Recent advances in understanding mental illness and psychotic experiences

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Executive summary

This report describes recent advances in understanding psychotic experiences. It is written for mental health service users, mental health professionals, and interested members of the public. The report is divided into three parts, covering understanding of mental illness, causes and help and treatment.

Part 1: Understanding mental illness

Section 1: What this report is about – Introduction

- This report presents psychological perspectives on serious mental illness. It refers to psychiatric diagnoses of 'schizophrenia', 'paranoid schizophrenia', 'psychosis', 'manic depression' and 'bipolar affective disorder'.

- These problems include hearing voices (hallucinations), holding unusual beliefs (delusions) and experiencing strong fluctuations in mood.

- Each individual's experiences are unique. Many people who have these kinds of experiences do not come into contact with clinical psychologists or psychiatrists because they do not find their experiences distressing. Some people, however, are so distressed by them that they seek professional help or others seek help on their behalf.

Section 2: How common are these experiences?

- About one person in a hundred is likely to receive a diagnosis of schizophrenia in their lifetime, and similarly about one person in a hundred is likely to receive a diagnosis of bipolar disorder (manic depression).

- 100,000 to 500,000 people in the UK today are likely to have been given the diagnosis of schizophrenia, and about 500,000 are likely to have received a diagnosis of bipolar disorder (manic depression).

- Social circumstances are very important. People from disadvantaged backgrounds, especially young men, seem at greatest risk of receiving a diagnosis of schizophrenia. However, although the risks might vary, almost anyone could have psychotic experiences in circumstances of extreme stress.

Section 3: Prognosis – course and outcome

- The course and outcome of psychotic experiences are very different for different people. Less than a quarter of people who have distressing psychotic experiences at some time in their lives remain permanently affected by them.

- People have poorer outcomes if their spouses or family members are highly critical or overprotective.

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- Psychiatric diagnoses are labels that describe certain types of behaviour. They do not indicate anything about the nature or causes of the experiences.

Section 5: A continuum between mental health and mental illness

- Mental health and 'mental illness' (and different types of mental 'illness') shade into each other and are not separate categories.

- Ten to 15 per cent of the population have heard voices or experienced hallucinations at some point in their life. These are frequently triggered by extreme experiences such as sleep deprivation.

- It may be appropriate to think in terms of 'stress-vulnerability' when explaining psychotic experiences. People may have greater or lesser levels of vulnerability to this type of experience, which are triggered by greater or fewer numbers of stressful events experienced.

- In some cultures hearing voices and seeing visions is seen as a spiritual gift rather than as a symptom of mental illness.

Part 2: Causes

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- Social, biological and psychological causes of psychotic experiences are all important, and interact with one another.

- Because there is a very close relationship between 'mind' and 'brain', it is very difficult to draw clear lines between biological and psychological factors. The causes of psychotic experiences are complex and one single 'cause' will not be found.

- Sometimes psychotic experiences can be triggered by something relatively minor, but become a problem as a result of some kind of vicious circle, involving the person's situation or their reaction to the experience.

Section 7: Biological factors in psychotic experiences

- In the main, research into genetics, brain chemistry, the physical environment and brain structure has not led to clear conclusions about physical causes.

- It is likely that genetics, brain chemistry, brain structure and the environment are all associated with vulnerabilities to a variety of general traits, which may in turn be related to psychotic experiences.

- It is clear that psychotic experiences involve brain events, and can be influenced by biological processes. It is important to remember, however, that every single thought we have involves chemical changes in the brain, and this is as true for 'normal' as well as 'psychotic' experience.

Section 8: Life circumstances and psychotic experiences

- Psychotic experiences can sometimes follow major events in someone's life, either negative (for example bereavement) or positive (for example winning the lottery).

- Many people who have psychotic experiences have experienced abuse or trauma at some point in their lives.

- If people who have had mental health problems live in a calm and relaxed home atmosphere, their problems are less likely to return.

Section 9: Psychological factors in psychotic experiences

- Psychological models of psychotic experiences focus on patterns of thought associated with these phenomena and on their meaning for the individual.

- These include: difficulties with attention, difficulties in understanding what other people are thinking, jumping to conclusions and the tendency to believe that the bad things that happen are the fault of other people.

- Hearing voices often appears to be the result of difficulty in distinguishing one's own, normal, inner speech from the words of other people.

- Psychotic experiences often have an important subjective meaning or significance for the individual.

Part 3: Help and treatment

Section 10: Assessment

- Clinical psychologists use a wide variety of information to reach a psychological 'formulation', an account of a person's problems developed in collaboration, that describes and accounts for the problems and offers a plan for help.

Section 11: Medication for psychotic experiences

- Traditional psychiatric drugs are by far the most common form of help offered to people with psychotic experiences.

- They are not a 'cure' but can alleviate 'symptoms'. They can be used for acute psychotic experiences and/or used long-term to try to prevent future problems.

- They do not help everyone. Two-thirds of people who take medication regularly are likely to experience a recurrence of their psychotic experiences within two years.

- They can have serious unwanted effects ('side effects') which for some people can be worse than the original problem.

- Newer drugs ('atypical antipsychotics' such as clozapine) are not necessarily any more effective, but can cause fewer adverse effects. Each individual should be able to make informed choices about which,if any, drug works best for them.

- Many people are on doses above recommended levels.

- The British Psychological Society has stated 'It is unsafe for people to be forced to use medication with potentially lethal side-effects against their wishes and without in-patient supervision'.

Section 12: Psychological interventions for psychotic experiences

- The most common form of psychological therapy for psychotic experiences is Cognitive Behaviour Therapy – CBT. This is a tried and tested intervention that examines patterns of thinking associated with a range of emotional and behavioural problems.

- There is convincing evidence that psychological interventions are effective for many people in reducing psychotic experiences and the distress and disability they cause.

- Despite the effectiveness of psychological interventions, and the fact that they appear to be cost-effective, more resources are needed, especially for training.

Section 13: Risk and psychotic experiences

Most people who have psychotic experiences are not dangerous. The increase in risk associated with a diagnosis of schizophrenia is minimal.

- The proportion of homicides committed by people with psychiatric diagnoses has fallen since the introduction of community care and is still falling.

- People who use mental health services are themselves at risk of becoming victims of violence. They are also at risk of self-neglect,suicide, abuse of human rights and the damaging consequences of treatments.

- There is an increase in risk associated with the diagnosis of Antisocial Personality Disorder. This is, however, a different type of problem from those described in this report. The term 'antisocial personality disorder' is used to describe someone whose behaviour is considered antisocial or dangerous and tells us little more than that.Such a description does not indicate that a person has psychotic experiences.

Section 14: Social exclusion

- People with psychiatric diagnoses are arguably one of the most socially excluded groups in society.

- Media accounts give a very biased picture and help to maintain public prejudices.

- The policy of community care has not failed. Most people who used to live in psychiatric hospitals have been successfully resettled and are well supported.

- There is a growing 'User/Survivor Movement' in which former and current mental health service users are campaigning for better services, for the acceptance of frameworks of understanding other than the 'medical model' and against stigma and discrimination.

Section 15: Implications of this report for mental health services

- Services need to adopt an individual and holistic approach.

- Services must respect each individual's understanding of their own experiences.

- Service users should be acknowledged as experts on their own experiences.

- The use of coercive powers (for instance detention under 'Section' and forcible treatment) should not be further extended.

- Psychological therapies should be readily accessible to people who have psychotic experiences.

- All mental health workers should be aware of and use a psychological understanding of psychotic experiences.

- Training is needed nationally to educate all mental health staff about the information contained in this report. It should also be part of the basic training of all the mental health professions.

- Prejudice and discrimination against people with mental health problems should become as unacceptable as racism or sexism.

Part 1: Understanding mental illness

Section 1: What this report is about – Introduction

Key points:

- This report is about those problems that are usually thought of as 'mental illness', or sometimes as 'mental health problems', a 'nervous breakdown' or 'madness'.

- Medical terms for these problems include 'schizophrenia', 'paranoid schizophrenia', 'psychosis', 'manic depression' and 'bipolar affective disorder'.

- These problems include hearing voices (hallucinations), holding unusual beliefs (delusions) and experiencing strong fluctuations in mood, as well as so-called 'negative symptoms'.

- Each individual's experiences are unique – no one person's problems, or ways of coping with them, are exactly the same as anyone else's.

- Many people who have these kinds of experiences do not come into contact with clinical psychologists or psychiatrists because they do not find their experiences distressing. Some people, however, are so distressed by them that they seek professional help or others seek help on their behalf.

1.1 Mental illness

This report is about those problems that are usually thought of as 'mental illness', or sometimes as a 'nervous breakdown' or 'madness'. Medical terms for these problems include 'schizophrenia', 'paranoid schizophrenia', 'psychosis', 'manic depression' and 'bipolar affective disorder'.

The types of experience discussed in this report include:

Hearing voices speaking when there is no-one there, or seeing or feeling things that other people do not. The medical term for these experiences is 'hallucinations'.

Holding strong beliefs that others in the person's social environment do not share. An example would be a belief that there is a conspiracy against the person by MI5, or that someone else is controlling their thoughts. The medical term for these beliefs is 'delusions', or if they are about other people wanting to harm the person, 'paranoid delusions'.

Experiencing extreme moods such as depression, elation, or even both at the same time. Often unusual beliefs or hallucinations accompany these experiences. Medical terms for extreme negative mood include 'clinical depression' and 'psychotic depression'. Extreme elation accompanied by overactivity is sometimes known as 'mania' or, when less severe, 'hypomania'. People who have these experiences often receive diagnoses such as 'manic depression', 'bipolar affective disorder' and 'schizoaffective disorder'.

Experiencing changes in perception, such as seeing colours much more brightly than normal or finding that time is passing much more quickly or slowly than normal.

Experiencing extreme changes in concentration and attention, such as suddenly finding it more difficult to pay attention to two things at once.

Feeling much better or worse about one's self than normal. For instance feeling extremely positive or even grandiose about one's own abilities, or alternatively feeling that you are a complete failure.

When they are having these kinds of experiences, people sometimes find it hard to concentrate on other things at the same time. They may appear distracted or perhaps 'talk back' to their voices (a strategy that some people find helpful). Others may talk in a way that other people find hard to follow, mentioning many apparently unrelated topics in quick succession. The medical term for this is 'thought disorder'.

At times, some people may appear unexpressive, withdrawn, listless, apathetic or unmotivated. They may find it difficult even to find the energy to prepare food for

themselves or to wash. Psychiatrists refer to these difficulties as 'negative symptoms'. Tiredness and listlessness can also be side-effects of the drugs (e.g. chlorpromazine) which are almost always prescribed for people who have these experiences.

Experience of Psychosis

In 1986, at the age of 18 over a seven-month period, I was admitted three times to psychiatric hospital. Initially I had experienced sleep deprivation and was very confused holding some grandiose and paranoid beliefs. I believed the television and radio had interactive messages for me. I also believed I had unknowingly been a spy and that the world was like a combination of the books '1984', and 'Blade-runner'. Nothing was as it appeared with robotic surveillance pets and sinister tracking devices.

I also saw familiar faces in strangers' faces, which lead to further espionage theories. I believed that I was in danger of losing my ability to think freely and spontaneously, that I would become an automaton as I reached full adulthood. My concentration was extremely poor. I was in a high state of vigilance, fear and tension, leading to psychosomatic chest pains. I also entertained other more spiritual beliefs focussing on good and evil and having special powers of communication. Due to having a family history of psychosis, it was easier for clinicians to quickly make a diagnosis of schizophrenia. My parents were told I had schizophrenia and that I would need to take medication for the rest of my life.

Dr Rufus May – personal account

The experience of voices

When I was an inmate in the hospital I was very confused and sometimes suicidal. I was feeling very desperate and self-harming regularly. Throughout this time I was battling with the voices. They would shout 'Cut, cut, cut'. Staff got really angry with me when I cut myself and often ignored me, or greeted me with sarcastic comments. Once they sent me to the Accident and Emergency Department on my own. I was finding it hard to distinguish between what everyone else said was reality and the bombardment of the voices. The voices were making it difficult to do anything. The TV was talking to me. People were following me and they could see inside my head and read my thoughts.

As I write, the voices often shout at me: 'Stop writing, you stupid cow', 'Fat ugly cow', 'No-one's interested', 'Cut yourself, cut yourself, you know you should you know you should', over and over again. There is nothing good about the voices - they constantly bash me. The voices, now mainly male, have a powerful influence on my life – a punishing scary entity. They are usually there all of my waking hours. Before I speak I have to check out what I'm going to say with the voices. Most of the time they say I'm talking rubbish, so I have to choose something else – which is usually not right either.

Val – personal account

1.2 Individuals have individual experiences

As with all types of human experience, no one person's problems, or ways of coping with them, are exactly the same as anyone else's. Some people will have only one of these experiences, others more than one. Some people experience them on only one occasion, others from time-to time (for example during periods of stress), and others frequently.[1] Many people who have psychotic experiences also have other psychological, medical or social problems. It is not uncommon for people to have problems with alcohol or drug use, depression or anxiety as well as psychotic experiences. These can arise for the same complex reasons as for any other individual. The combination of psychotic experiences and such difficulties can, however, present further problems.

Many people who have these kinds of experiences do not come into contact with clinical psychologists or psychiatrists because they do not find their experiences distressing.[2] For example, many people hear voices talking to them when there is no-one there, but the voices say relatively pleasant or neutral things so this is not a problem. Other people do find the experiences distressing, but develop ways of coping with them on their own.[3] Some people, however, are so distressed by their experiences that they seek professional help. Some come to the attention of professionals because other people consider their behaviour odd or abnormal. Only these last two groups of people who come into contact with mental health services are likely to be diagnosed as 'mentally ill'.

Part 1: Understanding mental illness *(cont.)*

1.3 Note on Terminology

There is considerable debate about the most helpful way of referring to the experiences described in this report. The different terms used by different people reflect the more general debate about the nature and causes of these experiences. That means that care must be taken to ensure that the terms used do not carry implications that are not intended. A further problem is that many commonly used words carry pejorative connotations.

Traditionally, psychotic experiences have been thought of as symptoms of 'mental illness' such as schizophrenia or manic depression, and the people who experience them have been referred to as 'patients' or 'sufferers'. More recently it has been suggested that there are other ways of thinking about these experiences, and that, therefore, medical terms are not always the only or best ones to use.

Throughout this report we have attempted to use terms which are as neutral as possible and do not imply a particular 'framework of understanding' (e.g. a medical one). We refer to the experiences in question as 'experiences' rather than as symptoms of an illness. We use the term 'people diagnosed with' rather than 'people with (for example) schizophrenia'. This is because we do not wish to give the impression that everyone agrees that there is an underlying illness, when in fact this assumption is debated. Finally, we refer to people who have these experiences as 'people', rather than as 'patients'.

Of course, much of what has been written in this area previously has used a medical framework and has therefore used medical terminology. When describing this work we have used quotation marks round these terms.

We have avoided pejorative terms such as 'schizophrenics'. Not only do such terms assume the undisputed existence of physical illness, but in our view they also portray people as less than human.

One originally medical term for which no alternative is easily available, and which we have therefore used is 'psychotic'. Although this term is widely misused, it has a useful and specific meaning. Throughout the report we use 'psychotic experiences' as an umbrella term for unusual perceptions (e.g. hearing voices), or unusual beliefs. In both cases other people sometimes see the person as to some extent out of touch with reality.

Section 2: How common are these experiences?

Key Points:

- It is difficult to say how widespread these problems are, partly because of the way research has traditionally been conducted.

- Using medical definitions of the problems, about one person in one hundred is likely to receive a diagnosis of schizophrenia in their lifetime, and similarly about one person in one hundred is likely to receive a diagnosis of bipolar disorder (manic depression) in their lifetimes.

- 100,000 to 500,000 people in the UK today are likely to have been given a diagnosis of schizophrenia, and about 500,000 are likely to have been given a diagnosis of bipolar disorder (manic depression).

- It is clear that people's circumstances are very important. People from disadvantaged backgrounds, especially young men, seem at greatest risk of receiving a diagnosis of schizophrenia.

- Although the risks might vary, psychotic experiences may happen to anyone in circumstances of extreme stress.

2.1 How common is 'mental illness'?

As outlined elsewhere in this report, traditional psychiatric classifications of psychoses and serious mental illnesses are not necessarily consistent with psychological classifications and descriptions. In order to describe the issues involved, it may be useful to clarify the different roles of psychiatrists and clinical psychologists. Psychiatrists are medically trained doctors who specialise in mental health. Clinical psychologists have an academic training in psychology, and use this understanding of thought processes, emotion and behaviour to understand and help people with personal difficulties. Despite some differences, psychiatrists and clinical psychologists work closely together. Nevertheless, because of their training and background, psychiatrists tend

to understand mental health issues (including of course psychotic experiences) in terms of symptoms leading to diagnosis and treatment. Similarly, because of their training and background, clinical psychologists tend to see mental health issues and psychotic experiences as problems whose causes and solutions will be slightly different for each individual. Clinical psychologists have, therefore, questioned traditional classifications of psychological distress based on psychiatric diagnosis, and have begun to suggest alternatives.

Later in this report we will describe how psychologists have developed ways of describing and understanding psychological and emotional problems that do not involve the use of diagnosis. Nevertheless, at present, there have been few studies of the prevalence of psychotic experiences based on such approaches. In estimating how common such problems are we currently have to rely on research that looks at numbers of people with a certain diagnosis. The most frequent diagnoses given to people who experience psychotic problems are schizophrenia and bipolar disorder. Other diagnoses that people might have encountered are; paranoia, psychosis, psychotic illness, delusional disorder, schizoaffective disorder, manic depression and psychotic depression.

2.1.1 How many people are given the diagnosis of schizophrenia?

Different researchers have recorded different estimates of the incidence of schizophrenia using traditional medical definitions of the problem. Generally there is a consensus that about one person in a hundred will be diagnosed with schizophrenia during their lifetime.[4] The prevalence of the disorder (a slightly different statistic reflecting not an individual's risk, but the proportion of people experiencing problems at any one time) is estimated at between 0.2 and 1 per cent.[5] It tends first to be diagnosed in early adulthood (late teens and early twenties).[6] This means that, in the UK, between 100,000 and 500,000 people are experiencing such problems at any one time.

Schizophrenia is usually reported as slightly more common,[7] and possibly more severe,[8,9] in men, although this may be in doubt.[10] The majority of men who develop

the problems that lead to a diagnosis of schizophrenia do so before the age of 25.[11] Women tend to develop problems about five years later, although there is a very high level of variability.

2.1.2 How common are the problems that lead to a diagnosis of bipolar disorder?

Figures for the prevalence and incidence of bipolar disorder (also known as manic depression), using traditional medical definitions of the problem are very similar to those for schizophrenia. Estimates for the lifetime risk of developing bipolar disorder range from 0.6 per cent[12] to 1.2 per cent.[13] Again, this means that, in the UK, between 100,000 and 500,000 people will have this diagnosis.

2.1.3 Other diagnoses

Psychiatrists use a number of other diagnoses that are extremely similar to either schizophrenia or bipolar disorder. In general these refer to very similar problems.

People who become severely depressed sometimes have psychotic experiences (usually unusual beliefs – delusions – or hallucinations with very depressive content). Up to 3 per cent of men, and perhaps 4 to 9 per cent of women will be given a diagnosis of depression in its more general form.[14] Psychotic features are however relatively uncommon, probably represent only some 10 to 20 per cent of inpatients with a diagnosis of depression,[15] and most people, even if they attract such a label, are never admitted to hospital.

2.2 Social influences on the prevalence of mental illness

2.2.1 Problems that lead to a diagnosis of schizophrenia

Over the years, the diagnostic criteria for schizophrenia have frequently been revised in order to improve reliability. Following these revisions, very similar rates of the use of the diagnosis of schizophrenia have been revealed in America and the UK.[16,17,18,19] Many different cultures have, it is claimed, terms roughly translatable as 'madness' that describe the common psychotic experiences.[20,21]

However, the social environment generally is a vital part of the picture of many problems, including problems with both physical and mental health.[22] People living in deprived inner-city areas are much more likely to be given a diagnosis of schizophrenia than people living in more affluent suburban areas.[23] Faris and Dunham's social isolation theory[24] suggested that poverty and social isolation were likely to trigger psychosis in vulnerable individuals.

A second theory, the social drift theory,[25] suggests that people who are given a diagnosis of schizophrenia might be born in any socio-economic environment. However, the development of psychotic experiences (and the effects of treatment) is likely to prove disadvantageous for social functioning and employment opportunities. People with such problems therefore are likely to drift into lower socio-economic circumstances and end up in poor housing and employment. What is clear is that poverty and the diagnosis of schizophrenia are related, but whether as cause or effect is unknown.

2.2.2 Problems that lead to a diagnosis of bipolar disorder

There have been a number of studies of the influence of social class on the frequency of the diagnosis of bipolar disorder[26]. Unlike schizophrenia, these have not generally found that a diagnosis of bipolar disorder is associated with social disadvantages.

2.2.3 Psychotic experiences not attracting the attention of mental health services

A number of surveys have revealed that a sizeable proportion of the general population (including people who have never been thought of as meeting the diagnostic criteria for a mental illness) experience hallucinations. Perhaps as many as one in ten of the general public hear voices regularly.[27] If there are any factors that distinguish 'normal hallucinators' from people who come into contact with mental health services, these would appear to be the

distress caused by the experience and the degree to which these experiences are seen as normal.[28] Similarly, a large proportion of the general population[29] holds beliefs that others might consider unusual or paranoid.

Psychotic experiences not attracting the attention of mental health services

'In the course of our experiment (an invitation to contact researchers after a television programme about hearing voices was broadcast in the Netherlands) we met a considerable number of men and women who heard voices but had never been psychiatric patients nor considered themselves mentally ill. Nor, for that matter, were they seen as mentally ill by their family and friends. When we first met these people in the wake of the TV programme, we were quite astounded because, like most psychiatrists and indeed most lay people, we were used to regarding people who hear voices as mentally distressed. We were forced to change our ideas when we were confronted with well-balanced, healthy people who simply happened to hear voices: voices which were not heard by those around them, and which they experienced as coming from outside.'[30]

Many people who have psychotic experiences feel that the experiences are very significant in their lives. Some people feel that the experiences have religious or spiritual significance. Some people explain their experiences in terms of supernatural or religious forces, or see the experiences as giving them a deeper understanding of or insight into the world.[31,32]

Psychotic experiences and spiritual experiences

'There are people who have developed a very positive relationship with the experience of hearing voices, and have managed without any psychiatric treatment or support. They have adopted a theoretical frame of reference (such as parapsychology, reincarnation, metaphysics, the collective unconscious, or the spirituality of a higher consciousness) which connects them with others rather than isolating them: they have found a perspective that offers them a language in which to share their experiences. They enjoy a feeling of acceptance; their own rights are recognised, and they develop a sense of identity which can help them to make constructive use of their experiences for the benefit of themselves and others.'[33]

Section 3: Prognosis – course and outcome

Key Points:

- Many people assume that a diagnosis of a psychotic illness means that the individuals must resign themselves to a life of illness and disability. In fact, the course and outcome of psychotic experiences are very different for different people.

- Many people who have distressing psychotic experiences at some time in their lives never have them again, and less than a quarter remains permanently affected.

- Some people who continue to have psychotic experiences nonetheless manage to sustain a high quality of life. It is possible for people who experience enduring psychotic experiences to hold down a job or to enjoy lasting relationships. Many of the difficulties that people experience in these areas are products of stigmatisation, social isolation and poverty, rather than direct consequences of psychotic experiences.

- People have poorer outcomes if their spouses or family members are highly critical or overprotective.

3.1 Optimism

A diagnosis of a psychotic illness has often been viewed as a cause for pessimism. It is sometimes wrongly thought that psychotic experiences are permanent conditions, with either a recurring or deteriorating course and little hope for the long term. We have heard of instances when patients and their families have been told that there is no chance of recovery and that patients must resign themselves to a life of illness and disability.

In fact, outcome is a complex phenomenon. Each person may make progress, or continue to have problems, on a number of dimensions that are relatively independent of each other.[34] 'Clinical' outcome concerns whether or not someone continues to have psychotic experiences. Social outcome is measured in terms of the quality of the person's

social relations. Occupational outcome refers to the person's ability to sustain employment. Sometimes people who continue to have severe and enduring psychotic experiences nonetheless have normal lives in all other respects, such as work and relationships. On the other hand, some people benefit from complete or partial recovery from psychotic experiences but continue to find it difficult to work (for example because of difficulty concentrating) or experience difficulties in other areas such as relationships. Many people find that the hardest part of recovery is overcoming prejudice, stigma, lowered expectations and the pressure to subscribe to a 'sick role'.[35]

Optimism

'From a week into my second admission I was visited every day by the same friend, Catherine. She wasn't alienated by visiting a psychiatric hospital. This accepting and supportive approach was a very useful alternative story to most of my friends of the time who stayed away. Catherine recounts believing that the situation I was in was something I could get over. It was invaluable to have someone around who believed I could make a full recovery.'

'My recovery was about how to gain other people's confidence in my abilities and potential. The toughest part was changing other peoples' expectations.'

Dr Rufus May – personal account

3.2 Variability in outcomes

The course and outcome of psychotic experiences are highly unpredictable. Some people recover completely after only one episode, some people suffer from multiple episodes separated by periods of complete or partial recovery, and some remain continuously affected. Long term follow-up studies indicate that as many as a third of all people who have psychotic experiences completely recover, and that less than a quarter remain permanently affected.[36,37,38] Most people might reasonably hope to recover either completely or partially after a psychotic episode. Many mental health workers, who by definition only come into contact with people who continue to need their help (or for those who need help only occasionally, at times when they need it) fall into the trap known as the 'clinician's illusion'. They assume that recovery is

rare and that most service users are likely to be dependent on services for the rest of their lives. Likewise, although there are thousands of former service users who either no longer have psychotic experiences, or have found effective ways to cope with them and no longer need help from services, current service users rarely have the opportunity to meet them. Because of this both staff and service users are in danger of developing over-pessimistic views about the future.

Many people who continue to have psychotic experiences nonetheless manage to sustain a high quality of life. It is possible for people who experience enduring psychotic experiences to hold down a job and to enjoy lasting relationships. Many of the difficulties that people experience in these areas are products of stigmatisation, social isolation and poverty, rather than direct consequences of psychotic experiences.

The distinction between 'schizophrenia' and 'bipolar disorder' (manic depression) remains a matter of heated debate amongst clinical psychologists and psychiatrists. Outcomes for both diagnoses are enormously variable. On average, people with a classic 'bipolar' picture (that is, episodes of depression and mania with no hallucinations or delusions) have better outcomes than those with a classic 'schizophrenia' picture (hallucinations and delusions but no disturbance of mood).[39,40] For people who experience a mixture of both types of problem, there is an intermediate probability of a good outcome.

3.3 Influences on outcome

In people with diagnoses of both schizophrenia and bipolar disorder, it is clear that outcome is influenced by social factors. In particular, there is good evidence that:

(a) Outcome is generally better in developing countries than in the industrialised nations.[41] The cause of this difference is not known for certain. One possible reason seems to be that industrialised nations offer fewer socially valued roles for people with diagnoses of mental illnesses, leading to greater social exclusion. There may be stronger or more supportive social and family networks in the cultures of developing nations. It may also be the case that there is less stigma surrounding psychotic experiences in some developing countries.

(b) There is evidence that outcomes are less favourable for people who experience stressful relationships (especially with a spouse or with members of their family of origin) than people who enjoy less stressful relationships.[42] In particular, people have poorer outcomes if their spouses or family members are highly critical or overprotective. This finding has been made both for people with a diagnosis of schizophrenia[43] and also for people with a diagnosis of bipolar disorder.[44]

(c) There is also evidence that outcomes are better during periods of full employment compared with periods of economic recession.[45] This observation suggests that the opportunity to work and become a valued member of society is important.

Part 1: Understanding mental illness *(cont.)*

Section 4: Problems with 'diagnosis' in mental health

Key Points
- Experiences such as hearing voices, holding unusual beliefs and experiencing marked mood swings are usually thought of as symptoms of mental illnesses and are described using terms from psychiatry – hallucinations, delusions and mania.

- The most commonly used diagnoses are schizophrenia and bipolar disorder (manic depression).

- Psychiatric diagnoses are labels that describe certain types of behaviour and assign them to different categories. They do not tell you anything about nature or causes of the experiences. If care is not taken it may be assumed that diagnostic categories offer an explanation for unusual experiences, rather than merely a short-hand description.

- If diagnoses are 'valid', the symptoms should cluster together in a meaningful fashion. However this is not always the case. Many people who hear voices have no other symptoms of 'schizophrenia'. Many people have particular psychotic experiences once but never again, casting doubt on the usefulness of a diagnosis to predict a person's future mental health. Moreover, it does not always follow from a particular diagnosis which medication will be helpful for each individual.

4.1 Psychiatric Terminology

4.1.1 Symptoms
In psychiatric terms, the experiences discussed in Section 1 – hearing voices, holding unusual beliefs and experiencing marked mood swings are seen as 'symptoms' of underlying 'mental illnesses'. Therefore, the experiences themselves (hearing voices, holding unusual beliefs or experiencing marked mood swings) are thought of as symptoms, and referred to as hallucinations, delusions and mania respectively. These terms are useful to the extent that different professionals and members of the general public can communicate clearly. However, there are a number of problems with the diagnostic approach. These problems are described in this section.

4.1.2 Diagnoses
Again in traditional psychiatric terms, these 'symptoms' are thought of as manifestations of underlying mental illnesses. The most common diagnostic categories used to classify psychotic experiences are schizophrenia, schizo-affective disorder and bipolar disorder or manic-depression.[46,47]

4.2 Benefits of diagnosis
Many people think that diagnoses serve some very useful purposes, including simplifying communication and permitting a relatively brief and straightforward means of describing complex difficulties. Diagnoses are also used by medically trained doctors as a means of deciding upon appropriate treatment. Some people find having a diagnosis reassuring, because it implies that they are not alone in having the experiences, and gives hope that professionals will be able to help.

4.3 Problems with diagnosis
The symptom-diagnosis approach to thinking about psychotic behaviour and experiences is well established. Psychiatric diagnoses are labels which describe certain types of behaviour, they do not tell us anything about nature or causes of the experiences. If care is not taken it may be assumed that diagnostic categories offer an explanation for unusual experiences, rather than merely a short-hand description.

The diagnostic approach has not been as useful as was hoped and has been the subject of much scrutiny and debate. In order to understand why, it is helpful to look at the validity of the assumptions underlying the idea and practice of diagnosis.

4.3.1 (un) reliability of diagnosis
The use of diagnostic categories involves two basic assumptions about consistency and usefulness. It is assumed, first, that people can be reliably assigned to a particular category – that two clinicians can agree on which category to

use. Early research, however, showed that clinicians often disagreed about psychiatric diagnosis and that diagnostic practices differed from country to country.[48,49] Clinicians have put a great deal of effort into improving the consistency of diagnosis, most notably through the publication of specific manuals which specify which symptoms an individual must have for a specific diagnosis to be made. The best-known example is the Fourth Edition of the Diagnostic and Statistical Manual of the American Psychiatric Association,(DSM-IV 1994).[50] However, these efforts have had only limited success in normal clinical practice.[51]

4.3.2 (in) validity of diagnosis

A second set of assumptions about diagnostic categories involves their validity – whether they can be said to be scientifically meaningful and useful. We can look at this issue in several ways. Ideally, the usefulness of a diagnostic category is shown by its ability to predict new observations that cast light on the causes of a person's symptoms. For example, a diagnosis of 'malaria' would suggest that the individual has suffered a viral infection, and even that the person has recently travelled to tropical countries. It also tells you which treatment is likely to help and what the prognosis is. Similar predictions have never been successfully made from any of the psychosis categories.

If a diagnosis is valid, it should predict prognosis. However, as explained above, the outcome for people with a diagnosis of schizophrenia is extremely variable[52,53] and attempts to define a diagnostic group with a more uniform outcome have not been very successful.[54]

Diagnoses should also indicate what treatments will be effective. However, responses to medication for 'schizophrenia' and 'bipolar disorder' are also variable. For example, drugs such as Largactil (known as 'neuroleptics' or 'antipsychotics') are often thought of as specific treatments for schizophrenia. But not all people with this diagnosis appear to benefit significantly while some people with a diagnosis of affective disorder (traditionally thought of as unrelated to 'schizophrenia') do benefit.[55,56] The effectiveness of lithium, a drug traditionally used with people diagnosed as suffering from bipolar disorder, is similarly variable and non-specific. In one study, people were randomly assigned to either a neuroleptic, lithium, both or neither. It was found that drug response was related to specific problems but not diagnoses: delusions and hallucinations responded to the neuroleptic and mood swings responded to the lithium, irrespective of diagnosis.[57] Diagnostic categories are therefore of very limited use in predicting course or outcome.

Another way of examining the validity of diagnostic categories involves using statistical techniques to investigate whether people's psychotic experiences actually do cluster together in the way predicted by the diagnostic approach. The results of this research have not generally supported the validity of distinct diagnostic categories. For example[58] the correlation amongst psychotic symptoms has been found to be no greater than if the symptoms are put together randomly. Similarly,[59] cluster analysis – a statistical technique for assigning people to groups according to particular characteristics – has shown that the majority of psychiatric patients would not be assigned to any recognisable diagnostic group. Statistical techniques have also highlighted the extensive overlap between those diagnosed with schizophrenia and those diagnosed as having major affective disorder.[60,61]

The central issue in diagnosis is one of classification – the idea that particular psychological problems cluster together and can therefore be considered together. This has been termed 'carving nature at the joints'.[62] This means that it is assumed that the problems called 'schizophrenia' are different from the problems called 'bipolar disorder' in the same way that birds are different from reptiles. On the basis of the evidence reviewed above, many psychologists believe that these distinctions are invalid, that diagnostic approaches to psychological problems do not reflect real 'joints' in nature.

Section 5: A continuum between mental health and mental illness

Key Points:

- There is good reason to believe that mental health and 'mental illness' (and different types of mental 'illness') shade into each other and are not separate categories.

- There is evidence that psychotic experiences are more extreme expressions of traits present in the general population. There is a wide range of 'psychosis-proneness'.

- Healthy, well functioning individuals sometimes have 'psychotic' experiences. For example, 10 to 15 per cent of the population have heard voices or experienced hallucinations at some point in their life. These are frequently triggered by extreme experiences such as sleep deprivation.

- It is probably appropriate to think in terms of 'stress-vulnerability' when explaining psychotic experiences. People may have greater or lesser levels of vulnerability to this type of experience, which are triggered by greater or fewer numbers of stressful events experienced.

- In some cultures hearing voices and seeing visions is seen as a spiritual gift rather than as a symptom of mental illness.

5.1 A continuum from normality to psychosis

It has often been assumed that the behaviour and experiences of people who are placed in diagnostic categories such as 'schizophrenia' and 'bipolar disorder' are qualitatively different from 'normal' behaviour and experience. Research suggests that this assumption is false. It is often difficult to discriminate between 'normal' and 'abnormal' or psychotic experiences.

The view that there may be a thread of continuity between mental health and ill-health was already voiced at the beginning of the century,[63] but it is somewhat at odds with traditional medical approaches, which view 'mental illnesses' as qualitatively separate from normality.

5.2 A continuum from normal to abnormal

A number of clinical psychologists[64] have suggested that psychotic symptoms lie on a continuum with normality, and are the severe expression of traits that are present in the general population. Individuals range from the conventionally 'normal', through various shades of eccentricity, to those who experience severely distressing psychotic experiences. Thus, the distinction between signs of mental illness (i.e. symptoms) and the expression of human individuality (i.e. traits) becomes blurred. The presence of psychotic-like traits in the normal population has been termed 'psychosis-proneness' or 'schizotypy'.

This continuum view is easily understood if one imagines other common experiences such as anxiety. Individuals differ on how anxious they are in general. This is an enduring characteristic of their personality, and is likely to be due to a combination of genetic factors and their upbringing. Only a minority of individuals will ever experience extremes of anxiety such as a series of panic attacks, which are recognised in the diagnostic textbooks as justifying a diagnosis of an anxiety 'disorder'. Similarly, the state of extreme suspiciousness known as 'paranoia' is on a continuum with the feelings of suspiciousness that we all feel from time to time. People differ in this regard: we all know people with whom we have to be very careful what we do or say lest they interpret it as an insult. Similarly, situations vary in their tendency to provoke suspiciousness. We have all been in situations where it makes sense to be extra vigilant, and in such situations it is easy to be frightened by even the most innocent things.

Continuum with normality

I remember the time period just before other people became concerned about me. I was not sleeping very well and was daydreaming at work a lot. This daydreaming allowed me to escape from a dreary job and a generally depressing set of circumstances. On one occasion I had to deliver a parcel by train from London to Manchester. At Euston Station I lost my train ticket, minutes before departure. At the time I wondered to

myself whether a man who moments earlier had brushed by me had pick-pocketed me. As the departure whistle blew I decided to run around the barrier and managed to jump on to the guard's carriage as the train was moving off. Thinking that train officials might have seen me do this, I went into the train toilet and changed my appearance in order to avoid recognition. I used water to restyle my hair and changed my clothing as much as I could by putting my shirt on over my sweatshirt. I spent the rest of the journey using my wits to avoid the ticket collector. This was an exciting experience that had echoes of spy stories I had enjoyed when I was younger. I began to wonder if another passenger sitting near me was actually a plain-clothes train detective. I then returned to toying with spy scenarios. What if my feelings of being a spy really were true? I went back over the things that had happened. What if the pick pocketing was a test of how resourceful I could be if I had to deliver important documents in difficult circumstances? What if the company I worked for was actually a secret government agency? Maybe I was not an office dogsbody at the beginning of a dull career but an apprentice spy! On the return journey I came back down to earth when a diligent ticket collector insisted on waiting until I had vacated the train toilet. He decided to let me off the fine when I told him I was just an office junior.

This is an example of a kind of mental escapism that I started to indulge in more and more when I was alone and bored. From this time on I was increasingly to enter an imaginary world that quickly became more powerful and more real. In a matter of weeks I was admitted to psychiatric hospital and diagnosed as being in an acute psychotic state.

Dr Rufus May – personal account

Substantial evidence has accrued in favour of the idea that psychotic experiences are on a continuum with normality. So-called 'schizotypal' traits have been described which are believed to have similarities with thought processes observed in psychotic experiences. These can be measured in 'normal' individuals by the use of questionnaires.[65] Such questionnaire studies have demonstrated that there is a wide range of scores in the normal population, and that schizotypal traits tend to form clusters similar to different sorts of psychotic experiences (for example delusions and hallucinations).[66] Moreover,

individuals who score highly on such scales resemble individuals with psychotic experiences on a number of psychological measures, such as measures of attention and reasoning.[67] Recent psychiatric research has indicated that a dimensional approach to psychotic experiences can be more useful in terms of understanding and planning care than a categorical system.[68]

5.3 The normality of abnormal experiences

So-called 'abnormal' experiences can be seen in healthy, well-functioning individuals. For instance, 10 to 15 per cent of the normal population have had a hallucination at some point in their lives.[69] Recent studies show that 'psychotic-like' experiences are 50 times more prevalent than the narrower, medical concept of 'schizophrenia'.[70] Extreme circumstances, such as sensory or sleep deprivation, have been shown to lead to various disturbances, including paranoia and hallucinations.[71] There are individuals who have 'strange' experiences (such as visions, auditory hallucinations, or profound spiritual experiences) and which are conceptualised as spiritually enriching.[72,73] There is a huge diversity in what is considered an appropriate expression of distress in different cultures. Indeed, different cultures vary on whether particular experiences are seen as signs of 'mental illness', as normal (religious and spiritual beliefs and beliefs about spirit possession), or even as 'spiritual gifts' which are to be revered to some degree (such as in the case of 'Shamen'[74]). These findings suggest that although psychotic 'symptoms' can, for some individuals, be extremely distressing and disabling, it is also possible to have unusual experiences that are not necessarily noxious, and may even be adaptive and life enhancing.[75]

5.4 Alternatives to diagnosis

Given the problems of diagnosis outlined above, clinical psychologists have suggested alternative approaches.

5.4.1 Symptom approach

Many researchers have argued that the problems of diagnosis can be overcome by focusing on specific experiences and behaviours (symptoms, in medical terminology). In Britain, in particular, considerable progress has recently been achieved in understanding specific

psychological mechanisms that can lead to unusual beliefs, hallucinations and difficulties in communication.[76]

5.4.2 Psychological formulations

In order to understand and explain people's experiences, clinical psychologists have developed the approach termed 'formulation'.[77,78]

Psychological formulations are a way of helping people to make sense of their difficulties in a way that is meaningful to them. They comprise a statement of what the person sees as the problem (or problems), how these might have come about, and what is keeping them going[79,80]. Problems will usually be expressed in terms of what the person experiences (such as unhappiness, hearing voices, not functioning well at work, or fearing that people are trying to harm them) rather than in terms of 'symptoms' observed by others.[81]

Psychological Formulations

'The questions people put to me made me reflect on the voices I heard, which I had never really thought about. I was surprised to discover a pattern – whenever I think negatively, I find myself hearing a negative voice.'[82]

Clinical psychologists also attempt to develop, in collaboration with the client, ideas about what things might have led to the development of these problems. For this reason, formulations are very individual; tailored for each person and relevant to their specific problems.

Typically, a formulation will examine what events have happened in a person's life, and how they have interpreted and reacted to these. This can help the person to see that some of their problems have not just come 'out of the blue' but may be an understandable response to their circumstances. Even when it is not possible to pinpoint one particular cause, worker and client can explore together what might be maintaining the problem. For example, a vicious circle may be going on where the person's fear about what their experiences might mean is keeping them in a highly aroused state, which in turn leads to more psychotic experiences. An example might be the fear that hearing voices means that they are going mad or are possessed by a demon. Formulations tend to change as the psychologists and their clients learn more about the problems. Formulations are designed to be 'best guesses' about the problems, and these guesses are tested out over time[83,84]. The process of developing a formulation is collaborative. Psychologist and client work together to develop a picture of the problems and a joint theory as to what has caused them, and what might help.

Psychological case formulations are complex. Clinical psychologists draw on a large variety of psychological theories, each drawing on scientific research[85]. Although individual case formulation will not draw on all this research, each person may have a range of interrelated psychological difficulties. Training is essential, and professional bodies such as the British Psychological Society's Division of Clinical Psychology endeavour to guard the competence of practitioners.

Section 6: The complexity of psychotic experiences

Key Points:

- Very many things have been proposed as possible causes of psychotic experiences.

- Generally, these proposed causes of psychotic experiences have been divided into factors within the psychological make-up of the individual, social and environmental factors, and biological factors.

- All of these factors are important, and interact with one another.

- Because there is a very close relationship between 'mind' and 'brain', it is very difficult to draw clear lines between psychological and biological factors. Biological and psychological causes of psychotic experiences can be more or less important for different people.

- Even when we know more, the nature and causes of psychotic experiences will remain complex and mulitifactorial.

- Sometimes psychotic experiences can be triggered by something relatively minor, but are maintained by some kind of vicious circle, involving the person's situation or their reaction to the experience.

6.1 Possible causes

An enormous range of things have been proposed as possible causes of psychotic experiences. It has been suggested that everything known to affect human behaviour has been proposed as a cause of psychotic experiences[86], from cat fleas, through the phases of the moon to contaminated bread.

Generally, the enormous range of possible or proposed causes of psychotic experiences has been divided into broad categories. Many people will have heard of the 'nature – nurture' debate. This refers to the consideration of the relative contributions made by genetic or biological factors as opposed to upbringing and experience on human behaviour. Of course this debate also occurs with respect to the causes of psychotic experiences. Factors within the psychological make-up of the individual, social and environmental factors, and biological factors are all likely to play roles in the development of such experiences. Different factors will be more or less important for different individuals.

6.2 Interactions between causes

Of course, all of these factors are important; all three of these broad classes of possible causes of psychotic experiences (psychological, social and biological) are important and interact with each other. An interaction might mean, for example, that a person could have a biological makeup such that she tends to become more physically aroused in stressful situations, and unfortunately be exposed to more stressful events over her lifetime. If extremely unlucky, she might also have a psychological makeup such that she is likely to interpret certain situations in a negative light. Of course, this tendency might itself be at least partly a result of the stressful events she has experienced.

There is also a very close relationship between 'mind' and 'brain', in that every thought is both a brain-based event and a human experience. This means that it is very difficult to draw clear lines between biological and psychological factors. It is also true that biological and psychological aspects can be more or less important for different people. For some people, it appears likely that biological factors are most important in the development of their psychotic experiences. For others social or psychological factors, or the events they experience, seem more important. Often there is little point in trying to identify one cause; the trigger can be something relatively minor, but the person's reaction or environment sets up a vicious circle that causes the problem to escalate. An example might be the way in which fears of 'going mad' might make hearing voices a more terrifying and distressing experience[87].

The attempt to explain the causes of psychotic experiences is a controversial topic. It is a philosophical as

well as an empirical question. Different professions have slightly different (but equally legitimate) perspectives, and even within professions, different individuals will have different views. Traditionally, psychiatry has taken a more biological tack, reflecting the medical basis of the profession. This pattern is changing, however. Some psychiatrists are rapidly becoming more focused on social issues. Many are becoming champions of Cognitive Behaviour Therapy (a form of psychological therapy) and are therefore increasingly examining psychological causes of their patients' distress.

Similarly, clinical psychology has a tradition of seeing distress (including psychotic experiences) as stemming principally from aspects of an individual's psychological make-up. Increasingly clinical psychologists are developing a stance that sees things more in terms of interactions as described above. Thus clinical psychologists recognise influences of biology on the way in which people interpret events in their lives, as well as emphasising how apparently reflex or 'natural' processes can be influenced by expectation or experience. They are also becoming increasingly aware of the impact of the social environment on the development of psychotic experiences.

Clearly the nature and causes of psychotic experiences will remain complex and mulitifactorial even when we know more. Over time, we will learn more about the different causes, and how they interact. A single cause of 'schizophrenia' will not suddenly be identified.

Moreover, even in the highly unlikely event that the cause of any one person's psychotic experience was ever to be known with scientific clarity, this truth would not hold for everyone. Clinical psychologists therefore respect the individual's own experience and perspective.

6.3 A psychological perspective
In order to try to make some sense out of this complexity, clinical psychologists attempt to focus on the way in which people make sense of their experiences.

Psychologists tend to assume that people who report

psychotic experiences are either having unusual perceptual experiences (that is they are experiencing things like hallucinations that are, in themselves, unusual) or are interpreting normal experiences in an unusual way (perhaps having strange intrusive thoughts that appear alien). Of course, it is entirely possible that both events are occurring.

Clinical psychologists then attempt to account for why people might have unusual experiences and why they might interpret things in an unusual way. Unusual experiences sometimes occur for medical or biochemical reasons – people can become delirious when ill and can hallucinate when they have taken street drugs. For some people it is possible that physical problems with the structure or functioning of the brain might lead to abnormal experiences. Physical influences like street drugs can also create unusual experiences. For other people, psychotic experiences might arise from misinterpretations of normal events. For instance, it is possible that paranoia (the belief that people are trying to harm you) might develop if you tend to read malevolent intent into other people's behaviour. It is also possible that you might begin to believe that aliens are talking to you if you misinterpret your internal speech as not being your own (you might be talking to yourself without realising it, but feel as if someone else is doing the talking). Psychologists are interested in why these sorts of interpretations of events might develop.

Experience and research in a wide range of psychological problems such as depression and anxiety have clearly demonstrated that traumatic, abusive or unpleasant events during a person's childhood can affect the way that the person interprets information later in life. An example might be people who grow up in a school environment where they are persistently bullied. Those people might develop beliefs that they were worthless, that other people are likely to harm them, and that the world is a callous and unfeeling place. There is evidence that many people who have psychotic experiences have experienced abuse or trauma at some point in their lives[88].

Abuse and trauma

'Mad people hear voices, not me. Jenny was the first voice – she was good, a comfort. But then, after a while, she stopped being safe, being fun, and she started to shout at me. She became a torment.'

'When I was four (or five) my brother started sexually abusing me. It started off as an innocent, even reciprocal, relationship. It started as an innocent act of morning cuddles, until I accidentally called him 'daddy'. My father died when I was a baby. My brother got very angry – so angry I cried – and said my father's death was my fault and the abuse was my punishment. It was about this time, I think, that Jenny started to hate me, and other voices appeared. My brother said that if I told of what was going on, my mother would hate me, that she would think I was dirty – reinforcing what I already believed about myself. I was, and still am, terrified of her rejection.'

Val – personal account

Further research in these areas is undoubtedly needed. Clinical psychologists do, however, have the knowledge at present to make some conclusions about biological and psychological factors in psychotic experiences, together with the role of the social environment, and to offer a framework that could link these.

Section 7: Biological factors in psychotic experiences

Key Points:

● Physical things such as brain tumours or taking street drugs can occasionally cause psychotic experiences. However, for the majority of psychotic experiences, research into genetics,brain chemistry, the physical environment and brain structure has not led to definite conclusions about physical causes.

● Genetics:It is true that psychotic experiences appear to 'run in families'.However research findings are a subject of debate. It is likely that many different genes are associated with a vulnerability to general traits, which may be more distantly related to psychotic experiences.

● Brain chemistry:Drugs that reduce levels of a brain chemical called dopamine can help reduce psychotic experiences.Although interesting,this does not necessarily mean dopamine abnormalities cause psychosis.

● Brain structure:Particular brain structures, the lateral ventricles, are often larger in people who have psychotic experiences. We do not know if this represents a cause of the psychotic experiences or a result of the drugs that were prescribed.

● The environment:Researchers have also looked at the possible effect of the environment on the biology of the brain. They have examined such things as difficulties during birth or the effect of viruses in the womb. No firm conclusions can be drawn.

● It is clear that psychotic experiences involve brain events, and can be influenced by chemical processes.It is important to remember, however that every single thought we have involves chemical changes in the brain.

Biological causes of psychotic experiences

It is widely assumed that psychotic experiences have some kind of biological cause, although precisely what this is may not yet be clear. Such views have become more prominent over the last two decades,and tend to be reported uncritically by the media.

The stress-vulnerability model (which will be described further later in this report) suggests that both psychological and biological factors may leave some people more vulnerable than others to environmental stressors.Although this is not, in itself, an explanation for psychotic experiences, it can help us to understand how both biological and psychological factors may contribute to problems.

There are clearly cases in which psychotic experiences are attributable to biological factors such as brain tumours, taking street drugs or illnesses like Alzheimer's disease. However, the evidence is weaker than is sometimes claimed that such factors play a role in causing similar experiences in the vast majority of people with diagnoses of schizophrenia and bipolar disorder. Current theories can be grouped under four main headings:

7.1.1 Genetics

Genetic factors are likely to be important, but should not be thought of as providing a complete causal explanation for psychotic experiences.Evidence for a genetic element to psychotic experiences comes mainly from studies that compare identical and non-identical twins and from adoption studies that compare the biological and adoptive relatives of people who were subsequently given a diagnosis of schizophrenia or bipolar disorder.

The closer the biological relationship, the greater the risk of a relative also having the diagnosis.The best estimate is that the risk of being given a diagnosis of schizophrenia is 46 per cent for the child of two parents with the diagnosis, 13 per cent for the child of one parent with the diagnosis,and 9 per cent for siblings.This is compared to the overall risk of 1 per cent for the general population[89]. Similar findings have been reported for a genetic contribution to bipolar disorder[90].

It is clear that psychotic experiences tend to 'run in families'. However this is not necessarily due to genetic causes. There are numerous problems in trying to disentangle genetic inheritance from environmental factors such as upbringing. In the studies relating to 'schizophrenia', doubts have been raised about methods of determining the genetic similarity of the twins, the length of time adopted children had spent with their families of origin, and the mental health status of some of the adoptive families[91,92]. Some reviewers have identified more serious flaws that cast doubt on the validity of the data. Examples of these flaws include; terms such as 'schizophrenia spectrum' rather than diagnoses made according to agreed criteria, making diagnoses on the basis of third-party reports, and using dubious methods for calculating the frequency with which siblings share diagnoses[93,94,95,96,97].

Another, more high-tech, approach is the attempt to identify family patterns of genetic markers for particular diagnoses. Reports of breakthroughs – for example, of an abnormal cluster of genes on chromosome 5 that predisposes to 'schizophrenia'[98] – have not been replicated.

A major recent study from Finland compared the adopted children of mothers with a diagnosis of schizophrenia with a group of adopted children whose biological mothers did not have the diagnosis[99]. The first group was found to be more likely to contain people with more severe diagnoses, including that of schizophrenia. However, clear differences between the two groups were only found where the adoptive families were rated as 'disturbed'. All children, even those who were believed to be carrying some genetic vulnerability, did well in 'healthy' adoptive families. In other words, families seemed to play a crucial role both in increasing, and protecting against, genetic risk. It was noted that this genetic risk may well consist of a 'non-specific' predisposition, a kind of general sensitivity to the environment, which leads to the development of serious psychopathology only under unfavourable psychological circumstances.'[100].

In summary, genetic factors may be important in a very general sense, but the existence of a specific genetic component to the various psychoses is not as clearly established as is sometimes reported. Most of the studies reported are evidence for a combination of genetic and environmental influences. There may be relevant non-specific hereditary factors such as temperamental sensitivity.

7.1.2 Biochemical theories

It has been argued that if genetic factors do have a role in causing people to have psychotic experiences, they do so through biochemical abnormalities. The dopamine hypothesis – the theory that schizophrenia may result from overproduction of the neurotransmitter (brain chemical) dopamine – has been extensively researched over the last 20 years. This theory is based on two observations. First, some neuroleptic ('anti-psychotic') drugs affect the chemical dopamine and can induce Parkinsonism (abnormal movements similar to those seen in Parkinson's Disease). Parkinsonism is known to be related to low dopamine levels. Second, drugs such as amphetamines, which increase dopamine production, can also produce psychotic-like experiences.

However, neither of these statements allows us to draw definite conclusions about cause. The first argument (about the effect of dopamine-influencing medication) is rather like arguing that headaches are caused by lack of aspirin. Nor does the theory explain why symptoms improve only gradually on neuroleptic medication, although the drugs have an immediate effect on dopamine in the brain. Secondly, the possibility that taking amphetamines CAN lead to psychotic experiences does not mean that chemicals (whether taken as drugs or already existing in the brain) are their only or main cause.

The new 'atypical' neuroleptics such as clozapine affect a different neurotransmitter – serotonin – rather than dopamine. Researchers are now investigating the possible role of serotonin in psychotic experiences.

Similar arguments have been made about the role of neurotransmitters (especially serotonin and noradrenalin)

in producing the extreme changes in mood and activity that lead to a diagnosis of bipolar disorder.

It should be noted that, even if a reliable relationship between a biochemical abnormality and a particular mental state (such as hallucinations) were found, this would not necessarily tell us anything about cause and effect.It may be the case that the experience leads to biochemical changes.It is also possible that some third factor, such as medication usually given to help people experiencing hallucinations,may be responsible for the chemical changes observed.At present,our knowledge of the biochemistry of psychotic experiences (and indeed of the biochemistry of most other forms of human experience) is extremely limited,and we are not in a position to make any firm statements about biochemical causes.

7.1.3 Environmental theories
The fact that people with a diagnosis of schizophrenia are more likely to have been born in the early months of the year has been put forward as evidence for some environmental influence at work.Difficulties during birth and exposure to viruses in the womb have also been suggested as factors,but so far such hypotheses remain speculative.

7.1.4 Brain structure
Research has also examined possible abnormalities in brain structure or function.A recent,detailed, overview of such studies[101] noted that findings were complex and often contradictory, with the only well-established structural abnormality being enlarged lateral ventricles (fluid-filled spaces within the brain).

More recent technological approaches have examined patterns of blood flow and patterns of electrical activity in the brain[102,103]. The results suggest that different types of psychotic experiences are associated with different patterns of activity. In particular, low levels of activity in the frontal lobes of the brain have been observed in people experiencing 'negative symptoms' (see Section 1).

However, the differences between people with and without a history of psychotic experiences are usually modest, with a large overlap between the groups. In most studies the people with a history of psychotic experiences have also taken powerful medication for many years, and this is not always taken into account.It is also possible that life experiences,psychological trauma,severe distress, and psychotic experiences may themselves leave physical traces on the brain,as well as the other way round[104]. For instance, recent research has indicated that practice at complex memory tasks actually makes parts of the brain grow in size. Brain scans of London taxi-drivers, who have to learn an enormous amount of information about the London streets ('the knowledge'),show enlargement of certain brain structures[105].

A complete list of all the factors that have been identified as potential causes of psychotic experiences would cover every aspect of biological functioning. Recent reviews of research in this area concluded that: 'Although the concept of schizophrenia has been in existence for nearly a century … there has been no identification of any underlying causal pathology'[106]. 'Few findings stand the test of time, most of the pieces of this particular jigsaw appear to be missing, and it is not easy to make sense of those that are available. Even 'hard' scientific findings fail to be replicated'[107].

7.2 Problems with biological research
An enormous amount of research has examined possible physical causes of psychotic experiences.This research has yielded some interesting findings,but no definitive conclusions can yet be drawn. Work in understanding biological influences on psychotic experiences may have been hampered by a number of problems:

- The use of unreliable and invalid diagnoses.If diagnoses are misleading, real physical processes that are related to only some of the psychotic experiences might be hidden.

- The fact that two things happen together does not mean that one has caused the other. Few studies have made this distinction.

- The effects of complicating factors (such as medication) have not always been taken into account.

- It has often been assumed from the outset that the reason for these experiences is likely to be a biological one and so other possible reasons have not been investigated.

It has often been assumed that there is likely to be just one cause. It is of course possible (indeed likely) that a number of things need to come together for someone to have these kinds of experiences. For example, someone may have an inherited sensitive temperament but only have psychotic experiences if at some point in their life they experience extreme stress.

There are, of course, biological and brain events that correlate with all aspects of our mental functioning. This is equally true for 'normal' and 'abnormal' experiences. However, it is incorrect therefore to conclude that biological abnormalities are the primary causes of a complex range of experiences. The undoubted existence of biological aspects to our experiences does not in itself justify categorising them as medical illnesses.

Few people would wish to deny that there may be some kind of inherited tendency to break down under stressful conditions. It is the nature of this tendency that is under dispute. It is likely that it may be a widely-distributed and non-specific trait such as temperamental sensitivity.

7.3 Conclusions

The evidence for specific biological mechanisms underlying psychotic experiences is inconclusive. It may, in fact be unproveable, at least if the search continues in its present form and based upon its present assumptions. Some individuals may well be more sensitive to environmental stressors than others, and this will inevitably be reflected in some way at the level of brain chemistry. However, this falls far short of the definition of a biologically-based medical illness.

The widespread acceptance that diagnoses such as 'schizophrenia' and 'manic-depression' refer to biological illnesses has, however, contributed to a climate in which the main, or only, treatment tends to be medication, with psychosocial factors given relatively less emphasis. This in turn has meant that psychological approaches to helping, such as talking treatments have often been unavailable.

Section 8: Life circumstances and psychotic experiences

Key Points:

- There is evidence that psychotic experiences can sometimes follow major events in someone's life, either negative (for example bereavement) or positive (for example winning the lottery).

- Many people who have psychotic experiences have experienced abuse or trauma at some point in their lives.

- The possible role of family relationships in the development of psychotic experiences has been a subject of debate over the last 40 years. For obvious reasons this has been an area of great controversy, with strong feelings on both sides.

- There is evidence that,if people who have had mental health problems live in a calm and relaxed home atmosphere, their problems are less likely to return.

8.1 Beyond traditional medical views of psychotic experiences

The traditional psychiatric assumption – that psychotic experiences are evidence of a biological 'illness' such as schizophrenia – has had a long legacy, and there are still many professionals who consider that biological factors are the most important areas to investigate in psychotic experiences.

More recently, however, there has been more interest in the possible effect of environmental factors such as cultural influences,traumatic or 'life events',family factors and societal influences such as stigma and 'labelling' on psychotic experiences.(See Section 5.4.2 on formulations.)

8.2 Stress-vulnerability model

As in most areas of human life, research into the causes of psychotic experiences indicates that both biological and environmental factors are important.As might be expected,these two broad types of factors interact.

Moreover, no one single cause has been identified,and it is likely that many aspects of an individual's life are significant in producing psychotic experiences.

This idea has been described as the 'stress-vulnerability' model[108]. In the stress-vulnerability model,it is suggested that everybody has a different level of vulnerability to the development of psychotic experiences. People are believed to be more or less vulnerable as a result of both biological factors (which could well be the result of either genetic factors or biological changes following birth) and psychological factors (for instance, being very sensitive – or resilient – to stress in a psychological rather than biological sense). Sensitivity to particular stresses may, of course, be at least partly a result of events that have happened previously in the person's life.

In the stress-vulnerability model,it is suggested that vulnerability will result in the development of problems only when environmental stresses are present. If the vulnerability is great, relatively low levels of environmental stress might be enough to cause problems.If the vulnerability is lower – the individual is more resilient – problems will develop only when higher levels of environmental stress are experienced.

This model explains why some people develop problems and others do not, even when they go through similar traumas. It explains why extreme stress can lead to psychotic experiences in almost anyone. It helps explain why some people recover from psychotic experiences faster than others, and are less likely to experience a reoccurrence of their problems. It also offers the continuing possibility of recovery over time; as even those with the most difficult problems may be able to avoid or reduce the likelihood of further episodes by finding ways of reducing their exposure to situations that they find particularly stressful. The model also acknowledges the idea of psychotic experiences being on a continuum with other psychological problems such as anxiety. Finally, it also tries to explain the fact that people who are prone to psychotic experiences may have long periods of recovery, but may develop new difficulties ('relapse') at various times.

8.3 Cultural factors

It is unclear whether people in all countries are equally likely to have psychotic experiences.However, the World Health Organisation has reported that psychotic experiences occur in many different cultures,and appear at least superficially to be similar even when the cultures are very different[109]. People in different cultures describe psychological problems in different ways. For instance, in some cultures, some psychological problems might be described in terms of physical pain or discomfort, in other cultures such experiences are described using emotional terms such as fears or anxiety. Cultural patterns may also influence the ways individuals explain their experiences. Unpleasant or upsetting experiences are often explained using the common cultural beliefs ('ghosts','the devil', 'space aliens' or 'evil eye').Sometimes explanations used by people from ethnic minorities can be misinterpreted as psychosis if the context is not understood.In some cultures, for example, many people believe in the possibility of being possessed by demons.Sometimes someone's belief that he or she is possessed might be wrongly thought to be a psychotic or 'delusional' belief.

8.3.1 Racism

People of African Caribbean origin living in the UK are three times more likely to receive a diagnosis of schizophrenia than are white people[110]. It has been suggested that the racism and social exclusion which black people living in Britain often experience may increase the likelihood of developing psychotic experiences[111]. These sociocultural aspects of vulnerability to psychosis are likely to have much in common with other experiences of abuse and marginalisation and require further investigation.Black people are also more likely to receive a diagnosis of schizophrenia than white people even if the experiences they describe are the same[112].

8.4 Life events

We all deal with many stressful events in our lives;birth,death, divorce, moving house, taking an exam.Such life events are generally thought to be stressful even if they are positive; even winning the lottery could produce stressful life changes. At their worst,life events can either be traumatic, or shade into ongoing

'hassles',or chronic stresses (such as overworking,poor relationships or ongoing financial problems).

Life events

Resi Ottespeer is 15 and lives with her parents in a small hamlet.She has heard voices for a year. She also hears knocking and loud,thumping music. The voices she hears are as loud as real voices.They forbid her to do things and they comment on her drawings – they tell her they look awful,like the drawings of a whore. They also want her to harm or sometimes kill herself.The voices confuse her so much that it is difficult for her to concentrate at school,so she does not want to go any more. She hears them all the time:they are in control and Resi does not want to contradict them.Her voices started when a policeman interviewed her at the police station after she was raped by a boy with the aid of two of his friends.She recalls that the policeman was kind but the questions he asked were 'nasty'.Her voices belong to a group of boys aged 16 to 20,the age group of her assailants.[113]

Many people who have psychotic experiences have experienced abuse or trauma at some point in their lives. They are also likely to have experienced a greater number of stressful events in the 6 months before an episode[114,115,116]. It appears that stress is associated with the onset of psychotic symptoms in vulnerable individuals, and once someone has experienced a psychotic episode, high levels of stress make it more likely that the problems will return.

8.5 Family relationships.

The idea that families cause psychotic experiences,or more specifically that parents are responsible if their children have psychotic experiences,was popular in the 1960s.A term 'schizophrenogenic (schizophrenia-causing) mother' was even developed.

Recent research has suggested that, as with other problems, difficult family relationships in childhood and adolescence may be an important contributing factor for some people, but not all. It is unlikely that we will ever be able to say with any certainty exactly which combination of

factors, in what proportions, has caused any one individual to develop psychotic experiences at a particular time.

However, research has revealed an important role the family can play in helping in the recovery of a person with psychotic experiences. In particular, attitudes of friends and relatives towards the person, and how they understand and react to the person's experiences are very important. They can also influence the extent to which the person is able to recover.

Family relationships

'As a result of the conference (a national conference of people who hear voices, many of whom have no contact with mental health services), both my parents and my husband came to accept my voices, and this made my life much easier. Also, my social life has improved, because people around me now realise that sometimes – because of the voices – I am not open to communication with them. My family are more supportive towards me and accept me more readily when I behave differently.[117]

The evidence is now fairly clear, and has been repeated on many occasions, that family members' attitudes can affect the outcome for people diagnosed with schizophrenia or bipolar disorder[118,119]. There are two important aspects to this. The first is that friends and relatives occasionally find dealing with some of the problems that can be associated with psychotic experiences (particularly embarrassing, socially disruptive or socially withdrawn behaviour) frustrating and difficult, and sometimes become critical or actively hostile towards the individual. The second reaction is to find the changes very upsetting and to try to look after the person rather as if they were a child again. While this 'emotionally over-involved' reaction is understandable and can be helpful in the short term, during recovery it can lead to dependence in the individual and exhaustion in the carer. Either or both of these attitudes in carers (i.e. criticism or over-involvement) have been described as 'High Expressed Emotion'. If they become extreme, they have been found to lead to poorer outcome and an increased likelihood of a return of psychotic experiences. In contrast, people living in more supportive, tolerant, low Expressed

Emotion environments tend to have a lower likelihood of a return of psychotic experiences, better social functioning, and better outcome.

Perhaps unsurprisingly, relatives who find caring particularly stressful also tend to have high levels of Expressed Emotion[120,121]. The way someone's psychotic experiences are understood and explained by their friends, relatives and other people helping them is very important, and can help determine the extent to which they are able to recover[122].

8.5.1 Staff relationships

Not all carers are relatives; some individuals live in hostels, for example, and have important relationships with staff and other carers. It has been found that both relatives and staff carers find the same problems difficult (disruptive behaviour and social withdrawal). Up to 40 per cent demonstrate high levels of Expressed Emotion, mainly criticism[123]. Clearly any relationship, whether with family or staff, can be problematic. It is important to remember that this is true not only for psychotic experiences but also in a wide range of other long term and ongoing difficulties, such as depression, epilepsy, and even obesity.

8.6 Conclusion

Research over the last few decades has shown that psychotic experiences are influenced by social and psychological factors as well as biological ones. When psychological, social and biological factors interact, especially when stresses occur, psychotic experiences can be the result. This is termed the 'stress-vulnerability' model.

One important factor in determining the extent to which someone is able to recover, and the rate at which they recover, is their social environment. The most frequently researched influences are those found in family settings, and successful interventions have been developed which can improve those relationships for carers and for individuals. Although family therapy has been proved to be effective, it is not widely and routinely available as yet. There is a powerful argument that it should be.

Section 9: Psychological factors in psychotic experiences

Key Points:

- Psychological models of psychotic experiences focus on patterns of thought that are associated with these phenomena.

- Psychological researchers have studied two quite distinct types of problems:deficits (impaired thought processes) and biases – where people's experiences have led them to interpret the world in particular ways. Many psychotic experiences are thought to involve a combination of the two.

- There is evidence that people with a diagnosis of schizophrenia tend to have difficulties with various aspects of attention.

- People who have psychotic experiences sometimes appear to have difficulty understanding what other people might be thinking, at least when they are distressed.

- Unusual beliefs are often associated with an increased tendency to jump to rapid conclusions.Paranoia is associated with the tendency to believe that the bad things that happen are the fault of other people.

- Hearing voices often appears to be the result of difficulties distinguishing one's own, normal,inner speech from the words of other people.

- Incoherent speech ('thought disorder') appears to reflect a general difficulty in adjusting conversations to the needs of the listener. It is often associated with high levels of arousal or agitation.

- Mania is a term used to describe a combination of increased activity or agitation,incoherent speech and, usually, a combination of euphoria, depression and irritability. These experiences are thought to be related to disruptions of the physiological and psychological mechanisms that control our emotions.

9.1 Psychological approaches to psychotic experiences

Psychological approaches to psychotic experiences focus on the patterns of thought that are associated with them. As explained in Section 6.2,there is little conflict between psychological theories and biological mechanisms,because all psychological processes are associated with specific brain activity. Indeed,in recent years,brain scanning techniques have allowed blood-flow and electrical activity in different brain regions to be identified as people perform specific tasks.

Researchers have studied two quite distinct phenomena thought to be related to the development of some psychotic experiences[124]. Cognitive 'deficits' are general impairments in processes such as perception,memory and attention. The word cognition is simply another term for 'thought'.They are often thought to be caused by brain damage or physical abnormalities,although they might also be the result of people's experiences such as trauma or an impoverished environment. Temporary 'deficits' can also result from depression,demoralisation, or poor motivation.Cognitive 'biases',on the other hand, are said to be present when people notice, pay attention to or remember some types of information better than others. For example, it has been known for some time that depressed people tend to notice and recall negative information more than people who are not depressed[125]. Similarly, different people interpret information differently. This can lead to biases.Again,people who are depressed tend to interpret information in a negative way. For example, they see the glass as half-empty, not half-full[126]. Because cognitive biases cannot usually be accounted for by general deficits (because some types of information are processed normally) they are unlikely to be the consequence of brain damage.

As discussed above, traumatic, abusive or unpleasant events during a person's childhood can affect the way that the person interprets information and reacts to events later in life. This can,of course, mean that such events might lead to the sorts of cognitive biases discussed here.

People who have psychotic experiences very commonly report having had highly distressing or traumatic life experiences such as bereavements, abuse and assault[127]. The common themes appear to be extreme threat, abuse or events that lead to overwhelming emotions.

Understandably, such events will affect the way the person sees the world. Everybody interprets new events and challenges in the light of previous experience. Abusive, threatening or overwhelming events are likely to lead to feelings of powerlessness and expectations of more abuse. One metaphor that has been used is that of a lock and key[128]. If the key fits the lock, the door can be opened. If your psychological perspective includes feelings of powerlessness and expectations of abuse, a street mugging might have particularly dramatic consequences.

All events, including psychotic experiences, will be interpreted from the perspective that the person has developed. People therefore respond differently to life challenges, and also in the ways they understand and make sense of psychotic experiences.

Individual, psychological, understanding

If a person like you had found a way to talk to me when I was first going crazy … at all the times of my delusion that I was a grand military figure … I knew that this (delusion) was a way that I was trying to tell myself that I could overcome my panic and fear … You (the professionals) were always checking me out, to see if I knew what you knew rather than to find a way to talk with me. You would ask, 'Is this an ashtray' to see if I knew or not. It was as if you knew and wanted to see if I knew … that only made me more frightened, more panicked. If you could have talked with the 'me' that knew how frightened I was. If you had been able to understand how crazy I had to be so that I could be strong enough to deal with this life threatening fear … then we could have handled that crazy general.[129]

9.2 Cognitive deficits and psychotic experiences

Until recently, most cognitive research into psychotic experiences has focused on people with a broad diagnosis of schizophrenia. This work has focused almost exclusively on cognitive deficits.

There is good evidence that some people with a diagnosis of schizophrenia have difficulties on a variety of measures of attention[130,131]. For example, there is evidence of difficulties for some people in the very earliest stages of processing visual information. Many people with a diagnosis of schizophrenia appear more easily distracted than people who do not have psychotic experiences.

A number of researchers[132] have suggested that difficulties in understanding other people's behaviour might explain a number of psychotic experiences. It is generally believed that ordinary social behaviour depends on our ability to use other people's actions and conversation as clues for understanding what they might be thinking. Some people who are having psychotic experiences appear to show difficulties with this skill, although it seems to improve when the experiences become less distressing[133]. It is possible that these difficulties are related to the very high levels of stress and confusion that sometimes accompany psychotic experiences.

Such problems with what is termed 'Theory of Mind' have been suggested as possible explanations for reduced levels of emotional expression during episodes of psychotic experiences[134], disorganised speech[135], hearing voices[136] and unusual beliefs[137].

Some of these findings have been observed in people who have recovered from psychotic experiences, in the children of people with a diagnosis of schizophrenia (who are thought to carry a risk of developing psychotic experiences) and in people who score highly on 'schizotypy' questionnaires. On the other hand, these deficits are generally greater in people who are currently experiencing psychotic phenomena. These findings have been used to support three conclusions. First, that subtle deficits in information processing can leave people vulnerable to psychotic experiences. Second, that when people with such vulnerabilities experience stressful events, these deficits may make it harder for them to cope

effectively. Third, that the emotional stress associated with stressful events can itself lead to increased cognitive deficits, which in turn can lead to further problems and the development of vicious circles.

One early theory of 'schizophrenia' was that it reflected a 'loosening of connections' in the brain[138]. (That idea actually led to the use of the term 'schizophrenia' meaning 'fragmented mind'). Psychotic experiences such as hearing voices, unusual beliefs and 'thought disorder' appear to involve making unusual connections between apparently unrelated events. This is not in itself either good or bad. Sometimes making unusual connections between things is valuable, when it is termed 'lateral thinking' or 'creativity'. In fact, people who score highly on measures of 'schizotypy' also score highly on measures of creativity[139]. It is even possible to imagine how the ability to make

Cognitive deficits seem to be associated with psychotic experiences and vulnerability to psychotic experiences, rather than with 'schizophrenia'. Whenever comparisons have been made between people with a diagnosis of bipolar disorder and people with a diagnosis of schizophrenia on these kinds of cognitive tests, few differences have been found.

Most research on cognitive deficits has involved broad diagnostic categories such as 'schizophrenia' and 'bipolar disorder'. Because of the problems with these diagnoses, and because such deficits do not fully explain psychotic experiences, many clinical psychologists (especially in Britain) have begun to investigate the psychological processes which may be involved in particular experiences. Considerable progress has been achieved in this respect over the last ten years, and only a few of the most important findings can be mentioned here. Cognitive 'biases' have therefore been studied in relation to specific experiences.

9.3 Cognitive biases and unusual beliefs

Many studies have shown that people who have unusual or delusional beliefs tend to 'jump to conclusions' when faced with limited or contradictory information[140,141]. By comparison, people who do not hold such beliefs tend to be more cautious when evaluating evidence.

The two most common kinds of unusual belief that people report are the fear that people are trying to harm or kill them (persecutory delusions) and the belief that they have special powers or abilities or that they are famous or powerful (grandiose delusions). Studies suggest that these unusual beliefs are associated with specific biases in reasoning about social situations[142]. The evidence suggests that many people who experience paranoia have a general tendency to assume that other people cause the things that go wrong in their lives. Some researchers have argued that these kinds of beliefs therefore have a defensive function (protecting the individual from low self-esteem) although this claim remains controversial[143,144].

9.4 Cognitive biases and hearing voices

Most people often experience an 'inner voice' when thinking in words (for example, when deciding what to do, or when struggling with a problem). There is evidence that some people who experience verbal hallucinations (voices) have difficulty distinguishing their inner speech from speech from an external source. Some of this evidence has emerged from physiological studies (for example, brain scanning experiments) in which it has been shown that speech areas in the brain are active when people hear voices[145]. Other psychological experiments show that some people who hear voices experience difficulty when they are asked to distinguish between their thoughts and words spoken to them[146].

9.5 Incoherent speech ('thought disorder')

Although incoherent speech has traditionally been regarded as a symptom of 'schizophrenia', studies show that it occurs more frequently in people experiencing mania[147] and reflects a difficulty in adjusting speech to the needs of the hearer. Most people only become thought disordered when emotionally stressed and, for most of the time, their speech is perfectly coherent[148].

9.6 Mania

Mania is a term used to describe a complex cluster of

'symptoms', which includes grandiose delusions,increased activity, incoherent speech and,in most cases, a paradoxical combination of both positive emotions (euphoria) and negative emotions (depression and irritability)[149]. People experiencing mania sometimes believe that they are particularly famous or important. These beliefs are traditionally termed grandiose delusions. Recent studies have suggested that they are associated with patterns of thought similar to those seen in paranoia[150]. Both paranoia and mania might play a role in protecting self-esteem.Some researchers think that the increased energy and activity seen in people experiencing mania may sometimes be caused by disruption of the physiological mechanisms that control the sleep-wake cycle[151].

9.7 Summary: no one single cause

It is possible to understand many psychotic experiences as stemming from either how the person sees the world,or particular problems with thought processes,or a combination of both.Of course, each person will have a different set of expectations and beliefs.It is also obvious that,while some people with psychotic experiences have major difficulties with thought processes such as attention, concentration and memory, other people appear to have no such problems.

Psychologists believe that psychotic experiences often result from a combination of these processes. For example, if you are feeling confused and experiencing overwhelming emotions, you may find it particularly hard to interpret other people's actions and intentions accurately. This might mean that interactions with other people are very anxiety provoking and ambiguous.If the events in your life have led you to believe that people tend to abuse and hurt you at every opportunity, and you also have a tendency (again exaggerated in a state of stress) to jump to conclusions,it is understandable that you might occasionally feel paranoid.

The last three Sections have demonstrated how different psychological, social and biological processes can contribute to psychological experiences. The evidence presented in Parts 1 and 2 of this report have demonstrated that each person's difficulties are likely to have arisen and be maintained by a unique combination of interacting factors.Part 3 of this report concerns the help or treatment that is or should be available.

Part 3: Help and treatment

Section 10:Assessment

Key Points:

● In order to develop an appropriate psychological formulation,a clinical psychologist might assess:

● What problems the person is experiencing and what he or she would like to change;

● The person's view of why this is happening and of their problems in general;

● The person's life situation (accommodation, work and/or leisure activities, relationships with friends and relatives) and what he or she would like to change.

● Skills,abilities and areas of difficulty:Clinical psychologists have designed inventories and formal tests which can sometimes be useful in measuring problems or skills and comparing them to what is average for the population.

● Self-esteem: People who have psychotic experiences often have very low self-esteem, partly as a result of the prejudice and discrimination that they experience. This can often cause more distress than the experiences themselves.

● What help the person is receiving from other people and from services.

● What additional help he or she feels he or she needs.

● What has and what has not been helpful in the past.

10.1 Reasons for assessment

Assessment is carried out for many reasons[152]. For psychologists,the main purpose of assessment is to develop an appropriate psychological formulation – in other words to help the person to come to an understanding of the problem and to decide what is likely to help. (See Section 5.4.2.) Obviously, different things will be relevant for different people, and so a 'whole person'

approach is needed, examining all the different factors that may each be playing a role. This section describes some of the different areas that might be covered,and describes some of the tools that can help with the process of assessment.These include questionnaires as well as more formal tests of memory and concentration.Information can come from a number of sources including the person him or herself, relatives, key worker and other carers.

It is important to bear in mind that many service users will have experienced numerous 'assessments' in various contexts. Care needs to be taken to ensure that assessment is a respectful and collaborative process.

Below is a brief description of the sorts of areas an assessment might cover.

10.2 Types of Assessments

All formal assessment tools,such as questionnaires,should meet the basic criteria for scientific measurement. They should be valid – appropriate to the problem and actually assessing what they appear to measure. They should be reliable – the information they provide should be an accurate assessment that could be repeated to produce the same answer. Reliability is essential because it must be possible to interpret changes in scores on an assessment measure as a real change in an individual's experiences and not something to do with the unreliability of the scale[153].

10.2.1 Psychotic experiences

Scales that measure the general seriousness of problematic experiences and behaviours are useful for examining changes over a short period of time and are quick to administer. They are most useful for clinical audit and evaluation of services or therapy.

Scales that are used in psychological therapy need to be more detailed and are usually completed by the individuals themselves.The most commonly used scales measure aspects of the experience of hearing voices and unusual beliefs but there are also new scales which measure the experience of anhedonia (lack of emotional experience) that people often report as distressing.

10.2.2 Social and Occupational problems

People with psychotic experiences sometimes have problems in their social lives. They may have problems in continuing with their work, which may have serious effects on their general well being. These social problems can be analysed in more detail for the purposes of designing support and therapy. For instance, if it is known that the person has difficulty communicating, they might decide to improve their skills or alternatively they may wish to take part in activities, occupational and leisure, which do not require high levels of these skills.

The assessment of occupational and social problems is also important in the wider planning of services.

10.2.3 Self esteem

One of the goals of therapy is usually to improve the person's self-esteem and self-confidence. Assessment of self-esteem is therefore important.

10.2.4 Psychometric assessment – Testing memory and concentration

Psychometric assessment, the testing of abilities such as memory, concentration and intelligence, may also be relevant. People's verbal memory and skills in solving problems (usually termed executive functioning) can be measured reasonably accurately.

In the past global measures such as IQ have been used but more recently detailed assessments of working memory and planning have been used[154]. The results of these assessments can be used to plan the intervention and make therapy more appropriate for each individual. For instance the person might be offered specific help with cognitive skills, or therapy could be adapted to take account of the person's strengths and weaknesses.

10.2.5 Quality of life

There are a number of measures of quality of life. Some measure subjective indicators such as satisfaction with life. Some look at more objective factors such as whether the person has things in their lives that others generally value. Some look at both. These are usually most relevant for

assessing the effectiveness of services for a group of people rather than one individual's experiences.

10.2.6 Satisfaction with services

Satisfaction with services is very difficult to measure as people's responses depend on the way in which the questions are asked. For example, the reported level of satisfaction will increase if the clinicians themselves ask the person to complete the scale in front of them. Satisfaction with services is also highly related to levels of depression and so will change if this improves or worsens. It is clearly very important that service providers collect such information anonymously in order to monitor performance.

10.2.7 Insight

'Insight' is a controversial area. Insight traditionally refers to the agreement of the patient that they have a diagnosable mental illness. Since many people (including many clinical psychologists) feel that 'diagnosable mental illnesses' are highly dubious concepts, it seems odd to insist that people share one view of their problems.

However, insight can also be interpreted, more reasonably, as the willingness or ability of the person to accept that they have acted differently during an episode of psychotic experiences compared to their 'normal' behaviour. This may allow the person to engage with services to prevent such problems in the future that may interrupt or interfere with their lives[155].

Insight

The feeling that the diagnosed mentally ill don't know what they are talking about limits the scope of our lives. The concept of insight – perhaps lack of insight would be more accurate from the psychiatric perspective – is one of the most powerful and insidious forces eroding our position as competent, creative individuals. If I am to be consigned to a category of persons whose experience is devalued, status diminished and rational evidence dismissed, simply because at certain time or times I lost contact with the consensus view of reality agreed on by my peers, then it is scarcely possible to expect that my control over my life will ever be more than severely circumscribed. If my

experience is not valued I cannot be whole. It is particularly discouraging to speak to some psychiatric professionals and have my experience validated only as a particular and very sad blemish in an otherwise benign conception. This is no validation whatsoever. I am not the one regrettable bacillus in the otherwise sterile supplies room. My experience is shared and is relevant.[156]

Peter Campbell – personal account

10.2.8 Needs for care

Scales that measure an individual's needs cover a wide variety of different areas such as residential care and relationships. Often individuals, their carers and staff disagree about the levels of need and these scales can be helpful in making different perspectives clear so they can be discussed.

Section 11: Medication for psychotic experiences

Key Points:

- Traditional psychiatric drugs are the most common forms of help offered to people with psychotic experiences. Neuroleptics are the most common but lithium is sometimes used where the diagnosis is manic depression. ECT (Electro-Convulsive Therapy) is also sometimes used.

- They are not a 'cure' but can alleviate symptoms. They can be used for acute psychotic experiences and/or used long-term to try to prevent future problems.

- They do not help everyone. Two thirds of people who take medication regularly are likely to experience a reoccurrence of their psychotic experiences within two years.

- They can have serious unwanted effects ('side effects') which for some people can be worse than the original problem.

- Newer drugs ('atypical antipsychotics' such as clozapine) are not necessarily any more effective, but can cause fewer adverse effects.

- There is no way of predicting accurately what dose of which drug will suit a particular individual. Adjustments are likely to be needed before the person finds the optimum drug and dose.

- Many people are on doses above recommended levels.

- Levels of non-compliance with psychiatric medication are similar to those in the physical health field and the reasons for non-compliance are also similar. The British Psychological Society has stated 'It is unsafe for people to be forced to use medication with potentially lethal side-effects against their wishes and without in-patient supervision'[157].

- A good, collaborative relationship between patient and prescriber is likely to improve outcome.

11.1 Antipsychotic medication – neuroleptics

A range of drug treatments is commonly prescribed for people who have psychotic experiences. The most important are 'antipsychotic' drugs. These drugs (sometimes called neuroleptics or major tranquillisers) were first developed in the late 1940s and have since been regarded as the preferred medical treatment for psychotic experiences. There are many of these drugs including chlorpromazine, thioridazine, trifluoperazine, sulpiride, haloperidol, flupenthixol, and fluphenazine. Recently, a new class of 'atypical' neuroleptics (for example clozapine, risperidone and olanzapine) has come into use.

Antipsychotic medication – 'pro's

'Without major tranquillisers myself and my family feel I may not have survived, as hyperactivity and starvation led to rapid weight loss as well as psychological symptoms.'

'The drug blocks out most of the damaging voices and delusions and keeps my mood stable.'

'Injections seem to dampen down the voices. They decrease the voices, but not altogether, and the side effects are unpleasant.'

'Medication is a necessary evil as I have very little to fall back on otherwise. The medication stops psychotic symptoms, or has in the past.'

Antipsychotic medication – 'con's'

'They do not cure the causes of conditions, they have the side effects of making you unnaturally doped, enormously fat.'

'The dosages depressed me and made me feel my motivation, ideas and whole autonomy being removed.'

'With major tranquillisers, I feel as if I'm in a trance. I don't feel like myself.'

*****Anonymous – personal accounts**[158]*

11.2 Acute and preventative treatment

Neuroleptic drugs may be used in the acute phase of psychosis (when experiences are most intense or distressing).Afterwards,they can be used either intermittently (when the person feels unwell,distressed or under stress) or prophylactically (when the person has partly or totally recovered in order to try to prevent further episodes). For many people, prophylactic treatment can be important in preventing further episodes and hospital admissions[159,160]. However, some people wish to avoid long-term drug treatment and prefer to use non-medical approaches for coping with psychotic experiences or to use medication only at times when the experiences are distressing.Prescribers need to discuss these issues in a collaborative manner.

Acute and preventative treatment

'I took neuroleptics for some time, but then chose to stop taking them because I felt like a zombie. I could no longer even read a book.I do still use medicine, but these days it is more of a maintenance dose with fewer side effects.When voices threaten to overpower me, I increase the dosage temporarily.'[161]

11.3 Problems with neuroleptics

Neuroleptics are not perfect treatments. They are not 'cures' even though they may make psychotic experiences less intense and distressing. They do not help everyone, and rarely remove problems completely[162,163]. Moreover, neuroleptic treatment can cause adverse effects (side effects) which can be serious and distressing. These include the following;

(a) About 40 per cent of people experience a dysphoric response (depression and restlessness) within a few hours of receiving neuroleptic treatment[164,165,166]. For the majority of people, this adverse effect reduces during the first week of treatment.

(b) Extrapyramidal side effects (EPSEs) include Parkinsonianism (tremor, muscle stiffness and difficulty controlling movements, affecting about 15 to 25 per cent of patients),akathisia (a highly unpleasant subjective sense of restlessness,affecting the majority of people at some point in their treatment),dystonias (involuntary muscle contractions,affecting about 10 per cent of patients) and, more rarely, tardive dyskinesia (a condition involving involuntary and unsightly movements of the mouth and tongue, which may be difficult to reverse once established)[167,168,169,170]. With the exception of tardive dyskinesia,the EPSEs can be partially controlled by anticholinergic drugs such as procyclidine. Unfortunately, these have their own adverse effects (see below).

(c) Anticholinergic adverse effects (which may be caused by some neuroleptics and also by anticholinergic drugs prescribed to control EPSEs) include dry mouth, constipation,difficulty urinating and memory problems. It has been estimated that up to 40 per cent of people experience these problems[171].

(d) There is a slight but proven risk of cardiac arrest[172].

(e) There is a proven risk of liver disease[173].

(f) The neuroleptic malignant syndrome is a rare adverse effect which initially presents as a fever which effects about 0.5 per cent of people[174]. It can be fatal unless neuroleptic treatment is discontinued immediately.

(g) There is a risk of serious blood disease such as agranulocytosis,which can also be fatal unless neuroleptic treatment is discontinued immediately[175]. This occurs rarely following treatment with most neuroleptics but affects about 1 to 2 per cent of people treated with clozapine.

(h) A variety of other adverse effects commonly reported include weight gain[168], breast enlargement and sexual dysfunction[176].

(i) Many people find that neuroleptic treatment results in a loss of motivation,sometimes described as a 'neuroleptic induced deficit syndrome' (NIDS)[177]. One clinical trial showed that people treated with neuroleptics, although experiencing fewer 'symptoms',made fewer life achievements than a control group treated with placebo[178].

These adverse effects vary according to exact medication used.The new atypical neuroleptics typically produce fewer EPSEs.Clozapine carries a high risk of agranulocytosis and, for this reason,people treated with this drug must have regular blood tests.

Side effects
With akathisia there is never any peace from this insistent urge to move, be it rock backwards and forwards in a chair, shuffle around the wards, kneel and huddle in a chair or go for a walk. It is like a tinnitus of the body;there is never a moment of inner silence. I remember one day staring into a mirror on Ward 3.My eyeballs were bulging, my skin was greasy and grainy, my hair like rats' tails, I was stiffened and troubled by constipation and simultaneously racked by akathisia.I looked like everybody's image of a mental patient – but it was entirely a medication effect.[179]

Dr Peter Chadwick

11.5 Relative benefits of different neuroleptics
There is little evidence that any neuroleptic is superior to others.Claims have been made for the superior efficacy of clozapine[180] but these have been made on the basis of trials of short duration,and/or with comparison doses of conventional neuroleptics that have been less than optimal.Atypical neuroleptics seem at least as effective as the traditional medications.A preference for atypical neuroleptics over 'typicals' may be justified because of their less severe EPSEs.Atypical neuroleptics do, of course, have their own range of potential adverse effects. These can include weight gain and lethargy[181].

11.6 High doses of neuroleptics
There is no evidence that high doses of neuroleptics confer clinical advantages over low doses[182]. However, there is clear evidence that high doses cause more severe adverse effects. For this reason,The Royal College of Psychiatrists has recommended that high doses should be used only under exceptional circumstances[183].

One study has indicated that patients on unnecessarily high doses of medication may benefit from a dose reduction[184]. Nonetheless,it is our experience that high doses continue to be used in routine treatment and we view this matter with considerable concern.

11.7 'Compliance'
Poor compliance with neuroleptics has been cited as an important cause of continuing illness and further hospitalisation[185]. Noncompliance is often attributed to lack of insight (the individual does not understand or refuses to accept that she/he has an 'illness').However:

(a) People's beliefs about their experiences are complex, and cannot be reduced to a simple dimension of insight. (See Section 10.2.7.) For example, some prefer to think of their problems in psychological terms rather than embracing the medical model.

(b) The strategies that people take in order to manage their medication are also complex.Many people are neither compliant nor noncompliant but vary their medication according to circumstances[186].

(c) For many people, the balance between the advantages of neuroleptic treatment (for example, a reduction in the frequency or intensity of psychotic experiences) and the disadvantages (for example, adverse effects) is a fine one. In one study it was found that 'side effects' were as bothersome to people as their psychotic experiences[187]. Other studies have found that people harbour a wide variety of opinions about their drug treatment,varying from the unequivocally positive to the unequivocally negative[188,189].

(d) People who refuse neuroleptic drugs completely do so for a variety of reasons.In one study it was found that some refused because they perceived their drug treatment to be ineffective and some because they were distressed by adverse effects[190]. Only a few gave reasons that were judged to be psychotic.

(e) In general levels of 'noncompliance' with psychiatric medication are similar to those in the physical health field and the reasons for noncompliance are also similar[191,192].

For these reasons it is wrong to assume that it is always

rational to comply with neuroleptic treatment. Any constructive approach towards ensuring that people receive optimum medical treatment must take into account people's views on and personal experience of their drug treatment[193].

11.8 Psychiatrist – patient relationships
Drug treatment should always be based on a collaborative relationship between prescribers and patients[194,195,196]. This means that:

(a) People should always be fully informed about the likely effects of their drug treatment. There is no evidence that informing patients about side effects deters them from accepting treatment.

(b) People should be encouraged to ask questions about their treatment, and their questions should be answered as fully as possible.

(c) People's attitudes, side effects and response to treatment should be monitored at regular intervals. There are a number of simple standardised scales designed for this purpose[197,198].

There is evidence that a good collaborative relationship between prescriber and patient results in a better outcome for the individual in the long term[199].

11.9 A collaborative approach to medication
Mental health service users should be able to make appropriate choices about their own medication. Prescription has traditionally been seen as a process in which doctors make the decisions and patients follow. We recommend that professionals take a more collaborative stance, which enables service users to play a more active role. Specific approaches that may be useful include:

(a) Giving people information about the benefits and hazards of treatment.

(b) The use of simple behavioural strategies such as diaries and reminders to help people remember when to take their drugs[200,201].

(c) 'Compliance therapy' is based on the approach known as 'motivational interviewing' which is often used in substance misuse services. A recent study of this approach found that it led to improved adherence with medication and a better outcome in terms of global functioning[202]. However, others have argued that such approaches do not sufficiently take into account the fact that not everyone benefits from medication[203]. Each individual needs to be able to make an accurate appraisal for him or herself of the benefits and costs of taking medication.

(d) Other drugs may be prescribed in addition to or instead of antipsychotic drugs. In some parts of the world, it is common to offer people short courses of benzodiazapine medication (e.g. valium) in order to reduce anxiety in the short term prior to determining whether treatment with a neuroleptic is necessary. Antidepressant medication may also be prescribed if appropriate.

(e) If, having considered all the relevant information, the service-user decides not to use medication, this decision should be respected and he or she should continue to be offered support by mental health services. We view with considerable concern the practice adopted by some clinicians of equating such a decision with 'refusing treatment' and withdrawing support as a result.

A negative experience of treatment
My experience of neuroleptic medication when I was psychotic was that it seemed to be used as a substitute for good care rather than as part of a good care package. I believe that time, rest, low levels of short-term medication and discussing my experiences would have best helped me to recover and begin to rebuild my life. This combination was unfortunately unavailable. During my hospital admissions, I instead received minimal staff interaction, and was living highly sedated with fellow patients with a broad range of madness, disabilities and levels of institutionalisation. The only occasions I was asked to discuss my beliefs were in the brief but influential ward round.

I know that some people find neuroleptics helpful, but for me the main effects were the negative ones often thought of as 'side effects'. These included being considerably mentally slowed, as

well as restlessness, Parkinsonism (tremors in the arms and legs and shuffling of the feet),physical weakness and impotence. I was determined to come off them at the first possible opportunity. At no point during my initial admission was I consulted at all about the medication I was being given. Nobody told me about possible side effects or gave me a chance to engage in decisions about my treatment. My experience was of being treated as a second class citizen, who was expected obediently to take drugs that felt to me very noxious.

As the staff were making decisions about me without listening to me I decided not to trust them or their decisions. I was determined to withdraw from the medication at the first available opportunity. It was a very difficult thing to do as the withdrawal effects lasted for many months and included 'rebound' hyperactive states that were interpreted by some as psychotic relapses. It was at least partly as a result of this that I had two further hospital admissions before eventually, at the third attempt I managed to withdraw successfully from the medication.

I did this alone without any support and it was an extremely challenging task.It would have helped if I had been given specialist advice on practical ways to cope with the withdrawal effects. However, mental health workers appeared to assume that if I did not take my medication,I was effectively disengaging from mental health services.

Dr Rufus May – personal account

11.10 Mood stabilisers

Mood stabilising medication may be prescribed for people who experience excessive mood swings, especially mania. The most common mood stabiliser is lithium carbonate. More recently, it has been discovered that anticonvulsant medication (medication for epilepsy), for example carbamazepine, can have mood stabilising effects,although these have not been as thoroughly evaluated.

Mood stabilisers – 'pro's

'Since stabilising on lithium I have not been dotty.'Helpful' therefore is an understatement for my use of lithium gave me sanity.'

'Has stabilised my moods giving me the confidence to resume normal life and build up a career again.'

Mood stabilisers – 'con's

'I feel trapped by having said it was helpful.It is a drug and I hate it. It has not really helped me but right now I need to take it as there is no other alternative.'

'I find Lithium (and carbamazepine) hamper one's ability to think normally. Between episodes I prefer to do without.That way there is more joy in life.The drugs leave you without feeling and it is very difficult to be in touch with one's inner self.'[204]

Anonymous – personal accounts

11.11 Adverse effects of lithium

Common adverse effects of lithium treatment include nausea and diarrhoea in the short term.These symptoms often subside after a few weeks.Longer term effects include tremor (often affecting the fingers),increased production of urine (sometimes disturbing sleep and leading to thirst), weight gain and hypothyroidism (suppression of thyroid function).Adverse effects of carbamazepine can include drowsiness,dizziness,nausea and double vision[205].

11.12 Effectiveness of lithium

The effectiveness of mood stabilising medication has been less well evaluated than the effectiveness of the neuroleptics[206].Although it is widely believed that prophylactic medication can prevent future episodes of illness, especially in people who have experienced mania, most of the clinical trials that have been conducted with lithium have suffered from quite serious methodological limitations.A recent study found that about 50 percent of people treated with lithium experienced severe mood swings during a one year period[207].

Discontinuation of lithium is often followed by a manic episode. However, it is not clear that this is caused by the re-emergence of 'illness'.It is possible that this phenomenon is a kind of 'rebound' effect.Consistent with this theory, it has been found that a manic episode is more likely following rapid discontinuation of lithium compared with a tapered reduction of medication[208].

Long-term adherence with lithium therapy is often poor, but this is often because of the unpleasant side effects. As in the case of neuroleptic medication, adherence is most likely to be achieved if there is a collaborative relationship between patient and prescriber, and if the person is adequately informed of the benefits and costs of medication. Cognitive behavioural methods similar to those used in the management of neuroleptic medication have a role in helping people to achieve the best from lithium therapy.

11.13 Conclusions

Antipsychotic medication is almost universally prescribed for people who have psychotic experiences and come into contact with the mental health services. Many people find them useful. Equally, they can have distressing and even dangerous adverse effects ('side-effects').

It is important to be aware that such medication can only be used pragmatically – these are not 'cures' but they may be beneficial. Ultimately the individuals themselves are the best judges as to what is most helpful. Decisions on medication should be collaborative. Treatment with powerful drugs against the person's wishes is an extreme and serious step. In common with many groups, The British Psychological Society has expressed its considerable concern about proposals to use compulsory treatment in the community[209]. It is unsafe for people to be forced to use medication with potentially dangerous side effects against their wishes without inpatient supervision.

Section 12: Psychological interventions for psychotic experiences

Key Points:

- Psychological interventions are based on a psychological framework of understanding and aim to help people work out their own understanding of the nature of their difficulties and what is likely to help.

- Psychological interventions are based on a collaborative working alliance between psychologists (or therapists) and clients. It is possible that this is the main 'active ingredient'. It is certainly vital.

- The most common form of psychological therapy for psychotic experiences is Cognitive Behaviour Therapy – CBT. This is a tried and tested intervention that examines maladaptive patterns of thinking associated with a range of emotional and behavioural problems.

- There is convincing evidence that psychological interventions are effective in reducing psychotic experiences and the distress and disability they cause. Psychological interventions are effective for hearing voices (hallucinations), unusual beliefs (delusions) and the extreme moods of bipolar disorder.

- Despite the effectiveness of psychological interventions, and the fact that they appear to be cost-effective, more resources are needed, especially for training.

12.1 Psychological interventions

Psychological interventions (talking treatments) are usually used in conjunction with medication. Some people, however, prefer to use alternatives to drug treatments for psychotic experiences. Other people may find medication helpful when in acute distress, but do not want to take it long-term. Some psychologists feel that psychological interventions could offer an alternative to long-term medical treatment for some people.

The integration of medical, psychological and practical approaches echoes the growing recognition that social and psychological factors interact strongly with biological factors in psychotic experiences[210].

Many individuals with psychotic experiences have complex difficulties. The psychotic experiences themselves, the framework within which people understand them, their coping responses as well as the disruptions of relationships and social networks, and the depression and anxiety that can follow are all important. All these demand a careful therapeutic response. In addition, special emphasis has recently been given to implementing 'early intervention' services for people showing the first signs of psychotic experiences. Finally carers often experience substantial burdens, and sometimes also need help.

12.2 The effectiveness of psychosocial interventions

It is increasingly recognised that psychosocial interventions can reduce the probability of psychotic experiences returning. 'Relapse rates' can be reduced by as much as 50 per cent by including psychosocial interventions[211]. Such interventions include family therapy, social, cognitive and occupational rehabilitation, cognitive behaviour therapy (CBT) and interventions early in the development of problems.

The effectiveness of psychological interventions

I am one of the fortunate few (being white and middle class has a great deal to do with it, I have no doubt) who has been privileged enough to experience a range of talking therapies despite various diagnoses, including schizophrenia … even now I don't know how much change is possible or whether I will ever feel that life is worth living. Yet I know that without it I would not be alive today; and while my doubts and pain remain, the quality of my life has changed beyond recognition, and I have hope that things will continue to get easier.[212]

Psychosocial interventions reduce the distress associated with psychotic experiences and can also reduce the intensity and frequency of the experiences themselves[213,214].

A recent review of psychotherapy in the NHS found talking treatments to be as important a component of healthcare as medication,but also found that such treatments are often not available to people who have psychotic experiences[215].

Currently, most people who have psychotic experiences and receive talking treatments also receive medication. However, research in the United States has suggested that for some people, psychotherapy can be more effective without medication,and that it can sometimes be more effective than medication alone[216].

As outlined above there are several different psychological,psychosocial and psychotherapeutic approaches.These all have slightly different names and slightly different emphases.There are important differences between approaches.Different approaches may be more or less suitable for different people, and some psychologists or therapists prefer to work in one way rather than another. However, there are more similarities than differences between these different 'brand-name' approaches.In the past there has sometimes been a degree of antipathy between different 'schools' of therapy. However, this is changing. Part of the reason is the increasing recognition on all sides of the importance of the subjective meaning of psychotic experiences. The value, common to all therapies, of the opportunity for people to talk and think about their experiences in a calm, supportive and non-judgmental atmosphere is also increasingly being recognised. Sometimes the onset of psychotic experiences can be traumatic and lead to major life changes:emotional support and the opportunity to talk is very important.All psychological interventions should be based on a trusting,collaborative working relationship between the professional and the client.It is possible that this is often the main 'active ingredient'[217]. It is certainly vital, and it is important that service users should be able to find a therapist or worker with whom they feel comfortable.

12.3 Cognitive Behaviour Therapy (CBT)
Cognitive Behaviour Therapy (CBT) has proved promising as a psychological intervention for psychotic experiences[218]. The main assumption behind CBT is that psychological difficulties depend on how people think or interpret events (cognitions),how people respond to these events (behaviour),and how it makes them feel (emotions)[219]. CBT aims to break the vicious cycle between thoughts, feelings and behaviours by helping people to learn more useful ways of thinking and coping.

Cognitive Behaviour Therapy
I have been receiving cognitive therapy for about a year. Regarding the cost:it may well be more expensive initially, but in my own case my medication (antidepressants and tranquillisers) has been reduced by two thirds this year, and I expect to be off all medication by the end of the year. Since I am only 47 years old, the long-term saving should be quite considerable … I was originally told by a consultant psychiatrist to surround myself with cotton wool and accept the fact that I would be unable to work again … I have just started a part-time retraining course on computers and information technology. I for one view the outcome very positively.[220]

CBT shares with other approaches such as psychodynamic psychotherapy and psychoanalysis an emphasis on the meaning of an experience for the individual. CBT and other therapies aim to help people understand and possibly change the ways that they understand, interpret and respond to experiences.

Anonymous – personal account

12.3.1 CBT interventions with voices (hallucinations)
Although people occasionally have hallucinations which are visual (seeing things),olfactory (smelling things) and tactile (feeling things),psychological interventions so far have concentrated on voices (auditory hallucinations).Although the phenomenon and its causes are complex,most clinical psychologists agree that some people who hear voices have difficulty distinguishing their own thoughts or inner speech from voices with an external origin[221]. It is known that hallucinations tend to be worst when people are highly aroused[222]. It is also known that people's beliefs and explanations about their voices affect how distressed they become[223].

Part 3: Help and treatment *(cont.)*

These findings suggest that therapy should address problems in identifying where voices are coming from, should reduce stress or arousal, and also address beliefs about the experiences. The personal meaning and relevance of voices in a person's life may be addressed during therapy if the person feels this is relevant.

The use of CBT for voices is relatively new, but comprehensive reviews have concluded that CBT for hallucinations is effective[224,225]. Recent studies suggest that group therapy may also be useful[226]. Therapy can have a significant impact on people's lives by changing factors such as distress, perceived control or beliefs about the voices even if the frequency of the hallucinations does not change.

CBT for voices

Starting therapy with Paul – the clinical psychologist – was terrifying. I sat, avoiding eye contact, even avoiding looking up from the ground. Often I shook and often jumped at any unexpected sound. I was terrified. But it soon became clear that Paul was not interested in my psychiatric label. And it was also clear he was prepared to address the issue of my voices without belittling them or treating them as weird. The first session the voices were shouting and it was hard to concentrate. Paul recognised this and actually asked me what was going on with the voices. I didn't feel at all 'loony'. Paul made me feel that I was of some importance. Paul spoke – I needed him to speak and put me at my ease. Previously I had seen a psychotherapist who waited for me to speak and often would not reply even when I had braved to utter a word.

The collaborative relationship I have with Paul gives me confidence that my ideas, as well as his, are important. I get to say what I want to work on – I have some power in this relationship. Paul gives me feedback and some idea of his reaction and tells me what areas he might like us to cover. He does this whilst giving me a lot of power and I feel that I am in control.

Talking about the 'voices thing' became open and normal. It has not been shied away from. We have discussed: where the voices come from, the effect they have on me, how the voices feed on my present feelings and how I can, hopefully, partially control them.

We have discussed coping strategies, some successful, some not so, and some just plain silly (humming whilst they are speaking: I could only think of Dionne Warwick songs!). One long-term strategy – challenging the voices – has proved to be the hardest but the most successful. As soon as a voice pops into my head I try to test out, with previous evidence, what the voice is saying. The voices often come up and interrupt sessions. We don't just ignore them, we deal with them.

It now seems to me that the voices always feed off negative images I have about myself. I can think about the voices being a by-product of my own self-image.

                                        Val – personal account

12.3.3 Unusual beliefs – Delusions

Unusual beliefs (delusions) share many characteristics with normal beliefs or prejudices. As with all beliefs, they involve a resistance to change and a bias towards evidence that confirms one's initial suspicions[227]. As with voices, there is a healthy debate within clinical psychology over details of different theories. Current theories of unusual (delusional) beliefs emphasise thinking errors such as a tendency to 'jump-to-conclusions', the way that some unusual beliefs may protect self-esteem and the consequences of difficulties in understanding social situations[228].

During therapy, people's unusual beliefs are not challenged directly, but rather the evidence supporting them is examined, and the distress that they cause is targeted. 'Experiments' are also set up in collaboration with the individual to test out the reality of the beliefs and their supporting evidence.

As with hearing voices, psychotic beliefs have a number of different dimensions such as levels of conviction, preoccupation, interference and distress, which can vary relatively independently over the course of therapy[229]. Again, the available evidence clearly demonstrates that CBT approaches are helpful for people with unusual beliefs[230,231].

12.3.4 The effectiveness of CBT

Several published reports of randomised controlled trials (the 'gold-standard' of clinical research) are now available[232,233]. The largest trial to date (SOCRATES – Study Of Cognitive Reality Alignment Therapy in Early Schizophrenia),with 330 people in their first or second episode of psychotic experiences,is reaching its final stages.There are a number of 'treatment manuals' (detailed descriptions of the therapy) currently available[234,235,236].

A 25 per cent reduction in 'symptom severity' measured by standard psychiatric rating scales has been reported as a result of CBT[237], produced mainly by changes in unusual beliefs.It is worth noting that this is similar to the effects of the medication Clozapine[238]. CBT is highly acceptable to patients,with 80 per cent reporting being satisfied. Approximately 50 per cent of the people who were involved in the trials benefited from CBT. They tend to be people who have some flexibility in thinking about their delusions,but benefits do not seem to be related to people's intelligence or severity of problems.

Perhaps most interestingly, two studies have found that people continue to improve even after therapy ends[239,240]. It appears likely that CBT is cost-effective[241] in the long run.

Most of the CBT packages are offered to people who are able to attend out-patients appointments,but who have some distressing experiences.There is also evidence, however, that people who are hospital in-patients with acute and severe problems may benefit from a psychological intervention based on the same principles[242,243].

12.4 Early Intervention

Psychological interventions are frequently designed to reduce distress or disabilities associated with current psychotic experiences.'Early intervention' aims to prevent, cut short or reduce the severity of psychotic problems before they are fully developed. Psychologists involved in early intervention are often as concerned with the establishment of services as they are with conducting one-to-one therapy. Sometimes the emphasis is on people who have never before had psychotic experiences.At other times,the emphasis is on helping people who have had psychotic experiences in the past,learn to recognise early signs of a reoccurrence of the problems.

Early intervention is believed to offer long-term benefits. We know that in general the longer the delay before people with distressing psychotic experiences receive help, the more serious the consequences[244]. It follows that help should be offered swiftly. Many psychologists believe that it is during the early phase of psychotic experiences that crucial psychological and biological changes occur[245].

Early intervention involves identifying the early warning signs of psychotic experiences and offering help early. Specific strategies have been suggested[246]. Community education programmes could emphasise the fact that help is available, focusing on those who are likely to meet people with psychotic experiences (e.g.college counsellors, homeless agencies,police).G.P.s could be trained to recognise psychotic experiences.An appropriate keyworker should be assigned early, to promote service engagement and avoid social isolation. Treatment should be provided at home or in a non-stigmatised setting whenever possible. Finally, it is important to involve relatives (or main carers) in any plans that are made.

Pioneering services such as the Early Psychosis Service in Birmingham[247] in the UK,and the Early Psychosis Prevention and Intervention Centre – EPPIC – in Australia[248] have been influential in the setting up of services in Britain. Detailed scientific evaluation of the effectiveness of these services is currently ongoing.

12.5 Family interventions

As mentioned elsewhere in this report,the impact of caring for a relative with psychotic problems can be quite substantial[249]. While there is no evidence that families are 'the cause of' schizophrenia,nevertheless the stress of caring can affect the quality of the relationship.

Clinical psychologists have been able to develop therapeutic approaches that offer help to carers and are designed to improve these relationships. Family interventions can reduce the frequency of episodes of psychotic experiences and improve people's employment prospects[250,251]. These positive effects are still apparent 8 years after the intervention[252]. Such approaches have also been found to reduce stress in other members of the person's family[253]. A variety of manuals describe the approaches that can be used[254,255,256,257].

Not all people who have psychotic experiences live with their families. Relationships with staff carers are subject to the same factors[258,259]. This work suggests that mental health teams need to train, supervise and support staff carers to reduce the potentially negative effects of unhelpful relationships.

Although family interventions are effective and save money[260], they are uncommon in routine practice, and remain an effective but underused intervention.

12.6 Rehabilitation

The focus of rehabilitation tends to be the social, cognitive, and occupational disabilities that sometimes accompany psychotic experiences. Four types of help have often been provided: social skills training, cognitive remediation, helping people to engage in purposeful activity and providing support in the person's environment.

12.6.1 Skills training

In the past, people who had psychotic experiences sometimes lived in institutions for many years. They often had few opportunities to learn everyday skills. People who experience ongoing confusion can also sometimes benefit form help with learning and remembering social routines such as how to order a meal in a café or present oneself for a job interview. Social skills training (SST) aims to address the interpersonal problems that are sometimes associated with psychotic experiences. It appears to be relatively successful[261], with benefits maintained for long periods[262,263]. However, its benefits do not appear to generalise, and the benefits may not always last[264].

12.6.2 Cognitive remediation

Some people who have psychotic experiences also experience problems with concentration, attention, memory and thought processes. These can affect relationships[265] and treatment outcome[266]. Cognitive remediation attempts to help people improve their performance through practice and rehearsal[267]. The evidence for its effectiveness is mixed[268,269].

There is a well-known relationship between engagement in meaningful occupation and health status, both in the general population[270] and in those with mental health problems[271]. Occupational therapy[272] and specific programmes for vocational rehabilitation[273] may be beneficial. There is evidence that employment may have a greater positive impact than any other single factor[372].

12.6.4 Ongoing support

Some people experience distress or confusion to that the extent that they need ongoing support in order to live the kinds of lives they want to lead. For example, some people may need reminding about things. Others may need practical help such as provision of meals, or emotional support if they experience severe anxiety or frequent low mood.

12.7 Conclusions

Recent years have seen the development of a number of effective psychological interventions for psychotic experiences. However, different services differ markedly in the degree of implementation of each of the approaches described above. Even the most successful therapies, such as family interventions, are not included routinely. Organisational changes will therefore need to be made in future services to accommodate family and psychosocial management approaches for psychotic experiences.

Section 13: Risk and psychotic experiences

Key Points:

- Most people who have psychotic experiences are not dangerous.

- The increase in risk associated with a diagnosis of schizophrenia is minimal.

- The numbers of homicides by people with psychiatric diagnoses have fallen since the introduction of community care and are still falling.

- People who use mental health services are themselves at risk of becoming victims of violence. They are also at risk of self-neglect, suicide, abuse of human rights and the damaging consequences of treatments.

- There is an increase in risk associated with the diagnosis of Antisocial Personality Disorder. This is, however, a different type of problem from those described in this report. The term 'antisocial personality disorder' is used to describe someone whose behaviour is considered antisocial or dangerous and tells us little more than that. Such a description does not indicate that a person has psychotic experiences.

13. Risk and psychotic experiences

The common stereotype of a person with a diagnosis of a psychiatric illness is of an unpredictable homicidal madman. This is despite the fact that the most common psychiatric diagnosis is depression[274] and the vast majority of people with psychotic experiences are not dangerous. Tabloid and broadsheet newspapers alike emphasise homicidal acts by psychiatric patients but fail to report a whole range of other relevant issues of mental health[275].

Politicians, the media and a large number of ordinary members of the public have often only been concerned about the risk *from* people who have psychotic experiences. The issue of dangerousness has led politicians to consider legal measures to enforce medical treatment in the community. However, what is often overlooked is that people with psychotic experiences are at considerable risk themselves. They are, for instance, much more likely than others to be the victims of violence[276].

13.1 Risk of violence to other people

A very few people with diagnoses of mental illnesses commit violent acts, including homicide (murder and manslaughter). It is very slightly more common for people with such diagnoses to commit such violent crimes than it is for those without diagnoses. However, 95 per cent of homicides are not committed by psychiatric patients and most psychiatric patients are not dangerous[277,278,279]. Moreover, specific diagnoses like 'schizophrenia' do not predict dangerousness.

Risk of violence to other people

It's no wonder that a kind of liberation movement has arisen, determined to assert its rights. 'Users' argue that we have moved beyond blaming all Black people for the actions of the odd black criminal, yet we still punish all the mentally ill for the violence of a few. We no longer tolerate headlines about 'yids' or 'niggers' yet 'psycho' is still acceptable… All this has happened while the rest of us have been stuck in the old thinking about nutcases and weirdos. The lunatics have not yet taken over the asylum – but they are raising their voice.[280]

Jonathan Freedland in The Guardian

Some specific psychotic experiences are linked to slightly higher rates of violence. These include 'command hallucinations' and 'delusions with hostile content'. Command hallucinations are voices that tell the individuals to harm others and that the individuals feel they must obey. A delusion with hostile content refers to a fixed and rigid belief about the need to harm others (for example to counter a conspiracy, avenge a misdeed or even carry out a noble mission). Specific psychological characteristics of the experiences themselves are important in the assessment of risk to others, but the person's diagnosis is not relevant.

The widespread belief that people with 'mental illness' are

dangerous may be at least partly a result of selective reporting in the media. A survey by the Health Education Authority found that almost 46 per cent of all press coverage of mental health issues was about crime, harm to others and self-harm. It found that both broadsheets and tabloids made a clear link between mental ill health, criminality and violence, and that stories making this link were generally given more prominence than more positive pieces[281]. Television dramas also often depict people with mental health problems as violent and unpredictable[282,283,284].

Thoughtful media coverage

'What we're concerned about is the backlash against people with mental health problems,' explains Mind's spokesperson Sue Baker, 'that has come as a result of an awful lot of negative media coverage about community care and people with mental health problems – and which has fuelled the myth that they are more violent than others, when that's simply not true.' The truth is, paradoxically, the opposite of public perception. An article in the British Journal of Psychiatry last year demonstrated conclusively, using the Home Office's own statistics, that the proportion of homicides committed by people with a mental disorder (at most, 10 per cent of all homicides in any case) has declined year on year, not only since the advent of community care, but ever since the late Fifties when asylum populations were at their peak. The 'schizophrenic', in particular, has become a kind of modern bogeyman from whom we need to be protected.[285]

Matt Seaton in the London Evening Standard Magazine

13.2 'Dangerous people with severe personality disorders'

Some people who have been given a diagnosis of a 'personality disorder' are more likely to commit serious violent offences, especially if they use alcohol or street drugs[286]. Personality disorder is a category under the current Mental Health Act that is the basis for the detention of 'mentally disordered offenders'. More specific diagnostic labels commonly used include 'antisocial personality disorder' and 'psychopathic disorder'. Neither of these terms are related to psychotic experiences, but

to people who are believed to be abnormally aggressive or anti-social.

This definition is circular. That is, people may receive the diagnosis because their behaviour is considered aggressive or anti-social and then their violent and antisocial behaviour is seen as being a product of the 'disorder'. In this light, it is not surprising that the diagnosis of 'psychopathic disorder' predicts dangerousness.

There has been considerable government concern at this, resulting in draft proposals for the care and treatment of people given such diagnoses[287]. There is considerable debate amongst psychologists and psychiatrists about this issue[288]. But it is worth emphasising that this is a separate issue to those discussed in this report. The vast majority of people who have psychotic experiences, or are diagnosed 'mentally ill' are no more dangerous than anyone else.

13.3 Specific predictors of violence

Diagnoses are not good predictors of violence. The presence of some very specific experiences (command hallucinations and delusions with negative content) is slightly better. The interaction of these experiences with the use of street drugs and or alcohol is also important. Not only do illicit drug use and alcohol abuse predict dangerousness in the general population (for example in relation to public and domestic violence and reckless driving) they are a particular risk factor in conjunction with psychotic experiences.

A recent large scale study in the USA[289] has demonstrated that people recently discharged from psychiatric care pose no general greater threat of violence than any of their neighbours. However, those who abuse drugs or alcohol are more of a risk than people with a drug or alcohol problem who have not received a psychiatric diagnosis.

Variables other than psychotic experiences are much better predictors of violence. These include: alcohol and drug abuse; being male; being young; social exclusion; and past history of violence[290]. If you wanted to predict

whether a person was going to be violent in the future, the most important factor to consider would be whether they had been violent in the past. Whether or not they had a diagnosis of mental illness would be less important than their alcohol or drug use, their age, their gender and their social circumstances and their relationship to the potential victim.

13.4 The risk of people to themselves

13.4.1 Risk of suicide
Although it receives less publicity than homicide, suicide is a much more common for people with a diagnosis of mental illness[291]. Successive governments in recent years have set suicide reduction targets as a measure of improving mental health. The problem of increased risk of suicide for people with psychiatric problems remains a real concern for users themselves and for those working in mental health services[292].

As with violence, factors other than diagnosis are predictors of suicide (e.g. unemployed status, previous self-harm, chronic physical health problems, and the availability of the means of self-harm)[293].

13.4.2 Risk of self-neglect
In addition to the risk of suicide, the confusion or disorganisation that can sometimes accompany psychotic experiences can put people at risk. For example, some people are at times unable to organise themselves sufficiently to maintain an adequate diet. Someone who is confused is also likely to be at risk of exploitation and abuse from other people.

13.5 The risk of service contact
All treatments bring with them the risk of adverse effects. The negative effects of psychiatric drugs are well documented. These problems are often under-recognised and understated by professionals and the general public[294]. Some people also at times become distressed when receiving psychological therapies.

Mental health services have been associated in the past

thirty years with mistreatment, triggering a series of official inquiries into their functioning. The mistreatment has included emotional and physical neglect and abuse[295]. Women on mixed-sex psychiatric wards are very frequently at risk of sexual assault and exploitation[296]. In the USA there have been a number of law suits against therapists relating to the sexual or emotional exploitation of clients[297]. Even when properly conducted, psychological therapies often involve talking about painful issues that can be distressing. It is important that people are adequately informed about what is involved before making a commitment to beginning therapy.

Leaving aside neglect and abuse, long term residence in institutions can sometimes be harmful[298]. Even short-term stays in acute psychiatric units may disrupt people's lives and relationships[299]. What people generally like most about psychiatric inpatient units is leaving them[300]. The recent Sainsbury Centre national audit of such units described hospital care as 'non-therapeutic'[301].

Being admitted to hospital involuntarily is a distressing experience[302]. People are sometimes put under pressure to enter hospital even though they are apparently giving their consent. This means they can experience an admission to hospital that they do not want, but without proper legal protection[303,304].

13.6 Implications for risk management
Risk assessment and risk management should be part of routine care. Risks to others should be assessed and addressed. Similarly, risks to the individual user of the mental health services – from suicide, self-harm, violence and the adverse effects of treatments and services – should also be assessed.

At present there is great local variability, raising the need for national guidelines on risk assessment protocols. Risk management relies on taking an assessment and identifying aspects of the individual's behaviour and lifestyle that can be changed to reduce risk.

There is a false assumption that if people take their medication, they will pose no risk to society or themselves. As we have outlined above, there is large individual variation in response to medication. A more sophisticated approach is badly needed.

Risk of suicide or self-harm needs to be assessed and managed. Disabilities associated with psychotic experiences, negative consequences of medication, as well as the difficult life circumstances of many service users can all increase the risk of self-harm. Risk management should identify and address each of these as they apply to particular individuals. Although 100 per cent accurate risk assessment will never be passible with regard to human behaviour, The British Psychological Society Centre for Outcomes Research and Effectiveness has published guides on risk assessment that may be useful[305,306].

Monitoring of adverse effects of treatments should be continuous. Patients should be informed of possible adverse effects and be involved as partners in decisions about any treatment. Polypharmacy (prescribing many different medications) and prescriptions at dangerously high levels should be eliminated. Mental health workers using psychological interventions should be appropriately trained. Effective mechanisms of professional regulation of incompetent or abusive therapists should exist.

Hospitalisation is sometimes necessary, but should be kept to a minimum. If admitted to hospital, the person's contacts with their community should be maintained and care taken to ensure that their lives are disrupted as little as possible. Particular attention should be paid to ensuring that if at all possible they are able to keep their job, if they have one. Attention should also be paid to personal safety and privacy for patients.

There are arguments for the statutory hospitalisation of people without their consent in particular circumstances. However, it must be recognised that such a course of action is serious and highly distressing. Force or coercion will usually aggravate rather than help mental health problems.

Section 14: Social exclusion

Key Points:

- People with psychiatric diagnoses are arguably one of the most socially excluded groups in society.

- They are subject to prejudice and discrimination.

- They are often financially poor and are discriminated against when applying for jobs even where their past mental health problems are irrelevant.

- Media accounts give a very biased picture and help to maintain public prejudices.

- Much of what is assumed to be the effects of mental illness and used to justify social exclusion is the result of either long term neuroleptic use, the effects of living in an institution all one's life, or both.

- Social support and the ability to work are important for recovery. If these are not available because of social exclusion, a vicious circle is set up.

- The policy of community care has not failed. Most people who used to live in psychiatric hospitals have been successfully resettled and are well supported. It is a myth that people have been discharged unsupported in large numbers to live on the streets. The increase in the homeless population is largely due to other factors, for example unemployment rates.

- There is a growing 'User/Survivor Movement' in which former and current mental health service users are campaigning for better services, for the acceptance of frameworks of understanding other than the 'medical model' and against stigma and discrimination. There is a growing 'Mad Pride' movement.

14.1 Evidence of social exclusion

People with psychotic experiences who receive a psychiatric diagnosis are excluded from many aspects of society that others take for granted. This happens whether they live in hospital or in the community. They are significantly poorer than the rest of the population and less likely to be in paid employment. The public in general is prejudiced against people who are identified as 'mentally ill'[307]. It is not surprising, therefore, that people with a diagnosis of schizophrenia tend to have smaller social networks than those of their neighbours[308,309]. Those who have had repeated hospital admissions have smaller networks than those with only one admission[310]. A study of people attending long-term psychiatric day care found that about one-third did not use any recreational community facilities (e.g. clubs, pubs, libraries and public entertainments). A small but significant percentage did not even use public services (such as shops, public transport and the Post Office) that are essential for independent community living[311].

Social exclusion

Discrimination in employment is standard. There are many with psychiatric records who are forced to rinse their talents down the sink and take jobs far beneath their capabilities. I find it humiliating to have to lie to be in with a chance of work. To be advised to lie, to choose to do so and hereby admit a shame about my past, which is not justified, and which I in no way really feel, has demeaned me more than any other single event of my life outside hospital.[312]

Peter Campbell – personal account

A MIND survey of 778 mental health service users in 1996 found that a third said they had been unfairly dismissed or forced to resign from jobs. Nearly 70 per cent had been put off applying for jobs for fear of unfair treatment. Almost half had been abused or harassed in public, and 14 per cent had been physically attacked. A quarter felt at risk inside their own homes. 26 per cent had been forced to move home because of harassment. 45 per cent thought that discrimination had increased in the last five years, compared with 18 per cent who thought it had decreased.[313]

I love the small town where I lived, and where my son was born, but I was afraid he would get name called as often as I was, so we moved to a larger town ... I have suffered more

because of the ignorance of certain people than I have throughout my actual mental health problems.

On two occasions I lied when I applied for jobs. On both these occasions I said that my two-and-a-half year absence from employment was due to a term spent in prison. I was accepted for the first and shortlisted for the second. Whenever I have been truthful about my psychiatric past, I have never been accepted for a job.

I find I conceal the information about my illness, rather than risk rejection, which means I feel ashamed and miss opportunities to increase other people's knowledge of mental illness – so the stigma and taboos are perpetuated.

Personal accounts

The social exclusion of people diagnosed with severe mental illness is not solely a consequence of difficulties in social functioning. Being identified as someone with a mental illness can also contribute to social exclusion. For example, people undergoing psychiatric treatment as outpatients were disadvantaged in terms of both income and work status relative to individuals with similar experiences and difficulties, but who had not received a psychiatric diagnosis[314]. People are also less likely to be offered jobs if they admit that they have previously been patients in a psychiatric hospital[315].

14.2 Effect of social exclusion on people with psychotic experiences.

There is, of course, a strong moral argument against the social exclusion of those of us with mental health problems. This should be sufficient justification for investing resources in attempting to combat it. In addition, there is evidence that social exclusion makes both psychotic experiences and social functioning worse. Again, some of what is assumed to be a direct result of illness could actually be due to social factors.

Three decades ago, an intensive study of the culture and atmosphere of three psychiatric hospitals[316] concluded, 'a substantial proportion … of the morbidity shown by long-stay psychiatric patients in mental hospitals is a product of

their environment'. Much of what had been understood as symptoms of an illness (particularly things like lack of emotional responsiveness and social isolation) could be explained by lack of activity within the hospital.

Hospital admission rates for 'schizophrenia' increase and outcomes are less favourable during periods of economic slump[317]. Conversely, rehabilitation services and recovery rates improve during times of full employment or labour shortage. Employment is an important contributory factor in recovery from the problems that lead to diagnoses such as schizophrenia. Indeed, there is evidence that getting back to work has a greater positive impact than any other factor[318].

Individuals are profoundly affected by lowered social status and receiving a psychiatric label. Acceptance of a label of mental illness is associated with depressed mood and low self esteem[319,320,321]. In a role-play of an interview, ex-psychiatric patients felt less appreciated, were judged by the interviewer to be more tense, anxious and poorly adjusted, and even performed a task more poorly and found it more difficult, when they were led to believe that the interviewer was aware of their patient status[322]. The pain of social exclusion is clear in service user's own accounts of their experiences.

Social inclusion

I get so depressed because I sometimes feel as though I have no future. I just think I'm going to be a psychiatric patient for the rest of my life, with no social life and not much money … To try to be accepted, that's it. It's as though you've got to try and be accepted by people, to be normal.[323]

Personal account

14.3 Promoting social inclusion by community education

Given the negative attitudes that exist towards mental illness, some hospital closure programmes have included a public education component, in an attempt to improve the social integration of the people being discharged into the community. Researchers have evaluated[324] an educational campaign comprising information (both

written and by video), social events and informal discussions associated with the opening of staffed group houses for people discharged from long-stay hospital. The effect of the programme was to increase contact between staff and residents of the new facility and their neighbours that resulted in a lessening of fearful and rejecting attitudes within the community. Also, as a result of the education programme more ex-patients reported having made contact and friendships with their neighbours.

14.4 Promoting social inclusion by enhancing social roles

We derive our sense of self from the various roles that we take on within society, such as that of parent, son/daughter, neighbour, consumer, employee, driver, etc. All too often, for people diagnosed with mental illness, the social role of 'patient' takes over. Individuals may develop greater self-esteem and greater acceptance by others[325] if they have a more socially acceptable role in addition to that of 'mental patient'. People with mental health problems living in hostels have more opportunities for developing friendships if their neighbours have been offered education about psychosis[326].

The disabilities experienced by people with psychotic experiences can sometimes get in the way of forming and maintaining relationships. For example, experiences such as hearing voices can make concentration difficult and so make it hard to hold a conversation. The fear of rejection, because of the stigma of mental illness, can make it extra hard to go out and meet people. Sometimes befriending schemes in which volunteers link up with an individual who has similar interests but also a mental health problem can provide people with the benefits of having a friend that they might otherwise be deprived of. Support for the befrienders can be provided by voluntary or statutory agencies.

14.5 Work/employment

For many of us, a major source of self-esteem comes from our work role. In addition to providing money, work, or employment, can provide a number of psychological

benefits that are not so readily available from other activities. These include a regular routine, social contact, externally generated goals, opportunities to use skills, and social status[327,328]. However, not all work environments provide these benefits and it seems especially important that people who are already vulnerable as a result of mental health problems should have work opportunities that do not make their difficulties worse or increase their sense of stigma.

Work can bring about clinical improvement, particularly when this work is paid[329]. However, there are a range of different types of work geared towards people with severe mental health problems and currently there is not a lot of information about their effectiveness. Research into the benefits of work for people with severe mental health problems has indicated that self-esteem is related to how important workers feel the general public believe their work to be[330].

Promoting social inclusion by changing the agenda

I suppose what attracts me to some of the Mad Pride initiatives,' says Rachel Perkins, 'and I'm not the going-on-the-streets-demonstrating sort of person – is that I certainly believe we need to challenge the stereotypes people have.' An engaging, energetic woman in her early forties, with a blonde ponytail and large glasses, Dr Perkins works as Clinical Director at the Springfield Hospital in Balham. She is also a manic depressive. 'What concerns me is that the whole agenda around mental health is driven by issues of violence, vulnerability, containment, support – really presenting an incredibly negative picture of the possibilities of life with a mental health problem. My concern is to change that agenda, and look at the contribution that people with mental health problems can and do make to our community.[331]

Matt Seaton in the **London Evening Standard Magazine**

14.6 Leisure

Our use of our leisure time also provides us with the potential for additional valued social roles. Some people with mental health problems may have difficulty in

accessing and using leisure facilities. For example, they may not have enough money, or they may feel unwelcome. In Britain, leisure has not received the same attention from researchers or professionals as it has in the USA and Canada. There the Therapeutic Recreation Movement[332] sees the promotion of leisure attitudes and awareness, social interaction skills, leisure activity skills, self-awareness, knowledge of leisure resources and decision making as essential components of the rehabilitation of people with a wide range of special needs.

14.7 Community Care

Concerns have been expressed about the so-called failure of community care. It is worth bearing in mind that such a major social change, in the context of negative attitudes and fears about mental illness, is unlikely to proceed without some problems.

It is reasonable for the public to be concerned about apparent failures of the system to provide vulnerable people with the support that they require. However, regrettable incidents should be considered in context, and not taken as proof that community care as a whole has failed. There is a popular myth that people have been discharged homeless and unsupported in large numbers to live on the streets. There is no evidence for this. Indeed, the evidence concerning the resettlement of people from long-stay psychiatric hospitals indicates that it has been a tremendous success[333]. The increase in the homeless population is largely due to economic factors, such as unemployment and lack of affordable housing, and is not unique to mental distress.

14.8 The User Movements

There is now a growing service user movement in the UK. This has a number of aims, e.g. self-help; challenge to assumptions about 'mental illness'; advocacy; campaigning for improved services and combating stigma.

The User Movements

The movement of 'users' of mental health services … challenge the entire canon of received wisdom on mental illness. Spend an afternoon with some of their most energetic advocates, and

the prejudices fall away … Start with the scary statistic that someone is killed by a mental patient every fortnight. It sound like confirmation of the psycho-killer myth – but it hardly survives scrutiny. For the roughly two dozen homicides by mental patients are a tiny fraction of the nearly 700 murders in Britain every year. Tabloid tales of 'crazed killers' are statistical flam, designed to tap into a deep and ancient fear of the lunatic mad, bad and dangerous.[334]

Jonathan Freedland in The Guardian

The User Movements

I have a vision:

That the mental health services that exist will focus more on our abilities than our disabilities, think more about our assets than our deficits, think more about helping us to grow, develop, pursue our lives.

That we will evaluate what we do in services in terms of the extent to which we enable people to live ordinary lives.

That having those who have experienced mental health problems working in mental health services will be no more unusual than having doctors and nurses who have received physical health care working in general hospitals and primary care services.[335]

Dr Rachel Perkins

A sense of control over our lives is important for anyone's mental health. For people with mental health problems, having a sense of mastery over one's life appears to be very important for recovery[336]. One of the ways in which people who have psychotic experiences can take more control over their lives is to find a way of counteracting the negative perceptions of psychotic experiences held by the general public and many health professionals. Contrary to widespread lay and professional beliefs, many people who hear voices are not particularly troubled by the experience[337] and have no psychiatric problems. This knowledge has been particularly beneficial to mental health service users and has enabled them to come together in 'hearing voices' groups to discuss their experiences and coping strategies in a non-stigmatising

manner[338]. It is important for professionals, public and people who themselves have psychotic experiences to become more aware of other ways in which such experiences can be viewed in a positive light[339]. Individuals differ in what they see as positive, but often people find a psychosocial framework for understanding their distress to be less stigmatising than a medical one. There is a growing 'Mad Pride' movement, a consciousness-raising initiative that follows the principles of the black, gay and disability rights movements[340].

Mad Pride

Mad Pride – the equivalent of Gay Pride for people who have suffered mental ill-health – has truly arrived. There have been Mad Pride gigs, featuring acts ranging from the veteran-punk Alternative TV to the highly regarded C&W band The Arlenes, there have been Mad Pride marches and Mad Pride demos; there is a Mad Pride website, a forthcoming Mad Pride anthology and there are even plans for a Mad Pride Week later this year. Mad Pride is different because, above all, it wants to change the way in which society views people with mental health problems. Knife-wielding loners who jump into lions' dens, 'danger patients' set loose on society like 'bombs waiting to explode', 'lepers' who cannot live safely and sanely among the rest of us, these are the headlines that are driving Mad Pride activists mad. So, using a classic civil rights tactic to combat these misleading stereotypes, Mad Pride takes the label with a negative value ('mad') and reappropriates it. 'Glad to be Mad' is its slogan.[341]

Matt Seaton in the London Evening Standard Magazine

People who rely on services for support in their lives are often placed in a dependent position and thereby deprived of the sense of gratification that can be obtained through helping others. However, the experience of mental health problems and being a mental health service user is a source of expertise in itself, that can be used to great benefit. Section 15 gives some examples. The user movement is now an established part of the culture of mental health services in Britain, with a number of organisations campaigning to improve services[342,343]. However, the service user voice can still be dismissed if it does not agree with those in powerful positions[344,345]. Those who use mental health services because of psychotic experiences are at risk of having their opinions marginalised. Extra effort is needed to ensure that their opinions are heard and acted upon.

The problem with services as they stand at the moment is that, in trying to help people, we often make their situation worse. Traditionally, services remove people's choices and sense of control and give them a social identity that is not valued by themselves or others.

A more recent development is the role of service users in the provision of services. Again, Section 15 gives some examples. Mental health services that are provided by people who themselves have experience of mental health problems can be more relevant and more acceptable to the recipients, and instil greater hope of recovery. Benefits to the providers themselves may be improved self-esteem and the development of skills that may open up further employment opportunities. Such services can also help other (non mental health service user) staff to overcome some of their own difficulties concerning the stigma of mental illness[346].

Section 15: Implications of this report for mental health services

Key Points:

- A 'one size fits all' approach that sees all psychotic experiences as arising from one cause, and the only answer as lying in one particular type of treatment, cannot be justified from the evidence. Services, therefore, need to adopt an individual and holistic approach.

- The nature and causes of mental health problems are complex and incompletely understood. Services must therefore respect each individual's understanding of their own experiences. Service users should be acknowledged as experts on their own experiences.

- Staff attitudes are particularly important. The effectiveness of any treatment depends on a good, trusting and collaborative relationship between the service user and the clinician.

- The use of coercive powers (for instance detention under 'Section' and forcible treatment) can undermine collaboration between service users and clinicians. Such powers should not be further extended.

- Services should be based on the recognition that recovery is possible and that recovery means different things to different people. Psychological therapies should be readily accessible to people who have psychotic experiences. Help with housing, income, work and maintaining social roles can often be as important as 'treatment' or 'therapy'.

- People who have personal experience of mental health problems become experts as a result of their experience. Their help can be particularly valuable in supporting others, in helping to improve existing services and develop new ones and in training staff.

- Training is needed nationally to educate all mental health staff about the information contained in this report. It should also be part of the basic training of all the mental health professions.

- A large-scale campaign of public education is needed to break the vicious cycle of social exclusion and mental health problems. Prejudice and discrimination against people with mental health problems should become as unacceptable as racism or sexism.

15.1 Putting these findings into practice: the need for a whole-person approach in UK mental health services

This report describes recent scientific advances in understanding psychotic experiences. It is unfortunate that this knowledge has not yet been widely used to improve mental health services in the UK. Much needs to be done[347]. However, there are some good examples of services based on these principles in the UK and in other countries, notably Australia[348], as well as the Netherlands, Scandinavian countries, Germany and the United States.

The final section of this report outlines what a service based on these principles might look like, and suggests the direction in which current mental health services should develop. The emphasis of this section is on values, principles and 'frameworks of understanding'. As this report has demonstrated, these are as important as the specific treatments or types of help which services provide.

15.2 A whole-person approach to assessment

As this report has demonstrated, a 'one size fits all' approach that sees all psychotic experiences as arising from one cause, and the only answer as lying in one particular type of treatment, cannot be justified from the evidence. This has important implications for the process of assessment.

15.2.1 Multiple causes

As we have shown, each person's difficulties are likely to have arisen from, and be maintained by, a unique combination of factors, all of which interact with each other. Cultural factors (e.g. religious beliefs), biological factors (e.g. genetics, brain chemistry, and drug use),

environmental factors (such as stress or trauma) and psychological factors (such as a tendency to interpret events in a certain way) will all be involved. As with many other human experiences – such as happiness, for example – a psychotic experience such as hearing voices is likely to be the final result of a combination of these factors, which is different for each individual. We can never know with 100 per cent certainty exactly what combination of factors has contributed to a particular psychotic experience, or their relative importance.

15.2.2 Respect for people's own frameworks of understanding

One important implication is that professionals and other mental health workers should not insist that all service users accept any one particular framework of understanding. This means, for example, that professionals should not insist that people agree with their view that experiences such as such as hearing voices and holding unusual beliefs are always symptoms of an 'underlying illness' such as schizophrenia. Some people will find this a useful way of thinking about their difficulties and others will not.

Respect for people's own frameworks of understanding

1. Use of a 'non-illness' model
Loss of control, whether truly lost or merely removed by others, and the attempt to re-establish that control have been central elements in my life since the age of 18. My argument is that the psychiatric system, as currently established, does too little to help people retain control of their lives through periods of emotional distress, and does far too much to frustrate their subsequent efforts to regain self-control. To live 18 years with a diagnosed illness is not incentive for a positive self-image. Illness is a one-way street, especially when the experts toss the concept of cure out of the window and congratulate themselves on candour. The idea of illness, of illness that can never go away, is not a dynamic, liberating force. Illness creates victims. While we harbour thoughts of emotional distress as some kind of deadly plague, it is not unrealistic to expect that many so-called victims will lead limited, powerless and unfulfilling lives.[349]

Peter Campbell

2. Use of an 'illness' model
It is impossible for any sane person even to begin to imagine how I felt. It is also obvious to anyone with a shred of common sense that I was ill. Any characterisation of my behaviour as merely 'bizarre', that such an 'illness' attribution would then be an act of social control (to empower the medical profession) is clearly utterly absurd. My only source of consolation came from … one must never despair of the love of God.[350]

Dr Peter Chadwick

Professionals and other workers should respect and work collaboratively with the service user's frame of reference – whether he or she sees the experience primarily as a medical, psychological or perhaps even spiritual phenomenon. Often, of course, people are unsure, or even actively searching for a way of understanding and coping with their experiences. These people may find the research described in this report helpful.

15.2.3 The importance of taking the person's cultural context into account

There is a huge diversity in what is considered an appropriate expression of distress in different cultures. If professionals are not sufficiently familiar with a person's culture, there is a risk that such expressions might be mistaken for psychotic experiences. This is also a danger with religious and spiritual beliefs and beliefs about spirit possession. There is evidence that such misunderstandings are common[351]. Part of the reason for this is that few mental health workers currently receive much training in cultural sensitivity, and there is an urgent need for such training. Mainstream services should also make links with local voluntary sector groups that have more expertise in this area. It is also well documented that the effects of racism are likely to increase vulnerability to developing psychotic experiences[352].

The importance of taking cultural factors into account
I don't think they treat black people the same as they treat white people … We have a different culture from white people, and because we talk loud and we laugh out loud – our behaviour is more loud than white people – they think it is mental illness.[353]

As noted in Section 8, people of African Caribbean origin are more likely to receive a diagnosis of schizophrenia than are white people. They are also more likely to be detained compulsorily or to be admitted to hospital via police custody[354]. There is also a tendency for prescription of higher doses of neuroleptic medication to black people[355]. Some researchers have linked this more 'heavy-handed' approach to negative stereotypes of black people as more likely to be dangerous or violent[356]. Mental Health Services have a poor record of engaging black and ethnic minority people in long term care[357]. Some research into Asian people's experience of services has revealed despair in relation to services, particularly by those unable to communicate in English. There is therefore a need for services to address the cultural needs of clients. This should include anti-discriminatory practice training for all mental health workers[358].

15.2.4 Arriving at a joint understanding

One obvious implication of this report is that services need to offer a broader assessment process, one which enables the professional and the service user together to explore all the different factors that may be playing a role. An important part of this will be for the worker to ask about what the experiences mean to the person and how he or she understands them. It is vital that this process should take into account cultural differences, and should extend beyond those factors usually considered by health services to look at the person's possible needs in the areas of housing, employment, leisure, finances and friendships.

It is only when they have looked at all the possible contributing factors in turn that the client and professional can arrive at the most accurate and helpful understanding of the person's experiences. What they are likely to identify is some sort of vicious circle that is maintaining the situation in its present state. This emerging understanding will suggest what is most likely to help. For example, the most important thing to do might be to make changes in the person's environment. If the person is living in a stressful environment, the most important 'treatment' might be to help them find somewhere less

stressful to live. On the other hand, it may be that the person can usefully make changes in the way he or she responds to the environment, for example by identifying a tendency to interpret situations in particular ways and attempting to change this. Alternatively, if medication is helpful, the first thing to do might be to try to find the most helpful drug and dose. Each change that a person makes will also provide more information about what is and what is not helpful. This systematic approach is rather like an experiment: a picture of what is going on can gradually be built up, adding or removing links over time.

15.2.5 Changing the culture of mental health services

Traditionally, mental health services have been based on a view of psychotic experiences which sees them primarily as symptoms of an illness to be treated by medication. The idea that this is not the only approach, and that such experiences can be understood in the same way as other human beliefs and experiences, has wide-ranging implications. A fundamental change is needed in the culture of mental health services. The widespread dissemination and use of the information contained in this report will be an important first step.

15.3 A whole-person approach to helping

15.3.1 Not everyone needs or wants help

Perhaps the first thing that the professional needs to ask about is whether the person is distressed by his or her experiences. If the person is not – for example, if he or she has an apparently strange or unwarranted belief but is content with it, or hears voices but is not distressed by them – there is usually no need for services to intervene at all. If the person's friends or relatives disagree, then it may be worthwhile focusing efforts to help around that network rather than the one person. Sometimes the best thing mental health services can do for someone is to help them negotiate the changes needed to live the sort of life they want (holding down a job, for example) rather than attempting to remove their psychotic experiences or unusual beliefs.

15.3.2 Provision of multiple forms of help

Naturally a whole-person framework of understanding implies that mental health services should adopt a whole-person approach in the types of help that they offer people, paying attention to all the aspects of someone's life that may be playing a role. This whole-person approach should be the cornerstone of services. Mental health services have traditionally concentrated on the biological aspects of psychotic experiences, seeing them as part of an illness and concentrating efforts to help on trying to alter levels of brain chemicals using medication. However, it is now clear that services need to be much broader, and should provide help in a number of different ways, depending on what seems to be most important for each individual rather than on the basis of the diagnostic category to which he or she has been allocated. Different things may also be more or less important for the same person at different times.

15.3.3 The central importance of good, collaborative relationships between staff and service users

One of the most important implications of this report is that mental health workers should see themselves as collaborators with service users rather than as experts whose job is to know all the answers.

Any treatment (including drug treatment) is unlikely to be very helpful in the long term unless the clinician and the service user have a good, trusting and collaborative relationship[359]. This trusting, collaborative relationship is therefore a necessary prerequisite of, and arguably as important as any specific treatment. Although the importance of effective relationships between staff and users is intuitively obvious, services often do not operate as if this were the case.

Relationships between workers and service users:

I needed someone who would just be there – solid, non-judging, not trying to force me to do this or that, just being with me and helping me to make sense of some very frightening, but also very beautiful and visionary experiences. My essential

need was to be grounded, connected to life and the world, not excluded and punished.[360]

Personal account

It is important for both workers and service users to bear in mind the power differential between them. Professional staff always have power over users and it is important to acknowledge this. Good practice is about recognising this power (and also the contradictory roles of care and control played by mental health services – see below) and avoiding its abuse by making the relationship as collaborative as possible.

Working with people who have psychotic experiences can be stressful. Workers themselves need regular supervision and emotional support in order to maintain an open and collaborative approach towards service users.

15.4 Information and choice

As there is no way of knowing from the outset exactly which treatments will help a particular individual, people may need time and a certain degree of 'trial and error' to work out what is most helpful. It is, therefore, important that people are offered information and choice about treatments, and that professionals acknowledge the limitations in what they know. Information and choice are also important in their own right, both because it is unethical to give treatment without 'informed consent' and also because research has demonstrated that treatments which accord with people's preferences are generally more effective[361]. Information and choice are also fundamental principles endorsed by the government's Patient's Charter[362].

The patients' charter

You have a right to be given detailed information about:

Choice and explanation
You have the right to have any proposed treatment explained, including any risk involved in that treatment and any alternatives before you decide whether to agree with it. You can expect to be able to ask for an explanation of your diagnosis in plain language, and to ask for more

information if you do not understand the explanation.

To be told about any drugs you are prescribed including possible side effects

To be told what treatments are available other than medication.[363]

15.4.1 Information and Choice: antipsychotic medication

As outlined in Section 11, for many people antipsychotic drugs can help to make unpleasant experiences such as hearing voices less intense and frequent. However, they do not help everyone, and those people who do find them helpful will often have to try more than one (in collaboration with their prescribing doctor) before they find the drug and dose which suits them best.

Information and Choice: antipsychotic medication

In the central nervous system, where there is a multiplicity of receptors for each drug to act on, and where all of us have different proportions of each of these, the likelihood of a uniform response to any one drug is rather low. A diversity of responses, rather than uniformity, should be expected.[364]

Professor David Healy

All drugs (and other treatments) have the potential to do harm as well as good. In helping someone to arrive at the medication strategy that works best for them, it is important that professionals give them as much information as possible about the drugs that are available and their likely effects, including unwanted effects (sometimes called side effects).

People should have access to independent and impartial sources of information about drugs, for example local pharmacy departments and the National Psychiatric Drug Information Line based at the Maudsley Hospital in London (0207 919 2999). All mental health workers should be aware of such resources and inform their clients about them. This is particularly important in view of the large sums which drug companies spend on advertising their products and in view of the fact that many people are prescribed doses above recommended limits (see Section 11).

Professionals involved in prescribing and administering medication should explore with clients the pros and cons of medication, and help them to explore whether medication is helpful, and if so which drug, and which dose suits them best. They should also help people to work out the medication strategy that is right for them, for example whether they should take medication regularly or only at certain times. As shown in Section 11, this will be different for different people. Some people find it helpful to take medication regularly. Others may only need medication at times of crisis. Others may use it intermittently, i.e. when they recognise certain signs that indicate to them that an increase in the frequency or intensity of psychotic experiences is likely (a relapse, in medical language). This is the principle behind the early intervention approach described in Section 12. Finally, it is important for professionals to recognise that a decision not to take medication is not necessarily irrational or illness-related, and may be in the best interests of the person.

Information and Choice: antipsychotic medication
A negative experience of medication

It was very difficult as an 18-year-old man to do all the necessary learning about social skills and emotions, to develop a sense of identity, and to think about a career and what I wanted out of life, whilst on medium to high levels of neuroleptics. I was at art college, trying to not let hand tremors affect my painting, always feeling half a second out of time with the other students. People told me that when I came off medication, I seemed much more in touch with myself. I was suddenly able to express more complex thought processes again. There is a need to support people if they choose to move beyond maintenance medication as part of their recovery. I believe that I came very close to developing a long-term sick role as a schizophrenic. To escape this prophecy felt like wading through miles and miles of swamp and this was very lonely journey. I had no guides and no stories of success.

Dr Rufus May – personal account

A positive experience of medication

It was helpful for me to regard myself as having had an illness. This made me respectful of the need to maintain and titrate medication.I was eventually able to get perfectly well on a low dose of haloperidol,and I have stayed on that dosage ever since 1981.I have had no relapses worthy of the term,and the medication has helped me to make more, not less, use of my psychological insight and thus genuinely to gain ground.I have deliberately taken only very few 'drug holidays'. […] It has none the less to be said that for this ... to be maintained over years, spiritual, psychosocial and cognitive-behavioural methods were required – otherwise medication dosage would have needed to have been extremely high.[365]

Dr Peter Chadwick – personal account

In the past,medication has sometimes been the only treatment on offer for people with psychotic experiences. However, other forms of help have also been shown to be effective, and should be made available within every service. It is vital that service users should be given information and choice about all the available treatments. Different individuals will find different combinations helpful.

15.4.2 Information and Choice: talking treatments

Users of mental health services are often very keen to have access to talking treatments such as cognitive therapy. Demands for such treatments far outstrip supply in the NHS[366] (another relevant reference is the NHSE Psychotherapy Review[215]).The content of any talking treatment should be tailored to the individual. For example, some people might find it helpful to try and identify what has caused their problems,whilst others might prefer to focus on how to make positive practical changes in their life[367].

As shown in Section 12 of this report,there is now good evidence from large-scale trials that talking treatments can be very helpful. However, despite their effectiveness and their popularity they are not yet widely available on the NHS for people who have psychotic experiences, especially for those who have been given a diagnosis of

schizophrenia.There is a powerful argument that they should be more widely available. **Psychological help should be available to every service user who wants it,either individually or in a group depending on their preference.** This is one of the most important messages of this report.

There are a number of different 'brand name' therapies, some of which are described in Section 12 of this report. However, the basis of all of them (and,some would argue, the most important 'active ingredient') is the establishment of a good,trusting and collaborative relationship between client and worker so that the person is able to talk and think about their experiences in a calm, supportive and non-judgmental atmosphere. This can,of course also happen outside of a formal 'talking treatment', for example between a client and his or her key worker in the context of a community mental health team. Both client and worker also need access to the information contained in this report in order to make an informed judgement about what is likely to be maintaining the problem and what is likely to help. **All mental health workers should be able to use psychological frameworks of understanding in their work with service users.**

Collaborative Alliance?

Clearly, any individual faced with living with serious mental health problems has some very hard thinking to do,some difficult decisions to make and perhaps some risky experiments to try.Anyone in such a situation might value an ally who could help them to work through the issues involved and come to decisions that are right for them. Having decided on a course of action,the person may well then require … assistance that will enable them to carry through their chosen course and help them to review their decisions from time to time in the light of events. But that is not compliance, rather collaborative alliance.[368]

Dr Rachel Perkins and Julie Pepper

The importance of being able to talk about psychotic experiences

Only once in 15 years of psychiatric intervention, and at the age of 36, was I able to find someone who was willing to listen.This

proved a turning point for me, and from this I was able to break out of being a victim and start owning my experience. The nurse actually found time to listen to my experiences and feelings. She always made me feel welcome, and would make arrangements so that we would not be disturbed. She would switch off her bleeper and take her phone off the hook, and sometimes, as there were people outside her room, she would close the blinds. These actions made me feel at ease. She would sit to one side of me instead of across a desk…Slowly, as trust grew between us I was able to tell her about the abuse, but also about the voices … At last I had found someone who recognised the pain I was feeling. She helped me realise that my voices were part of me, and had a purpose and validity. Over a six-month period, I was able to develop a basic strategy for coping. The most important thing that she did was that she was honest – honest in her motivations and in her responses to what I told her … Thanks to the support this worker gave, I have been able to develop a range of coping mechanisms.[369]

Personal account

15.4.3. Information and Choice: practical help

Many people find either medication, talking treatments or both helpful. However, this is not the case for everyone and even for those who do, help with things like housing, income, work and maintaining social roles can often be equally important in their recovery. Services should be flexible enough to offer each individual what he or she finds most helpful, and as outlined in Section 15.3.2, sometimes this will be practical help (for example with accommodation or employment) rather than 'treatment' or 'therapy'.

Work and/or education are often particularly important. People who are under-occupied are much more likely than others to experience an increase in the intensity or frequency of their psychotic experiences[370] and work can bring about clinical improvement, particularly when this work is paid[371]. Indeed, there is evidence that getting back to work has a greater positive impact than any other single factor[372]. Helping people to find meaningful employment (or places on educational or training courses), and supporting them whilst they are in it, should therefore be a core task for mental health workers[373,374].

Importance of employment

Starting employment doing work that was not too demanding, was an important way for me to recover starting off with part time work a month or so after my third and final admission. The job was working in Highgate cemetery as a night security guard. I did once fall asleep on a late shift but my boss took an understanding approach and I held it down for the full nine months. I had a range of jobs followed by four months doing voluntary care work with adults with learning disabilities. Being trusted to carry out responsible and challenging work that I was valued for, was a real breakthrough and gave me the confidence to apply for paid work and make long term plans to train as a clinical psychologist.

Dr Rufus May – personal account

15.4.4 Information and choice: complementary therapies

A recent report from the Mental Health Foundation[375] has highlighted the high level of demand from service users for access to complementary therapies such as massage. Many of these therapies are effective in reducing the high levels of stress and arousal, which, as shown in Section 6 can often play a role in psychotic experiences, and they can be very helpful. There is a good argument that they should be more widely available.

15.4.5. Information and choice: self-help

Many people find self-help groups very useful. Professionals and other workers should give their clients information about such groups. Examples include the Depression Alliance, (http://www.depressionalliance.org, tel. 020 733 0557) and the Manic Depression Fellowship (tel. 020 7793 2615), which runs a popular self-management scheme. This scheme helps people learn to recognise early signs of depression or 'mania' and take active steps to manage the situation. People who are experienced at this then help train others. Similarly, material written by, or drawing on the experience of other people who have experienced similar problems can be very helpful (e.g. Baker, P. (1995) *The Voice Inside: A Practical Guide to Coping with Hearing Voices.* Manchester: Handsell Publications/Hearing Voices Network; Coleman, R. & Smith, M. (1997) *Working with Voices! Victim to Victor.* Runcorn: Handsell Publications; and

Chadwick,P (1995) *Understanding Paranoia:What Causes it, How it Feels and What to do About it.* London: Thorsons[376,377,378]).There are also a growing number of services run by and for service users and ex-users[379].

15.4.6. Information and choice: crisis services

Many people need help only occasionally. Some only experience psychosis at times of increased stress. For others there are times when ongoing psychotic experiences that they are usually able to cope with become more intense, frequent or distressing than usual. Sometimes people's friends or relatives may become worried about them and suggest that they need help.At these times, workers need to bear in mind that those making this suggestion may have coped with their friend or relative for some time, and try to understand why help is being sought now. What do the friends/relatives and the potential service-user actually want from professionals? Is it possible to negotiate a contract of work with commonly agreed goals? There is a need for more creative responses to such situations,which build on what service users themselves say is helpful.In the past, often the only help available at such times has been admission to an acute psychiatric ward, and the only treatment has been medication. Sometimes the person has had little opportunity to talk about the reason for their admission and has been left feeling powerless and confused.A recent report by the Sainsbury Centre for Mental Health found that 'hospital care is a non therapeutic environment' and recommended an overhaul of the care and amenities on acute wards[380]. Talking treatments should be available in hospital, and the importance of 'ordinary human interaction' between staff and patients cannot be overemphasised[381]. It has been suggested that part of the reason for the current low levels of staff-patient interaction is that the concept of 'care' has been devalued in favour of 'treatment'[382]. The increasing administrative burden on staff in psychiatric wards can also make it difficult for them to find time to talk to patients.Many nurses find this frustrating and demoralising,and since patients often find interaction with nurses the most helpful aspect of their stay in hospital, it also represents a considerable waste of resources[383]. Hospital as well as

community staff need to have access to the information contained in this report if psychiatric wards are to become more therapeutic environments.

A range of alternatives to acute psychiatric hospital admission have recently been developed.Such alternatives, which include non-hospital crisis houses as well as home treatment services,should be universally available.A number have been awarded 'NHS Beacon' status, for example the Bradford Home Treatment Team[384] (26 Edmund Street, Bradford BD5 0BJ, tel 01274 414007) and the women's crisis house run by Camden and Islington Community NHS Trust (32 Drayton Park, London N5 1PB, tel. 0207 607 2777).There are also examples of crisis services run by service users and ex-users, for example the Wokingham Crisis House[385].

Workers should help every service user who wants it to draw up an 'advance directive' stating what he or she wants to happen should a crisis occur in which he or she is considered temporarily unable to exercise proper judgement.'Crisis Cards' which summarise these wishes should also be available to all users of mental health services.All service users should also have access to independent advocacy[386].

15.4.7 Information and Choice: Making rights and expectations explicit

All treatments have the potential to do harm as well as good and so workers need safeguard the principle of informed consent.Service users should have access to the same information that is available to workers (research reports, for example), and should have the right to refuse treatments, including medication, ECT and psychological interventions.

The British Psychological Society's Division of Clinical Psychology recommends that each service should publish an explicit statement of what users can expect.One possible example would be the following. Not everything on this list would be possible in every service, especially in settings such as wards where some service users are being detained against their will,and it would need to be adapted for local circumstances[387].

- As a client you have the right to:

- Receive respectful treatment;

- Refuse treatment or a particular intervention strategy;

- Ask questions at any time;

- Know your worker's availability and waiting period;

- Have full information about your worker's qualifications including registration, training and experience;

- Have full information about your worker's areas of specialisation and limitations;

- Have full information about your worker's therapeutic orientation and any technique that is routinely used;

- Have full information about your diagnosis, if used;

- Consult as many workers as you choose until you find one you are happy with;

- Experience a safe setting free from physical, sexual or emotional abuse;

- Agree to a written contract of treatment/care;

- Talk about your treatment with anyone you choose, including another worker;

- Choose your own lifestyle and have that choice respected by your worker/s;

- Ask questions about your workers' values, background and attitudes that are relevant to therapy and to be given respectful answers;

- Request that your worker/s evaluate the progress of therapy/treatment;

- Have full information about the limits of confidentiality;

- Have full information about the extent of written or taped records of your therapy/treatment and your right of access;

- Terminate therapy/treatment at any time;

- Disclose only that personal information that you choose;

- Require a written report on therapy/treatment;

- Have access to any written summaries about your therapy/treatment.

15.4.8 Information and choice: The issue of coercion and mental health legislation

The issue of information and choice is particularly important because of the legal context within which mental health services operate. In the past, mental health services have often adopted a paternalistic approach, and in the context of limited resources extensive use has been made of the powers of coercion available under mental health legislation. This has led to a situation where many people have experienced mental health services as coercive and restrictive, and has often been a barrier to the establishment of the trusting, collaborative working relationships which are the cornerstone of an effective service.

Coercion

In the context of my own experiences of psychosis I am ever ready to support consideration of alternative models of care where there is less emphasis on coercive treatment. I still wake up from nightmares that I have been readmitted and highly medicated against my will. In my community work I recognise the same fear in clients who are desperate to not be misunderstood or judged hospitalisable. This fear of losing one's freedom is a massive obstacle to collaborative mental health care. Where possible therefore I believe it is important to not see sectioning and locked wards as given and fundamentally necessary.

Dr Rufus May – personal account

A psychological approach to psychotic experiences such as that described in this report necessitates a willingness to discuss psychotic experiences openly and frankly. It is unfortunate that historically this has often led to unpleasant consequences for people such as involuntary hospitalisation and forced medication. Any extension of powers of compulsion would be likely to continue this trend and thereby make it even harder for services to engage collaboratively and openly with people who have psychotic experiences.

Many psychologists feel that the very existence of separate legislation that only applies to people deemed 'mentally ill' is discriminatory, especially given the difficulties in defining 'mental illness' referred to above. An alternative would be more general legislation based on someone's ability to make decisions ('capacity') rather than on whether he or she has a psychiatric diagnosis[388].

15.5 Risk Assessment

At the time of publication of this report, the government is considering proposals for the extension of compulsory powers. These proposals have been largely driven by a perception that such powers would reduce risk to service users and to the public. However, the information contained in this report suggests that such powers would be likely to have the opposite effect and, if anything, to increase risk. Firstly, many people who currently use services would be likely to start actively avoiding them even when they really need help and are most at risk[389]. Secondly, ongoing conflict between staff and service users is likely substantially to reduce the effectiveness of any treatment offered, including medication[390]. Thirdly, a collaborative relationship between service user and worker, which is a prerequisite of good risk assessment, depends on the client being honest about how he or she feels and what he or she is experiencing.

Whilst risk assessment is a necessary part of Community Mental Health Team work, public debate should also be encouraged with regard to the dominant media and government rhetoric concerning risk to users and the general public. While there is never room for

complacency on this topic, the limitations of techniques for risk assessment also need to be acknowledged[391]. It has been suggested that 'risk factors are somewhat like weather prediction: better at providing an overall picture than a guarantee that we can be sure of what will happen in any specific situation'[392]. In light of this 'perhaps our most appropriate approach should be to refine and evaluate our basic clinical skills. Suicide rates might well then look after themselves'[393].

The central importance of the working relationship between professional and service user should be emphasised, both with respect to overall outcome and specifically with regard to risk assessment. The Confidential Inquiry into Homicides and Suicides by Mentally Ill People[394] found that: 'Although it was evident that regular contact had been made with most patients prior to the death, we were concerned that the time for one-to-one contact, where skills in developing a therapeutic relationship and opportunity for listening to the patient might be used were very limited … Audit programmes should address the extent and quality of direct staff:patient contact'.

It is true that some people value services taking control when they encounter a mental health crisis. However current legal powers are enough to ensure that this takes place appropriately and the use of advance directives and crisis cards allow people to state what they would like to happen when they temporarily lose their ability to effectively exercise judgement.

For all these reasons The British Psychological Society is opposed to the extension of powers of coercion[395]. We would also recommend a system of checks and balances for clinical decision making in the areas of legitimate scientific debate outlined in this report, for example about risk assessment, the diagnosis of schizophrenia and the effects of antipsychotic medication when taken for many years.

15.6 Getting from A to B: Improving Services

15.6.1 Learning from users and ex users of services

It is only by listening to what service users and ex-users have to say about services and treatments that professionals can learn what really is helpful to people. Mechanisms should be in place for service users to be involved at all levels, including planning the service as a whole, providing feedback to individual teams and planning their own care. Service users and ex-users are 'experts by experience', and a number of services now not only involve service users in decision making at a high level, but also employ service users and ex service users as members of clinical teams.

15.6.2 Employing 'Experts by experience' as workers

One example of such a service is the South West London and St George's Mental Health Trust, which aims to have at least a quarter of posts, including nursing posts, filled by people with experience of using mental health services. This award-winning service has also resulted in considerable net savings to public funds because of savings in benefit payments, reduced treatment costs and the like[396,397]. Another example is the Bradford Home Treatment Team[398]. Case management services are also increasingly employing current or ex-service users in case management roles[399,400,401] and randomised trials find them to be as effective as case managers as are non-service users[402].

A positive experience

[In hospital] ... I was listened to seriously and attentively; my requests ...were all complied with quickly and treated with respect. Doctors did not look straight over or through me, they treated me like a substantial human being and were very sympathetic, especially concerning the terrible feelings of humiliation I had about my delusions. Nurses did not generally adopt a controlling, domineering attitude but were usually sensitive, responsive and human. Even ward domestics played a significant role in my recovery.[403]

Dr Peter Chadwick

15.6.3 Service users as trainers

Service users, ex-users and relatives should also be involved in providing training for mental health workers. Clear standards should be set and audited in this regard both for professional training courses and for in-service training for mental health teams (such as ward or Community Mental Health Team 'awaydays')[404,405,406,407,408,409].

15.7 Improving services: Making services more recovery-oriented

One important aspect of what service users and ex-users can contribute is stories of hope and recovery. As discussed in Section 3 of this report, many mental health workers only come into contact with people who continue to need their help (or for those who need help only occasionally, at those times that they need it) and so fall into the trap known as the 'clinician's illusion'. They assume that recovery is rare and that most service users are likely to continue to use services for the rest of their lives. Likewise, although there are thousands of former service users who either no longer have psychotic experiences, or have found effective ways to cope with them and no longer, or only occasionally, need help from services, current service users rarely have the opportunity to meet them. Because of this both staff and service users are in danger of developing over-pessimistic views about the future. Rufus May (see quotation) has described this phenomenon as a form of 'learned hopelessness'. One way of overcoming it is for people who have recovered to be involved both in working directly with service users and in staff training, in order to give both staff and service users access to stories of hope and recovery. Services should be based on the recognition that everyone can recover and that recovery means different things to different people. Some people, for example, will continue to need help from services but can still find ways of leading fulfilling lives and achieving their ambitions.

Stories of hope and recovery

Mental health workers tend to get a very negative view of people with psychosis as they usually only see people when they are most disturbed. They don't see the ones like me who

got away. Therefore they have very little concept of recovery from mental health problems or the positive aspects of madness. Psychiatry and psychology have to ask themselves why despite the millions of pounds spent on researching psychosis, we have neglected to look at those who manage to rebuild their lives and live with their difficulties, who have positive outcomes. This neglect has the consequence of perpetuating a learned hopelessness amongst both workers and patients.

Although I am very critical of the medical treatment I received, from a positive perspective I can see psychiatric hospital as acting for my family and me as a safety net. My main complaint was the lack of 'springiness' in the net to allow me to get back on the tightrope. I suppose you could say that I've gone back into mental health services as a clinical psychologist to encourage 'springiness'.

Dr Rufus May – personal account

15.7.1 Improving services: Research and Development

Research and evaluation should be a core activity of any service to ensure continued quality and effectiveness of the service.

However, it is important that quality assurance processes are based on those aspects of change that are most valued by service users, such as improved quality of life, rather than on criteria chosen by professionals[410]. There are now well-established approaches to service evaluation, such as User Focused Monitoring[411] which employ service users to talk to other users about their experience of services using specific protocols. The Mental Health Foundation, which has recently published a *Guide to Survivor Research*[412], has stated that 'It is through user-led research that a clearer picture will emerge of what exactly constitutes good practice in mental health care'[413].

There are also a number of problems with the exclusive use of randomised controlled trials as the basis for 'evidence based practice'[414]. Such methods provide useful information about doing the same thing (e.g. giving medication) to groups (e.g. people with a diagnosis of

'schizophrenia'). They are particularly suited to testing interventions which fit this 'black box' model, in which the thing given is always the same, and in which groups of people with a diagnosis of 'schizophrenia' are treated as being in all relevant respects identical. This type of research involves ignoring individual variation. Studies therefore actively discount the experience of service users, are based on diagnostic groups which are of questionable validity, and when used to investigate talking therapies often involve testing a poor analogue of what will be possible in routine mental health services. This type of research therefore exaggerates the effectiveness of medication compared with other types of therapy or help.

Clinical governance (defined as: 'the means by which organisations ensure the provision of quality clinical care by making individuals accountable for setting, maintaining and monitoring performance standards'[415]) may help improve mental health service provision in the UK. However, its implementation will require an acknowledgement of the importance of organisational culture and ideology, and the training, leadership and approaches to evaluation required to shape it[416] Ultimately, the achievement of relationships in which service users can shape their own destiny should be the standard against which such innovations are judged.

The issue of funding for research is also important. Traditionally, drug companies[417] have funded much research into psychotic experiences and this has been based on the assumption that such experiences are primarily biological phenomena. As this report has demonstrated, both this assumption and also the view that that everyone who has psychotic experiences needs to take medication long term, are increasingly being challenged. As drug companies are unlikely to be interested in funding research that is likely to challenge these assumptions, there is an urgent need for alternative sources of funding. Although the Department of Health does not fund drug trials, much of the currently funded research is into 'schizophrenia' or other diagnostic groups. Given the inherent imbalance in research funding for biologically-based research (from drug companies) and other types of research, the evidence

presented in this report implies a need to focus more research funding on 'symptom'-based (rather than diagnosis-based) and psychological understandings of psychosis.

15.7.2 Improving services: Training and educating mental health workers

Perhaps even more important than the availability of specific talking treatments is the need for all mental health workers to be aware of the information contained in this report. Many workers are unaware of the recent advances that have been made in understanding psychotic experiences, and are unfamiliar with the research described in this report. In particular, many workers still view psychotic experiences as fundamentally incomprehensible and continue to concentrate efforts to help on removing or lessening them. A fundamental message of this report is that psychotic experiences are meaningful and understandable in similar ways to other human experiences or beliefs, and can be approached in the same way.

An extensive, national programme of training and supervision is needed for primary care, Accident and Emergency and particularly for mental health service staff. Mental health trusts should ensure that the information and ideas presented in this report are made available to all staff by means of an ongoing programme of training and supervision. Each trust should organise a series of training events on psychological approaches to psychosis for both inpatient (including night and ancillary) and community mental health team staff. Making use of the information presented in this report, such training should not be focused primarily on specific skills but on attitudes and beliefs about psychotic experiences. A culture change is needed in mental health services: with this in mind, training should be delivered on a whole-team basis, and should include managers and team leaders.

Educating policy makers and the public

One group in the country has fewer rights than the rest of us. No one listens to what they say, they are mocked in harsh, ugly language and some can't even vote. They can be discriminated against at work and locked up even when they have

committed no crime. Comedians joke about them and now the Government is set to erode their liberty yet further. They are the mentally ill and their anger is growing – driving what could become Britain's next great movement for civil rights.[418]

Jonathan Freedland in The Guardian

Educating policy makers and the public

The whole language in which we think about those of us who experience discrimination and exclusion as a result of our mental health problems is one of violence, danger, treatment, compliance and needs for services. For me, the problem lies in our continued insistence on seeing madness in purely 'health' terms. Mental health legislation focuses on which treatments and services should be available and whether we should be forced to comply with them. The mental health world argues about which is better, physical treatments or talking therapies or complementary therapies. I really don't mind – the domain is the same – one of treatment and cure. The wider disability movement did not reject medicalisation in favour of a nicer therapeutic approach. They rejected it in favour of rights – to employment, to be educated, to travel, to vote, to stand as a politician. And now they have civil rights law, and a commission to enforce it, which happily mental health users and survivors can benefit from, if we seize the opportunities it provides. But still the mental health world puts most of its energies into debating which treatments and services people should have – rather than the rights that could transform our lives so much more profoundly. It is my contention that those of us who experience mental health problems don't need services so much as we need a life. Mental health problems are not a full time job – we have lives to lead. Any services, or treatments, or interventions, or supports must be judged in these terms – how much they allow us to lead the lives we wish to lead. As for other oppressed groups – the reduction in discrimination – our inclusion in as ordinary in everyday life lies not in the domain of 'health', but in the domain of rights.[419]

Dr Rachel Perkins

15.8 Changing attitudes: educating policy makers and the public

Perhaps an even greater challenge is to educate the public about the information contained in this report. The report has shown how people can be affected as much by the

reaction of people around them as by the actual psychotic experiences themselves. For example, people who are seen as 'mentally ill' often experience prejudice, rejection and social exclusion, which can be significant – sometimes even insurmountable – obstacles to recovery. For many people, prejudice based on misinformation presents a greater obstacle to recovery (in terms of being able to lead a fulfilling life) than the original mental health problems.

Changing attitudes

My recovery involved a battle with dominant social expectations, which was more challenging than recovering from the confusion itself[420].

Dr Rufus May

The harmful effects on health of discrimination and social exclusion were highlighted in the recent National Service Framework for Mental Health[421], which states that health and social services should 'combat discrimination against individuals and groups with mental health problems, and promote their social inclusion'. An extensive, national, government funded campaign is needed to educate journalists, politicians, policy makers and the public about the information contained in this report and to challenge the 'us and them' thinking which is so widespread. Truly helpful responses from services and the community as a whole will only be possible when it is widely recognised that psychotic experiences are not something completely other and alien, but something we could all experience in certain circumstances, and which can be thought about in the same way as other human experiences.

15.8.2 Changing attitudes: The role of the media

For many people, the mass media are a major source and for some perhaps the only source of information about mental health. The media will have a very important role to play in informing policy makers and the public about the information and ideas contained in this report, and in helping to change attitudes.

In Section 13 we referred to the unhelpful way in which

mental health issues are currently often portrayed in the media. Part of the reason for this is the lack of good information available to journalists. In the absence of other sources of material, journalists currently often have to rely on court cases and inquiries. Obviously this will lead to a preponderance of stories about crime and tragedy, and the current practice of conducting a major inquiry after every incident has led to an increase in the amount of such material available. Alternative sources of material are badly needed. Initiatives by service users and professionals can help here. One example is the publication of this report, which we hope will be a useful source of such information. A second is the media agency which has recently been set up by the organisation Mad Pride (http://www.ctono.freeserve.co.uk/index.htm).

There are signs that more positive reporting is on the increase. Two examples are *The Guardian* article by Jonathan Freedland and the *London Evening Standard* article by Matt Seaton which are quoted at points in this report. The National Union of Journalists has issued a guide for its members entitled 'Shock Treatment: a guide to better mental health reporting'. Service users and professionals need to develop a better understanding of media practices and priorities in order to help create news reports, documentaries and dramas that portray 'mental illness' in a human and sympathetic way[422]. Service users need to be centre-stage in this. The tendency to see those with mental health problems as different and as abnormal will only be challenged by audiences seeing that service users are only ordinary people.

15.8.2 Changing attitudes: Discrimination

There is an urgent need for a new debate about the ethics of mental health care. For its part, the government should take steps to tackle the social exclusion of those who experience mental health problems. Models for this already exist in equal opportunity legislation for disabled people, and anti-discrimination legislation aimed at making racism and sexism unacceptable. The newly formed Disability Rights Commission will have an important role to play, but there should also be specific legislation to make discrimination against people with mental health

problems an offence. The government should establish an Equal Rights Commission charged with the responsibility of challenging discrimination against those who have experienced mental health problems in all areas of society including the media, the workplace and housing. Such a body would campaign for much needed change in other areas such as employment and benefit law and policy, to make it easier for people who have experienced mental health problems to participate more fully in society. We hope that this report will prove to be part of an ongoing major shift in public attitudes that sees prejudice against people with mental health problems become as unacceptable as racism or sexism.

Social inclusion

I have a vision:

That one day I will be able to talk about my mental health problems and attract no more than interest in those around me.

That I can go back to work after a stay in a psychiatric hospital and have my colleagues ask what it was like, rather than delicately avoiding the subject.

That one day the law will be changed to allow me to do jury service.

That one day we will see a prime minister who openly talks about his or her experience of mental health problems.

That one day I will be able to get travel insurance, life assurance, just like everybody else.[423]

Dr Rachel Perkins

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