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MENTAL HEALTH PREJUDICE, DISCRIMINATION AND EPISTEMIC INJUSTICE

Moving beyond stigma and biomedical dominance

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Introduction

This chapter focuses on the way in which some people experience prejudice and discrimination on the grounds of their mental health. Concepts of mental health are contested and culturally specific and so it is important, at the outset, to draw attention to five aspects of this chapter's context. Firstly, it is written from a European context and draws largely on research published in English in high income countries (e.g. Europe, North America, Australia and New Zealand). Concepts of mental health vary considerably across cultures. For example, a study of local understandings in Burundi, South Sudan and the Democratic Republic of the Congo identified some similarities but also significant differences in how problems seen by the researchers as 'mental illness' were construed in the different countries (Ventevogel, Jordans, Reis, & de Jong, 2013). The authors reported that causal attributions about problems ranged from the supernatural to the psychosocial and those in the natural world like infectious diseases. However, increasingly, Western constructs of mental health and of stigma are being exported across the world via diagnostic manuals and international 'awareness' campaigns (Mills, 2014; Watters, 2011). As a result, readers will need to determine which aspects of our argument, if any, have relevance in their own context. To facilitate this process, for studies we discuss, we will identify the countries in which they were conducted. Secondly, in a Euro-American context the dominant cultural construct of mental health is a biomedical psychiatric one – for example, the term 'mental illness' is often used. This assumes that such problems in living are best understood by drawing on a conceptual framework designed for understanding bodily illness and where causes of mental health problems are viewed as primarily biological in nature with psychosocial causes as secondary. The problems of this perspective will be a theme running through the chapter. Thirdly, this means that many studies use psychiatric diagnostic categories despite there being significant debate about their reliability and validity even in the Global North (Cromby, Harper, & Reavey, 2013). Though many of the studies reviewed in this chapter refer uncritically to diagnoses and terms like 'mental illness' we adopt a descriptive approach so when we refer to people as having been given certain diagnoses we do not intend to imply that such diagnoses are accurate or uncontested. Fourthly,

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the concept of 'mental health' has historically developed to cover two quite different issues: both subjective experiences of psychological distress (which might attract diagnoses like 'anxiety' and 'depression') and conduct which concerns and troubles others (which might, for example, attract diagnoses like 'personality disorder' and 'schizophrenia'). Finally, stigma theory is currently the dominant frame for understanding mental health discrimination and prejudice. However, we will argue that a focus on injustice, particularly 'epistemic injustice' (Fricker, 2007) is likely to lead to more effective work to counter prejudice and discrimination.

There are a range of ways in which those who attract psychiatric diagnoses experience social injustice. For example, evidence suggests that psychological distress is causally influenced by a range of forms of social inequality (Cromby & Harper, 2009; Cromby et al., 2013). Moreover, given the level of subjectivity involved in psychiatric diagnosis, social stereotypes about gender, 'race', class and so on may affect diagnosers' judgements (Caplan & Cosgrove, 2004; Harper, 2011). Thus, the higher levels of paranoia reported amongst African American undergraduates (Combs, Penn, & Fenigstein, 2002) could lead to an over-diagnosis of psychosis when, instead, this may reflect the '"healthy" cultural paranoia' (Grier & Cobbs, 1992, p. 161) necessary for survival in racist societies. Once people come into contact with mental health services, social inequality affects the kinds of treatment they may receive. In the United Kingdom, for example, more socially deprived areas have higher rates of psychiatric medication (Anderson, Brownlie, & Given, 2009) and young black men are more likely to be treated compulsorily (Keating, Robertson, McCulloch & Francis, 2002). Of course, from an intersectional perspective, forms of social inequality, differential social sanction and the effects of cultural norms and stereotypes interact in complex ways.

In this chapter, we will focus primarily on how psychological distress and troubling conduct become a target of discrimination. In the first section, we examine the extent of the problem, beginning by examining research on public attitudes and then reviewing evidence of discrimination experienced by those with psychiatric diagnoses. In the second section, we discuss some of the factors related to these attitudes and behaviours, including the role of the media, and briefly review the conceptual models drawn on to understand them. In the third section, we discuss the conceptual limitations of the stigma construct and explore alternative approaches, with epistemic injustice as a central focus. In the fourth section, we discuss some findings from a qualitative study research on how people with psychiatric diagnoses respond to prejudice and discrimination and the strategies they use to manage it. In the fifth section, we review interventions to address prejudice and discrimination and, in the final section, we discuss potential future avenues for research and practice.

Extent of the problem

Attitudes about mental health

Angermeyer and Dietrich (2006) reviewed 33 national studies and 29 local and regional studies of attitudes towards mental illness, mostly conducted in Europe. They reported that the majority of the public in these studies consider people with mental health problems as in need of help and show pro-social reactions. Yet they also reported that a substantial proportion of people perceive those with mental health problems as unpredictable and dangerous, reacting with fear and with a tendency to distance themselves. Attitudes about mental health, however, are also variable and can appear contradictory. They are also influenced by how questions are framed (Hinshaw & Stier, 2008). Angermeyer and Dietrich (2006) noted that attitudes about mental health appear to vary between and within countries and there were somewhat inconsistent associations with demographic variables though a generally consistent finding was that knowing someone with mental health problems or having experienced them oneself was associated with more positive attitudes.

Mental health discrimination

Corker et al.'s (2013) interviews with psychiatric patients in England in 2011, revealed extensive discrimination across a range of areas of everyday life with 91% of participants reporting at least one experience of discrimination. The authors noted that 'the most commonly reported sources of discrimination were family, friends and social life contacts, or a general report of being avoided or shunned' (Corker et al., 2013, p. s61). Other areas of life where participants reported discrimination included: mental health staff (30.4%), welfare payments (24.9%), finding a job (18.6%), keeping a job (16.6%), the police (16.1%) and housing (13.3%).

In a study in Scotland, Berzins, Petch, and Atkinson (2003) compared interviews with 165 people with severe and enduring mental health problems and 165 people from the general population. Whilst 15% of the general population reported experiences of harassment in the community, the figure for the mental health sample was twice as high (40%), consisting primarily of verbal abuse from teenagers and neighbours about the person's mental health problems. In addition to harassment, people with psychiatric diagnoses are also more likely to be victims of crime. Khalifeh et al. (2015) found that, compared with a general population sample, a sample of London psychiatric patients were much more likely to report being a victim both of non-violent crime (14% versus 40%, respectively) and of violent assault (3% versus 19%, respectively).

Understanding prejudice and discrimination about mental health

Following the pioneering work of Erving Goffman (1963), researchers have attempted to understand mental health prejudice and discrimination primarily by drawing on stigma theory. This focuses on how stereotypes about mental health are associated with negative attributes and social rejection. In a review of this literature Hinshaw and Stier (2008) note that studies of behaviour often reveal discriminatory attitudes and sometimes even punitive behaviour towards people seen as mentally ill.

Different attitudes towards different forms of distress?

Angermeyer and Dietrich's review (2006) concluded that attitudes differed by diagnosis such that people with diagnoses of schizophrenia and alcohol problems were seen as more unpredictable and more likely to be dangerous and violent than those with diagnoses of anxiety or depression. Crisp, Gelder, Rix, Meltzer, and Rowlands (2000) reported, for example, that 71.3% of their U.K. respondents rated people with a diagnosis of schizophrenia as dangerous and 77.3% saw them as unpredictable.

To some degree these negative attitudes appear to be related to public perceptions both of the causes of distress and of the level of control a person is felt to have over their problem. For example, Link, Phelan, Bresnahan, Stueve and Pescosolido's (1999) U.S. study found that stressful circumstances were the most commonly endorsed cause of alcohol problems, depression, schizophrenia and cocaine dependence though the second most commonly endorsed cause differed: a chemical imbalance (depression and schizophrenia); how a person was raised (alcohol problems) and the person's own 'bad character' (cocaine dependence). Crisp et al.'s (2000) U.K. study found that people with diagnoses of eating disorder, alcohol problems and drug addiction were both much more likely to be blamed for their problems and seen as needing to 'pull themselves together' compared with those with diagnoses of schizophrenia.

In a German study, Schomerus, Matschinger, and Angermeyer (2014) examined the relationship between causal beliefs (biology, stress or childhood adversities) and social acceptance in relation to schizophrenia, depression and alcohol dependence. They also studied the mediating effect of perceptions of perceived differentness, dangerousness, treatability and perceived responsibility both for developing problems and for recovering from them. They found that biogenetic beliefs were associated with lower social acceptance of schizophrenia and depression (because of perceived differentness and dangerousness) but higher social acceptance of alcohol problems. However, they reported a complex picture with different beliefs and attributions often counterbalancing each other. Thus, belief in a biogenetic cause of alcohol dependence was also associated with perception of dangerousness but this was outweighed by a perception of reduced responsibility for its onset, leading to more social acceptance on balance. Belief in current stress as a cause of schizophrenia was associated with more social acceptance, mediated by reducing perceived differentness and increasing perceptions of treatability and responsibility for recovery. However, belief in the causal role of childhood adversity in depression resulted in lower social acceptance mediated by increased perceptions of differentness and dangerousness.

Of course, causal attributions are heavily influenced by local cultural constructions and there is a need for much more research studying the range of conceptualisations and causal models in different cultural contexts (e.g. Ventevogel et al., 2013). Moreover, researchers could usefully study the ways in which people may not just have one stable causal explanation for their own and others' difficulties but may, instead, draw on a range of different understandings which they move between depending on the context.

Changes over time: The increasing influence of biomedical explanations

A number of researchers have examined longitudinal changes in attitudes. In a systematic review of such studies from the United States, Europe and Australia, Schomerus et al. (2012) identified two major trends. Firstly, populations had become more accepting of a psychiatric conceptualisation of mental health: they were increasingly aware of diagnostic categories and adopted a biological explanatory model. Secondly, attitudes had not improved and, in some cases, had become worse.

These results are of concern because, in many countries, there have been concerted efforts in recent decades to change attitudes about mental health via 'anti-stigma' campaigns based on an approach often summarized as 'mental illness is an illness like any other' (Read, Haslam, Sayce, & Davies, 2006). This proposes that, if the public are educated about diagnostic categories and biomedical explanatory models (so-called psychiatric or mental health 'literacy') then they will be more likely to seek psychiatric treatment themselves and less likely either to blame others for their problems or engage in prejudice and discrimination. Examples of this approach include the United Kingdom's 'defeat depression' campaign (Paykel, Tylee, Wright, & Priest, 1997) and the Movement for Global Mental Health (http://globalmentalhealth.org/; Patel et al., 2011). This movement builds on a longstanding tendency within psychiatry to see its constructs and treatments (primarily pharmaceutical) as culturally universal as seen within the World Health Organization's (2018) *International classification of disease* (ICD-11) and the American Psychiatric Association's (2013) *Diagnostic and statistical manual of mental disorders* (DSM-5). DSM-5 is used in many countries outside of North America and has a major influence both on mental health research and on the development of the ICD. The Movement for Global Mental Health has been heavily criticized for the way in which biomedical constructs from the Global North are simply exported to other cultural contexts, in a neo-colonial manner, often with the support of pharmaceutical companies seeking to expand their markets (Clark, 2014; Mills, 2014; Watters, 2011).

As we have noted, Schomerus et al.'s (2012) findings suggest that, whilst these campaigns have led to an increased adoption of a bio-psychiatric model, they have failed to change attitudes and, in some cases, may even have worsened them. Why might this be? Read et al. (2006) reviewed a range of studies examining the effect of causal beliefs on attitudes towards people with schizophrenia diagnoses. They reported that, in contrast to the assumptions of most anti-stigma programmes, biomedical explanations were overwhelmingly associated with a range of negative attitudes like perceived dangerousness, unpredictability, fear and desire for social distance. As Hinshaw and Stier (2008) note, simply implying people are not responsible for their problems – as anti-stigma campaigns often do – does not necessarily reduce prejudice since, as shown in the present volume, there is significant prejudice about issues over which people have no control like their gender, ethnicity and so on. Moreover, even if the cause of distress is seen as external and uncontrollable people can still be seen as having some responsibility for the onset of problems – for example, we might be perceived as weak or having committed some sin. Finally, biogenetic models can enhance feelings of differentness and genetic inferiority.

For the public, the print, broadcast and increasingly online media are the most important sources of information about mental health. But biomedical research is often reported uncritically, and researchers note that it is based on a narrative of 'genetic optimism' (Conrad, 2001). However, in contrast to popular belief, many psychiatric drugs were 'discovered' serendipitously, and they alleviate symptoms rather than targeting specific – supposedly underlying – disorders (Moncrieff, 2008).

Moreover, there is significant debate, even amongst psychiatrists, about the value of this research given that it has not led to any fundamental changes in mental health assessment or intervention in recent years and is unlikely to in the near future given the state of current knowledge (Kingdon & Young, 2007). However, here we will focus on the media's influence on public attitudes to people with mental health problems via the shaping of social norms.

The influence of the media

Goulden et al. (2011) sampled U.K. newspaper articles relating to a variety of psychiatric diagnoses in 1992, 2000 and 2008. They reported that, in 2008, 14% of articles presented people with mental health problems as a 'danger' to others and 13% as 'strange, inept or burdensome'. There had been a reduction between 1992 and 2008 in the former but a slight increase in the latter. A U.K. survey by Shift (2006) suggested that articles relating to danger often concerned reports about particular cases of homicide and thus were highly variable over time. The Shift report authors interviewed media professionals who defended such articles on the basis of their newsworthiness. The authors concluded that 'by concentrating on dramatic and rare incidents the media is feeding the audience's interest in the unusual and the extreme' (2006, p. 31). Their focus group research with audiences noted that, as with previous studies they 'continue to take most of the messages they get from the media they favour more or less at face value – unless they have any personal experience of the topic being covered' (p. 31). However, personal experience does not always outweigh the effects of negative media coverage. Philo (1994) reported that, in 21% of cases in his group's study, audience members' positive personal experiences of people with mental health problems were 'overlaid' by negative media messages. These people apparently traced their beliefs to violent portrayals in fiction or news reporting.

Of course, when watching TV, people spend much more time watching fictional portrayals in dramas, 'soaps' and sitcoms, than news and current affairs programmes. A U.K. study by Time to Change (2014) reported that, of a sample of TV viewers, 45% said characters with mental health problems often posed a risk to others and that 39% said characters were often violent. This is, perhaps, not surprising given that Wilson, Nairn, Coverdale and Panapa (1999) noted that 15 out of the 20 characters in their New Zealand study were depicted as physically violent to themselves or others. However, in the Time to Change (2014) study 77% said characters often experienced discrimination due to their mental health whilst 57% said characters were often likeable and the authors noted that there had been some reduction in the presentation of characters as violent. Indeed, in soap storylines concerning mental health there is the potential to change negative attitudes since they can focus on a well-known and well-liked character and their distress can be seen in the context of their biography and social context. However, a recent study found that 'the "medical model" is prioritized in mainstream television drama and the causes of mental distress framed in biomedical terms' (Henderson, 2018, p. 206). Henderson (2018) interviewed service user consultants to broadcasters as well as TV executives, producers and script-writers. She found that 'storylines tend to emphasize the certain benefits of medication' and that 'medication provides a relatively simple on-screen solution to resolve complex stories' (p. 206). She concluded that:

> Mental distress and stigma are addressed at an individual, not collective level. Debates within the survivor movement and public mental health concerning medication, treatment and recovery tend to be obscured.
>
> (*Henderson, 2018, p. 206)*

With the rise of social media in the early twenty-first century, this has become an important vector to study and a recent study of Twitter has found that mental health is more stigmatized and trivialized than physical health conditions (Robinson, Turk, Jilka & Cella, 2019). This will become an increasingly important research topic in the future.

From stigma to discrimination: Mental health and epistemic injustice

The stigma paradigm has become the dominant frame for understanding prejudice and discrimination in mental health. A search for all documents and all years on the Scopus database reveals that, at the time of writing (July 2020) there are twice as many publications on 'mental health' and 'stigma' (12,761) than there are on 'mental health' and 'discrimination' (7,049) and, increasingly, there are also publications on 'mental health' and 'internalized stigma' (582) or 'self-stigma' (587). Yet stigma is a concept with significant limitations as Sayce (1998) has noted. For example, it shifts the emphasis away from issues of power and justice, directing attention away from those who are engaging in prejudiced and discriminatory behaviour and, instead focusing on the victim. Moreover, this concept is used in relation to mental health but much less, if at all, in relation to other forms of discrimination where concepts of oppression or internalized oppression might be used. For example, we don't talk about the 'stigma' of being a woman, or being a black person; we quite rightly talk about sexism and racism and we focus on the systems which facilitate such discrimination. This is not to say that all targets of prejudice and discrimination are the same but it is striking how dominant the stigma frame is in mental health, perhaps because it can be accommodated within the individualistic and intra-psychic focus of the psy-disciplines.

If the concept of stigma is problematic, how might we think differently about mental health prejudice and discrimination? One approach might be to draw on Miranda Fricker's (2007) notion of epistemic injustice. She delineates two specific forms of epistemic injustice:

- *Testimonial injustice* occurs when 'prejudice causes a hearer to give a deflated level of credibility to a speaker's word'
- *Hermeneutical injustice* occurs 'at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experience'

(*Fricker 2007, p. 1)*

Fricker's work has been taken up in psychiatry though there tends to be more of a focus on testimonial as opposed to hermeneutical injustice. For example, Crichton, Carel, and Kidd (2017) give examples of the varied ways in which psychiatric diagnostic labels act to reduce a person's credibility. Rogers and Pilgrim (2010) note that psychiatric labels tend to be given when a person's actions do not seem intelligible according to social norms and then these labels act to reduce a person's competence and credibility in the eyes of others.

In the next section, discussing service users' subjective experience of prejudice and discrimination, we will see that epistemic injustice is a key theme.

How people with a diagnosis of schizophrenia experience and respond to prejudice and discrimination: Examples from a qualitative study

Quantitative research can describe trends in discrimination at the level of particular populations and identify relevant factors. Qualitative research can complement such findings with a richer insight into the subjective experience of prejudice and discrimination. Moreover, it can also show how mental health service users are not simply passive victims of discrimination. Rather they develop a range of skilful strategies to manage the discrimination they face and to construct a more valued identity. To illustrate this we will draw on data from a qualitative study of eight mental health service users with a diagnosis of schizophrenia, living in London in the United Kingdom (Vakili, 2003).[1] Here, we take a critical realist perspective which, briefly, entails three assumptions (Pilgrim, 2020): that there is a potentially knowable world in which causal forces are at work (ontological realism); that our methods for investigating the world are imperfect (epistemological relativism); but that our knowledge is not arbitrary – rather, we can interpret and evaluate the data our methods produce by making reasoned judgements (judgemental rationality). In the extracts all names are pseudonyms. As we are presenting the material primarily for illustrative purposes, we will keep our interpretative comments brief and make reference throughout to relevant research and scholarship.

Strategies to manage the fear of exposure: Maintaining vigilance and passing as normal

Mental health service users regularly encounter testimonial injustice but it is not just their rationality which is doubted. In addition, as we have noted, those with psychosis diagnoses face the challenge that others may perceive them as dangerous and unpredictable (Angermeyer & Dietrich's, 2006; Crisp et al., 2000; Read et al., 2006). However, the situation is complex since mental health problems are generally not visible to others. Goffman (1963) observed that

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[1] The eight participants (six men and two women) were aged 29–50. All lived in the community and the length of time that they had had a diagnosis of schizophrenia ranged from 5 to 18 years. They were all recruited from NHS mental health services. Two were employed, two were engaged in voluntary work, three were unemployed and one was a student. They self-defined their ethnic backgrounds as: 'white British' (4 participants); 'Indian born in Tanzania' (1); 'African Caribbean' (1); 'Greek Cypriot' (1) and 'British born Pakistani' (1). The interviews focused on: participants' perceptions of societal attitudes about schizophrenia; in what ways, if any, it had affected the way they saw themselves, their behaviour or the behaviour of others towards them; and what impact it had had on either their psychotic experiences or recovery. For this chapter, the transcripts were analysed using thematic analysis which, as Braun and Clarke (2006) note, can be conducted from a range of epistemological standpoints. The second author (KV) conducted, transcribed and coded the interviews and developed initial categories that were then reviewed and refined by the first author (DH), a process which continued in an iterative manner.

stigmatized conditions which were not visible could give rise to anxiety. As Hinshaw and Stier (2008) observe this can create concerns about whether one should disclose one's mental health status to others and a fear about whether it may be inadvertently revealed. As Hamid, one of our interviewees, put it, '[o]nce you say you are schizophrenic people think you are a very, very bad person you know'. As a result, some participants were careful in deciding who to disclose their mental health status to and what to disclose. Andreas explained why, in the past, he had chosen not to tell people about his diagnosis.

ANDREAS: … they would get worried you see? So you wouldn't say it. I wouldn't say it anyway, you know? … Because of because of the Jekyll and Hyde, you know, scenario.

The Jekyll and Hyde character neatly exemplifies public fears of unpredictability. The participants were often at pains to emphasize that these perceived risks were exaggerated:

AZIM: I've met people over the years who've told me they were suffering from schizophrenia and they wasn't dangerous at all you know, they were quite mellow people.

A recent review of qualitative studies reported that, since service users with psychosis diagnoses felt others feared violence and unpredictability, they felt shame and feared others, resulting in an understandable reluctance to disclose their mental health status to them (Wood et al., 2015). John described how he needed to remain vigilant in conversations with friends:

JOHN: [when the] conversation gets onto the health service and patients and that sort of thing. I'm very wary about, when it spreads to mental illness you know that sort of uh, monitoring, really, of the debate, a-, a-, in a, in a laddy sort of group, that sort of thing, certain information comes out and you're done for.

John highlights the influence of intersectionality here and how fears of exposure may be influenced by hegemonic masculinity. This vigilance also extended to a heightened awareness of the need to follow social conventions so as not to attract the attention of others. In his 1991 BBC TV series *Madness*, Jonathan Miller referred to how ordinary people were sensitive to the maintenance of social conventions in public space, what he referred to as a 'constitution of conduct':

> we can instantly and by a very subtle process recognize someone who is breaking that constitution. They're talking to themselves; they're not moving at the same rate; they're not avoiding other people with skill that pedestrians do in the street. The speed with which normal users of public places can recognize someone else as not being a normal user of it is where madness appears.
>
> *(Miller, 1991, cited in Rogers & Pilgrim, 2010, p. 31)*

Participants drew on their cultural knowledge of such conventions in order to navigate everyday life. Sam described how he sought to pass as 'normal' when using everyday public spaces:

SAM: You don't stick out like a sore thumb and you look relatively normal and you're not rocking anybody's boat and you're almost merging [laughs] … Yeah basically not to have eye-to-eye contact with people, keep your head to the ground as you pass somebody rather than eyeball them and stuff like that.

Sam's description of the skills necessary to navigate public space is similar to Westwood's (1990) description of young black men's engagement in 'streetwise' practices whereby they needed to be constantly aware of their surroundings, remaining vigilant for signs of danger.

Psychiatric diagnoses are associated in public discourse with a range of negative associations. In addition, psychiatric discourse is comprised, as Gergen (1990) has put it, of 'vocabularies of deficit'. As a result, service users were faced with dilemmas about how to construct their identity and they drew on a number of different strategies of identification.

Strategies of identification: Distancing, emphasizing common humanity and embracing difference

It appears likely that those who are visibly different in some way will attract more negative labelling from others (Hinshaw & Stier, 2008). The mental health status of service users can be made visible in a number of ways. For example, they may be so overwhelmed by 'psychotic' experiences that they may respond to them in a visible manner, for example, talking back to voices in public or acting in the way Jonathan Miller describes. Prescribed medication – like 'anti-psychotic' drugs – may include 'side effects' known as 'movement disorders' which might, for example, affect one's gait, which can be noticed by others. One strategy described by participants was to distance themselves from those service users with a diagnosis of schizophrenia who visibly breached social norms. Courtney was asked whether he socialized with other people with the same diagnosis.

COURTNEY: Not really because those people are really crazy [half laughs] they're not like me. Those ones like me, those ones that socialize with me well we get on well, your, see they're all straight and take medication [...] but we get along there are no problems, we're not acting foolishly or not acting ill or unwell. We are getting along fine doing what the doctors say.

Like Sam, Courtney appeared to be aware of the importance of not appearing visibly different, of not 'acting foolishly or not acting ill or unwell'. Practices of social distancing and downward social comparisons can increase self-esteem (Hinshaw & Stier, 2008) but, here, this strategy appears to have a protective function, enabling those who can pass as 'normal' to avoid indirectly exposing their mental health status. However, Courtney also orients to the power of psychiatry and the importance of compliance: of 'doing what the doctors say'. Thus, in addition to service users skilfully avoiding the breaching of social norms of public space, they were also aware of the importance of not breaching the social norms of being a 'good patient' (Chamberlin, 1998).

Distancing oneself from others with the same diagnosis was not the only identity strategy reported; another was to emphasize one's common humanity through the building of ordinary relationships. John described the validation he experienced from others in his social network when they expressed curiosity about his experiences, enabling him to adopt an educational role and to counter negative stereotypes:

JOHN: This negative stereotyping, you know with the axe-wielder and that sort of thing. They [acquaintances] are quite curious from somebody who has gone through it who is articulate and intelligent and can explain to them what it is all about.

Some participants also expressed their commonality with, rather difference from, other service users with similar diagnoses:

ANDREAS: I Identify that they have had problems as well you see, you know, they're like. Most people, most mentally ill people have had something go wrong in their life […] instantaneously you know I, I identify with them, you know. I'm a schizophrenic and depression, I identify with some trauma in their life and mine and that makes them close to me.

What appears to facilitate Andreas' identification with others, here, is a psychosocial causal model, emphasising the role of adverse life events on mental health. Yet such explanations do not appear to be routinely offered by professionals. In a recent U.K. qualitative study, the majority of the service users reported not having been given a causal explanation for their difficulties by mental health professionals (Carter, Read, Pyle, & Morrison, 2018). Some felt they had been given an explanation but, on further investigation, it appeared they had simply been given a psychiatric diagnosis but no specific cause for their difficulties had been proposed. This lack of access to explanatory models could be seen as an example of hermeneutical injustice in that service users are thus denied access to explanatory resources which might help them make sense of their experiences.

However, although they could emphasize commonality with others, both those with or without diagnoses, some service users with psychosis diagnoses can still feel very different to others (Wood et al., 2015). This can pose a challenge: how can a member of a group experiencing discrimination embrace their sense of being 'different' or 'special' without it being see as, in some way, inferior? Azim and John described strategies of identification which appeared to be successful. Azim talked about having met artists at a film workshop and how he identified with others who he also saw as 'different':

AZIM: I knew they were like me and you know they were different when they were at school. They were just like, there and it was great and I loved it.

JOHN: I think of myself as being rather special. Erm, not least because of the, the whole experience, uh, led, led me to writing so I write poetry now that's my main, erm, it's through, through that it's, it's up my life's specialness, if you like and in a way my worth to society is judged on those terms … so in that sense I feel quite special.

It is interesting that both Azim and John found the domain of artistic expression to be one where their experience of feeling different and special could be valued. Indeed, artists and poets have, historically, been members of sub-cultural communities which have provided socially sanctioned space to find meaning in and culturally value the experience of those who feel outside of conventional life (Curtis, Dellar, Leslie & Watson, 2000).

In Parker and Aggleton's (2003) work on HIV/AIDS, they argue for the need to theorize the relationship between constructions of identity and the response to stigma and discrimination. They suggest that these experiences can generate what Castells (1997) terms resistance identities and project identities. According to Castells (1997, p. 8), *resistance identities* are 'generated by those actors that are in positions/conditions devalued and/or stigmatized by the logic of domination'. *Project identities* are formed 'when social actors, on the basis of whatever cultural materials are available to them, build a new identity that redefines their position in society and, by so doing, seek the transformation of overall social structure' (Castells, 1997, p. 8). For Parker and Aggleton (2003, p. 22) there should be more of an emphasis 'on community mobilization aimed at unleashing resistance to stigmatization and discrimination' as well as 'structural interventions aimed at developing a rights-based approach' to prejudice and discrimination.

Azim's and John's celebration of difference appeared to be the result of their individual endeavours rather than through contact with the broader psychiatric service user movement. Thus it seemed more consistent with the notion of a resistance rather than a project identity. Indeed, none of the participants in our qualitative study had attended any meetings of service user advocacy organisations and they did not appear to be aware of them. This lack of awareness and contact is another example of epistemic injustice. Firstly, this lack of access might make testimonial injustice in mental healthcare more difficult to challenge given that advocacy organisations often inform people of their rights and support them to exercise those rights. Secondly, this lack of access can result in hermeneutical injustice since the psychiatric survivor movement is a source of a range of alternative non-medical explanations for mental distress. Although often struggling to find stable long-term funding, there are now a range of organisations and movements which seek to generate such resistance identities. Such groups include the Mad Pride movement (https://en.wikipedia.org/wiki/Mad_pride), the international Hearing Voices Movement (Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014), MindFreedom (https://mindfreedom.org/), psychiatric survivor proponents of the social model of disability (Beresford, Nettle, & Perring, 2010) and the recent development of Mad Studies (LeFrançois, Menzies, & Reaume, 2013). Increasingly, similar organisations are being developed outside of the Global North, including in Africa (Kleintjes, Lund, & Swartz, 2013) and Latin America (Ardila-Gómez et al., 2019).

Interventions to address stigma, prejudice and discrimination

Gronholm, Henderson, Deb, and Thornicroft (2017) review a range of different interventions aimed at countering mental health prejudice and discrimination, predominantly in high-income countries. They categorize them by their aims: educational; facilitating contact with mental health service users; or rights-based advocacy. They note that early anti-stigma campaigns focused primarily on education whereas, increasingly, interventions have included an element of contact with service users (e.g. describing their personal stories). Gronholm et al. (2017) also categorize interventions by their target audience. Many focus on improving the knowledge and attitudes of the general public whilst others focus on particular target groups like healthcare professionals, police officers or students.

However, as discussed earlier in the chapter, there are conceptual debates about the nature both of mental health and stigma itself (Read et al., 2006) and thus interventions can be viewed as lying along a spectrum ranging from those primarily promoting a biomedical approach to those primarily promoting a psychosocial approach and Table 3.1 contrasts their respective assumptions.

The biomedical approach is most associated with the slogan 'mental illness is an illness like any other' (Read et al., 2006) and is often referred to as 'mental health literacy'. A good example of this approach was the Defeat Depression Campaign in the United Kingdom between 1992 and 1996 conducted by the Royal College of Psychiatrists and the Royal College of General Practitioners together with a range of stakeholders (Paykel et al., 1997). The aims of the campaign were to distribute information about depression from a medical point of view. For example, materials in the campaign gave information about how to recognize symptoms and encouraged people to see their GP if they had these symptoms. They also aimed to reduce public concerns about the use of anti-depressant medication which those leading the initiative saw as unwarranted and inaccurate. The two key target audiences were the public (reached via briefing media outlets and producing leaflets, books and audiotapes) and GPs (reached via conferences, diagnosis and treatment guidelines, training materials and other publications).

Table 3.1 Contrasting the biomedical with a psychosocial approach to public education about mental health

Biomedical approach	*Psychosocial approach*
Sees the person's mental health problems as the main problem	Sees barriers in society as the main problem
Sees problems as a symptom of an underlying disease process and illness	Sees problems as an understandable response to adverse life events
Sees societal reactions as due to the stigma attached to having a mental health problem	Sees societal reactions as due to discrimination against a marginalized group (like racism, sexism, etc.)
Aim of public education is to remove perceived blame attached to the individual by 'blaming' the illness rather than the person	Rejects the relevance of notions of 'blame' and aims to promote diversity, reduce fear and increase empathy and understanding
Key public education slogan 'Mental illness is an illness like any other'	Key public education slogans: 'I'm crazy: so what?' 'It's normal to be different' 'Instead of asking what's wrong with me, ask what's happened to me'

Psychosocial approaches are associated with slogans like 'It's normal to be different' and 'Instead of asking what's wrong with me, ask what's happened to me'. An example of such an approach is a small-scale study in London in the United Kingdom based on two previous studies (Pinfold et al., 2003; Schulze, Richter-Werling, Matschinger & Angermeyer, 2003). The study is reported in two publications co-authored by the first author (Sholl, Korkie, & Harper, 2009, 2010). In the study, a trainee clinical psychologist and a mental health service user, who was also a clinical psychologist, facilitated four 50-minute sessions with 13–14 year olds in a school setting. The intervention was informed by a continuum model of distress (e.g. Wiesjahn, Brabban, Jung, Gebauer, & Lincoln, 2014) and assumed that adversities in life were a major cause of psychological distress. The two facilitators sought to use an active learning approach, rather than didactic methods and pupils were encouraged to ask the service user/psychologist questions about his experience. Sessions also focused on key things needed for a happy life as well as countering myths.

Gronholm et al. (2017) conclude that there is evidence of small to moderate effects on knowledge, attitudes and intended behaviour both for campaigns focused on the public and those focused on other target groups. A key problem with many studies is that they fail to include longer follow-up so it is unclear if these effects have a lasting impact. However, many reviews of anti-stigma interventions fail to consider the underlying conceptual assumptions of these interventions even though, as we saw earlier in the chapter, these are incredibly important (e.g. Read et al., 2006). For example, the evidence would suggest that biomedical anti-stigma campaigns have had some success in persuading the public in many countries in the Global North to adopt a medical perspective. Yet, as Schomerus et al. (2012) have found, at the same time stigma has not reduced and, in some cases, has worsened, challenging the assumption of these campaigns. This can, perhaps, be understood as the result of the 'mixed blessings' of biomedically oriented campaigns (Haslam & Kvaale, 2015):

> Although biogenetic explanations may soften public stigma by diminishing blame, they increase it by inducing pessimism, avoidance, and the belief that affected people are dangerous and unpredictable.
>
> *(Haslam and Kvaale, 2015, p. 399)*

As a result, it is important that those designing such interventions inform themselves about research on the complex attributions associated with different forms of distress (Schomerus et al., 2014) and on how to avoid the negative effects of biomedical explanatory models (e.g. Lebowitz & Appelbaum, 2019). Programmes need to be sensitive to the local cultural context, the different ways in which psychological distress and troubling conduct may be conceptualized and the range of causal models which might be relevant. For those in the Global North, Read et al. (2006) argue that psychosocial explanations of schizophrenia are more likely to result in increased acceptance since, in contrast with biomedical approaches they are more humanising, enabling an understanding of why someone might experience distress.

Such approaches can address testimonial injustice through the active involvement of people with direct personal experience who are presented as having expertise – thus addressing doubts about competence and credibility – and can render their distress intelligible in the context of their lives – thus increasing empathy. They can also address hermeneutical injustice, highlighting the different ways in which we can understand distress.

This is an area where theory and practice continue to develop. For example, new mental health service philosophies have emerged like trauma-informed care. This proposes that much psychological distress arises as a result of adversities and that, as a result, mental health services need to address the emotional legacy of adversity. Moreover, they should be designed in such a way that they do not, inadvertently, re-traumatize people (e.g. Sweeney, Clement, Filson & Kennedy, 2016).

How we should best counter mental health prejudice and discrimination depends to some extent on how we conceptualize distress and troubling conduct. Psychiatric diagnoses are not neutrally descriptive. Rather, they are derived from a medical conceptual framework designed to understand bodily illness rather than thoughts and feelings. A group of British psychologists and service users have sought to address such problems by developing the *Power Threat Meaning Framework* (PTMF; Boyle & Johnstone, 2020; Johnstone & Boyle, 2018). This proposes that distress and troubling conduct should be understood as intelligible responses to adversities which arise in contexts of unequal power relationships (e.g. social inequality). These adversities are seen as posing threats to common human needs. These threat responses are enabled by the body and learnt through culture. For example, when subject to victimising discrimination we may experience 'paranoia', becoming vigilant about threats. Similarly, if exposed to trauma from which we cannot escape, we may respond by disassociating ('the escape when there is no escape') and begin to hear voices others can't hear ('auditory hallucinations'). This approach not only provides an alternative non-medical way in which service users can understand their experiences (see, e.g. SHIFT Recovery Community, 2020) but it also raises questions about the need to change the societal conditions which produce distress (Boyle & Johnstone, 2020; Johnstone & Boyle, 2018).

Conclusion

In this chapter, we have documented the extent of mental health prejudice and discrimination and discussed some explanations for its persistence (including the failed efforts of biomedically oriented anti-stigma campaigners). We have also identified the skilful strategies employed by mental health service users as they navigate widespread prejudice and discrimination and try to construct more valued identities for themselves. We have reviewed current interventions to counter prejudice and discrimination. We have also proposed that, in the high-income countries where much of this research has been conducted, a psychosocial approach may be likely to lead to more epistemically just outcomes. Although the primary focus of this chapter has been on research and campaigns in the Global North these concerns may become increasingly relevant in other countries as the Movement for Global Mental Health (Patel et al., 2011) exports Western constructs of mental health and stigma to low and middle-income countries (Clark, 2014; Mills, 2014; Watters, 2011).

New developments like Trauma-Informed approaches and the PTMF offer alternative ways of understanding mental health and prejudice and discrimination. It seems clear that there is a need for a wholesale change of direction in the way in which the problem of mental health prejudice and discrimination is conceptualized and addressed. This will require a collective movement for change including psychiatric survivor activists and their allies, researchers, policymakers and legislators. The international public conversation about mental health needs rebalancing (Harper, 2020) in order to highlight the limitations of a biomedical approach, the benefits of alternative approaches and to emphasize that ideas of mental health are contested cultural constructs.

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