident that the type of messages and approach used in trying to tackle ignorance, prejudice and discrimination are critical. Sayce describes a number of approaches that have been adopted in efforts to decrease discrimination and exclusion [4]. Most prominent among these has been the biogenetic ‘brain disease’ approach, claiming that ‘mental illness is an illness like any other’ that has been adopted by the World Psychiatric Association [32] and many other antistigma initiatives across the world. The assumption is that if mental disorders are attributed to factors outside the individual’s control, then reactions to people with such disorders (and their relatives) will be less negative [33]. So

entrenched are such assumptions of the positive value of the 'mental illness is an illness like any other' message that it has been used as an indicator of a 'positive' attitude in many evaluations of beliefs and knowledge about mental health problems [34]. For example, the UK National Health Service Attitudes to Mental Illness survey includes 'mental illness is an illness like any other' among the statements indicating a positive attitude towards 'integrating people with mental illness into the community' [9].

Internationally, such campaigns and public education programs have apparently been successful in encouraging people to believe a brain disease construction of mental illness [31]. In the UK, the Attitudes to Mental Illness survey [9] reported an increase from 71% in 1994 to 77% in 2010 in the proportion of people endorsing the 'mental illness is an illness like any other' statement. However, there is now a wealth of evidence demonstrating that such explanations actively exacerbate prejudice and discrimination.

In their comprehensive review of international literature, Read *et al.* found that biogenetic explanations of schizophrenia were associated with negative attitudes (perceptions of dangerousness and unpredictability, fear and a desire for social distance) and that the public labeling of disturbed/disturbing behavior as 'mental illness' worsened discrimination [34]. Similarly, Phelan found that such explanations engendered a kind of 'genetic essentialism' that exacerbated stigma by increasing perceptions of persistence, seriousness and transmissibility. Biogenetic explanations increased the desire for social distance (especially close contact like dating, marriage and having children) from siblings and children who had never experienced mental health problems [35]. Pescosolido *et al.* found that holding a neurobiological understanding of schizophrenia increased the odds of preferring social distance by a factor of 2.2, and for depression increased perceptions of dangerousness to others by a factor of 2.7 [36].

Public attitudes and beliefs are important in determining not only individual discrimination, but also structural discrimination via shaping public policy and legislative frameworks, and the way in which individuals perceive themselves. However, new directions for change are needed based on a rethinking of the underlying mechanisms [36].

A wealth of evidence exists demonstrating that contact is powerful in decreasing prejudice and discrimination [37–42]. In a meta-analysis of

outcome studies Corrigan *et al.* showed that both education and contact had a positive impact, but personal contact with people who are known to have mental health problems was more effective in adults [43]. The English Time to Change antistigma campaign utilized social contact at a population level (via events that aim to engage members of the public with and without mental health problems) and demonstrated a significant (if somewhat modest) effect on stigma-related behavioral intentions [8,44,45].

Research into the impact of contact has adopted a range of methodologies (e.g., retrospective and prospective personal contact and opinions of vignettes) and types of contact (e.g., professional, personal, incidental and purposeful). These indicate that the nature of contact is important [37,38,46]. The Time to Change antistigma initiative showed that people were most likely to report experiencing discrimination from people with whom they had a great deal of contact: friends (53%), family (53%) and, worryingly, mental health staff (34%) [8]. Many reviews of the literature on the conditions under which social contact acts to decrease prejudice have been conducted [6,37,38,40,43,46]. These conclude that a number of conditions are necessary if social contact is to be effective in reducing prejudice:

- There is equal status between groups;
- Stereotypes are likely to be disconfirmed;
- There is intergroup co-operation, where people work together rather than being competitive with one another;
- There are common goals;
- There is intimate (one-to-one) contact;
- Participants can get to know each other properly;
- There is support from authorities and the law, and wider social norms/customs support equality.

Contact of this type also aims to reduce ignorance, and thereby address problems of knowledge, as well as problems of attitudes [6].

Conclusion & future perspective

Based on the research to date, a number of conclusions could be drawn concerning promising directions of attempts to promote inclusion and enable the participation of people diagnosed

with mental health problems as equal citizens in all facets of community life.

First, if education is to be effective the messages used are important. Neurobiological ‘mental illness is an illness like any other’ messages should be replaced by an approach that focuses on abilities, competencies and community integration of people with mental health problems [4,30,34,47].

Second, we need to focus on achieving contact on equal terms where people have common goals and work together [37,38,40,41]. While this may be achieved via mass campaign events [44], it might more generally be promoted via teams/services focusing on actively helping those whom they serve to participate in economic and social life within their communities as part of their routine practice in mental health services. Too often the assumption is that it is necessary to reduce ignorance and break down prejudice at a general level (via various forms of ‘awareness-raising’ campaigns) before the inclusion of individuals can be promoted. However, the research literature strongly suggests that it is by promoting inclusion in the warp and weft of everyday life that the type of contact that dispels ignorance, challenges prejudice and erodes discrimination can be achieved. If a person is assisted to access opportunities they value in the fields of employment, education, faith communities, collaborative sports and leisure activities, and civic life more generally (e.g., school governors, charitable trustees, ‘neighborhood watch’ schemes and other community projects, and standing for elected office), the one-to-one contact where they are of equal status will allow people to get to know each other properly and share common goals, and will probably result in stereotypes being disconfirmed.

Randomized controlled trials in many countries [48,49] clearly demonstrate that, with the right kind of support, people with serious mental health conditions can access and sustain open employment. It would seem reasonable to assume that these same principles would be equally applicable to participation in other domains:

- Focus on competitive employment/participation in open, mainstream settings (rather than segregated opportunities only for those with mental health conditions) and a ‘can-do’ attitude that raises expectations;
- Rapid job search – provide people with the support they need to access work/other opportunities as quickly as possible rather than engaging in preparatory training. The longer a person is out of work the less likely they are to go back;
- Integration of employment/assistance to access mainstream opportunities into support and treatment plans (‘treatment’ and ‘rehabilitation’ in parallel rather than in sequence as is too often the case);
- Eligibility for support based on client choice – help anyone who would like to give it a try rather than selecting people on the basis of their supposed ‘readiness’;
- Job search/choice of mainstream activities based on client preferences rather than clinician judgements about what is ‘best’ or ‘most suitable’;
- Ongoing supports for both the employee and employer/others involved in the situation should be provided. Participation involves a relationship in which both parties may need support. This may include negotiating ‘adjustments’ or ‘accommodations’ to enable the person to participate (e.g., a mentor/buddy, environmental adaptations and relief from certain noncore expectations/responsibilities);
- Assistance/advice on welfare benefits. It is important that people understand the implications for welfare payments of engagement in different activities and have access to all of the resources to which they are entitled (e.g., funding from disability employment programs for workplace adjustments and supports, and social care funding for nonwork activities).

Third, the importance of contact on equal terms and the need to emphasize abilities and competencies indicates that, where more general local and national initiatives are implemented to promote inclusion, people with mental health conditions themselves have the major role [4,50–52]. Henderson *et al.* argue that the frequency of discrimination experienced from mental health professionals (~33%) suggests caution about advocating their greater involvement [8]. Sayce emphasizes the importance of having people with a diagnosis of mental health problems delivering messages, backed up by ‘experts’ when this is tactically appropriate [4].

In addition to antistigma campaigns [101], this approach has been particularly effective in initiatives to create ‘dementia-friendly’ communities [53], where people with dementia and their relatives define what accessible communities might look like, design guidance and deliver training for people providing goods and services (e.g., shops and leisure centers) about how to accommodate people with dementia. One such program is the Early Dementia Users Cooperative Aiming To Educate [EDUCATE] initiative in Stockport, UK [102]. Perhaps the ‘peer support workers’ currently being introduced into many teams and mental health services [54] might have a more important role to play in this regard. Targeting messages to specific audiences (e.g., employers and education providers) so that dialog can be achieved, and working at national and ‘grass roots’ levels simultaneously, would appear to be the most promising approaches [4,6].

Fourth, we need to consider how we evaluate the outcomes of interventions and services by moving beyond a focus on symptom/problem reduction and assess effectiveness in terms of the outcomes for people’s lives (jobs, homes and friends) [2,3,12,17,47]. The English Mental Health Strategy identifies this in the second of six key outcomes: “More people who develop mental health problems will have a good quality of life – greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live.” [13].

Similarly, in evaluating the impact of anti-stigma/discrimination initiatives, we need to move beyond the focus on changing attitudes, behavioral intentions and self-reported experience of discrimination [8,40], and instead assess their impact on actual participation in different facets of the economic, social and civic life.

Finally, while grass roots action is important, contact alone is unlikely to be enough to fundamentally change structural discrimination and the power relationships on which it is founded [4,24,26,30]. If contact is to be effective then there must be support from authorities and the law, and wider social norms/customs must support equality. In this context, the UK Mental Health (Discrimination) Act, which received Royal Assent in February 2013, has been important in removing legislative barriers to participation

in public life (jury service, school governors and MPs). This is important in maintaining exclusion, both in themselves and in the messages they convey about the skills and competencies of people diagnosed with mental health problems. However, much structural discrimination continues (e.g., in ‘fitness to practice’ standards of professions [55] and in practices such as discriminating against people with ‘gaps’ in their CVs). In addition, few people with mental health conditions are aware of the rights they have under equalities legislation.

Perhaps, as Sayce concludes [4], there is much to be learned from the broader disability world and the success achieved in promoting participation and inclusion of people with physical impairments based on a social model of disability [2,6,23,52,56–59]. This model underpins the United Nations Convention on the Rights of Disabled People (to which the UK is a signatory) [103], the UK Equality Act [104] and the forthcoming UK Government Disability Strategy [60] (all of which explicitly encompass people with mental health conditions). Premised in a human rights approach, it focuses not on individual deficits and dysfunctions but on the barriers to participation and inclusion that people face (e.g., attitudes, actions, assumptions, legislation, social, cultural and physical structures) and the right to the support and adjustments necessary to overcome them.

Adopting such an approach to inclusion shifts the focus from clinical interventions to change people so that they ‘fit in’ to creating communities that can accommodate people. It requires a focus on competencies and skills, identification of the environmental barriers people experience in using their abilities and contributing to their communities, and working with both individuals and communities to ensure that there is access to the support and adjustments people need if they are to participate as equal citizens.

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