

Ignorance
+ Prejudice
+ Discrimination

= Stigma

Actions speak louder ...

Tackling discrimination against people with mental illness

by Professor Graham Thornicroft

Mental Health Foundation

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FOREWORD

People with direct experience of mental health problems - as service users, carers or professionals - have long been aware of the impact of discrimination against people with psychiatric diagnoses. Over recent decades research by organisations like the Mental Health Foundation has confirmed that discrimination has a huge impact on people's lives.

However, as a sector we have not always been clear about how discrimination works or how it can be tackled, or of the relationship between discrimination, stigma and ignorance. I have long disliked the term "stigma" because it projects the fear and anxiety felt by members of the general population onto the person with the diagnosis. People with a diagnosis do not really carry a mark that sets them aside. As a society we have spent many millions of pounds trying to tackle stigma and discrimination without a clear model of how change can be achieved. Yet despite all our efforts and all the services we deploy, outcomes for severe mental illness in Western society remain worse than in some developing countries.

I believe this report, which represents an exciting collaboration between the researcher and author, Professor Graham Thornicroft, and the Foundation, represents a major step forward in our thinking. It throws the real lived experience of service users, who have told Graham their stories, into sharp perspective.

The report pulls together a mass of evidence from across the world and highlights the impact that discrimination has. It takes a hard nosed view of the evidence and once again underlines the importance of an *experiential* approach where direct contact with service users is the catalyst for attitude change. It sets out a policy agenda for change based on key principles including user involvement, collecting and using evidence, and building a robust change model. The Mental Health Foundation is working to build capacity and support the development of user led initiatives across the UK in order to support the fight against discrimination which needs to be comprehensive and inter-sectoral.

I found this report both moving and stimulating – it appeals to both our heads and our hearts. I hope you too will find it a stimulus to action and to real change for some of the most marginalised people in our society.



Dr Andrew McCulloch
Chief Executive
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EXECUTIVE SUMMARY

Introduction

It is now beyond doubt that widespread discrimination adds to the disability of people with mental illness. The basic problem is this: many people with mental illness are subjected to systematic disadvantages in most areas of their lives. These forms of social exclusion occur at home, at work, in personal life, in social activities, in healthcare, and in the media.

This hard-hitting Mental Health Foundation policy paper both analyses these forms of social exclusion and sets a clear agenda for what policy makers need to do to tackle head-on such discrimination and social inequality. The focus here is upon policy change, based upon a thorough review of all the relevant evidence, and perhaps more importantly, from listening to the voices and views of people with mental illnesses who describe their experiences in their own words.

From Stigma to Ignorance, Prejudice and Discrimination

The concept of stigma is necessary to develop an understanding of experiences of social exclusion, but it is not sufficient to grasp the whole picture, nor to know what practical steps need to be taken to promote social inclusion. Stigma is best seen as three related problems:

Ignorance: strong evidence is presented here that most people have little knowledge about mental illnesses, and much of this information is factually incorrect. There is a pressing need to convey more useful information, for example about how to recognise the features of mental illness and where to get help, both to the whole population and to specific groups such as teenagers.

Prejudice: fear, anxiety and avoidance are common feelings both for people who do not have mental illness (when reacting to those who have), and for people with mental illness who anticipate rejection and discrimination and therefore impose upon themselves a form of 'self-stigma' or internalised stigma.

Discrimination: the scientific evidence and the strong message from service users and their advocates are clear that discrimination blights life for many people with mental illness, making marriage, childcare, work, and a normal social life much more difficult. Actions are needed to specifically redress the social exclusion of people with mental illness, and to use the legal measures intended to support all disabled people (such as the Disability Discrimination Act) for physical and mental disabilities on the basis of parity.

Action to support service user advocacy groups

Empowerment has been described as the opposite of self-stigmatisation. Policy makers should therefore provide specific financial support for ways in which individuals with mental illness can empower themselves or be empowered including the following:

- Participating in formulating care plans and crisis plans
- Using Cognitive Behavioural Therapy to reverse negative self-stigma
- Running regular assessments of consumer satisfaction with services
- Creating user-led and user-run services
- Developing peer support worker roles in mainstream mental health care
- Advocating for employers to give positive credit for experience of mental health illness
- Taking part in treatment and service evaluation and research

Action to support individuals and their families

A series of changes are necessary to assist individual people with mental illness and their carers and family members:

Action	By
Develop new ways to offer diagnoses	Mental health staff
Have information packages for family members that explain causes, nature and treatments of different types of mental illness	Mental health staff, service users and families
Actively provide factual information against popular myths	Mental health staff
Develop and rehearse accounts of mental illness experiences which do not alienate other people	Mental health staff and service user groups

Action to support people with mental illness at work

For some people with mental illness, allowance needs to be made at work for their personal requirements. In parallel with the modifications made for people with physical disabilities, people with mental illness-related disabilities may need what are called 'reasonable adjustments' in the Disability Discrimination Act. In practice this can include the following measures:

- for people with concentration problems, having a quieter work place with fewer distractions rather than a noisy open plan office, with a rest area for breaks
- more, or more frequent, supervision than usual to give feedback and guidance on job performance
- allowing a person to use headphones to block out distracting noise
- flexibility in work hours so that they can attend their healthcare appointments, or work when not impaired by medication
- providing an external job coach for counselling and support, and to mediate between employee and employer
- buddy/mentor scheme to provide on-site orientation, and assistance
- clear person specifications, job descriptions and task assignments to assist people who find ambiguity or uncertainty hard to cope with
- for people likely to become unwell for prolonged periods it may be necessary to make contract modifications to specifically allow whatever sickness leave they need
- a more gradual induction phase, for example with more time to complete tasks, for those who return to work after a prolonged absence, or who may have some cognitive impairment
- improved disability awareness in the workplace to reduce stigma and to underpin all other accommodations
- reallocation of marginal job functions which are disturbing to an individual
- allowing use of accrued paid and unpaid leave for periods of illness

Action needed at the local level

In local communities or health and social care economies the following initiatives are needed to promote the social inclusion of people with mental illness:

Action	By
Commission and provide supported work schemes in line with the Social Exclusion Unit's recommended action. Develop new ways to offer diagnoses.	Commissioners and mental health services, including non-statutory sector providers
Increase the availability of psychological treatments to improve cognition, self-esteem, confidence and social functioning.	Primary health services and secondary mental health services
Health and social care employers give recognition to the 'expertise by experience' of people with a history of mental illness through positive encouragement and support in recruitment and staff management practices.	Health and social care agencies in both the statutory and non-statutory sectors
Ensure people with mental illness and employers are properly informed of their rights and obligations under the Disability Discrimination Act, including changes that are coming into effect.	Mental health services, employers and business confederations, law organisations, CABx and other advice agencies
Mental health agencies and advice organisations actively encourage and support service users in securing their rights under the Act.	Mental health services, employers and business confederations, law organisations, CABx and other advice agencies
More widespread implementation, evaluation, and impact assessments of focused anti-discrimination interventions (including those that are part of SHIFT) with particular groups including school children, police and healthcare staff.	Educational organisations, police, health commissioning and providing organisations, research organisations
Provide accurate data on mental illness recovery rates to mental health practitioners and to service users and carers.	Professional training and accreditation organisations, mental health service providers
Encourage and support greater service user involvement in local speakers' bureaux and other anti-sigma and anti-discrimination initiatives.	SHIFT, service user organisations
Ensure local implementation of CPA includes care plans that are properly negotiated between staff and service users.	Mental health services, Commissioners, Healthcare Commission

Action needed at the national level

In terms of national policy, a series of changes are necessary which span governmental ministries, the non-governmental and independent sector, along with service user and professional groups. This is a vision of a long-term attack upon individual and systemic discrimination through a co-ordinated, multi-sectoral programme of action to promote the social inclusion of people with mental illness.

Action	By
Promote a social model of disability that incorporates mental health problems (including those of a temporary nature) within the mental health sector, which refers to human rights, social inclusion and citizenship.	NIMHE, mental health service commissioners and providers, professional training and accreditation organisations, professional organisations
Provide accurate data on mental illness recovery rates to the media.	SHIFT, print and broadcast media, Ofcom
Implement a national review of the Care Programme Approach (CPA) to identify barriers preventing care plans being properly negotiated between staff and service users.	DH, NIMHE, mental health service providers, research organisations
Promote service user-defined outcomes and examples of good practices in CPA where care plans are properly negotiated between staff and service users.	DH, NIMHE, mental health service providers, research organisations, Healthcare Commission
Ensure adequate funding is available and used for new supported employment schemes and greater availability of psychological treatments.	DH, Treasury, audit and inspection organisations
Continue to make available and disseminate widely information, guidance and advice on the Disability Discrimination Act (DDA) regarding mental health problems, including how employers can make reasonable adjustments/accommodations, and the new definitions of mental health problems that came into effect in December 2005.	DWP, DRC, NIMHE, other government departments, mental health service providers, employers
Commission and produce a ten year review of the application, enforcement and impact of the DDA for people with mental health problems.	DWP, DRC
Assess impact and evaluate SHIFT's programme of establishing service user speakers' bureaux to offer content to news stories and features on mental illness.	DH, NIMHE, SHIFT stakeholder organisations
Assess impact and evaluate SHIFT's media programme which is pressing for balanced and accurate reporting about people with mental health problems.	DH, NIMHE, SHIFT stakeholder organisations

Action needed at the national level

Action	By
Share between countries the experience of disability discrimination legislation (including any available research).	Legislators, lawyers, advocates, disability organisations and consumer groups, researchers
Understand and implement international legal obligations under binding declarations and covenants, including the actions laid out in the 2005 Helsinki declaration on Mental Health.	DH, DRC, all statutory and non-statutory mental health agencies, audit, inspection and regulation bodies, WHO collaborating centres
Audit compliance with codes of good practice in providing insurance.	DRC, Association of British Insurers, Financial Ombudsman Service, CABx and other organisations giving financial advice
Reform of Incapacity Benefit system (including the assessment of incapacity/disability) to maximise non-coercive incentives to disabled people ready to return to work.	DWP, NIMHE, non-statutory mental health sector
Publish results of Home Office and Department for Constitutional Affairs consultation on jury eligibility criteria with a view to changing the law to allow people with a history of mental illness a presumption of capacity to serve on juries.	Home Office, Department of Constitutional Affairs
Any new mental health legislation should include a principle of non-discrimination that clearly states that people with mental disorders should, wherever possible, retain the same rights and entitlements as those with other health needs.	Government, DH

1 FROM STIGMA TO IGNORANCE, PREJUDICE AND DISCRIMINATION

Many people with a diagnosis of mental illness are subjected to systematic disadvantages in most areas of their lives. This report describes these forms of disadvantage and sets a clear agenda for what we need to do to tackle such discrimination and social inequality head on. The focus here is upon action which is necessary by policy makers in England, and most of the recommendations relate to stigma in relation to adults with mental health problems, where stigma is best understood. On the way we shall consider both the evidence for the impact of stigma and discrimination and, perhaps more importantly, the voices and views of people with mental illnesses who describe their experiences in their own words.

"Often I have heard comments either said to me or about people with depression as 'lazy'. I was constantly tired and at low periods I would take to my bed and isolate myself from the outside world." Tania

Defining stigma

The unavoidable starting point for this discussion is the idea of stigma. This term was originally used to refer to an indelible dot left on the skin after stinging with a sharp instrument, sometimes used for a vagabond or slave ^{1,2}. The resulting spot or mark or stain led to a metaphorical use of 'stigma' to refer to stained or soiled individuals who were in some way morally reduced ^{3,4}. In modern times stigma has come to mean 'any attribute, trait or disorder that marks an individual as being unacceptably different from the 'normal' people with whom he or she routinely interacts, and that elicits some form of community sanction.' ^{5,6}

2 THE EXPERIENCE OF STIGMA AND DISCRIMINATION

How are stigmatisation and discrimination against people with mental illnesses made manifest? These forms of social exclusion occur at home, at work, in personal life, in social activities, in healthcare, in the media, and paradoxically also through self-stigma. So we shall first consider how these processes operate as sometimes overwhelming forces, all moving in the same direction: towards marginalisation.

"I'm a human being, with all the feelings that brings, but stigma makes my life harder to bare." Maria

Considering the global evidence that is available about stigma, several points are clear. First there is no known country, society or culture in which people with mental illness are considered to have the same value and to be as acceptable as people who do not have mental illness. Second, the quality of information that we have is relatively poor, with very few comparative studies between countries or looking at trends in stigma over time. Third, there do seem to be clear links between; (i) popular (mis)understandings of mental illness, (ii) whether people in mental distress seek help, and (iii) whether they feel able to disclose and discuss their problems⁷. The core experiences of shame (to oneself) and blame (from others) are common everywhere stigma has been studied. Where comparisons with other conditions have been made, then mental illnesses are far more stigmatised^{8,9} (and have been referred to as the 'ultimate stigma'¹⁰) than other conditions. Finally, rejection and avoidance of people with mental illness appear to be universal phenomena¹¹.

This report aims to inform policy-makers about the key issues and to offer an agenda for change. The focus is upon three areas of stigma and discrimination: home life, personal and intimate relationships, and work. Much more could also be said about exclusion in terms of social life, or in health care. For example, there is strong evidence about discrimination in: leisure and recreation¹², travel¹³, insurance and financial services¹⁴⁻¹⁶, debt¹⁷, the entitlements of citizenship (such as voting or serving on a jury),^{18;19;19-21} and physical vulnerability²²⁻²⁴. In addition, people with mental illness receive poorer quality healthcare (both by mental health²⁵⁻²⁹ and by primary care staff²⁶⁻³²). There is strong evidence that people with a diagnosis of a mental illness, for example, have less access to primary health care³³ and also receive inferior care for diabetes and heart attacks³⁴⁻³⁶, even though rates of physical illness and poor dental health among people with severe mentally illnesses are much higher than in the general population³⁷⁻⁴⁰, with especially high levels of cardio-vascular disease, obesity, diabetes and HIV/AIDS⁴¹. This combination of high rates of physical illness and low rates of effective treatment shows the fatal consequences of discrimination and neglect: all mental disorders have an increased risk of premature death⁴². These issues are discussed in more detail elsewhere⁴³.

"Some of the worst experiences I have had have been in psychiatric hospitals. I recognise the need to be kept safe but often I have felt that my rights and dignity had been stripped away. Being intimately searched again and again and constantly followed whilst under 'close observation' just leaves me feeling singled out and perceived as little more than a nuisance ("there's to be no trouble on my shift"). I have seen, unofficially, my hospital notes and there is more than one occasion when nurses have actually lied to cover their own backs after I have self-harmed. After I have self-harmed (just when I feel at my most vulnerable), I have encountered a wall of silence - as if talking about it will only encourage me to do it again. This is without the stigma attached to self-harm by many of my fellow patients. I have heard many comments along the lines of "oh she's cut again - why doesn't she just do it properly and kill herself." Sandra

2.1 Stigma and discrimination at home

"I feel lucky to have a supportive family...and a loving husband who looks after us. He is also my carer ... if he wasn't around I wouldn't be able to cope. Just before I met him I was going downhill, surviving on one meal a day and depressed, and no one noticed. Then I met my husband and together we look after our one year old."
Barbara

Many people with mental illnesses are given strong and vital support by their families when they are unwell. But many others are disappointed to find that when they are at very vulnerable points in their lives, they get least support from their relatives. The most common reactions of family members are to:

- urge the person to 'snap out of it'
- accuse the person of being weak or lazy
- react with amusement, as if the changed behaviour is comic
- withdraw from the person whose behaviour is impossible to understand
- react in silence thinking (mistakenly) that to talk about, for example suicidal ideas might make them more likely to turn into reality
- expect little prospect of recovery
- feel blamed by professionals for having somehow caused the difficulties.⁴⁴⁻⁴⁹

"I have also had problems with members of my family. Some members of my family, such as my mother and some friends, don't know how to react after a crisis. They seem scared to talk about it, almost as if they might be "infected" by my problems or fearful that anything they might say might spark off another crisis. They avoid the subject altogether and instead talk of trivialities." Nadia

At the same time family members are themselves also the recipients of 'stigma by association', in which having a relative with mental illness can bring (or be expected to bring) shame upon the whole family.⁵⁰⁻⁵³

"You might go through the difficult times but there will be good times when it's easy." Susan, wife of Harry

One recent study of almost 500 family members in New York, for example, compared the views of families of people diagnosed as having major depression, schizophrenia or bipolar disorder.⁵⁴ Interestingly no differences emerged between these three groups, but experience of ignorance and prejudice were the rule rather than the exception. Around half of the family members agreed with the following statements:

- most people in my community would rather not be friends with families of the relative who is mentally ill living with them
- most people look down on families that have a member who is mentally ill living with them
- most people would rather not visit families that have a member who is mentally ill.

"The next type of stigma that hit me was from strangers. A forensic hostel was proposed near me and all of a sudden I'm a target for their anger. I live in a special mental health project flat, that came under attack. I had dog mess pushed through my letterbox, closely followed by paint stripper thrown over the door causing a lot of damage that took me weeks to sort out." Maria

A related area of discrimination is from neighbours. People with mental illness commonly report adverse reactions, especially verbal abuse²². While such events are often reported by people with mental illness, they do not feature in the scientific literature. Nor do other experiences that often cause distress to mentally ill people, namely frustration with the poor quality of public housing available to them. It is usually unclear whether the types of houses or apartments they receive are worse than those offered to other low income people living in public sector accommodation. What is clear is that housing problems very often make their mental illness worse⁵⁵.

"If I am out and neighbours say 'There goes that mad woman!' What right have they to make that judgement, just because I don't conform to their ideas. It's like if people make fun of you and you say something back to them. They always say oh you're mad or paranoid. Well maybe, but it doesn't mean you are deaf." Louise

"At 16, in 1996, I suffered a bad mental breakdown where I was hospitalised for five years. It was very traumatic. There I was the eldest son suffering a sudden deep depression, crying and unable to work, often threatened by my confused Dad as being "weak", "a fuckup", and a "nutter". No-one else in the family going back generations had gone "mad" like that. I was told not to tell any of the neighbours what was happening, to stop the gossip, but I was far too ill to socialize until I was admitted as a day patient at a local mental hospital – formerly a workhouse – where I was to spend the next three years. Or was it four? Being with other "nutters" and having a certain amount of freedom I soon became institutionalised." Paul

2.2 Stigma and discrimination in personal and intimate relationships

"I have lost all my friends since the onset of my mental illness. My ex-colleagues at work have also ceased all contact with me. I lost my career, my own flat, my car. Mental illness has destroyed my life." Fiona

How can mental illnesses affect friendship? To summarise the research in this field, people with more severe forms of mental illness have been found to have smaller social networks than others, to have relatively more family members than friends in their social circle, and to have relationships that are somewhat more dependent rather than inter-dependent^{56,57}. Several studies show that people with smaller social networks, with fewer intimate relationships, find it more difficult to manage social situations⁵⁸⁻⁶⁰. In particular, there is often a tendency for people with more long-lasting mental illnesses to have relationships mainly with other people in the same position.

"The problem always has been human contact. Sometimes I feel like I'm the only one left in this world. I feel the need to speak to somebody but there is no one for me out there. Imagine that sometimes I miss my adolescence when all the children in my neighbourhood were teasing me. At least I was not feeling so lonely then." Ilias

Intriguingly, people with a diagnosis of mental illness report that, in general, friends and family often react either in a strongly supportive or a strongly avoidant way, but that they could not have guessed in advance who would fall into which category. Some of those who had been warm and kind before the onset of their mental health problems cooled noticeably or disappeared from their life, while others who had been acquaintances or distant relatives showed unexpected empathy and practical support after the mental illness began. There is no scientific literature on who is likely to stand by you or to desert you when life gets tough in this way.

"I don't think a person like me can have friends. I tried, I tried hard to keep some, but in vain. The psychosis makes people afraid of me. I don't know. Perhaps they are right." Ioannis

A common reaction under these circumstances is for mental health service users to heavily censor what they say about their condition to friends, in the hope that not disclosing information will prevent others from learning about the diagnosis. This social survival tactic, requiring constant vigilance, may be more successful in large than in small communities such as villages or colleges.

If friendships may be difficult between some people with mental illness and others, what do we know about intimate relationships? These are challenges which often affect people in early adulthood, at the same time when many mental illnesses begin ⁶¹. A survey of almost 200 young people with mental illnesses in Finland, for example, found that their problems 'could be identified in all central spheres of life as difficulties in relation to the self, school, parents, peers, dating and the future... focus should be made on the inner world of the young person, as well as on their behaviour within the different spheres of life.'⁶²

"Well the person I was friendly with, she ended it after I was in treatment here ... we were friends for like seven years. First, she kept her distance. We didn't have an argument. After that I stopped dating. I think about the fear when they find out eventually. I don't want to sit through that again. Once you get close to someone you start talking you might talk about what pills you take. For example, if they come to my house or I go to their house... they might see the pills and ask what it's for. I think that they would worry and stop the relationship."
Leroy

2.2.1 Marriage

Does having a mental illness affect marriage? Very often. A study of people with a diagnosis of schizophrenia in five different European countries, for example, found that two-thirds were effectively single, and only 17% were married. The proportions of people with mental illness who were married in each country (compared with the general population) were as follows: Amsterdam (Holland) 10% (compared with 28%), Copenhagen (Denmark) 11% (compared with 21%), London (England) 16% (compared with 22%), Santander (Spain) 16% (compared with 47%), and Verona (Italy) 24% (compared with 55%). So it is clear that having a diagnosis of mental illness can reduce a person's chances of marrying or remaining married ⁶³.

"Once I had a partner and when I told her that I have schizophrenia, she started shaking. I never saw her again. After that I hid it." Emanouil

Within marriage, the effects of mental illness can add pressures that are hard to withstand. In a large nationwide study in the United States, for example, married men and women who had a diagnosis of severe depression said that they had fewer positive interactions and more negative interactions with their spouse or partner, compared with people with other types of mental illness, and compared with people with no mental illness. The researchers concluded that poor quality intimate relationships are characteristic of people with severe depression ⁶⁴

"I inhibit myself on topics of close relationships with women, and marriage." Ali

2.2.2 Parenting

In terms of parenting we find a mixed picture. A significant proportion of mothers with psychotic disorders have parenting difficulties or lose custody of their infant⁶⁵. On the other hand, the physical health of babies who live with mothers who have psychotic disorders is not significantly different from that of other babies⁶⁶. A diagnosis of schizophrenia for a mother is more often linked to social services supervision, and one British study concluded that preventative interventions targeting social and financial problems, the early treatment of symptoms, and assessing if the father also needs help for a mental illness, may be helpful in improving parenting⁶⁷.

Overall, research in this area is scarce, and there is little evidence suggesting that women diagnosed with a mental illness cannot parent. For example, one study of admissions to psychiatric mother and baby units in the UK found that the majority (70%) of women did not need social services support on discharge⁶⁸. Despite this, considerable evidence shows that women with severe mental illness lose custody of their children far more frequently than the general population⁶⁹⁻⁷¹. Even so, mental health services seem to pay scant attention to childcare problems among people they treat⁷², and usually they leave these needs unmet⁷³. In general it seems fair to say that there may be considerable discrimination against mentally ill parents, but that this has not yet been established.

2.3 Stigma and discrimination at work

There is strong evidence that many people with mental illness suffer unjustified restrictions in getting and keeping work^{20,74-82}. A review in England, for example, using the standard National Labour Force Survey, found that in recent years the proportion of the whole adult population who were employed was about 75%, for people with physical health problems the figure was about 65%, while for people with more severe mental health problems only about 20% were employed⁷⁴. Even for people with more common types of mental illness, such as depression, only about half are competitively employed⁸³. There is some evidence that the UK may be worse than other EU countries in this respect. In a study of people with a diagnosis of schizophrenia in five European countries, the lowest employment rate was in England (5%), compared with 20% and 23% in the Spanish and Italian sites⁶³.

At the same time it needs to be acknowledged that some mental illnesses do have profound and negative effects upon the extent to which people with such conditions can find and keep jobs⁸⁴.

'I had 20 jobs in five years, and I was being sacked because I really wasn't very well. For the librarian's job, they should have had a proper chat with me rather than just sack me. But at that point I went off my medication and from their point of view I just wasn't doing the job properly. So I didn't complain, but I think it could have been handled differently. I've been sacked from two or three jobs, some without any real explanation.' Rachel

It is clear that although the primary disability can affect a person's ability to find and keep work, the flexibility of the employment environment also plays a large part in shaping how far people with diagnoses of mental illness are included in the workforce. The figures are formidable: in England one third of people with mental health problems say that they have been dismissed or forced to resign from their jobs¹⁴, 40% say that they were denied a job because of their history of psychiatric treatment¹⁴, and about 60% say that they have been put off applying for a job as they expect to be dealt with unfairly. Indeed for some people discrimination in the work place is far greater than in any other domain.

'I am now 59 years old, living in a flat which I own, and I am very happy and contented. I have not experienced stigma or discrimination since leaving work.' Stephen

The Experience of Stigma and Discrimination

Such discrimination does not necessarily signal resignation. One survey found that people with mental disorders had the highest 'want to work' rate: while overall 52% of the disabled people interviewed wanted to find a job, among people with 'mental illness, phobias and panics' this figure rose to 86%⁸⁵.

"Somebody like me can never expect to work again." Leroy

The challenge of finding work is one that many people with mental illness come to believe is beyond them. Some have heard the fatal words from their doctor 'You'll never be capable of holding down a job'⁸⁶, and conclude that they should adjust to permanent unemployment. Others reach the same conclusion after many unsuccessful attempts to find a job⁸⁷. Why is finding and keeping a job so difficult for so many people with a diagnosis of mental illness?

One explanation is that employers discriminate against applicants who declare a history of psychiatric treatment. In a study of 200 Human Resource Officers in UK companies, vignettes of job applicants were submitted which were identical except for the presence or absence of a diagnosis of depression. The mention of a mental illness significantly reduced the chances of employment, compared with a history of diabetes. This differential treatment was made based upon perceptions of potential poor work performance, rather than expectations of future absenteeism⁸⁸.

Similar results came from another national study of employers in Britain. Fewer than 40% said that they would consider employing a person with a history of mental health problems, compared with 60% for people with a physical disability, and about 80% for long-term unemployed people and lone parents^{74;89;90}. One possible check to such direct discrimination are the policies of Occupational Health departments, but fewer than half of employers in the UK, for example, have such staff⁹¹.

The factor that is perhaps the most powerful deterrent against entering the workforce in many countries is the effect on welfare benefits payments. In many of the more economically developed countries, there are systems of entitlements for people who have severe or long-lasting disabilities, and often over 90% of people with psychotic conditions, for example, depend on this for their income⁹². Very often the application process is so complex and time-consuming that service users are reluctant to forego this type of secure income in case a new job might not last. Related to this are rules on additional earning which can be very restrictive and difficult to understand⁸⁴. The combined effect is to act as a powerful disincentive to look for a job.

A real dilemma faced by people with a history of psychiatric treatment is whether to disclose this when applying for a job. From what we have seen there are strong reasons to believe that disclosure will reduce the likelihood of success. On the other hand, failure to disclose may break an employment contract, and also mean that the person is not able to ask for modifications to the job to make it more manageable (usually called 'reasonable adjustments')^{93 77}. So there is no easy solution to this dilemma, or how to describe gaps in the employment history. One approach is to make a balance sheet of advantages and disadvantages of declaring a history of mental illness, and to use this in making a decision⁷⁵.

"I was working in a solicitor's as a trainee receptionist. I couldn't tell my boss I had to see a psychiatrist every week, so I told him I was on a training scheme one day a week. When I had to tell him I was being taken into hospital his reaction said it all. He sat back in his seat wanting to keep as far away from me as possible. As soon as mental illness is mentioned people literally back off from you." Jo²⁰

While finding work may be difficult, this is only one half of the battle. It can be just as hard to keep a job when you have a mental illness. A large survey of over 500 working people who had diagnoses of various mental illnesses asked them to describe their main problems. The difficulties they described were: loss of confidence, feeling isolated and this leading to poor work performance, lack of understanding from colleagues, fear of disclosing the diagnosis, being bullied or given demeaning jobs with poor prospects of promotion, struggling to cope with the social aspects of the workplace, and frequent stress and anxiety⁹⁴.

"I was transferred to another section in 1980, and worked for a male Senior Executive Officer who was a friend of the woman supervisor bully. He pressurised me by picking on me, giving me horrible jobs. I was placed in a basement cellar without windows to work on my own packing parcels and store work. The pressure was so much that I was unhappy and took another overdose of psychiatric drugs." Stephen

Perhaps the best summary is from a report of the direct experience of service users. It was such findings that led the Mental Health Foundation to conduct a large-scale survey⁹⁵ specifically about work-related experiences among people with a diagnosis of mental illness. In total 411 people took part in this survey and these were the main findings:

- over half believed that they had definitely or possibly been turned down for a job in the past because of their mental health problems
- only one third felt confident in disclosing their experience of mental health problems on job application forms
- people with anxiety or depression were more likely to be employed than people with a more severe diagnosis - but still fewer than 60% were employed full-time or part-time
- fewer than half of the people who responded with psychosis, schizophrenia, bipolar disorder or phobias were in full-time or part-time employment
- people with mental health problems make a major contribution to society with one in five doing voluntary work, and the groups who are least likely to be paid for their work (particularly people with bipolar disorder or schizophrenia) are those most likely to be working in a voluntary capacity
- nine out of ten people currently in employment had informed somebody in the workplace about their experience of mental health problems
- of those who had been open about their mental health problems in the workplace, over half usually had support when they needed it, and two-thirds reported that people at work were always or often very accepting
- however, about a quarter reported that sometimes too much account was taken of their mental health problems, and that they felt more patronised or monitored than other colleagues
- over 15% believed that they had been passed over for promotion because of their mental health problem
- 10% believed that colleagues made sarcastic remarks or that colleagues avoided them because of their mental health problem
- a third believed that bullying at work had caused or added to their mental health problems.

3 UNDERSTANDING STIGMA

There is now a voluminous literature on stigma^{5;10;96-106}. The most complete model of the component processes of stigmatisation has four key components¹⁰⁷. (i) Labelling, in which some key personal characteristics are signalled to others or recognised by others as conveying an important difference. (ii) Stereotyping, which is the linkage of these differences to undesirable characteristics. (iii) Separating, which means making a distinction between the 'normal' group and the labelled group. (iv) Status loss and discrimination: devaluing, rejecting, and excluding the labelled group. Interestingly, more recently the authors of this model have added a revision to include the emotional reactions which may accompany each of these stages¹⁰⁸.

3.1 Shortcomings of stigma models

A number of features have limited the usefulness of these stigma models¹⁰⁹. First, while these processes are undoubtedly complex, the approach taken by academics has been dominated by those within social psychology or sociology⁵⁹⁶⁻⁹⁸, and in particular there have been relatively few connections with the fields of clinical practice or disability policy¹¹⁰⁻¹¹². Legislation such as the Americans with Disability Act, and the Disability Discrimination Act in the UK have been applied relatively infrequently, for example, to cases involving mental illness¹¹³⁻¹¹⁵.

The focus upon the core concept of stigma rather than upon prejudice and discrimination has also separated the field of mental illness from the mainstream of disability-related policy, and in particular has offered policymakers and politicians few recommendations for action. Further, parallels have rarely been drawn with other areas of unequal treatment such as for people with HIV/AIDS^{116;117}.

Overwhelmingly, most work on mental illness and stigma is descriptive, commonly describing the results of public attitude surveys, or the coverage on specified conditions, such as mental illness by the media. Very little is known about effective interventions to reduce stigma^{118;119}. There have been notably few contributions to this literature from service users themselves, and little reference to their direct experiences of how others react to them because of their diagnoses¹²⁰⁻²². There has been an underlying view that stigma is deeply historically rooted, difficult to change, and that over-optimism about its reduction should be avoided¹²².

The formulation of the stigmatising relationship between 'perceiver' and 'target' has focused research attention largely upon the level of one-to-one or small-group interactions⁹⁷, and has sometimes seen those who are disadvantaged as passive victims⁹⁷. Furthermore this takes the focus away from the question of how much power and influence are held by people with mental illnesses^{123;124}, and away from structural factors which manifest the low value accorded to disadvantaged groups, such as the level of investment in health care facilities¹²⁵.

Related to this, stigma research has rarely connected to the domains of civil liberties and human rights^{126;127}, and the potential to use such declarations and conventions to improve treatment and care, especially for those undergoing compulsory treatment¹²⁸. Finally, the predominant emphasis upon psychological factors has paid less attention to how far particular abilities/disabilities confer a disadvantage only within specific contexts.

It has been clear for many years, from reading the personal experiences of service users, that mental disorders can have serious and sometimes devastating implications which disrupt personal relationships, parenting and childcare, education, training, work and housing^{63;76;129-131}, and that the reactions of others may bring greater disadvantage than the primary condition itself^{132;133}. Recently, some recognition of this has been evident in a trend to develop a clearer focus upon discrimination, and to understand the behavioural consequences of stigma^{109;110;123;134-136}.

3.2 Three core problems

Before spelling out what actions are necessary to combat stigma, first of all it is important to have a useful map to know where we are and where we want to go.

The concept of stigma has been necessary to develop an understanding of feelings and experiences of social exclusion, but it has not been sufficient to grasp the whole picture, nor to know what practical steps need to be taken to promote social inclusion⁷⁴. Stigma can best be seen as an overarching term that reflects three closely related constituent elements: problems of knowledge (ignorance), problems of negative attitudes (prejudice), and problems of behaviour (discrimination)¹³⁷⁻¹⁴¹.

3.2.1 Ignorance: the problem of knowledge

Wherever it has been studied, it is found that average levels of public knowledge about mental illness are remarkably low. One common misunderstanding, for example, is that schizophrenia means 'split-mind', usually misinterpreted to mean a 'split-personality'. Surveys of over 12,000 individuals in several European countries have discovered that such views are common, and are supported by many or even most people in: Austria (29%), Germany (80%), Greece (81%), Poland (50%) Slovakia (61%), and Turkey (39%)^{101;142;143}.

At a time when there is an unprecedented volume of information in the public domain about health problems in general, the level of general knowledge about mental illnesses is universally meagre. In a population survey in England, for example, most people (55%) believed that the statement 'someone who cannot be held responsible for his or her own actions' describes a person who is mentally ill¹⁴⁴. Many (63%) thought that fewer than 10% of the population would experience a mental illness at some time in their lives. In Northern Italy it was found that people who had more information about mental illnesses were less fearful and more willing to favour working with people with a history of mental illness¹⁴⁵, and exactly the same finding came from a Canadian study¹⁴⁶. Most studies also agree with the findings of a Swiss survey that age matters: older people are both less well informed about mental illness and less favourable towards people with mental illnesses¹⁴⁷. Women also tend to offer more favourable views about people with mental illness in most Western surveys^{148;149}.

There are also striking knowledge gaps about how to find help. In Scotland most children did not know what to do if they had a mental health problem or what to recommend to a friend with mental problems: only 1% mentioned school counselling, 1% nominated helplines, 4% recommended talking with friends, 10% said that they would turn to a doctor, but over a third (35%) were unsure where to find help¹⁵⁰.

The public level of knowledge about mental illnesses and their treatments has sometimes been called 'mental health literacy'^{151;152}. In Australia over 2000 adults were asked about the features of two mental illnesses and their treatment. Many (72%) could identify the key characteristics of depression, but relatively few (27%) could accurately recognise schizophrenia. Many standard psychiatric treatments (antidepressant and antipsychotic medication, or admission to a psychiatric ward) were more often rated as harmful than helpful, and most people more readily recommend the use of vitamins¹⁵³. Among people with depression, many have strong and often ambivalent feelings about taking anti-depressant drugs, although interestingly the rate of acceptance of these medications is higher among people who have taken them for a previous episode of depression^{154;155}. Such findings have led many, especially in Australia where much of this work has been pioneered, to conclude that it is necessary to provide far more information on the nature of conditions, such as depression, and on the treatments options which are available, so that both the general population, and those who are depressed at any one time, can make decisions about getting help on a fully informed basis¹⁵⁶⁻¹⁵⁸. In other words, the best remedy for ignorance is information, where such information will include full details of both the wanted and unwanted effects of the available treatments, how specific they are for particular diagnoses, their likelihood of being effective, and the need for a full care package to address the range of needs of each individual.

Is stigma getting better or worse? As we have seen elsewhere in this report, sometimes the literature is loquacious (for example on perceived threat and violence) and sometimes it whispers or remains silent. Trends in stigma are a quiet zone. There has been active academic work in the field of stigma for over half a century^{139;140;159-163}, but few surveys have been repeated to see if attitudes are becoming more or less favourable. In Greece, a comparison was made between public views about mental illness in 1980 and 1994¹⁴⁸. Significant improvements were identified for: social discrimination, restrictiveness, and social integration, with, for example, more people saying that they would accept a mentally ill person as a neighbour or work colleague.

There are also some indirect indications that popular views of mental illness have changed, for example the fact that increasing numbers in many countries do now seek help for mental illnesses¹⁶⁴, although most still do not¹⁶⁵. An important study in the USA compared popular views of mental illness in 1950 and 1996¹⁶⁴. Over this period it found evidence that there was a broadening of what was seen as mental illness, to more often include non-psychotic disorders, as well as behaviour characterised by social deviance or impaired judgement.

The second focus of this study was on 'frightening characteristics', and the results here were not heartening. There was a significant increase (almost two-fold) over the 46 year period in public expectations linking mental illness to violence in terms of: extreme, unstable, excessive, unpredictable, uncontrolled or irrational behaviour. This link was especially marked for public views of psychotic disorders, whereas dangerousness was less often mentioned as typical of non-psychotic conditions in 1996. In other words depression and anxiety-related disorders had become 'less alien and less extreme', while schizophrenia and similar conditions had grown in their perceived threat¹⁶⁴. The authors examined the hypothesis that closing large psychiatric hospitals had led to this greater disapproval and rejection. In fact they found the opposite: those who reported frequently seeing people in public who seemed to be mentally ill were significantly less likely to perceive them as dangerous¹⁶⁶. The authors concluded that 'something has occurred in our culture that has increased the connection between psychosis and violence in the public mind.'¹⁶⁴

There is evidence that deliberate interventions to improve public knowledge about depression can be successful. In a campaign in Australia to increase knowledge about depression and its treatment, some states and territories received a co-ordinated programme, while other did not^{167;168}. In areas which had received the programme respondents more often recognised the features of depression, were more likely to support seeking help for depression, and to accept treatment with counselling and medication¹⁶⁹.

In Great Britain there have been confusing and conflicting findings about trends in attitudes to mental illness. A series of governmental surveys have been carried out from 1993 to 2003 and give a mixed picture¹⁷⁰. On one hand there are some clear improvements, for example the proportion thinking that people with mental illness can be easily distinguished from 'normal people' fell from 30% to 20%¹⁴⁴. On the other hand some views became significantly less favourable, shown by the percentage of those agreeing with the following statements:

- it is frightening to think of people with mental problems living in residential neighbourhoods (increased from 33% to 42%)
- residents have nothing to fear from people coming into their neighbourhood to obtain mental health services (decreased from 70% to 55%)
- people with mental illness are far less of a danger than most people suppose (decreased from 65% to 58%)
- less emphasis should be placed on protecting the public from people with mental illness (decreased from 38% to 31%).

How is it possible that different studies seem to show that public attitudes are becoming both more favourable and more rejecting? One key seems to be diagnosis. Before and after its campaign called 'Changing Minds' the UK Royal College of Psychiatrists commissioned national opinion polls of nearly 2000 adults, asking about mental illness¹⁷¹. Unusually, they asked each of the key questions separately for a series of different diagnoses. Significant changes were reported in the following percentage of people who agreed with the following items between 1998 and 2003:

- 'danger posed to others': depression (fell from 23% to 19%), schizophrenia (fell from 71% to 66%), but no change for alcoholism or drug addiction
- 'hard to talk to': depression (fell from 62% to 56%), schizophrenia (fell from 58% to 52%), alcoholism (fell from 59% to 55%)
- 'never fully recover': schizophrenia (decrease from 51% to 42%), eating disorders (increase from 11% to 15%), alcoholism (increase 24% to 29%), and drug addiction (increase from 23% to 26%)
- 'feel different from us': depression (decrease 43% to 30%), schizophrenia (decrease 57% to 37%)
dementia (decrease 61% to 42%).

It is clear from these trends that complicated and mixed pictures emerge of both favourable and unfavourable change across a wide spectrum of conditions¹⁷². These marked variations suggest that public opinion surveys which ask about 'the mentally ill' in general terms, are likely to produce a composite and possibly uninformative response which summarises these conflicting trends. Overall it seems that popular views about depression in some countries appear to be improving in some Western countries in recent years, in terms of less social rejection, but the evidence about views on people with psychotic disorders suggest at best no change, and at worst (in the UK) deterioration.

Common myths about disability and mental illness

It is clear that lay opinions about mental illnesses are more informed by myth than by fact. Myths particular to people with mental illness ^{74;173;174}, for example, include:

- schizophrenia means a split personality
- all 'schizophrenics' are violent and dangerous
- people with serious mental illness are completely disabled
- having schizophrenia means that you can never do anything with your life
- schizophrenia represents a form of creative imagination or 'inner journey'
- they're lazy and not trying
- it's all the fault of the genes
- they can't work
- they are incapable of making their own decisions
- there's no hope for people with mental illnesses
- mental illnesses cannot affect me
- mental illness is the same as learning disability¹⁷⁵
- once people develop mental illnesses, they will never recover
- mental illnesses are brought on by a weakness of character
- psychiatric disorders are not true medical illnesses like diabetes
- depression results from a personality weakness or character flaw, and people who are depressed could just snap out of it if they tried hard enough
- depression is a normal part of the aging process
- if you have a mental illness, you can will it away, and being treated for a psychiatric disorder means an individual has in some way 'failed' or is weak.

That many of these ideas still have a common currency shows that the factual base of understanding mental illnesses among most members of the general population is still weak.

"I think that the reason for the stigma is firstly that the mentally ill can cause serious social problems including violence, threats of violence, they can be continually morose, talk endless streams of nonsense, they can be manipulative, attention seeking, obsessive, arrogant, they can seem extremely lazy. These are all traits of people that nobody could like to be around, whether or not this is due to an illness. What is happening to them has no properly understood step by step solution, so when we see somebody in a state that is clearly abnormal, we are scared because we are aware that nobody really knows how they got that way, how to get them out of this state, or whether it will even be possible for them to be returned to a more normal state. I think it is much more scary to see a man with an amputated leg than a man with a leg in plaster, because we know that the leg in plaster is getting better, whereas we know that the amputated leg will not return as far as science allows. I think if science did allow the amputated leg to 'grow back' then there would be no fear of looking at an amputee. Similarly I don't think that the stigma and conflicting views of the mentally ill would exist if science allowed all the sufferers to rapidly return to health by a fairly unstoppable means." Robert

3.2.2 Prejudice: the problem of negative attitudes

If ignorance is the first great hurdle faced by people with mental illness, prejudice is its close companion. Although the term prejudice has been used extensively in relation to some groups which undergo particular disadvantage, for example minority ethnic groups, it is rarely employed in relation to people with mental illness^{176;177}. Social psychologists have focused for almost a half a century on thoughts (cognition), rather than feelings (affect) or behaviour^{97;178-180}. In particular they have long been interested in stereotypes (widely held and fixed images about a particular type of person), and degrees of social distance to such stereotypes^{139;159;160}.

"Another thing that I was brought up with was that it was OK for women to get ill, or suffer from "nerves", whereas a man was tough and robust enough to weather any storm life threw at him." Paul

But reactions of rejection usually involve not just negative thoughts but also negative feelings such as anxiety, anger, resentment, hostility, distaste, or disgust¹⁰⁸. In fact prejudice (negative attitudes which include opinions and feelings) may more strongly predict discrimination (negative behaviours to a specific category of people) than do stereotypes¹³⁸. First, so called 'gut level' prejudices¹³⁹ may stem from anticipated group threats, or in other words, how far a member of an 'out-group' is seen to threaten the goals or the interests of the person concerned. Perceiving possible harm may provoke anger (if the person seen to threaten harm does not do so justifiably), fear (if the harm is in the certain future), anxiety (if the harm is in the uncertain future), or sadness (if the harm is in the past)¹³⁹. Some writers have made a distinction between 'hot' prejudices, in which strong emotions are more prominent than negative thoughts, and 'cold' forms of rejection, for example in failing to promote a member of staff, when stereotypes are activated in the absence of negative feelings¹⁸¹.

Emotional reactions may also be a consequence of direct contact with the 'target' group. This may be experienced as discomfort, anxiety, ambivalence, or as a rejection of intimacy¹⁴⁰. Such feelings have been shown to be stronger in individuals who have a relatively authoritarian personality, and among people who tend to believe that the world is basically just (and so people get what they deserve)^{182;183}. Such emotional aspects of rejection have been studied extensively in the fields of HIV/AIDS^{184;185}, and in those conditions which produce visible marks which contravene aesthetic conventions¹⁸⁶, such as the use of catheters or colostomies^{187;188}. Interestingly, probably because research on exclusion and mental health has been almost entirely carried out using the concept of stigma rather than prejudice, there is almost nothing published about emotional reactions to mental illness apart from that which describes a fear of violence^{147;176;189}.

"I have learnt to recognize the types of people who may be less prejudiced. Anyone humble or who knows a close friend/family member who has suffered, anyone who has been abused, or had a stressful childhood experience eg. Coming out as a homosexual, anyone well travelled, anyone with medical training, anyone who knows many different people. I believe that the prejudiced people are just believers in will power and getting on with things. People who have never had a problem that they can't deal with or sidestep somehow. Their achievements in their lives rest firmly on the shoulders of their courage and determination against the odds, and frankly if others wind up mentally ill, then it's probably because they've lacked the iron will and sense to get on with things? In a cynical moment I'll say that people revel in the misfortune of others. We're built to compete and to see someone stricken with mental illness gives everyone the relief and satisfaction that it didn't happen to them." Robert

3.2.3 Discrimination: the problem of behaviour

We have seen earlier in this report that most attention in research on mental illness has focused on attitudes towards mental illness. Much of this work is concerned with asking people, usually members of the general public, about either what they would do in given situations or what they think 'most people' would do, for example, when faced with a neighbour or work colleague with mental illness. In short, with some exceptions, such research has focused on hypothetical rather than real situations¹⁰⁹, shorn of emotions and feelings^{139;140}, divorced from context¹³⁵, indirectly rather than directly experienced⁷⁷, and without clear implications for how to reduce social rejection¹⁹⁰. The stigma field has been, to a large extent, beside the point.

If we deliberately shift focus from stigma to discrimination, there are a number of advantages. First attention moves from intentions to actual behaviour, not if an employer *would* hire a person with mental illness, but if he or she *does*. Second, interventions can be tried and tested to change behaviour towards people with mental illness, without *necessarily* changing knowledge or attitudes towards such people. Third, people who have a diagnosis of mental illness can expect to benefit from all the relevant anti-discrimination provisions and laws in their country or jurisdiction, on a basis of parity with people with physical disabilities. Fourth a discrimination perspective requires us to change viewpoint from that of the person within the 'in-group' to that of the person in the 'out-group', namely people with mental illness. In sum, this means sharpening our sights upon injustice and human rights as experienced by people with mental illness^{120;128;191-193}.

"I remember the first time a psychiatrist told me that if I had broken my leg, it would take a long time to heal and that your mind can take a long time to heal too. The day that the stigma vs mental illness is the same as the stigma vs a broken leg will be the time to stop talking about it. Until then I think that, although the mentally ill can be a pest during the peaks of their suffering, if people are treated with respect just like you might help someone with a broken leg to walk up some stairs, people may be able to recover quicker, and feel less isolated after." Robert

4 AGENDA FOR POLICY MAKERS

4.1 The policy framework

A series of mental health policies set the context for anti-stigma activities in England. Standard One of the National Service Framework for Mental Health ¹⁹⁴ states that health and social services should: (i) promote mental health for all, working with individuals and communities, and (ii) combat discrimination against individuals and groups with mental health problems, and promote their social inclusion. To date a substantial series of activities have been stimulated throughout England by this policy ¹¹⁹, although few of these projects have been evaluated to allow understanding of which interventions are effective.

The Social Exclusion Unit within the Office of the Deputy Prime Minister has identified widespread forms of exclusion as experienced by people with mental illnesses ⁷⁴. Their key recommendations fall under six headings:

- **Stigma and discrimination:** a sustained programme to challenge negative attitudes and to promote awareness of people's rights
- **Health and social care:** implementing evidence-based practice in vocational services, enabling reintegration into the community
- **Employment:** giving people with mental health problems a chance of sustained paid work
- **Supporting families and community participation:** enabling people to lead fulfilling lives the way they choose
- **Basic services:** access to decent homes, financial advice and transport
- **Implementation:** establishing clear arrangements to put these priorities into practice

A subsequent policy specific to stigma and discrimination in England ^{195;196} accepts that a 'disability inclusion model'²¹ is the most productive approach, and sets out four priority groups to be targeted: young people; the public sector; private, voluntary and professional organisations; and the media along with the public ¹⁹⁵.

At the European level, in 2005 the 'Mental Health Declaration for Europe' and the 'Mental Health Action Plan for Europe' were endorsed by the Ministers of Health of the 52 member states in the European Region of the World Health Organisation (WHO), at a meeting in Helsinki ¹⁹⁷⁻¹⁹⁹. There is clear evidence that in European countries there are serious violations of basic human rights ^{74;200;201}. The Action Plan recommends a series of particular steps: to foster awareness of mental well-being, to tackle stigma, to implement comprehensive mental health services, to provide a competent workforce, and to recognise the experience and importance of service users and carers in planning and developing services.

4.2 Policy action needed to support individuals and their families

"I have friends from the place I hang out. I've got two healthy friends, who have invited me to their weddings, but I have never talked to them about my disease or the fact that I'm on medication. I don't want them to know, because they might not take it well and I don't want to lose them". Paraskeuas

It is tempting to see ignorance, prejudice and discrimination as what are 'done to' service users and consumers, but this is unhelpful for two reasons. First, stigmatisation is applied by people with mental illnesses to themselves, as well as applied to them by others. Second, accepting the role of passive victim to stigma and discrimination is not one that assists recovery from mental illness and its consequences²⁰². So policy makers can contribute to reducing stigma and discrimination in part by supporting actions by consumers and service users themselves to cope with and minimise these forces²⁰³.

"It rips me apart lets put it that way, ok?" Kim

Concealment and disclosure

When a person starts to have a mental illness, then the question arises: what to tell other people? This is one of the most difficult questions of all²⁰⁴. Admitting one's diagnosis has been described as removing the stress of having to keep a secret²⁰⁵. Telling one's story has also been described as a liberating and empowering experience²⁰⁶, reducing social isolation and loneliness.

At the same time there are a series of potential drawbacks from disclosure. It directly allows others to draw upon their own ignorance or misinformation, along with negative emotional reactions, to react in a discriminatory way. It means that such a declaration may be seen as a 'master status' and colour, for example, the views of doctors when investigating physical problems. Disclosure may substantially reduce opportunities for employment, while non-disclosure prevents employers from making 'reasonable adjustments/accommodations'.

"I have had to be careful who I tell about my illness, because a lot of the time people throw it back in your face. They say well you are mad you have to see a psychiatrist." Louise

It is therefore clear that decisions by a person with a mental illness about what to tell, when to tell and to whom are fraught and far from straightforward^{131;207}. One practical approach is to draw up a balance sheet, for example of short term and long term expected benefits and costs of disclosing or not disclosing a diagnosis²⁰⁶. An anticipated tolerance for diversity may not in fact happen^{193;208}. A survey of over 1000 service users in the USA found evidence for caution here⁹⁹:

- 'I have been treated as less competent by other when they learned I am a service user' (70% agreed that this happened sometimes, often or very often)
- 'I have been shunned or avoided by other when it was revealed that I was a service user' (60% agreed that this happened sometimes, often or very often)
- 'I have been advised to lower my expectations of life because I am a service user' (57% agreed that this happened sometimes, often or very often).

For these reasons this survey also found that many service users were reluctant or very selective in disclosing information about their difficulties to others, for example regarding the statement *'I have avoided indicating on written applications that I am a service user for fear that this information will be used against me'*, 71% agreed that this happened sometimes, often or very often. Trying to keep secret one's identity as a person who has (or has had) a diagnosis of mental illness can itself be a source of considerable stress²⁰⁹. The price of privacy may be constant

vigilance and worry about discovery²¹⁰. This can be so severe and persistent that it has been described as a 'private hell'²¹¹. One implication of this for policy makers is to put in place measures that allow people with mental illnesses to conceal their condition (for example at job interview) if they wish, and to provide support (such as making reasonable adjustments) in practice, when choosing to disclose the condition.

'I think people are frightened by 'the mind illness' whereas 'physical illness' is there to be seen.' Sonia

Self-management and recovery

Mental health services are essentially different from all other health services in that they routinely force some patients to undergo treatment²¹². Psychiatrists are different from all other medical specialists in having such legal and professional powers to use on a regular basis. One of the consequences of having such powers is that some people with mental illness avoid mental health services for fear of having unwanted treatment forced upon them. Others who have been treated without their consent try to avoid any repetition of this²¹³ by not continuing contact with mental health services²¹⁴. This reason, added to the wish to avoid psychiatric treatment so as not to become stigmatised as 'insane' (the most common reason cited in one Israeli study of mentally ill people who chose not to go to psychiatric services²¹⁵), decrease the likelihood that people who need specialist help will receive it. In other words maintaining personal control over the situation is of paramount importance for many people with mental illnesses.

*'My anger and rebellion against being considered a failure and invalid'*²¹⁶

One way to try to achieve this is self-management²¹⁶⁻²¹⁸. This involves a person with a chronic condition 'engaging in activities that protect and promote health, monitoring and managing symptoms and signs of illness, managing the impacts of illness on functioning, emotions and inter-personal relationships and adhering to treatment regimes'²¹⁹. Self-management is often seen within a partnership with treatment services that offer self-management support, which is defined as 'the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support'²²⁰.

Self-management has been developed for a wide range of chronic health conditions²²¹, including asthma²²², arthritis²²³, and diabetes²²⁴. These methods have only recently been used by people with mental illnesses^{225,226}, including those with diagnoses of depression^{227,228}, panic disorder, phobias and obsessive-compulsive disorder²²⁹, and psychotic disorders^{230,231}.

Types of self-management range from approaches which are a form of 'do-it-yourself' for consumers²³², through to programmes which are 'professional-based interventions designed to help consumers and professionals collaborate in the treatment of mental illness, reduce susceptibility to relapses, and develop effective coping strategies for the management of symptoms'²²⁶. For example, consumers' views can shape their care through the use of crisis plans and advance directives^{233,234}. In this view of self-management four specific elements which have been shown to be beneficial^{225,226}:

- Psycho-education
- Strategies addressing medication non-adherence
- Relapse prevention training
- Coping skills training

The concept of recovery has become increasingly important in recent years. Although there is no consensus on what this term should mean²³⁵, it is usually used in a wider sense than to mean a complete cure²³⁶. More often it is now used by consumers to mean different things for different people: from 'enjoying the pleasures life has to offer, pursuing personal dreams and goals, developing rewarding relationships, and learning to cope with or grow past one's mental illness despite symptoms or setbacks'²²⁶, or 'reducing relapses, becoming free of symptoms, staying out of the hospital or getting a job'²²⁶. The term is seen to be an indication that service users and consumers can and should take the initiative in defining their own goals and the language which helps to achieve them^{237;238}.

Another type of initiative which service users can take on their own behalf consists of measures to enhance empowerment and self-advocacy^{239;240}. An empowerment orientation by consumers has been found to be positively associated with quality of life, self-esteem, social support and psychiatric symptoms²⁴¹. Indeed empowerment has been described as the opposite of self-stigmatisation^{242;243}. Policy makers can therefore provide specific financial support for ways in which individuals with mental illness can empower themselves or be empowered include the following:²⁴⁴

- Participating in formulating care plans and crisis plans²⁴⁵
- Using Cognitive Behavioural Therapy to reverse negative self-stigma^{246;247}
- Running regular assessments of consumer satisfaction with services²⁴⁸
- Creating user-led and user-run services^{192;249;250}
- Developing peer support worker roles in mainstream mental health care²⁵¹
- Advocating for employers to give positive credit for experience of mental health illness^{76;252}
- Taking part in treatment and service evaluation and research^{253;254}

Collective approaches to reducing discrimination

Apart from what individuals can do to reduce discrimination, what can groups of people do in terms of collective action^{255;256}? First, groups can protest against misrepresentations of mental illnesses and campaign for more accurate and fair portrayals²⁵⁷⁻²⁶⁰. They deliberately start from the actions of local self-help organisations, and build larger national and international coalitions¹¹⁰. Examples include, among many others, the following organisations:

- Mad Pride
- MindFreedom
- StigmaBusters (National Alliance for the Mentally Ill)
- National Anti-Stigma Clearing House
- National Mental Health Awareness Campaign
- Mental Health Self-Help Network

Media involvement

A further way in which people with a diagnosis of mental illness can take action to try to reduce prejudice and discrimination is to contribute to the coverage of mental health issues in the print, broadcast and electronic media²⁶¹⁻²⁶⁶. Although mental illness-related stories and features are covered relatively often, it is rare for people with mental illness to be quoted in their own words¹²¹. More often journalists will editorialise, usually in ways that are consistent with popular views of mental illness. In particular, it is rare to feature stories about people who have recovered from a mental illness²⁶⁷. One way of organising to respond to this deficit is to arrange 'speakers bureaux', which are now common, for example, in many parts of the United States. This is a core element of the current SHIFT campaign plans in England²⁶⁸. As yet there is no published research about the effectiveness of such specific interventions. Indeed consumer-led attempts to reduce stigmatisation have so far hardly been researched at all. Nevertheless, speakers bureaux can be seen as promising candidate interventions, because there is now fairly strong evidence for the positive effect of direct social contact with mentally ill people to reduce discrimination, which can be seen as a form of experiential learning^{269,270}. At the same time it is necessary for mental health professionals to play a more active role in putting accurate information on mental illnesses in to the public domain.

"Well I suffer from some sort of mental illness, I wish I could get more reading about it. I'm not sure if it's schizophrenia, but I obviously do suffer from a mental illness." Jean

As we saw earlier, popular knowledge about mental illnesses is a potent cocktail of profound ignorance²⁷¹ and pernicious misinformation²⁷². Professionals working in mental health services are mistaken if they think that their initial task is simply to provide neutral, factual information to a person newly diagnosed as having a mental illness. Staff in general health and mental health services can therefore support actions taken by consumers directly on their own behalf. Second, staff can supplement their current range of treatments with measures specifically designed to reduce discrimination.

"The worst thing about my illness was in the high, manic phase, which is the part that the public seemed to understand much less. What I found most difficult was that people can't distinguish what to count as part of you and what to count as part of the illness." Robert

Predominant views of mental illnesses are so negative that mental health staff need to understand that the diagnoses that they offer may be seen as most unwelcome. One challenge facing staff is to develop ways of providing diagnostic information that are more acceptable to people with these conditions. It is likely that these new methods will start by having to undo misunderstandings about, for example, what schizophrenia means. Staff need to understand better what psychiatric diagnoses mean from the perspective of the people on the receiving end.

"Certainly to my self-esteem, to the people I go to church with, the people that I've worked with, to my family, to former friends, it's been a big disadvantage." Jean (On having been given a diagnosis of schizophrenia)

"They tried to make me take Prozac in the evening, without explaining why. So I refused and put them in the drawer. I refuse to be treated like that... So now I don't like hospitals, and I won't go to one unless I'm on my last legs, I'm scared of what they would do to me. And never again will I try to get help for my phobia... because I don't like the way I'm treated by people because of being under psychiatric care, I'd rather suffer. If this is what happens to me, and I can speak for myself, what happens to people who have severe mental health problems?" Eva

By extension, building on the evidence from psychoeducational interventions, mental health professionals need to give more clear and accurate information to family members about diagnoses, both about what they do and what they do not mean, and to explicitly undermine popular misconceptions. One issue that is likely to be central to such programmes is to stress that mental illnesses in general do not arise because of something that the affected person has done or not done²⁷³. In other words, the person affected is not responsible for becoming unwell, and should not additionally suffer from being blamed for somehow causing the condition.

"I've got family and relatives in America who see me as a sort of like, a weak person or an uncle Tom. They don't particularly like the fact that I'm mentally ill. They just see me as stupid and inadequate, feeble." Jean

The research evidence is clear that attitudes towards mentally ill people are more favourable where the public believe that the condition has arisen 'through no fault of their own'²⁷⁴⁻²⁸⁰. It is therefore important, for consumers and for family members, to be given information which clearly describes what is known about the causes of mental illnesses, and which does not suggest that responsibility for the onset lies with the person affected or with the family^{281;282}.

"Well, he's looking down on me. I've told people that I suffer from depression and people they just change their opinion towards me." Kim

Such information about causes is important not just for service users directly, but also to provide family members with knowledge that they can use against 'courtesy stigma'^{50;283}. In other words to arm relatives with the information they need so that they can tell their friends, neighbours and colleagues that the condition affecting their relation is no-one's 'fault'^{284;285}. Some particular myths may need to be openly undermined, for example that people with psychotic disorders are usually dangerous, that depression indicates laziness and a lack of willpower, or that anxiety disorders are a sign of personal weakness²⁸⁶⁻²⁸⁸.

"I always get this remark that I should take it easy, I shouldn't stress myself as if I'm a weakling, or maybe because of what has happened to me I can no longer do things that I used to do and I don't like that. I want to feel like everybody else." Diana

One way to do this is to develop routine information packs, for consumers and their families, not only on what mental illnesses are, but also on what they are not²⁸⁹. This would mean spelling out common myths and undermining their existence through providing clear information. As such approaches are not routinely used now, they need to be developed with consumers and family members²⁹⁰, tested and refined. Such information packs will need to be tested both for their direct effects, and as part of integrated information and treatment programmes, specifically developed for people with different conditions^{226;291;292}. One part of such a package is balanced information about violence and mental illness, to correct misinformation or exaggerated concerns²⁹³, while acknowledging that people with some types of mental illness do have a somewhat higher risk of being violent²⁹⁴. Such approaches may be explicitly based upon stereotype suppression so that popular stereotypes and misperceptions are acknowledged and then rebutted^{183;295}. Additional modules are likely to be necessary so that people with a history of mental illness can develop and rehearse a 'storyline' about their condition, which allows them to tell their story in a largely positive way that does not alienate other people.

"Well there was this guy I was involved with when I was about 25, and he said that one of his friends had blurted out that he had ended up with a mental cripple." Teresa

Table 1. Policy action needed to support individuals and their families

Action	By
Develop new ways to offer diagnoses	Mental health staff
Have information packages for family members that explain causes, nature and treatments of different types of mental illness	Mental health staff, service users and families
Actively provide factual information against popular myths	Mental health staff
Develop and rehearse accounts of mental illness experiences which do not alienate other people	Mental health staff and user groups

4.3 Policy action needed at the local level

Work

"I lost my job ... I was unwell. I was having a lot of difficulties. I couldn't tolerate being sacked again. I've given up. Once bitten once twice shy." Kim

Perhaps the single most important step to support a process of recovery is to work^{74;84;296}. Rates of unemployment for people with psychotic disorders, for example, are often in excess of 75%. Over time, unemployment often leads to material poverty, a loss of confidence, an impoverished social network, and a sense of being without any social value. Interestingly less economically developed countries appear to be more successful than more industrialised nations in providing opportunities for meaningful employment^{297;298}. While there is a wide range of types of vocational rehabilitation, sheltered work and day care, few have been shown to be effective in achieving open market employment^{81;299-304}.

"I think when there is stigma, there is often ignorance around the corner." Robert

The evidence is strongest for supported work schemes in which people with a history of mental illness are supported by job coaches (employment advisers) to find a paid job and to continue in work^{76;301;305;306}. Problems with concentration and memory can harm a person's chance of getting or keeping a job³⁰⁷, and it is likely that some people will need both occupational support to find jobs, and psychological treatment to help them with their cognitive problems³⁰⁸⁻³¹⁰. The evidence for supported work schemes is now increasingly strong. Typically about 50% of people receiving such support do go on to gain paid jobs compared with about 20% of people in more traditional sheltered occupation (which are segregated facilities for disabled people)³⁰⁰.

The key principles of the supported work approach are: (i) competitive employment as the goal, (ii) rapid job search and placement, (iii) integration of vocational rehabilitation and mental health services, (iv) attention to the mentally ill person's preferences, (v) continuous assessment, and (vi) that support is not time limited^{84;311}. Implementing such schemes on a routine basis presents very considerable challenges to mental health and employment services.

"The overall thing is that I'm no longer the person I used to be." Diana

There is one way to jump-start this process: to encourage health and social care agencies to see the experience of mental illness as a positive attribute when hiring staff. In many countries health and social services are among the largest employers, for example the National Health Service in the UK is the largest employer in Europe. Paradoxically, such organisations have been particularly poor both in keeping staff who become mentally ill, and in taking on new staff who have a history of mental illness^{77;80;87}. They can do this by making it clear, from the advertising stage, that a personal knowledge of mental illness, for example as a consumer or a carer, can be seen as a positive advantage if an applicant is otherwise qualified for a particular post. A study in Connecticut, for example, found that former consumers were as able to work as case managers as anyone else³¹². Another approach is to develop new roles, such as peer support worker³¹³, in which a former consumer is employed within a mental health team and where his or her experience is seen as a particular asset, for example in engaging consumers in treatment. However this is done, it means reversing the common tendency in human service organisations to see workers as either healthy and strong and the donors of care, or as weak and vulnerable recipients. The need is to stop shunning 'wounded healers'^{314;315}.

"Well when I was first having my first breakdown I used to work for a supermarket and I kept on breaking down and they kept on taking me back. Because I think they valued the amount of work that I did. I was told by managers that I was a good worker... they wouldn't sack me ... and every time I fell ill and went into hospital they always took me back - on about four occasions." Teresa

.For some people who have, or who have had, mental illness an allowance needs to be made at work for their personal requirements. In parallel with the modifications made for people in wheelchairs, people with mental health-related disabilities may need (but this should not be assumed) what are called 'reasonable adjustments'^{16;113-115;316-320}. What does this mean in practice²⁰⁶? One of the challenges here is that while employers can understand the need for an entrance ramp for people in wheelchairs, often they do not know how to apply this concept to people with mental illnesses²⁹⁶. Such 'reasonable adjustments' might include:

- for people with concentration problems, having a quieter work place with fewer distractions rather than a noisy open plan office, with a rest area for breaks
- more, or more frequent, supervision than usual to give feedback and guidance on job performance
- allowing a person to use headphones to block out distracting noise
- flexibility in work hours so that people can attend their healthcare appointments, or work when not impaired by medication
- providing an external job coach for counselling and support, and to mediate between employee and employer
- buddy/mentor schemes to provide on-site orientation, and assistance
- clear person specifications, job descriptions and task assignments to assist people who find ambiguity or uncertainty hard to cope with
- for people likely to become unwell for prolonged periods it may be necessary to make contract modifications to specifically allow whatever sickness leave they need

- a more gradual induction phase, for example, with more time to complete tasks for those who return to work after a prolonged absence, or who may have some cognitive impairment
- improved disability awareness in the workplace to reduce stigma and to underpin all other accommodations
- reallocation of marginal job functions which are disturbing to an individual
- allowing the use of accrued paid and unpaid leave for periods of illness.

At the same time such accommodations may be resented by regular staff, who may see these as preferential terms and conditions which they cannot themselves enjoy. In this case it may be important for trades unions and staff representative bodies to be fully involved in such general negotiations, and to ensure that people without mental illness do not suffer disadvantage as a result of such policies. Also such work adjustments can only apply to people who disclose their mental illness (or history) and this is a sharp and unforgiving double-edged sword³²¹.

The accommodations needed by an individual may well change over time and need to be reviewed regularly. There will need to be clear arrangements on confidentiality, in other words, if a job applicant does disclose having a mental illness and does receive accommodations, who needs to know this? In particular, for people working in the same organisation in which they are treated for their mental illness, particular safeguards are needed to see that the confidentiality of clinical information is safeguarded³²².

Where employers, especially small organisations and those without a human resources department, may be unaware of the relevant disability laws, it is important to inform them of their statutory obligations³²³. Employers' concerns may be exaggerated. For example, a survey in England found that among employers with physically disabled employees more than half did not need to make any adjustments to the physical environment, and where changes were needed, they were usually not costly or difficult to make³²⁴.

"I haven't applied for any jobs since I've become ill. To stop me applying is a part of the anxieties and the things that I have as part of the syndrome of mine and is just lack of confidence you know. Thought processes and memories are kind of damaged. I mean I can't think as fast as before I was ill. And I have trouble with the memory. I don't really have that much ambitious goals, just get a decent job and you know a decent reasonable living. That's what I wanted to do. But I haven't been able to do that yet because of my illness so far. But I feel much better now I'm getting ready to get back to employment." Leroy

Many people with mental illness experience demoralisation, reduced self-esteem, loss of confidence, and sometimes depression³²⁵⁻³²⁹. It is therefore likely that support programmes assisting people with mental illness to gain employment will need to assess whether structured psychological treatment is also needed³³⁰⁻³³².

"I would have gone back to university back in the early 90's but there's no way I could get in with my mental health, ... because I had such low self-esteem and because I didn't think I could get those jobs or university places because of my mental health problems." Jean

Anti-discrimination interventions for targeted groups

It has long been known that direct personal contact with people with mental illness is one of the most potent ways to improve general attitudes towards people with mental illness^{176;178;333-336;337}. It appears that for this to work requires the opportunity to meet someone who is able to express their experiences clearly and without attacking the audience, and the chance to see this as a condition affecting a real person (rather than thinking of 'the mentally ill' in the abstract).

"I have three best friends, that take me as I am, phobias and all. My main friend, David, has a better understanding of my phobias because he has gone through it with me, as we have been friends since I was 12 years old." Eva

For this reason there has been a trend in recent years to move away from large scale mental health awareness campaigns towards local interventions targeted at specific groups^{123;190;338}. In the anti-stigma network of the World Psychiatric Association (called 'Open the Doors'), for example, such interventions have most often been applied to medical staff, journalists, school children, police, employers and church leaders^{100;101;339-341}.

Within schools, for example, there have been a series of studies which have educated students about mental illnesses to reduce ignorance, prejudice and discrimination³⁴². In Germany these took place against a background where many young people were very poorly informed about these issues³⁴³. The intervention programme led to a substantial reduction in the use of negative stereotypes by 14-18 year olds^{344;345}. In Chicago and Texas mental health awareness programmes had a similar impact^{346;347}. In England 14 year old school students received both factual information about mental illnesses and detailed discussions with a mental health service consumer and showed improvements in several aspects of their knowledge and attitudes^{119;348}, and the same findings came from a Canadian intervention study³⁴⁹. This is all the more remarkable since children's attitudes to mental illness otherwise seem to remain stable from the kindergarten stage³⁵⁰.

Such changes may have very important implications as we know that among the factors which make young people with mental health difficulties reluctant to seek help are low levels of information and negative feelings about mental illnesses^{351;352}.

As educational interventions alone have tended to produce little change, the direct contribution of service users/consumers seems to be the key active ingredient to these programmes¹¹⁹. The nature and the context of the contact are important. The most effective contact is with a person who moderately disconfirms a pre-existing stereotype. Behaviour consistent with a stereotype can reinforce it or make it worse. Individuals who appear to strongly disconfirm stereotypes can be dismissed as 'special exceptions'³⁵³. Productive social contact also needs to have³⁵⁴: (i) the same status for the different groups involved, (ii) shared goals for the session or programme, (iii) a tone of collaboration rather than competition, and (iv) senior managerial support for the initiative.

"The only practical way to stop stigma and discrimination is by better education of schoolchildren at an early age and to reinforce this message through life long learning. Each course or class should not only start with 'household' messages about fire escapes, etc, but that bullying or discrimination will not be tolerated whilst on the course." Paul

A second example of successful targeted interventions concerns the police³⁵⁵. The content of the intervention will necessarily vary here. Many police officers have frequent contact with people with mental illness, usually at times of crisis. They may have little or no experience of meeting people with psychotic disorders who are well at the time. Studies in Israel, for example, have found levels of knowledge among the police to be the same as in the general population³⁵⁶. Police attitudes may even be less favourable than popular opinions. An intervention programme in Chicago found that the police tended to discount information from victims or eyewitnesses who had a mental illness, in the belief that they were not credible informants^{357;358}. Such misunderstandings can have

fatal consequences. A series of fatal shootings of suspects (some of whom were mentally ill) by police officers in Victoria, Australia, led to Project Beacon in which all police officers in the state received mandatory training about mental illnesses. The number of fatalities among people with mental illness stopped until the programme was discontinued, but then rose again ³⁵⁹. This programme may have direct relevance for policy in England, where half of the 38 people who died in police custody in 2004 had some form of mental illness (see www.ipcc.gov.uk/pr200105_conference.htm).

Another key target group is healthcare professionals. Service users surprisingly often describe that their experiences of general healthcare and mental healthcare staff reveal levels of ignorance, prejudice and discrimination that they find deeply distressing. This has been confirmed in studies in Australia, Brazil, Canada, Croatia, England, Malaysia, Spain and Turkey, ³⁶⁰⁻³⁶⁸. Based on the principle 'catch them young', several programmes have given anti-stigma interventions to medical students ^{365;369-372}. As is usual in the field of stigma and discrimination, there is more research describing stigma than assessing which interventions are effective in tackling the problem. In Japan one study found that the usual medical curriculum had mixed results: students became more accepting of mentally ill people and mental health services, and more optimistic about the outlook with treatment, but there was no impact on their views about the human rights of people with mental illness ³⁷³. Positive changes in all of these domains were achieved with a one-hour supplementary educational programme ³⁷⁴.

There is mixed evidence about whether psychiatrists can be seen as stigmatisers or destigmatisers³². Mental health nurses have also been found to have more and less favourable views about people with mental illness than the general public³⁶². Interestingly, nurses, like the general population, tend to be more favourable if they have a friend who is mentally ill, in other words if there is a perceived similarity and equality with the person affected ³⁷⁵.

In this case what should mental health staff do? Direct involvement in the media is a vital route that professionals can use more often, with proper preparation and training. They also need to set their own house in order by promoting information within their training curricula, continuing professional development (continuing medical education) and relicensing/revalidation procedures which assess whether they have accurate information, for example, about recovery rates for various disorders ³⁷⁶. Second, practitioners may in future need to pay greater attention to what service users and family members say about their experiences of discrimination, for example in relation to work or housing, and to directly support them to combat unfair or illegal forms of social exclusion ³⁷⁷. Third, it is clear that service user groups increasingly seek change to the terms of engagement between themselves and mental health professionals, and to move from paternalism to negotiation ¹⁹². Vehicles to support such shared decision making include: crisis plans ²⁴⁵ (which seem able to reduce the frequency of compulsory treatment ²³³), advance directives ²³⁴, shared care agreements ³⁷⁸, and patient held records ³⁷⁹. The key issue is that service users want direct involvement in formulating their care plans ³⁸⁰.

"I also have trouble with the small of my back, it gives out every now and then, but its been getting worse. So I tried to get help for that, but the doctor asked me how long had I been under a psychiatrist? I asked him what that had to do with a bad back, but he dismissed it as a part of my mental health problem. When I told him the only problem I have is a phobia, he didn't want to know, and gave me painkillers, which they know I can't take because they make my stomach bleed. So now I don't go to the doctor anymore, I still have bad irritable bowel syndrome and back problems, but I'm not going to keep being fobbed off and treated like I'm stupid every time I go there." Eva

At the local level other targeted interventions may be important. Landlords may need information on the facts about dangerousness to counteract their reluctance to lease/let apartments. Judges and lawyers may benefit from education about how far people with mental illness are responsible and to blame for their conditions, in relation to sentencing, and on their options for referral of individuals to mental health services. Local policy makers may well need to be informed if their financial allocations for mental health care show unintended systemic/structural discrimination against people with mental rather than physical disorders. Researchers need to establish whether the claim that smaller, community-based mental health centres are less stigmatising is true or not ³⁸¹⁻³⁸³.

Table 2. Policy action needed at the local level

Action	By
Commission and provide supported work schemes in line with the Social Exclusion Unit's recommended action. Develop new ways to offer diagnoses.	Commissioners and mental health services, including non-statutory sector providers
Increase the availability of psychological treatments to improve cognition, self-esteem, confidence and social functioning.	Primary health services and secondary mental health services
Health and social care employers give recognition to the 'expertise by experience' of people with a history of mental illness through positive encouragement and support in recruitment and staff management practices.	Health and social care agencies in both the statutory and non-statutory sectors
Ensure people with mental illness and employers are properly informed of their rights and obligations under the Disability Discrimination Act, including changes that are coming into effect.	Mental health services, employers and business confederations, law organisations, CABx and other advice agencies
Mental health agencies and advice organisations actively encourage and support service users in securing their rights under the Act.	Mental health services, employers and business confederations, law organisations, CABx and other advice agencies
More widespread implementation, evaluation, and impact assessments of focused anti-discrimination interventions (including those that are part of SHIFT) with particular groups including school children, police and healthcare staff.	Educational organisations, police, health commissioning and providing organisations, research organisations
Provide accurate data on mental illness recovery rates to mental health practitioners and to service users and carers.	Professional training and accreditation organisations, mental health service providers
Encourage and support greater service user involvement in local speakers' bureaux and other anti-sigma and anti-discrimination initiatives.	SHIFT, service user organisations
Ensure local implementation of CPA includes care plans that are properly negotiated between staff and service users.	Mental health services, Commissioners, Healthcare Commission

4.4 Policy action needed at the national level

What needs to be done at the national level? The starting point is to appreciate that the forms of stigmatisation described in this report are widespread, severe and incompatible with a humane society. It is fair to say, in every country where this has been examined, that people with mental illness are more discriminated against than any other group³⁸⁴. For example, a survey in 15 European countries showed that 87% thought that people with mental health problems or learning disabilities would have less chance of finding a job than anyone else^{21;385}. Second, it is necessary to stress that this is a changeable situation. We know that the nature and degree of discrimination seem to have improved for particular disorders (eg HIV/AIDS)³⁸⁶, social characteristics (eg single parents), and ethnic and cultural groups (in overt racism). These changes have followed social and political recognition that these issues are problems which need to be confronted by concerted cultural and legal actions¹³⁴.

One necessary step to tackle stigmatisation in relation to mental illness is to frame the problems in ways that lead to action. The framework proposed in this report is to see stigma as made up of three distinct problems:

- The problem of knowledge: Ignorance
- The problem of attitudes: Prejudice
- The problem of behaviour: Discrimination

Which concepts are useful? Three views are most common: the biomedical model (locating the key problems within the individual), the individual growth model (suggesting a continuum between emotional well-being and ill-health), and the disability-inclusion model (which identifies the main problem as how society reacts to disabled individuals)^{110;387}. Each has strengths for particular purposes, for example the brain disease approach is yielding rapid progress in relation to Alzheimer's Disease. For the purposes of reducing discrimination, however, the disability-inclusion model is the strongest conceptual approach.

One advantage of framing the wider social problems associated with having a diagnosis of mental illness as disabilities is that such individuals may have legal rights to particular benefits, rather than be assessed as 'worthy poor' to receive discretionary charity. One barrier is that there is no internationally agreed legal definition of disability³⁸⁸. Within the European Union, for example, there has been a paradigm shift from a charity-based to a rights-based disability policy. On this basis disabled individuals may be able to benefit from exercising their legal entitlements using disability discrimination laws. Such laws offer direct recourse for disabled people but also send the powerful wider social message that discrimination is wrong and puts up unfair barriers to prevent disabled people taking a full part in society.

Even when a disability approach is used, certain details in its application can be counterproductive. For example, the Americans with Disability Act has been used in practice to apply to people who are substantially limited in a range of daily life activities. The image shaping this definition is again a person with severe physical impairments as the person who is 'truly disabled', and the assumption is that only severely disabled people suffer discrimination^{319;320;388}. Another example of this is the UK Disability Discrimination Act, which uses the following definition (see Appendix 2).

'a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse affect on his ability to carry out normal day-to-day activities.' Disability Discrimination Act UK, 1995

So even when countries do have laws designed to protect disabled individuals from discrimination, they may apply them narrowly only to people with very severe problems, or they may be interpreted in the courts to apply particularly to physical disabilities which more closely fit popular views of visibly disabled people. In other words, where these provisions are applied to people with mental illnesses, as in the Disability Discrimination Act (DDA) in Australia, they may be used without parity. This DDA, for example, applies to people with physical disability with more than 5% impairment, but to claim for psychiatric injury it is necessary to have almost twice this level of impairment³⁸⁹.

Even so, the way in which disability laws are applied is to allow *individuals* to take legal steps to enjoy their full entitlements. A wider view is that which is sometimes called *social adaptation*. This approach sees the problem as lying in the *interaction* between the person with impairments and particular environments. To start again with a physical analogy, the user of a wheelchair is not disabled if moving around a workplace is possible with lifts/elevators, whereas only having stairs in that building will profoundly disable that person. In other words, it is a question of the match between particular impairments and the adaptation of the environment to minimise or eliminate disabling consequences following the primary impairments. This approach has not so far been systematically applied in the field of mental health³⁹⁰. It would mean, for example, assessing the needs of the person returning to work after a period of depression, but who has not yet fully recovered, and then making particular changes to his or her work setting, for example, to reduce the ambient noise level if noise sensitivity is a problem. This social model of disability sees the organisation of society, and the attitudes of most members of society, as imposing limitations upon people with impairments. This approach has been influential among groups advocating for people with physical disabilities for over 30 years^{391;392}.

A related view, which also sees individual people with disabilities directly within their environment, is that which considers social exclusion and social inclusion^{21;74}. Much of the writing around social inclusion and exclusion has spoken either of the rights of disabled people (see the legal measures below), or has stressed the importance of reduced participation in: 'consumption, production, social participation and political participation'^{393;394}. In particular this view often advocates measures to support people with mental illness in the workplace³⁹⁵.

Going further, the disability-inclusion approach sees people with disabilities as having just the same rights to active citizenship as everyone else^{396;397}. The idea of citizenship has a number of advantages. It allows service users to challenge narrow disease-based definitions of disability. It supports the assumption that the human rights of mentally ill people should be respected. It offers a benchmark to assess the success of measures for self-determination. It acts as a point of reference in calls for social change. It fixes a responsibility with governments to respond to legitimate demands for parity of treatment, and to respond by committing resources. It provides a basis for routine consultation with mentally ill people on all measures that affect them, and legitimises their voice³⁹⁸. It offers a point of shared aspiration for people across many disability groups, around which they can organise. It moves away from a social response based upon pity, or the 'stigma of benevolence'^{176;193}. Finally, this approach assumes the innate dignity of all concerned^{21;110;387}.

Information and Knowledge

The evidence shows that members of the general public have remarkably little accurate factual knowledge about mental illnesses, although most do know someone affected¹⁷². The extent of ignorance is hard to underestimate, with some surveys showing that many of the people asked could not distinguish between epilepsy, mental illness and a learning disability. It is therefore perhaps less surprising to find that public attitudes on how to treat people with mental illness are often sharply different from those of professionals. For example, one study in Switzerland found that the general public were remarkably restrictive in their views about how to treat people with mental illness. Compared with psychiatrists, a sample of the general population were more likely to support withdrawing driving licences (7% vs 54%), suggesting abortions for mentally ill women who are pregnant (6% vs 19%), and withdrawing the right to vote (1% vs 17%)³⁹⁹.

We cannot resist several conclusions. Despite the profusion of news and feature stories on health topics in the mass media, the level of factual knowledge about mental illnesses in the general population is low. The information that is mostly present in the public domain emphasises the danger of violence from mentally ill people almost to the exclusion of all other aspects. Such a body of public knowledge presents a solid rock of ignorance which deters people with mental health problems from seeking help. Such popular received wisdom, on balance, promotes social exclusion rather than social inclusion.

What remedies are available? In North America public opinion surveys have been conducted for half a century¹⁶¹⁻¹⁶³, usually describing attitudes without any associated intervention programme^{164;259;400-402}. An exception was an early intervention programme in Saskatchewan, Canada, which found that most people were reluctant to have close contact with mentally ill people and that the attempts to reduce social distance were unsuccessful, producing hostility to the research staff^{164;403}. Relatively early, therefore, it became common to think that public education campaigns rarely produce meaningful and sustainable change.

More recent evidence has begun to challenge this received wisdom, and suggests that campaigns to raise the level of 'literacy' about mental illness can have a positive effect, as they have had for HIV/AIDS^{184;185}. In Australia 'beyondblue' is a concerted programme to convey accurate information about depression. Its initial evaluation showed a series of benefits including better community recognition of people with depression; reforms in life insurance and income protection, and the initiation of awareness and intervention programmes in schools^{167;404}. An important aspect of the programme was that some of the Australian States and Territories had a high level of exposure to the beyondblue intervention, and the others a low level of exposure, to allow a comparison of the impact. Compared with the low-exposure States, the high-exposure States had greater change in beliefs about some treatments for depression, particularly counselling and medication, and a higher recognition of the benefits of help-seeking in general. Between 1995 and 2003 the recognition of depression improved greatly throughout all of Australia, but slightly more so in the high-exposure states¹⁶⁹.

In Germany, public attitudes surveys have been conducted since 1990 and show that over the next decade the German public became more ready to recommend help from psychiatrists or psychotherapists for schizophrenia or major depression. There was also an increase in the willingness to recommend treatment in general, especially drug treatment or psychotherapy, for people with schizophrenia. Since there were no controlled comparison of interventions over that period for the whole country, it is possible that these favourable changes are more linked to improvements in treatment services than to any public information campaigns^{405;406}. At the same time contradictory evidence has emerged that despite a greater appreciation of the biological contributions to the causes of schizophrenia, that attitudes to people with this condition have worsened in recent years⁴⁰⁷.

There have been several national initiatives in England. The 'Defeat Depression' campaign targeted primary care practitioners as well as members of the general public with information about depression⁴⁰⁸⁻⁴¹⁰. The results of the evaluation of this programme showed positive changes in attitudes to depression, which improved by about 5-10%. Generally attitudes to treatment by counselling were very favourable, but antidepressants were seen as addictive and less effective⁴¹¹. Among family doctors 40% reported that they had improved their recognition and treatment of depression, and this was especially so for younger doctors and those who had undertaken previous psychiatric training⁴¹². At the same time it needs to be appreciated that because there was no clear-cut comparison between regions which did and did not receive the interventions, so it is possible that these changes were not related to the campaign.

In Scotland there has been a series of co-ordinated anti-stigma activities since 2002, called 'see me'. Initial assessments of a nationwide publicity campaign indicate that over half of the public sampled could recall seeing some of the campaign material and that by far the most effective channel to reach the public is television⁴¹³. A series of annual public opinion surveys will provide information on whether popular attitudes change over the period that the campaign takes place⁴¹⁴. We need to interpret such findings with some caution. For example, public attitudes to people with mental illness improved during the 1990s in the absence of a national

intervention programme. So such secular trends can take place alongside specific measures, and only the use of a comparison group, such as in Australia, can reveal if such changes are caused by the campaign or by other factors.

National anti-stigma activities are also taking place in New Zealand in the 'Like Minds, Like Mine' campaign⁴¹⁵, which is explicitly based upon a human rights approach to mental health⁴¹⁶. The programme has set the following objectives:

- Engage the leadership and participation of individuals and groups of people with experience of mental illness
- Engage supporters and allies as partners
- Advocate for non-discriminatory policies and practices
- Use mass media, community education and other means to improve the social inclusion of people with experience of mental illness
- Develop specific approaches for Maori people, and for people from different cultures, ethnic groups and age groups
- Develop and strengthen infrastructure to improve co-operation and co-ordination.

An assessment in 2004 compared a public opinion survey with the results from 1997, although the baseline response rate was only 19%. After the first phase of the nationwide press and television campaign, seen by over 80% of respondents⁴¹⁷, improved attitudes were recorded for several of the items in the questionnaire, but an intriguing finding was that some attitudes had worsened before this phase of the campaign, when there had been little anti-stigma advertising. This suggests that a national level campaign may need to be a long-term commitment to avoid reversal of popular attitudes^{175;417}.

Nevertheless, generally speaking successful initiatives to provide effective public educational materials are hampered by a lack of strong evidence about what works. Without such evidence a series of beliefs are commonly held by those active in the health education field¹¹⁰, namely that:

- Mental illness and mental health should be described as a continuum
- It is helpful to stress how common mental illness is
- Governments should act to promote more positive popular attitudes
- Groups with less favourable attitudes to people with mental illness should be particularly targeted
- A stress on positive mental health will also bring favourable attitude changes to people with severely disabling mental illnesses
- Measures designed to encourage people to talk about mental illness will have positive consequences
- Interventions should stress that the public should show greater tolerance or acceptance of diversity.

In fact there is some evidence that each of these assumptions is wrong¹¹⁰. It is fair to say that at present little is known about which methods of conveying information to mass audiences are likely to be more effective. A series of techniques are possible contenders, including personal testimonies by people with mental illness, incorporating mental illness-related story lines into popular drama, such as 'soap operas', using commercial brand awareness public relations methods, adapting such techniques for 'social marketing'⁴¹⁸, or deliberately associating mental illness themes with positive attributes (such as creativity by producing exhibitions of excellent art by people with mental illness)⁴¹⁹. Each of these deserves to be implemented and assessed to see whether or not they work.

"As far as people like me are concerned, I guess that if the Disability Discrimination Act had been in force when I had my last job, then I guess that I wouldn't have been sacked. I was sacked for taking time off work due to mental health problems, and what they should have done was given me a less stressful job within the organisation, but I was medically retired. I think that my psychiatric history has been a disadvantage right from the beginning really, my father wanted to have me exorcised when it first cropped up. Even when I went to study for a higher degree, I had been a teacher, and none of the rest of my cohort had been teachers, but they were all given teaching duties, which I thought was really, really unfair, because there was nothing to prevent me taking a seminar, but they thought that I was going to take an axe to the class or something like that." Veronica, who has a diagnosis of schizo-affective disorder

Legal measures

Legal measures will need to be used more often in the future to protect people with mental illness from unfair discrimination. Legislation in Australia, the Americans with Disability Act in the USA²⁰⁶, and the Disability Discrimination Act in the UK, have been framed primarily in relation to physical disability, and their achievements for people with mental illnesses have been few and disappointing^{110;113;420;421}. It is clear that such laws need to be either amended or interpreted in ways that provide legal parity for people with physical and mental disabilities in terms of their entitlement to work. The creation, amendment and implementation of such laws are likely to be better done if people with mental illness are directly involved at each stage⁴²².

The first step is therefore the introduction, where they do not exist, of laws to counteract discrimination against disabled people. Countries doing this now can draw upon the experience of those who have already enacted such legislation^{21;134}. Where these laws are already on the statute books, it is likely that they may need to be amended or interpreted to allow them to be applied fairly both for people whose disabilities are from physical and from mental conditions.

Experience of such laws is now accumulating and indeed almost a quarter (23%) of all cases pursued under the UK Disability Discrimination Act (DDA) in the last ten years were by people with mental illness. But the limitations of the initial implementation of such laws are now becoming clear, and can lie in the detail of the law. For example a review of the DDA in practice by the Disability Rights Commission has proposed that it should be unlawful for employers to ask job applicants questions about disability except in highly specified circumstances. Further they suggest that to qualify as disabled there should be impairments of 'normal day to day activities' that include both physical and mental impairments⁴²³. Where impairments are disclosed then it is still a common experience for people with mental illness to be treated as a member of a category, for example unsuitable to be a teacher because of a diagnosis of bipolar disorder, rather than to be assessed on their individual merits²¹. The very first case the British Disability Rights Commission taken up under the Disability Discrimination Act 1995 was for a man with a diagnosis of depression who had lost his job as an accountant working in local government. He won the case and was awarded £120,000 in compensation for estimated lost income.²¹

In the European Union anti-discrimination laws are now mandatory under the Article 13 Directive, and EU states must set up institutions to enforce such laws. The time is now right to share experience between EU nations about what has been learned in the implementation of anti-discrimination laws that have been successfully applied to reduce discrimination against people with mental illness^{21;317;420;424;425}.

Mental health laws can themselves be seen as discriminatory as no other category of health-related conditions commonly have special legislation. The argument has been advanced increasingly forcefully in recent years that the core issue at stake is when people, for whatever reason, lack capacity to make decisions in their own best interests, and that therefore what is necessary is not a mental health law, but a law which makes provisions for people who lack such capacity^{127;426-429}. There is widespread current concern that proposals for a new Mental Health Act in England are based too much upon public order rather than upon therapeutic benefit grounds, and that such an Act would increase rather than diminish stigma^{430;431-433}, especially among black and ethnic minorities where rates of compulsion are especially high⁴³⁴. Such views are reinforced by recent research showing that where specific mental health laws exist, then in many cases people who are admitted to hospital on a 'voluntary' basis may in fact be treated under some duress because they believe that if they attempted to discharge themselves then they would be legally detained^{435;436}.

A series of other areas require special attention. Firstly, insurance is a distinctly problematic for many people with mental illnesses^{115;437}. One survey in Britain found that a quarter of the people with mental illness questioned said that they had been refused insurance or other financial services¹⁴. This may well be unlawful. In the UK the Disability Discrimination Act 1995 makes it illegal to provide goods, facilities and services to a disabled person (including people with mental health problems) on terms which are unjustifiably different from those given to other people. Since 1996, this Act has made it illegal to refuse insurance, or charge higher premiums, unless the company can demonstrate statistically higher risks as a direct result of a specific mental health condition for that particular individual. However, people are reluctant to take out cases against big institutions and only a small handful of cases taken out under the Disability Discrimination Act have been successful.

Because of widespread concerns that discriminatory practices were making access to different types of insurance more difficult for disabled people, the Association of British Insurers (ABI) has produced a Code of Practice for its members on how to interpret the 1995 Disability Discrimination Act. In general, an insurance company must be fair and reasonable in its dealings with disabled people (including people with mental health problems) and must account for any difference in treatment between disabled and non-disabled people. Insurers' decisions must be based on information relevant to the assessment of the risk to be insured and from a reliable source. These may include: actuarial or statistical data, medical research information, a medical report, or an opinion on an individual from a reliable source. Insurers must make sure that the information is accurate and that their use of it is reasonable. It must be shown that the disabled person has a higher risk; if not, there should be no differentiation in their treatment. But in fact many insurance application forms ask for details of any pre-existing conditions, and may refuse cover if such conditions are present¹⁵. As many mental illnesses are either long-lasting or have cycles of relapse and remission, this disqualifies many people with mental illness from insurance cover¹⁶.

Welfare benefit rules also erect formidable barriers to work entry for many people with mental illnesses, and appear to be worse in the UK, for example, than in the USA^{134;438}. More imaginative and flexible arrangements (such as the provision of wage subsidies, higher levels of 'earnings disregard', raising the minimum wage, or guaranteeing jobs at non-poverty wages for all but the most disabled people)⁸⁴ are needed so that people who have been unemployed, often for long periods, can take paid work without reckoning that this creates an unacceptable risk to a secure income by threatening their entitlements to welfare benefits. Specific legal provisions which discriminate against people with mental illness, such as their prohibition to serve on juries, need to be reappraised and amended or repealed where necessary¹⁹.

The media

The media plays a very influential formative role in contributing to the pool of knowledge in the public domain about mental illnesses⁴³. The evidence is overwhelming that the mass media portrays mental illnesses in ways that evoke negative emotional reactions: principally fear and anxiety. In doing this they offer strong guidance to the public about what are appropriate emotional reactions to people with mental illnesses. In general, film and television and newspapers create unease around mental health issues which supports reactions focused on risk reduction and threat containment. In short the factual information contained in most mass media coverage of mental health issues is grossly unbalanced, and the emotional tone that it adopts is one that directly supports the view that mentally ill people should be shunned.

The effect of these media contributions is profound. Among the wide range of public views towards mentally ill people the core, repeated, themes in the majority of mass media coverage overwhelmingly reinforce only the most negative interpretations of what mental illnesses mean, and engender negative thinking about how to react to those affected. In other words the popular media lead the way in shaping our cultural expectations of mental illness. If we consider their role in terms of the three key problems of stigma (ignorance, prejudice and discrimination) then at present it is fair to conclude that they do more to distribute inaccurate than accurate information, more to foster negative than positive emotional reactions, and that their combined effect increases rather than decreases discrimination against people with mental illness⁴³⁹.

What can realistically be expected from these media? Their practitioners are quick to say that their role is more to entertain than to inform, more to cover the newsworthy than the worthy, and to command audiences and markets by connecting with popular concerns, rather than to perform health education.

One way forward is to bring social and cultural pressure upon those producing content for film, newspapers and television to give greater coverage to what people with mental illnesses say, in their own words. As we saw earlier, most news or feature items either include professional 'expert' contributions, or use editorialised journalistic content in which service users' views are reinterpreted to fit the overall storyline. To allow this to take place on a routine basis it may be necessary to fund, establish and maintain speakers' bureaux for groups of service users and consumers who wish to disclose their experience to be trained in handling the media. Such work can be expected to be particularly stressful if some journalists approach these speakers in a negative way, and as with other service user and consumer groups very careful arrangements are needed for preparation, debriefing and other ongoing support. Here a disability rights approach may be helpful as in recent years there has been a gradual cultural change in how some physical disabilities are portrayed, for example in relation to Para-Olympic athletic champions²⁶¹.

An additional form of response is to provide media response units which monitor media coverage of mental health related themes and which issue rapid rebuttals, objections or complaints where necessary⁴⁴⁰, as proposed by the SHIFT campaign²⁶⁸. For example in Australia, the StigmaWatch programme run by SANE Australia has an ongoing programme to require journalists to provide balanced mental health coverage, as does the Stigma Stopwatch group in Scotland. At present there is no formal evidence about the impact of such media watch interventions.

Also unevaluated are more subtle approaches which are referred to as 'cultural seeding'⁴⁴¹. This is somewhat similar to 'product placement' in films in that a signal is intended to be conveyed to the audience without it being explicit. The message which is to be conveyed is integrated into the media 'vehicle', not usually advertising, but embedded in an information source in which the audience invests legitimacy. In this way they do not appear to manipulate, but they do wish to create a contagious idea⁴⁴¹. For example, at a prominent awards ceremony, a new award could be added for an outstanding programme, film or newspaper report produced by someone with a mental disability. A related approach is to see the largely negative associations with mental illnesses as a problem of branding and to adopt standard public relations and marketing techniques to the 'rebranding' of the

reputations of these conditions. Such a co-ordinated and market-orientated approach has not so far been applied in any concerted way⁴⁴¹.

Cultural barriers can be encouraged by policy makers, as they have been in many countries in relation to describing minority ethnic groups, when reporting or featuring mental illness. Just as it has recently become more unacceptable to use terms which are regarded, for example by African-Americans, as abusive or disrespectful, this process has begun to be applied to some groups of disabled people⁴⁴², and terms such as 'cripple', or 'spastic' have less currency in some parts of the English speaking world. No such cultural pressures have so far been meaningfully applied to the mass media so that the terminology they use avoids causing offence. The development of such 'good reporting guidelines' needs to be done with care, and the mental health field can learn from how this has been successfully done in other areas of discrimination⁴⁴³. The key is to see the use of derogatory terminology as a form of real discrimination, rather than as a vague form of stigma, and to put political and social pressure upon governmental bodies and media organisations to apply the same restraints as they would for words that may be seen as racist.

Voluntary codes of practice have so far failed to make any substantial impact. For example the National Union of Journalists (NUJ) Code of Practice 1998 stated: 'A journalist shall only mention a person's age, race, colour, creed, illegitimacy, disability, marital status, gender or sexual orientation if this information is strictly relevant. A journalist shall neither originate nor process material which encourages discrimination, ridicule, prejudice or hatred on any of the above-mentioned grounds.' On the other hand there is some evidence that the introduction of guidelines on the reporting of suicides^{444;445} can improve the quality of such articles⁴⁴⁶.

"It was definitely a disadvantage... what I was trying to do was to compare the stigma attached to me with the stigma attached to being black. OK I was lost for words and I didn't quite explain myself properly because I was trying to say that it's wrong to discriminate against blacks, but it's wrong to discriminate against mental people." Kim, who has diagnoses of schizophrenia and depression

It is clear that at present there are no effective constraints upon the print, broadcast, electronic and film media from using grossly discriminatory portrayals of people with mental illness as a matter of routine^{190;265;442;447-451}. Policy makers may wish to introduce clear voluntary guidelines to shape and reduce such media misrepresentation. Another approach is to directly apply the full force of law so that offensive references to mentally ill people are treated as no more acceptable than racist references or comments that incite religious hatred.

Research

With the exception of social contact as discussed above, we have little evidence for other types of effective intervention at present. Therefore we need to assess each new anti-stigma intervention to see if it actually works or not. One systematic approach to this challenge is to identify candidate interventions (including those shown in Tables 1-3) and to assess how far they produce positive changes on: (i) knowledge about mental illnesses, (ii) negative emotions and attitudes towards mentally ill people, and (iii) negative discriminatory behaviour towards people with mental illness. The initiation of anti-stigma projects in the absence of evaluation will mean that the effects of such projects remain unknown, and so knowledge cannot be shared on what works to reduce stigma and discrimination^{96;98;119;452}.

As we have seen, the research which has been done so far in this field largely consists of attitude surveys. There is an underlying assumption from some authors that knowledge change is likely to lead to attitude change, and that both of these will produce behaviour change to reduce discrimination. Unfortunately these are largely untested assumptions, and the large body of work in health psychology suggests that the inter-relationships between knowledge, attitudes and behaviour are far from simple^{179;180;453-455}. If the main issue is to achieve behaviour change so that discrimination against people with mental illness reduces, then future research will

need to establish which interventions, aimed at knowledge, attitude or behaviour change, achieve these goals, either separately or in combination. This means identifying a series of candidate interventions and testing their effectiveness^{96,98}.

Evidence in one particular area of research is notably absent: multiple discrimination. Although it is commonly accepted in the field of mental health that some groups of people are subjected to several different types of stigma at the same time, research about this is very scarce^{456,457}. These claims have been made, for instance, for people who both have a mental illness and who also:

- are non-white (in white host population countries)⁴⁵⁸⁻⁴⁶¹
- have a forensic history or criminal justice record⁴⁶²
- have learning disability
- have drug or alcohol misuse or dependence^{463,464}
- are older adults⁴⁶⁵

There are clear grounds for concern about the contribution of research. A recent UK Medical Research Council report found that current levels of investment in mental health research are low in relation to the impact of these conditions on society. It also notes that engagement with research is not prioritised by the mental health community, that the research culture is poorly developed in comparison with other areas of health, and that there is some evidence that research capacity is in decline⁴⁶⁶.

Without such research, we do not know the answers to many important questions. These include:

- Are members of ethnic minorities who are mentally ill more discriminated against than members of the host population who have a mental illness?
- If an individual has characteristics which are stigmatised, eg mental illness and a criminal justice system record, is the total amount of discrimination the sum of these two, or more or less?
- Do self-stigma and self-discrimination in relation to mental illness vary according to experience of, for example, prior racial discrimination?
- If multiple discrimination does exist, does it have an effect on willingness to seek treatment, accept treatment recommendations and remain in contact with mental health services on a voluntary basis?
- Which interventions are effective to reduce discrimination against those with multiply stigmatised characteristics?

Table 3. Policy action needed at the national level

Action	By
Promote a social model of disability that incorporates mental health problems (including those of a temporary nature) within the mental health sector, which refers to human rights, social inclusion and citizenship.	NIMHE, mental health service commissioners and providers, professional training and accreditation organisations, professional organisations
Provide accurate data on mental illness recovery rates to the media.	SHIFT, print and broadcast media, Ofcom
Implement a national review of the Care Programme Approach (CPA) to identify barriers preventing care plans being properly negotiated between staff and service users.	DH, NIMHE, mental health service providers, research organisations
Promote service user-defined outcomes and examples of good practices in CPA where care plans are properly negotiated between staff and service users.	DH, NIMHE, mental health service providers, research organisations, Healthcare Commission
Ensure adequate funding is available and used for new supported employment schemes and greater availability of psychological treatments.	DH, Treasury, audit and inspection organisations
Continue to make available and disseminate widely information, guidance and advice on the Disability Discrimination Act (DDA) regarding mental health problems, including how employers can make reasonable adjustments/accommodations, and the new definitions of mental health problems that came into effect in December 2005.	DWP, DRC, NIMHE, other government departments, mental health service providers, employers
Commission and produce a ten year review of the application, enforcement and impact of the DDA for people with mental health problems.	DWP, DRC
Assess impact and evaluate SHIFT'S programme of establishing service user speakers' bureaux to offer content to news stories and features on mental illness.	DH, NIMHE, SHIFT stakeholder organisations
Assess impact and evaluate SHIFT'S media programme which is pressing for balanced and accurate reporting about people with mental health problems.	DH, NIMHE, SHIFT stakeholder organisations
Share between countries the experience of disability discrimination legislation (including any available research).	Legislators, lawyers, advocates, disability organisations and consumer groups, researchers

Action	By
Understand and implement international legal obligations under binding declarations and covenants, including the actions laid out in the 2005 Helsinki declaration on Mental Health.	DH, DRC, all statutory and non-statutory mental health agencies, audit, inspection and regulation bodies, WHO collaborating centres
Audit compliance with codes of good practice in providing insurance.	DRC, Association of British Insurers, Financial Ombudsman Service, CABx and other organisations giving financial advice
Reform of incapacity benefit system (including the assessment of incapacity/disability) to maximise non-coercive incentives to disabled people ready to return to work.	DWP, NIMHE, non-statutory mental health sector
Publish results of Home Office and Department for Constitutional Affairs consultation on jury eligibility criteria with a view to changing the law to allow people with a history of mental illness a presumption of capacity to serve on juries.	Home Office, Department of Constitutional Affairs
Any new mental health legislation should include a principle of non-discrimination that clearly states that people with mental disorders should, wherever possible, retain the same rights and entitlements as those with other health needs.	Government, DH
Further develop and refine existing mental health impact assessment and evaluative tools to incorporate indicators for stigma and discrimination.	DRC, NIMHE, research organisations
Meta-analysis of service user satisfaction surveys and service user-led research to identify evidence base to further support anti-stigma and anti-discrimination initiatives.	NIMHE, research organisations

5 CONCLUSION: DEMOLISHING STRUCTURAL DISCRIMINATION

“After my breakdown in 1999 I found that hospitals and psychiatry had changed in the sense that I was not only told my diagnosis but participated in drawing up my care plan; the secrecy I had known had gone along with those large hospitals.” Paul, who has a diagnosis of depression

Despite the realisation, for almost a century ¹⁷⁸, that discrimination against people with mental illness is both common and severe, little real progress has been made in the UK to ensure social inclusion. While there is some evidence that attitudes, especially towards people with depression, may be improving ^{467;169}, attitudes in England toward people with mental illnesses as a whole have substantially deteriorated in recent years ¹⁴⁴. The idea of parity with people with other forms of disability, let alone with non-disabled people, is very far from the everyday experience of most people with mental illnesses. It is encouraging to see that the future work programme of the SHIFT campaign led by the Department of Health intends to address some of these key areas of discrimination (Table 4) ²⁶⁸, although the investment in this programme is low compared with those in Scotland and New Zealand ⁴¹⁴.

Table 4.
Priorities of Department of Health SHIFT Anti-Stigma Campaign in England

- To use a disability-inclusion model to advance the civil rights agenda against stigma
- Target audiences will be: young people; public sector; private, voluntary and professional organisations; media and public
- Underpinning priorities: service user and carer involvement; resources and knowledge sharing; evidence and evaluation
- Collaboration across government between: the Healthy Schools Programme (Department of Health); the disability unit of the Department for Work and Pensions; the Office of the Deputy Prime Minister; the Home Office; the Department for Culture, Media and Sport; and the Disability Rights Commission.

As every aspect of personal, social and work life can be damaged^{191;55}, and as some forms of social exclusion (such as poorer physical health care treatment) do not seem to be clearly intentional, the totality of such social exclusion of people with mental illness has been described as *structural discrimination*^{135;468;469}. This is closely similar to the idea of institutional racism⁴⁷⁰, which Lord MacPherson has described in these terms:

‘Taking all that we have heard and read into account we grapple with the problem. For the purposes of our Inquiry the concept of institutional racism, which we apply, consists of: the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people... It persists because of the failure of the organisation openly and adequately to recognise and address its existence and causes by policy, example and leadership. Without recognition and action to eliminate such racism it can prevail as part of the ethos or culture of the organisation. It is a corrosive disease.’⁴⁷⁰

Just as concerted legal, social and cultural measures have been necessary to begin to reverse the forms of social exclusion for members of black and minority ethnic communities in Britain, so the same policy determination is now necessary to promote the social inclusion of people with mental illnesses within society. The steps outlined above in Tables 1-3 are an agenda for change, based upon the available evidence. More important than this is to systematically understand the real experiences of discrimination by people with mental illnesses^{192;443;471-474}, and their priorities for determined and long-term interventions to offer a greater range of opportunities for social participation, and the full exercise of basic rights for citizenship. All this amounts to no less than the need to demolish both direct and structural discrimination against people with mental illnesses.

‘At the end of the day I am still a person. I hold down a good job. I go out. I have a family. It’s just an illness.’
Emile, who has a diagnosis of bipolar disorder

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Terminology

At present there is an active international debate on the appropriate terminology to use in the mental health field. This report reflects such diverse and conflicting views, and uses a range of terms to refer to mental illnesses and to people who experience these conditions and their consequences. While the report does use the conventional international classification and diagnostic systems (DSM and ICD) ^{475,476}, it is acknowledged that these systems are controversial and that some service user/consumer groups believe that such diagnostic terms are themselves stigmatising.

APPENDIX 1. INTERNET RESOURCES

www.adscenter.org

U.S. Department of Health and Human Services Resource Center to Address Discrimination and Stigma.

www.bazelon.org

The Bazelon Center for Mental Health Law aims to protect and advance the rights of adults and children who have mental disabilities.

www.beyondblue.org.au

Beyondblue is a national, independent, not-for-profit organisation working to address issues associated with depression, anxiety and related substance misuse disorders in Australia, with the key goal of raising community awareness about depression and reducing stigma associated with the illness.

www.blackdoginstitute.org.au

The Black Dog Institute is a clinical, research and educational body dedicated to improving understanding, diagnosis and treatment of depression and bipolar disorder.

www.community-2.webtv.net/stigmanet/AbouttheNational/index.html

The National Stigma Clearinghouse tracks negative stereotypes of mental illnesses and to provides information about fighting prejudice to concerned activists.

www.drc-gb.org

The goal of the UK Disability Rights Commission is 'a society where all disabled people can participate fully as equal citizens'.

www.iop.kcl.ac.uk/iopweb/departments/home/default.aspx?locator=461

Evidence of effective interventions against stigma, from research conducted at the Institute of Psychiatry, King's College London.

www.mdac.info

The Mental Disability Advocacy Center aims to promote and protect the human rights of people with mental health problems and intellectual disabilities across central and eastern Europe and central Asia.

www.mdri.org

Mental Disability Rights International documents conditions, publishes reports on human rights enforcement, and promotes international oversight of the rights of people with mental disabilities.

www.mediawise.org.uk

The MediaWise Trust promotes, for the benefit of the public, compliance with ethical standards of conduct and with the law by journalists, broadcasters and all others engaged in or responsible for the media.

www.mentalhealthcare.org.uk

A source of evidence-based information on a range of mental illnesses, provided by Rethink and the Institute of Psychiatry, King's College London.

www.openthedoors.com

The Global Programme to Fight the Stigma and Discrimination because of Schizophrenia of the World Psychiatric Association (WPA) embarked on an International aims to: increase the awareness and knowledge of the nature of schizophrenia and treatment options; improve public attitudes about those who have or have had schizophrenia and their families; and generate action to eliminate discrimination and prejudice.

www.power2u.org

The National Empowerment Center envisions a future when everyone with a mental illness will recover.

www.rcpsych.ac.uk/campaigns/cminds

The Changing Minds campaign of the Royal College of Psychiatrists aims to increase public and professional understanding of mental health problems and to reduce stigma and discrimination.

www.seemescotland.org

The 'See Me' campaign challenges stigma and discrimination around mental ill-health in Scotland.

www.shift.org.uk

SHIFT is an initiative of the National Institute for Mental Health in England (NIMHE), to tackle stigma and discrimination surrounding mental health issues. Its aim is to create a society where people who experience mental health problems enjoy the same rights as other people.

www.stigmaresearch.org

The Chicago Consortium for Stigma Research is dedicated to understanding the phenomenon of stigma, developing and testing models that explain why it occurs, and evaluating strategies that help to diminish its effects.

www.unhcr.ch/html/menu3/b/68.htm

Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care. Resolution Adopted by General Assembly of the United Nations 46/119 of 17 December 1991.

www.uhweb.hartford.edu/owahl/resources.htm

Resource page on fighting discrimination and stigma, maintained by Dr. Otto Wahl.

APPENDIX 2. UK DISABILITY DISCRIMINATION ACT (DDA) 1995

Key points:

- The DDA makes treating disabled people less favourably than other people, without justification, unlawful in areas such as buying goods, using services, finding a job, and buying or renting land or property.
- Disability is defined as 'a physical or mental impairment, which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities.'
- The rights under the DDA also apply to people who have had a disability in the past.
- Discrimination occurs when: (i) a disabled person is treated less favourably than someone else, and (ii) the treatment is for a reason relating to the person's disability, and (iii) this treatment cannot be justified; or (iv) there is a failure to make a reasonable adjustment for a disabled person; and that failure cannot be justified; or (v) victimisation occurs in employment.
- All organisations that provide goods, services or facilities to the public, paid or free, are covered by the DDA, both large and small organisations.
- Where it is impossible or unreasonably difficult for a disabled person to use a service, the service provided must take reasonable steps to: (i) change its practices, policies and procedures; (ii) provide a reasonable alternative method for making their services available to disabled people, and (iii) provide an auxiliary aid or service for disabled people.
- It is unlawful for all employers (including small organisations since October 2004) to discriminate against disabled employees or job applicants.
- Employers have a duty to make reasonable adjustments to change any working arrangements that put disabled people at a substantial disadvantage compared with non-disabled people.
- The harassment of disabled people is unlawful, where this is defined as, 'a person subjects a disabled person to harassment where, for a reason which relates to the disabled person's disability, he engages in unwanted conduct which has the purpose or effect of: violating the disabled person's dignity, or creating an intimidating, hostile, degrading, humiliating or offensive environment for him.'⁴²³

APPENDIX 3.

INTERNATIONAL DECLARATIONS AND COVENANTS ON HUMAN RIGHTS

People with mental illnesses in many countries are treated in ways which prevent them from exercising some of their basic human rights⁴⁷⁷. It is hardly an exaggeration to say that we can estimate the value attached to people in this category quite precisely from seeing how much or how little attention is paid to ensuring that they are treated in fully humane ways⁴⁷⁸. Several legally binding conventions and declarations apply to disabled people in general and to people with mental health related disabilities in particular^{126,479}.

'All persons have the right to the best available mental health care, which shall be part of the health and social care system.' Mental Illness Principle of the United Nations International Covenant on Economic, Social and Cultural Rights

The primary source of international human rights within the United Nations (UN) is the Universal Declaration of Human Rights (UDHR), which refers to civil, political, economic, social and cultural rights. Civil and political rights, such as the right to liberty, to a fair trial, and to vote, are set out in an internationally binding treaty, the International Covenant on Civil and Political Rights (ICCPR). Economic, social and cultural rights, such as the rights to an adequate standard of living, the highest attainable standard of physical and mental health, and to education, are described in a second binding treaty, the International Covenant on Economic, Social and Cultural Rights (ICESCR). The UN High Commissioner for Human Rights (UNHCHR) reports to the UN on the implementation of these principles. Countries which have ratified this declaration and this convention are then obliged under international law to guarantee to every person on their territory, without discrimination, all the rights enshrined in both⁴⁸⁰⁻⁴⁸⁴.

More specifically in relation to mental illness, the UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care were adopted in 1991, and elaborate the basic rights and freedoms of people with a mental illness that must be secured if states are to be in full compliance with the ICESCR. The 'The Right to Mental Health' is stated in Article 12 of the ICESCR, which provides the right of everyone to the enjoyment of the highest attainable standard of physical and mental health", and identifies some of the measures states should take "to achieve the full realisation of this right". These Mental Illness Principles apply to all people with a mental illness, whether or not in in-patient psychiatric care, and to all people admitted to psychiatric facilities, whether or not they are diagnosed as having a mental illness. They provide criteria for the determination of mental illness, protection of confidentiality, standards of care, the rights of people in mental health facilities, and the provision of resources. Mental Illness Principle 1 lays down the basic foundation upon which states' obligations towards people with mental illness are built: that "all persons with a mental illness, or who are being treated as such persons, shall be treated with humanity and respect for the inherent dignity of the human person", and "shall have the right to exercise all civil, political, economic, social and cultural rights as recognised in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and in other relevant instruments". It also provides that "all persons have the right to the best available mental health care". As the United Nations' health agency, the World Health Organisation (WHO) reflects the UN's understanding of what is meant by "the best available mental health care"⁴⁸⁵.

In addition to these agreements, 43 member states of the Council of Europe are bound by particular human rights principles^{127,128}. These include the 1950 European Convention on Human Rights and Fundamental Freedoms (ECHR), and the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment. Table 4 shows 12 principles which appear most often among such policy documents⁴⁸⁶.

Table 4. Principles Relevant to Comparison of Mental Health Policies and Mental Health Laws

Principle	England		Scotland 2003	United Nations 1991 (UN)	WHO 2001	World Psychiatric Association 1996 (WPA)
	National Service Framework for Mental Health 1999 (NSFMH)	Social Exclusion Unit 2003 (SEU)				
1. Participation	Involve service users	Regard to past and present wishes of patient, ... full patient participation			Consumer involvement ... right to information and participation	Patient should be accepted as a partner by right in therapeutic process
2. Therapeutic benefit to the individual patient	Effective care	Effective care to prevent crises	Importance of providing maximum benefit to patient	Right to the best available mental health care. Every patient shall have the right to receive such health and social care as is appropriate to his or her health needs ... in the best interest of the patient	Efficient treatment	Providing the best therapy available consistent with accepted scientific knowledge. Treatment must always be in the best interest of the patient
3. Choice of acceptable treatments	Acceptable care & choice	Genuine choices	Importance of providing appropriate services to patient		Wide range of services	Allow the patient to make free and informed decisions
4. Non discrimination	Non discriminatory	Fair access regardless of ethnicity, gender, age or sexuality	Have regard to encouragement of equal opportunities	These Principles shall be applied without discrimination of any kind	Equality and non discrimination	Fair & equal treatment of the mentally ill. Discrimination by psychiatrists on the basis of ethnicity or culture, whether directly or by aiding others, is unethical
5. Access	Accessible			Every patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives	Local services	

Appendix 3. Main International Declarations and Covenants on Human Rights

Principle	England		Scotland 2003	United Nations 1991 (UN)	WHO 2001	World Psychiatric Association 1996 (WPA)
	National Service Framework for Mental Health 1999 (NSFMH)	Social Exclusion Unit 2003 (SEU)				
6. Safety	Promote safety			To protect the health or safety of the person concerned or of others, or otherwise to protect public safety, order, health or morals or the fundamental rights and freedoms of others.	Physical integrity of service user	
7. Autonomy & empowerment	Independence	Maintain employment		Treatment ... directed towards preserving and enhancing personal autonomy.	Patient empowerment, autonomy	Provide the patient with relevant information so as to empower
8. Family involvement		Social and family participation	Have regard to needs and circumstances of patient's carer		Partnership with families, involvement of local community	Psychiatrist should consult with the family
9. Dignity				Treated with humanity and respect for the inherent dignity of the human person	Preserve dignity	Psychiatrists to be guided primarily by respect for patients and concern for their welfare and integrity... to safeguard the human dignity
10. Least restrictive form of care			Have regard to minimum restriction of the freedom of the patient necessary	Every patient shall have the right to be treated in the least restrictive environment		Therapeutic interventions that are least restrictive to the freedom of the patient
11. Advocacy			Have regard to views of patient's named person, carer, guardian, welfare attorney			
12. Capacity				The person whose capacity is at issue shall be entitled to be represented by a counsel		

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NOTES

Mental Health Foundation

About the Mental Health Foundation

Founded in 1949, the Mental Health Foundation is the leading UK charity working in mental health and learning disabilities.

We are unique in the way we work. We bring together teams that undertake research, develop services, design training, influence policy and raise public awareness within one organisation. We are keen to tackle difficult issues and try different approaches, many of them led by service users themselves. We use our findings to promote survival, recovery and prevention. We do this by working with statutory and voluntary organisations, from GP practices to primary schools. We enable them to provide better help for people with mental health problems or learning disabilities, and promote mental well-being.

We also work to influence policy, including Government at the highest levels. We use our knowledge to raise awareness and to help tackle stigma attached to mental illness and learning disabilities. We reach millions of people every year through our media work, information booklets and online services.

If you would like to find out more about our work, please contact us.

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