New Philanthropy Capital

# Don't mind me

## Adults with mental health problems

A guide for donors and funders

March 2006

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This report has been funded by The Tudor Trust and Mike Metcalfe.
Cover photo supplied by Mental Health Media.

# Executive summary

## What is mental ill health?

**One in four people will experience a mental health problem at some point in their life**. Up to 700,000 adults in the UK experience a severe and enduring mental illness in the course of a year.

Mental ill health is not caused by genetic predisposition alone. Childhood trauma, job loss, other stressful events or substance abuse can trigger or amplify mental distress. A period in hospital or time off sick can lead to unemployment, homelessness, debt and isolation. People face prejudiced and hostile communities. All this leads to worsening mental health and a downward cycle of ill health and social deprivation.

As well as the human cost, the cost to the taxpayer is substantial: £18bn was spent in England on healthcare and benefits for people with mental ill health in 2002/2003.

## How is mental ill health treated?

**Every year 12 million people with mental ill health will visit their GP; some of these will be referred to specialist services; and around 200,000 will spend time on an inpatient ward**. How a person is treated and cared for will have a powerful effect on his or her recovery. Yet many people encounter services that are sub-standard and do not promote recovery. Treatments other than medication need to be more readily available.

Charities can help people by working with government to develop more effective services delivering a wider range of treatments. Providing crisis support helps people directly, as do advocacy services and arts therapy in psychiatric wards. Alternatively charities can put pressure on government to improve the present system. Charities provide a voice for people with mental health problems wanting to contribute to change.

## How else is mental health improved?

**People's social circumstances affect how they feel, how they cope with mental health problems and their chances of recovery**. Social problems can trigger mental distress, so tackling these problems early prevents ill health. Stigma and discrimination, lack of work—there are nearly one million people out of work because of mental health problems—debt, housing problems, social isolation and family pressures all exacerbate a person's mental ill health.

Charities work to prevent mental ill health and to promote good health. Charities also provide invaluable social support to people in mental distress. They tackle the stigma and discrimination that is at the root of numerous problems faced by people with mental health problems. They help people to find and retain employment and housing suited to their circumstances. Their activities enable people to overcome isolation and regain confidence. Charities also help carers to cope.

## What to fund?

**There are a host of opportunities for donors to help people experiencing mental distress**. NPC focused on the following priorities: preventing mental ill health; tackling stigma and discrimination; helping with employment and work-related activity; and improving health services for people with mental health problems. In all these areas, NPC found charities working successfully to improve people's lives.

One in four people will experience a mental health problem during their life. Priority areas for donor support include prevention, employment, tackling stigma and improving treatment.

**Different**
**by Simon Myers, survivor**

If I am different when you see me,

Do not panic;

It may only be a trick of the light.

If I am different when you see me,

It may only be a temporary phase,

A slight aberration

Of little concern.

But please bear in mind who you thought I was

And do not judge me upon your definition.

If I am different when you see me

Do not be sad

Or attempt to run,

I am not a danger to anyone

Apart from myself.

Please do not consign me to an irrelevant phase

Or a nonsense person

Without any rights.

If I am different when you see me,

Do not panic,

It may only be a trick of the light.

# Contents

# Introduction

Correct treatment and social support have transformed Vivian's life from one of trauma to stability and quiet enjoyment.

## Vivian's story

Vivian was an easy-going child, fitting in at school and performing averagely well.[33] She started showing signs of anorexia when she was 13 years old and her teenage years were generally marred by poor school performance and increasing emotional instability. Psychiatrists contradicted each other as to how much or how little her parents should 'support' or 'interfere'. Initially her parents received little information about her condition and no effective guidance on how best to cope and help. By the time she was 20, Vivian's behaviour was erratic and she started having hallucinations. She was not successful in holding down jobs or studying and she was forced to rely on benefits to pay for supported housing.

Vivian was 'treated' sporadically but unsuccessfully in hospitals and received little support with living independently. Over time the housing became squalid and she found it difficult to pay the rent. Eventually she was evicted, which resulted in a major breakdown. Thereafter police assistance became increasingly necessary and she was detained under the 1983 Mental Health Act ('sectioned'), but frequently absconded from hospital care. Her incarceration at one hospital was traumatic. She was locked in a padded cell (even when behaving calmly), sedated and given forced baths and bed times. Effective psychotherapy was not made available. For much of the 1980s, when Vivian was in her 20s, the attitude of some professionals seemed to be that she should 'snap out of it'.

*Photograph supplied by Vivian Bain*

During this time, her family had to cope with extreme situations. There were episodes when Vivian would damage property, or someone would find her running half-clothed down a busy road. There were occasional suicide attempts. There was also the trauma of her being sectioned, with police and professionals dragging a weeping and struggling Vivian into ambulances.

Vivian was socially isolated throughout the 1980s. Her social worker made great efforts to support her and her family, but did not have the resources and tools to solve the problems of her psychosis. The stability of Vivian's life was constantly undermined by the psychotic 'voices' of schizophrenia. In retrospect, better family support (including accurate clinical information and carer support groups), as well as improved treatment within the community, would have mitigated some of the challenges of looking after a seriously disturbed young woman.

It was not until 1987 that Vivian was finally diagnosed with schizophrenia. Even then it took a further three years for her to receive effective medication.

The eventual breakthrough came when Vivian was finally prescribed Clozapine for her schizophrenia (after a ban on its use in Britain was lifted in 1990). The drug suited her very well. Matters improved further when she was referred to a well-run and welcoming hospital outside her own health authority. There she was treated sympathetically and after ten months she was discharged. Ten years on, Vivian is living semi-independently with support from caring doctors, psychiatric nurses and social workers. There have been occasional lapses when medication has been reduced to below optimal levels, but on the whole she is enjoying a stable but modest life. She talks positively about her home, the support she receives, and prospects for some part-time work.

The story of Vivian's struggle with mental ill health and her family's struggle to support her has spanned 25 years. She is now 42 and single. However, the last decade has been an improvement on the previous decade and a half, and shows how 'getting it right' is possible, and in the end, rewarding.

## The case for charities

Many of Vivian's problems took place in the 1980s and 1990s during the somewhat difficult shift from old-fashioned, asylum-style care to a different approach, where people with mental health problems were cared for in the community. Vivian's story is a poignant illustration of what can go wrong in the absence of appropriate medical intervention or social support.

Since then, the charitable sector has developed considerably. In 2006, charities specialising in mental health receive a combined income of nearly £500m pa, 68% of which comes from the state.[i]

Drugs and psychological therapies, generally the preserve of government and medical professionals, only go so far to help people with mental health difficulties. Charities can work alongside medical services to improve the social environment and life chances of people like Vivian in the following ways:

- supporting Vivian's parents with information and guidance on how to care for Vivian at home;
- advocating Vivian's rights to humane care in hospital and appropriate treatments;
- providing Vivian with housing including support with life skills;
- providing Vivian with supported employment opportunities;
- introducing her to positive social networks; and
- being patient with her and nurturing recovery over protracted periods of time.

Charities work on a number of different issues such as treatment and care, employment, housing, isolation, stigma, families and carers. They do so on a number of different levels, including:

- acting as responsible providers of services to individuals and families on behalf of (and paid for by) government;
- providing services, over and above statutory requirements, which add value to the lives of individuals and families (often paid for voluntarily);
- developing good practice from experimentation, sometimes in partnership with government, sometimes taking risks and challenging conservative models;
- disseminating good practice once developed;
- ensuring that the views of people affected are heard;
- influencing government on matters of policy (eg, the poor state of statutory services);
- providing research to inform government and other service providers of particular areas of need;
- researching into causes, diagnosis, treatment and care;
- changing attitudes of society towards mental health issues to reduce stigma and discrimination;
- improving the social fabric of society (at all levels) to encourage improved mental health; and
- helping to promote good mental health and finding ways to prevent mental ill health.

## Purpose of NPC and this report

New Philanthropy Capital (NPC) is a charity that advises donors and funders on how to give more effectively. It aims to increase the quantity and quality of resources available to the charitable sector. NPC does this through a combination of independent research and tailored advice. The research identifies charities, large or small, that are achieving excellent results. The advice for donors guides them on how to ensure their money has a high impact. In all of this, NPC focuses on the long-term benefit for the people served by the charities.

*Don't mind me* provides a guide for donors and funders who are interested in the mental health of the adult population in the UK. The report explores the activities of charities serving people with mental health problems and the issues faced by the sector, and provides the context around the charities' activities. The report is accompanied by a number of charity recommendations providing examples of charities that demonstrate excellent results.

The research was carried out in three stages: desk-based research, expert consultation and charity analysis. For a full methodology, visit the NPC website at www.philanthropycapital.org. For a list of experts and charities visited, see the Acknowledgements at the back of this report.

In 2006, charities specialising in mental health receive a combined income of nearly £500m pa, 68% of which comes from the state.

## Scope

Mental health problems, ranging from mild anxieties to chronic and severe disorders, affect 10 million people in the UK at any one time. Due to resource constraints the report does not consider mental health conditions individually. There may be nuanced approaches to specialist conditions, but there are also many activities that are beneficial regardless of condition. More general topics that have had to be set aside for the time being (due to restraints on time and resources), but may be the subject of future reports, include:

**Mental health of children and young people**: This is important given that the health of the young has a strong bearing on their health in later life. NPC has written, or is in the process of writing, reports on a number of issues that touch on the mental health of children and young people. Following their completion, NPC will review the need for a report devoted to this subject.

**Substance misuse:** The dual diagnosis in many cases of mental health and substance misuse is a complex area. The authors concluded that in order to do justice to the topic, they would need to understand issues of substance misuse in detail first.

**Mental health of disabled people:** Adult disability is a subject that NPC will attend to in future.

**Dementia, neurological conditions and learning disabilities:** These will be covered separately in a future report.

NPC has already published reports (available at www.philanthropycapital.org) that touch on the mental health of particular groups of people:

**Mental health of older people**: NPC's report on older people, *Grey matters,* provides pointers on how to help isolated older people who are at risk of developing mental health problems.

**Mental health of prisoners:** NPC's report on prisoners and offenders, *Inside and out,* includes a section on the mental health of prisoners, which has not been repeated in this report.

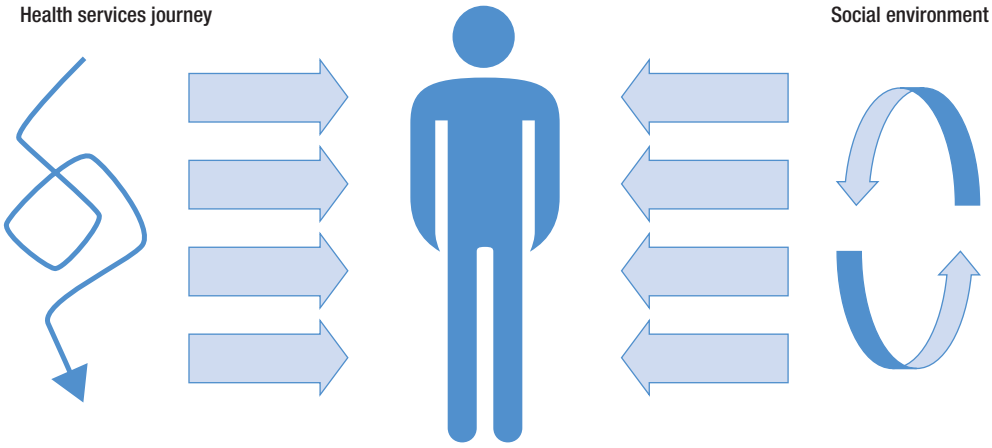
**Refugees and asylum seekers:** NPC's report, *Home truths,* includes a section on the mental health of refugees and asylum seekers.

Appendix 1 summarises the groups of mental disorders that are included in this report, as well as those that are excluded.

*Photograph supplied by Mosaic Clubhouse*

Mental health problems affect 10 million people in the UK at any one time.

**Figure 1: Two facets to the life of a person in mental distress**




## Structure

There are two facets to the life of a person in mental distress (see Figure 1):

- their interaction with the mental health services trying to treat the problem; and
- the social environment in which they find themselves.

The person's life can be viewed through either facet. Both are dynamic and interconnected.

The first is a meandering journey through a system provided by the state, which may or may not result in a positive outcome. The second is a situation involving multiple factors triggering and amplifying experiences and episodes. It too has the characteristics of a journey.

Ideally the two sides of the story could be presented simultaneously with a running commentary on the chaotic 24-hour experience of a person with severe mental illness (see Box 1).

However, in reality an orderly explanation is required to make sense of the issues. This report has been divided into four sections to answer the following questions:

### Section 1: What is mental ill health?

This section provides explanations of conditions, prevalence, trends, costs to society and causes and effects of mental ill health.

### Section 2: How is it treated?

This covers the health services perspective, including the role of charities in contributing to improvements in treatment and services.

### Section 3: How else can it be improved?

This covers the effect of the social environment, including how charities help individuals, families, communities and society to improve people's mental health.

### Section 4: What to fund?

This section discusses the role of charities and how donors can decide which charities to support.

**Box 1: A day in the life of a person with mental health problems**

| | |
|---|---|
| 2am | Can't sleep – take medication. |
| 10am | Wake up late and exhausted, missing IT training at the charity Mosaic Clubhouse. |
| 11am | Mosaic rings to check all is well. |
| 12noon | Go down to Mosaic Clubhouse for chat with friends and something to eat. Feel better. |
| 3pm | Go to hospital appointment with psychiatrist who checks medication. |
| 5pm | Home for a rest. |
| 8pm | Wake up hearing voices again. |
| 9pm | Not sure where to go to get help, as everything shut on Monday nights and can't get hold of Community Psychiatric Nurse. |
| 10pm | Call helpline recommended in Care Plan for reassurance. Chat helps. |

# What is mental ill health? 1

> Those whom the gods would destroy, they first make mad.
>
> Euripides

**Mental health problems, ranging from mild to moderate anxieties to chronic and severe disorders, affect millions of people. One in four people will experience a mental health problem at some point in their life. Up to 700,000 adults in the UK experience a severe and enduring mental illness in the course of a year.**

**Mental ill health can be triggered by one or a number of factors, including job loss, childhood trauma, drug misuse and genetic predisposition. A period in hospital or time off sick can lead to unemployment, homelessness, debt and isolation. These factors, as well as facing prejudiced and hostile communities, can lead to worsening mental health and a downward cycle of ill health and social deprivation.**

**The costs to society are enormous:**

- **£8bn in health and social services;**
- **£4bn in costs to individuals and carers; and**
- **£15bn in lost output.**

**Yet if people are provided with the right kind of help, these costs, and more importantly human suffering, can be greatly reduced.**

**Box 2: Individuals with good mental health:[17]**

- develop emotionally, creatively, intellectually and spiritually
- initiate, develop and sustain mutually satisfying personal relationships
- face problems, resolve them and learn from them
- are confident and assertive
- are aware of others and empathise with them
- use and enjoy solitude
- play and have fun
- laugh, both at themselves and at the world.

## Defining mental health

There is a great deal of ambiguity around definitions of 'mental health' and 'mental health problems'. The following section describes what it means to be in good and poor mental health.

### What is good mental health?

Good mental health is not just the absence of a mental health problem. It is more than that (see Box 2). It is *'the emotional and spiritual resilience which enables us to enjoy life and to survive pain, disappointment and sadness. It is a positive sense of well-being and an underlying belief in our own, and other's dignity and worth'.*[34]

Mental health is just as important as physical health. It influences how we feel, perceive, think, communicate and understand. Without good mental health, people are unable to fulfil their potential, or play an active part in everyday life.[35]

### What are mental health problems?[iii]

The phrase 'mental health problem' covers a wide variety of psychological experiences, from the anxieties we all experience as part of everyday life, to an extreme sense of personal isolation and complete loss of contact with reality. In this report 'mental health problem', 'mental distress' and 'mental ill health' will be used inter-changeably. The term 'mental illness' is usually used for more serious diagnoses.

#### Types of mental health problems

There are many different types of mental health problems (see Appendix 2). They are classified to enable professionals to refer people for appropriate treatment and care, although many people with mental health problems prefer not to be labelled with a medical diagnosis. Below are some better-known examples:

*Anorexia nervosa* is a type of eating disorder. People with anorexia do not eat enough, usually because they feel that their problems are caused by their appearance. They think that they appear fat even though they may look slim or even painfully thin to others. Their morale becomes low and their health can be seriously affected. Because they are not eating enough, anorexia sufferers may develop a number of physical problems including poor circulation, brittle bones and hair loss.[36]

*Anxiety* is a feeling of unease, worry and sometimes fear. It affects both the body and the mind. Physical effects include increased muscular tension, headaches and rising blood pressure. Psychological effects include heightened alertness, fear, irritability and the inability to relax. Sometimes anxiety can take the form of a panic attack (the rapid build-up of overwhelming sensations, such as a pounding heartbeat, feeling faint, sweating, nausea, chest pains, breathing discomfort, feelings of losing control and shaky limbs).[37]

*Bipolar disorder (manic depression)* involves mood swings from periods of deep depression to periods of overactive, excited behaviour known as mania. Mania may flare up periodically, but depression is the most consistent symptom.[38]

*Bulimia nervosa* is an eating disorder characterised by binge eating and vomiting. Sufferers purge themselves by making themselves sick or abusing laxatives. In extreme cases, sufferers can make themselves sick as often as 30 to 40 times a day. Bulimia is more common than anorexia, but because people keep their weight more stable, it is less visible.[36]

*Depression*, in its mildest form, can mean being in low spirits. It does not stop you leading your normal life, but makes everything harder to do and seem less worthwhile. At its most severe, depression can be life-threatening, because it can make people suicidal. Common symptoms of depression include a loss of pleasure in life, loss of interest in food, low libido, disrupted sleep and lack of concentration.[39]

*Obsessive compulsive disorder (OCD)* is a fairly common problem where people experience 'obsessions', recurring unwanted thoughts that are difficult to stop, and 'compulsions', rituals of checking behaviour or repetitive actions. These compulsions are carried out in an attempt to relieve the obsessive thoughts.[40]

*Personality disorder* refers to severe disturbances in thoughts, feelings and behaviour. Personality disorders usually appear in late childhood or adolescence and continue into adulthood. The thought patterns and behaviours cause distress to the person or to those around them. There are ten personality disorders that have very different characteristics, including antisocial personality disorder, dependent personality disorder and schizoid personality disorder.[41]

*Schizophrenia* has a broader definition than is often imagined. Doctors describe it as a psychosis. In their view, this means that a person cannot distinguish their own intense thoughts, perceptions and imaginings from reality. Hearing critical or disturbing voices, or believing that other people can control their thoughts, are typical symptoms, but they are not necessary for a diagnosis.[42]

### Problems with labelling and classification

A person's state of mental health is likely to be related to a complex interaction of biological, social and personal factors. As a consequence, no two experiences of mental health problems are the same, and individuals find that the classification of their problem does not always relate closely to their experience. Therefore the use of diagnoses should be treated with caution, and should not be seen as an indicator of the severity of mental ill health. For example, if an individual is diagnosed with bipolar disorder, it does not necessarily mean that they are unable to fulfil their potential and lead a full and active life.

### Suicide and self-harm

People with mental health problems are at particular risk of committing suicide. Box 3 gives an example of a young man, suffering from depression, who took his own life. Around 90% of all suicide victims have been suffering from a psychiatric disorder at the time of their death.[43] That said, people with no history of psychiatric disorder can find themselves 'in crisis' in response to events such as bereavement, relationship or employment difficulties. They may become so affected that they are at risk of suicide.

**Box 3: Charlie Waller's story**

**Charlie Waller was a strong, good looking, intelligent 28-year-old man with a wonderful partner, a loving family, lots of friends and a good position in an advertising job he loved. Nobody realised he was suffering from depression until he decided to kill himself. He no longer had the strength to face life. Shortly after his tragic death in 1997, Charlie's family founded The Charlie Waller Memorial Trust to increase awareness of the signs and the dangers of depression and to encourage those suffering from depression to seek professional help.[18]**

> "When I cut myself the pain in my wrist takes away the pain in my heart."
>
> Girl talking to nurse.

Self-harm is also common amongst people with mental health problems and is a physical manifestation of extreme distress. Self-harm describes a wide range of things that people do to themselves in a deliberate, damaging and usually hidden way. Forms of self-harm include cutting, burning, scalding, banging and self-poisoning. Self-harm occurs at times of extreme anger, distress and low self-esteem. For many people, it remains a way of coping with those feelings they cannot express. It can also be a way of avoiding or preventing suicide. Other people use self-harm to punish themselves, or as a way of taking control.[44] Awareness of self-harm is increasing as a consequence of people in the public eye, such as the Olympic gold medallist Kelly Holmes, admitting to harming themselves in the past.

One in four people will experience some kind of mental health problem at some point in their life.

## Prevalence and trends

### Prevalence[iv]

One in four people will experience some kind of mental health problem at some point in their life, and one in six people will experience a mental health problem at any one time.[v] Figure 2 gives a breakdown of the absolute number of people suffering from mental health problems in the UK.[4, 45] If you include relatives, friends and colleagues, almost everyone has had some sort of contact with mental ill health and knows about the suffering it can cause.

The prevalence of mental health problems can be measured in several ways: by the incidence of problems or episodes during a single year (annual prevalence); by prevalence of a condition at any one time; or by lifetime prevalence, which measures who in the population will experience a condition during their lifetime.

**Figure 2: People with mental health problems[vi, 45, 46]**

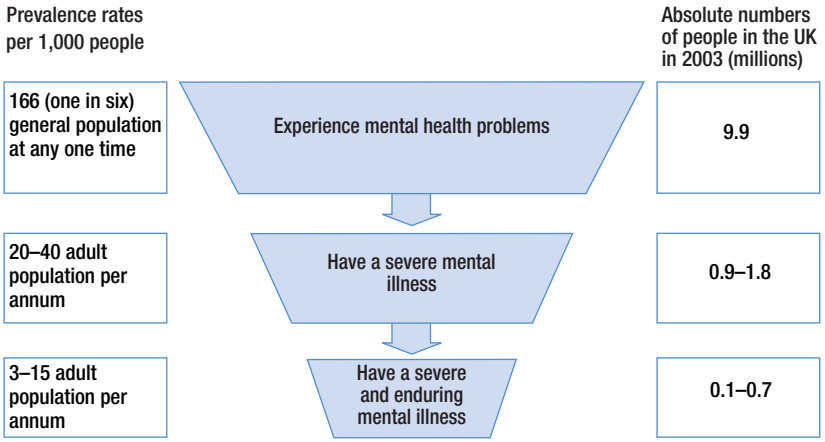



Table 1 describes the lifetime prevalence of different disorders. The most common mental health problem is depression. One in ten people will have some form of depression at any one time.[47] Psychotic problems, such as schizophrenia and bipolar disorder, affect four per 1,000 of the adult population in the course of a year.[48] One percent of women in the UK between the ages of 15–30 years have anorexia nervosa.[49]

**Table 1: Prevalence of different types of mental health problem**

| Mental health problem | Lifetime prevalence rate[50] |
|---|---|
| Depression | 1 in 6[51] |
| Severe anxiety | 1 in 10 |
| Bipolar disorder | 1 in 100 |
| Schizophrenia | 1 in 100 |

More than 5,800 people kill themselves each year in the UK.[52] Three quarters of victims are men.[44] Unemployed men under 35 years old are particularly vulnerable. Suicide is one of the leading causes of death in the 15–24 age group.[53] Overall, suicide accounts for 1.7 times as many fatalities as road accidents.[54] Suicide rates are also high in the over 65 age group.

Like anorexia, self-harm is more prevalent in teenagers. More than 24,000 teenagers are admitted to hospital in the UK each year after deliberately harming themselves.[55] Most have taken overdoses or cut themselves. One study, by the Samaritans and the Centre for Suicide Research, found that one in ten teenagers self-harm.[55] The National Institute for Clinical Excellence (NICE) suggests that almost four million people in the UK, including adults, have harmed themselves.[56]

### The old and the young

Mental health problems can affect anyone. Although this report is focused on adults of working age, NPC recognises that mental health problems can occur at any point in a person's life. According to the Department of Health, 10–15% of 15 year olds have a diagnosable mental health disorder.[57] Mental health problems are also on the rise in older people. In 2005 it was estimated that there were 750,000 people with dementia and at least one million with depression.[58]

## Vulnerable groups

There are certain groups of people who are more at risk of suffering from mental health problems. This reflects a number of cultural and social and economic factors. Vulnerable groups include:

- the black and minority ethnic (BME) population
- homeless people
- refugees and asylum seekers
- prisoners and offenders
- people with a substance misuse problem
- ex-servicemen and soldiers returning from conflict.

People in disadvantaged situations, for instance low-income families and families with a large care burden, are also particularly vulnerable to mental distress.

The mental health of prisoners and offenders, referred to in Box 4, and refugees and asylum seekers has been looked at in previous NPC reports, so this report will not consider these groups of people in any level of detail. The mental health of homeless people, substance misusers and ex-servicemen will be covered in future NPC reports. The mental health of the BME population is discussed in more depth in Section 3.

## Trends

There is considerable evidence that mental health problems are on the rise. The Psychiatric Morbidity Survey has been carried out twice, in 1993 and 2000.[48] Although there was no change in the number of women suffering from mental health problems, for men there was a significant increase over the seven years (from 12.5% to 14.5%).[48] This included an increase in serious depression from 1.9% to 2.6%. The World Health Organization (WHO) projects a worldwide increase in mental illness from 12% of the total burden of disease in 2003 to 15% in 2020. Depression is the most powerful driver of this increase. Now the fourth leading causes of disease and disability in the world, by 2020 it is expected to rank second.[59] It is not known why the incidence of depression has increased. However, hypotheses include improved diagnosis, poor diet, social and family fragmentation, growth of affluence and expectations, workplace stress and drug and alcohol misuse.[60]

Rates of self-harm have increased in the UK over the past decade and are reported to be amongst the highest in Europe.[61] According to a study published in 2005 by The Priory Group, family break-up, increased pressure to achieve at school, a lack of tolerance in society and an 'anything goes' attitude are all contributing to a rise in the number of young people pushed to the brink of suicide and self-harm.[62]

**Box 4: Prisoners and mental health**

The fact that 90% of people in prison have a mental illness might suggest that many people are imprisoned when they should be receiving treatment for mental illness.[14] The data does not distinguish between prisoners arriving in prison with mental health problems and those developing problems once incarcerated. Anecdotally, a disturbingly high number of prisoners suffer from mental health problems before they are jailed.[21] Untreated mental health problems are a likely cause of offending behaviour.[28]

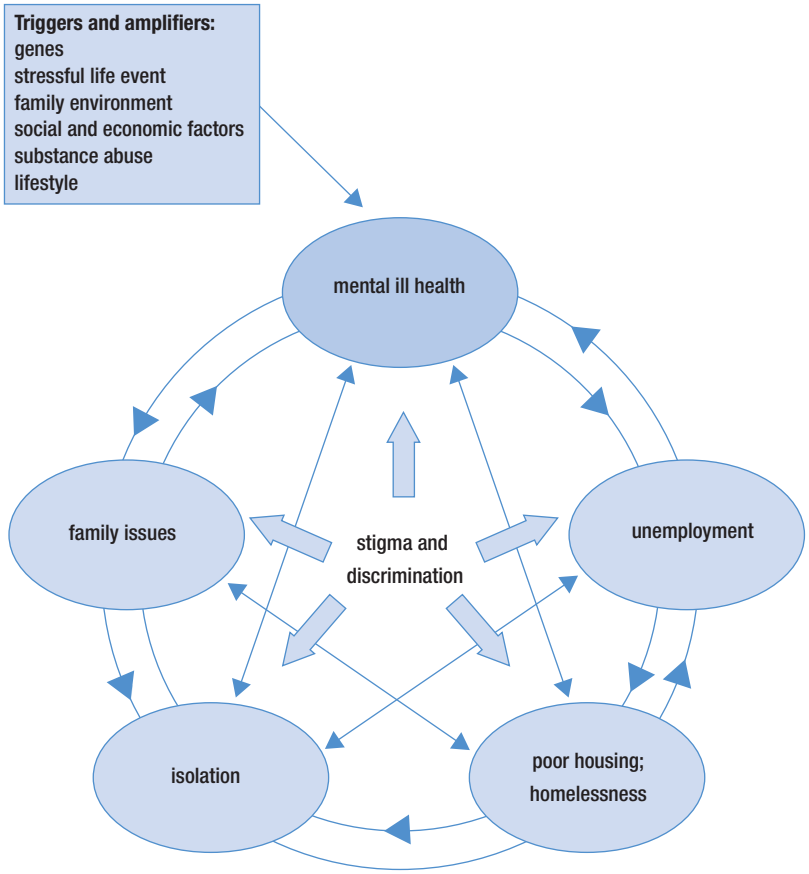
There is no statutory requirement for schemes to divert such cases away from courts and into mental health services. In fact, court diversion schemes are available in only a few places. People committing petty crimes (often as a result of mental health problems) end up being imprisoned. Once inside a prison cell, mental health problems increase. Imprisonment makes existing problems worse or causes the onset of new problems. NPC's report on prisons, Inside and out, describes the problems in detail (eg, suicide rates are roughly seven times higher in prison than among the general population, and self-harm is commonplace.

## Causes and effects

The relationship between cause and effect in mental health is complex. It is part of the wider debate around whether it is our genes or the environment we live in that makes us the way we are. It is clear that a number of different factors are at play, which can act alone or combine to trigger distress or amplify effects. The downward spiral of mental ill health is depicted in Figure 3.

People from deprived backgrounds are more likely to have mental health problems.[5]

**Figure 3: The downward spiral of mental ill health**



The overall result is a cycle of decline that is difficult, but not impossible, to break. Data gathered highlights correlations, but does not clearly disentangle cause and effect. Addressing the factors driving the cycle, regardless of whether they are the cause or the effect, is beneficial to those experiencing distress.

As depicted in Figure 3, the factors that might trigger (or amplify) a mental health problem include:

## Genes

Some genes predispose individuals towards mental illness or increase vulnerability. The National Institute of Mental Health in the USA states that 'at least 60% of the factors that give rise to schizophrenia may be related to a genetic susceptibility'. The remaining 40% are 'environmental factors'.[63] Like cancer, understanding the role of genetics in mental health is increasingly useful in developing treatments and prevention techniques. However, again drawing parallels with cancer, it would be a mistake to focus on genes without also considering social environments.

## Stressful life events

Many people go through a series of stressful life events, minor as well as major. These may be traumatic events, such as domestic violence (see Box 5), or longer-term struggles, such as being the victim of some form of harassment or oppression. More common stressful events, like the loss of a partner or a job, can also trigger the onset of mental health problems. Researchers and clinicians have observed that there is an accumulation of life events (both desirable and undesirable) immediately before the onset of a mental illness.[64, 65] Unsurprisingly, undesirable events predominate before the onset of depression and related illnesses.

**Box 5: Domestic violence and mental health**

**Around half a million women are affected by domestic violence each year in England and Wales.[13] The impact on their mental health, and that of their children, is significant:**

- **Between 35% and 73% of abused women experience depression or anxiety disorders. This implies that between 175,00 and 350,000 women suffer such disorders as a result of domestic violence each year.[22]**
- **Domestic violence commonly results in self-harm and attempted suicide: one third of female suicide attempts can be attributed to past experience of domestic violence.**
- **Children who witness domestic violence are at increased risk of behavioural problems, emotional trauma and mental health difficulties.**

**For further information, see NPC's 2003 report *Charity begins at home.***

## Family environment

Family environment is a determinant of mental health.[66] The emotional environment is important: growing up uncared for, in fear of a parent, or in extreme cases being sexually or physically abused can make people highly insecure and more vulnerable to mental health problems. Conversely, being over-protected as a child can also put individuals at risk. Early adverse experiences appear to contribute to vulnerability to depression, although onset of the illness is not automatic.[66] Research also demonstrates a correlation between the emotional environment within the family and relapses of schizophrenia.[65]

## Social and economic circumstances

People from deprived backgrounds are more likely to have mental health problems.[5] This is demonstrated by varying rates of prevalence between different socio-economic groups. Depression, for example, is around twice as prevalent amongst low-income groups than among those on higher incomes.[24]

Mental ill health can make people poor, through loss of employment, then loss of housing (stressful life events in themselves) and increased isolation. However, it is also true that people from poorer backgrounds are more likely to become mentally ill. They generally face an increased risk of physical health problems, have worse access to services and live in poor quality environments.

Poverty and mental illness are mutually reinforcing. Deciding which comes first can be problematic, and so seeing mental health and socio-economic factors as a linear relationship is not entirely helpful. Viewing the relationship as circular and complex—where unemployment, homelessness, debt and social isolation do not only cause mental health problems, but are consequences as well—is more constructive. According to academics in the field, changes in social and economic policy that reverse or reduce widening socio-economic inequalities in the UK will probably reduce the prevalence of common mental disorders.[67]

## Substance abuse

There remains debate about the extent to which substance use, including alcohol, can cause mental health problems. However, there is more agreement that substance abuse may trigger or exacerbate mental illness. An example frequently discussed in the press is cannabis use. Cannabis use has been found to be a component cause of psychosis, particularly where other risk factors are

present, for instance genetic susceptibility and youth.[68] Recent government reports stating that the risks associated with cannabis are low are misleading because they are taken from a broad cross-section of age groups rather than focusing on the most vulnerable groups.

Professionals are concerned by the link between cannabis and psychosis, given the emergence of more harmful varieties of cannabis, for example 'skunk' in the UK. One South London general practitioner (GP) expresses the conviction of many that there is a silent trend emerging:

*'Fifteen years ago there was absolutely nobody presenting with cannabis problems at all … but in the last ten years I've seen a steady stream of people coming to see me with problems relating to cannabis misuse—anxiety … paranoid feelings etc…'* [69]

The reason that psychosis levels appear stable in official figures is likely to be one of timing. It is a relatively new phenomenon. Data trends on psychosis prevalence rates run until the late 1990s. Data for this millennium is only now starting to emerge and the extent of any time bomb will only be seen when more of this data is published.

## Lifestyle

There is increasing evidence that diet,[70] lack of exercise and other lifestyle issues are linked to problems such as depression. The physical operation of the brain relies upon adequate intake of the right minerals and fatty acids found in fish and vegetables. Endorphins released during exercise also benefit the brain.

## The cost of mental health problems

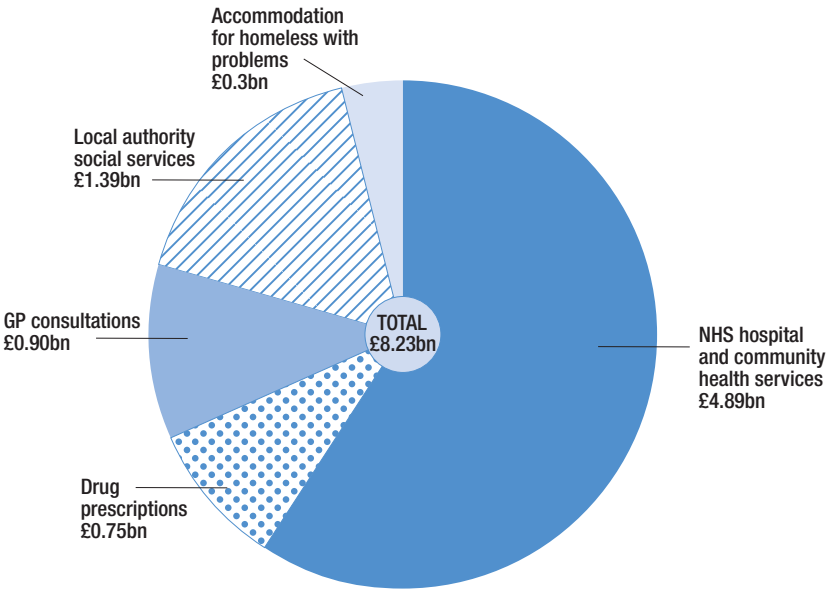
Mental illness is a human, economic and financial burden for individuals, their families and society. The costs to the taxpayer are most easily accounted for, and represent one way of looking at the costs. Another way is to count the economic cost of the lost output of people suffering from mental illness who are unable to work. There is also the cost of carers staying at home to look after people who are too ill to look after themselves. Then there is the human cost of the misery, disability and distress caused to the individuals and their loved ones.

## Costs to the government

### Health and social care

Public spending on mental health services was estimated to be £8.23bn in England in 2002/2003 (see Figure 4).[vii] This represents almost 12% of all public spending on health and social services by the National Health Service (NHS) and local authorities.[71]

**Figure 4: Government spending in England on mental health 2002/2003**[71]




### Benefits

Benefit payments represent another cost to the Exchequer. Of all the people coming onto incapacity benefits, 35% list mental health problems as their main disability, and such problems are a secondary factor for another 10% or more. There are 900,000 people on incapacity benefits in England due to mental health problems[72], and the annual cost of these benefits is around £10bn.[3]

### Tax losses

A further cost would be the lost taxes arising from the non-employment of people with mental health problems and their unpaid carers, estimated at £3bn a year.[3]

People in mental distress are the most unhappy people in our society, even more so than the poor.[3]

So the total annual cost of mental ill health to the Exchequer is at least £21bn, and would be higher if the health and social care costs beyond England were included. This is equivalent to £350 for each man, woman and child in the UK.[viii]

## Costs to individuals and families

Richard Layard, a leading economist at the London School of Economics, believes that people in mental distress are the most unhappy people in our society, even more so than the poor. The National Child Development Study provides some evidence: 5% of adults surveyed said they were not very happy or not at all happy. Of these, 25% were poor and 41% were mentally ill. Mental factors accounted for more of the unhappiness than low income.[3]

The human costs of such misery to individuals and families are difficult to measure and NPC has not attempted to do so.

However, it is estimated that in 2002/2003 people in England spent £200m privately on mental health services, and that the cost of informal care (ie, time spent caring) was £3.9bn.[ix,71]

## Costs to society

An alternative way of counting the cost of mental ill health is to calculate lost output.

Mental illness reduces economic activity, through time off sick and non-employment (unemployment and economic inactivity). The Confederation of British Industry (CBI) estimated in 2001 that annual lost output from sickness absence due to mental health problems was £3.9bn. Roughly 59 million working days are lost annually in the UK to mental distress.[71]

Only 24% of adults with long-term mental health problems are in work, the lowest employment rate for any of the main groups of disabled people.[5] If the employment rate of people with mental health problems is compared to that of people in good mental health, then the difference in employment rates implies lost output of £9.4bn. On top of this there is the cost of lost output attributable to premature mortality amounting to £1.8bn. This brings the total annual cost in terms of lost output to £15.1bn.[5]

Much of the analysis on costs and spending has been undertaken by a charity, the **Sainsbury Centre for Mental Health (SCMH)**. This information is useful for government, service providers and charities lobbying for more funds or reallocated resources.

## Summary

Mental health issues affect a large proportion of the population and cost a great deal in economic, social and human terms, so improving people's mental health is an important investment. Charities can help to improve the returns on the state's investment in this area. It is their activities that will be discussed in the following sections.

Roughly 59 million working days are lost annually in the UK to mental distress.[71]

# How is mental ill health treated?

2

**The treatment of patients is delivered through mental health services. Effective treatment and care require effective services. All three have a powerful effect on a person's recovery from an episode of mental distress. The numbers of people in the UK that come into contact with mental health services in any one year are considerable: 12 million will visit their GP; 1.3 million will be referred to specialist services; around 200,000 will experience a spell on an inpatient ward. Getting treatment right reduces unnecessary repetition of mental health problems. Yet many of these people will encounter services that are sub-standard and do not promote recovery. Charities can help by providing services directly, working with statutory providers to develop more effective services, putting pressure on the government to improve the present system, and providing a voice for people with mental health problems.**

This section considers the treatment and care of people with mental health problems from the perspective of the health services. Treatment and care is not divorced from the person's social environment, which is covered in the following section.

The world of mental health services is full of terminology that is confusing to the uninitiated. To help the reader, the next few pages are devoted to explaining the system and treatments available to patients. This section first explains the process of treatment and care in the following order:

- an illustration of patients' journeys through the system;
- how the system is structured; and
- what treatments are available.

It then highlights issues relating to treatment, care and service delivery, and how charities are working to improve the situation.

## Journeys through the system

Mental health services are broadly delivered at three different levels of care:

- primary care eg, GP practices;
- community care eg, community mental health teams; and
- inpatient care eg, hospitals.

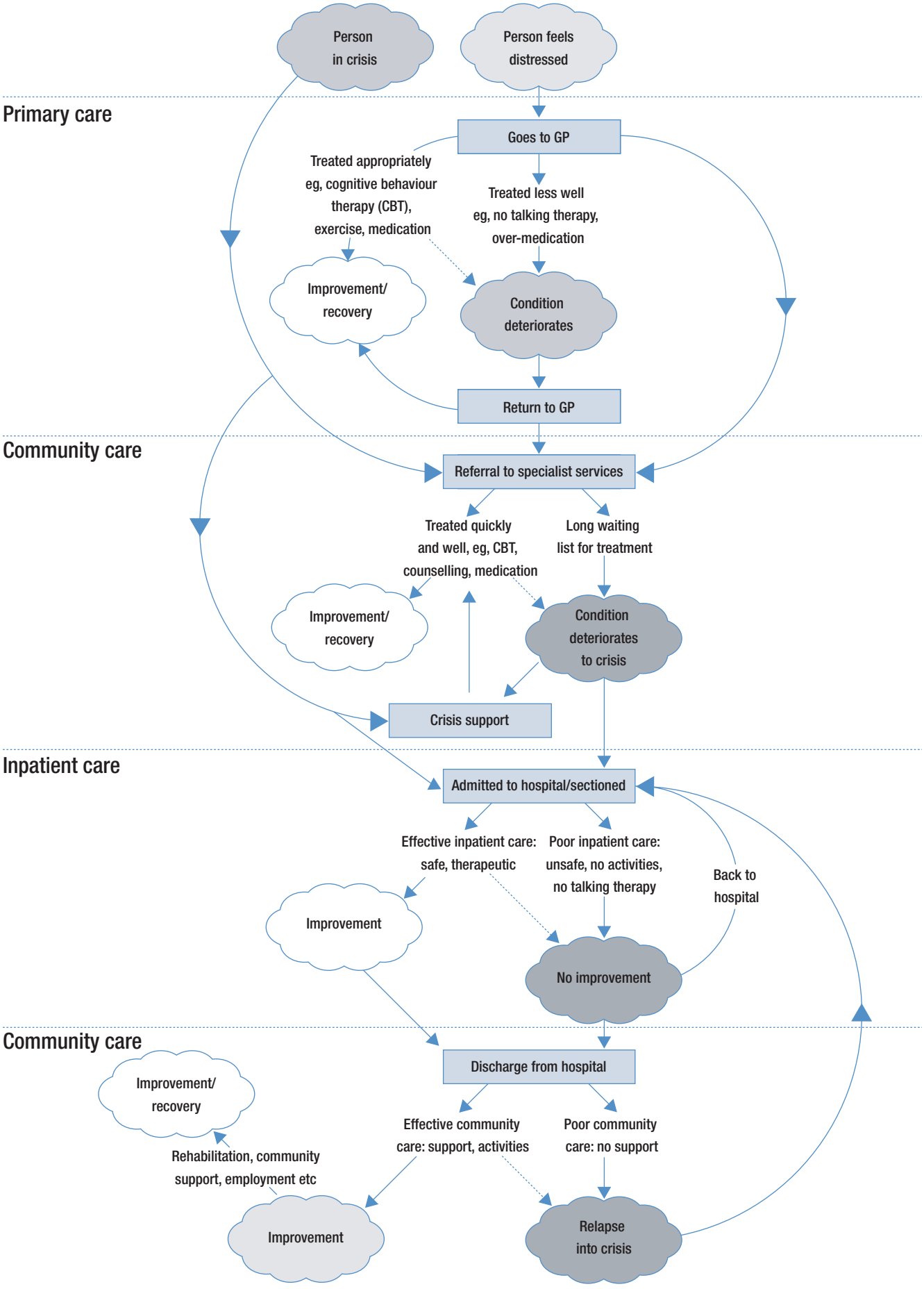
The schematic diagram in Figure 5 describes patients' pathways through the system. It simplifies the system and the circumstances of patients. An individual's experience will depend heavily on their condition. For instance, a person with schizophrenia is likely to spend much of their time in the bottom half of Figure 5 moving in and out of community care and inpatient care. A person with moderate depression would be mainly accessing primary care services.

The diagram is laid out in the form of a 'decision tree' in order to show how problems ignored or inadequate services can be costly for both the individual and the service provider. Social and environmental issues discussed in later sections also have an important bearing but are not included in this diagram for the sake of simplicity.

Keeping people out of hospital through early intervention and careful management of conditions is not only therapeutically desirable, but at around £260 per bed per night in a new inpatient unit, it is also economically desirable.[73]

Over 12 million people in the UK come into contact with the health services as a result of mental distress each year.[6]

**Figure 5: The journey through the mental health system**



## Structure of services

Figure 6 shows how the different services, illustrated in the patient pathways, are structured into the three broad levels of care.

Figure 7 shows the number of people using the different services in England and Wales. Primary care services are the most heavily utilised.

### Primary care

#### GP practices

Most people's first point of contact with the mental health services is via their family GP. Many problems such as stress or depression can be helped directly by a GP, who usually provides advice and information and prescribes medication. Larger practices often have counsellors attached, and sometimes clinical psychologists who can provide counselling and psychological support.[74] It is the responsibility of the GP to refer individuals who require more specialist help on to secondary care services, including people diagnosed with severe mental health problems (schizophrenia, bipolar disorder, obsessive compulsive disorder and clinical depression).

Around 90% of people with mental health problems are treated by primary care services.[6, 24, 75] Roughly one third of GP consultations relate to mental health issues.[5]

### Community care

#### Outpatient clinics

Individuals who are referred to outpatient clinics will be seen by a psychiatrist. The psychiatrist will most probably prescribe medication, and may also refer the patient on to other forms of talking therapy such as counselling or psychotherapy. The psychiatrist may also refer the patient to the community mental health team (CMHT) or, if the problem is more serious, may admit the patient to hospital.

#### Community mental health teams

Community mental health teams (CMHTs) are able to support people with serious forms of mental health problems, such as schizophrenia and bipolar disorder. The teams are made up of different mental health professionals, including social workers, community psychiatric nurses (CPNs), occupational therapists, psychiatrists and psychologists. The NHS or social services employ members of the team. As well as having their own specific professional roles, members also have a general team responsibility to ensure that service users' health and social care needs are met in the community.[76] CMHTs assess and monitor each service user's mental health needs via a system known as the Care Programme Approach (CPA). Box 6 outlines the two types of CPA.

**Figure 6: Mental health services in England**

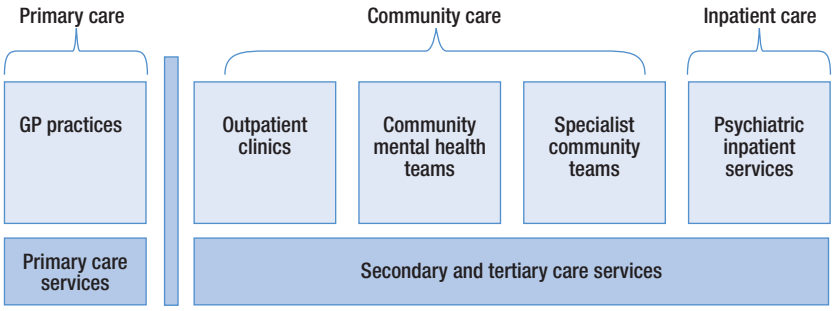
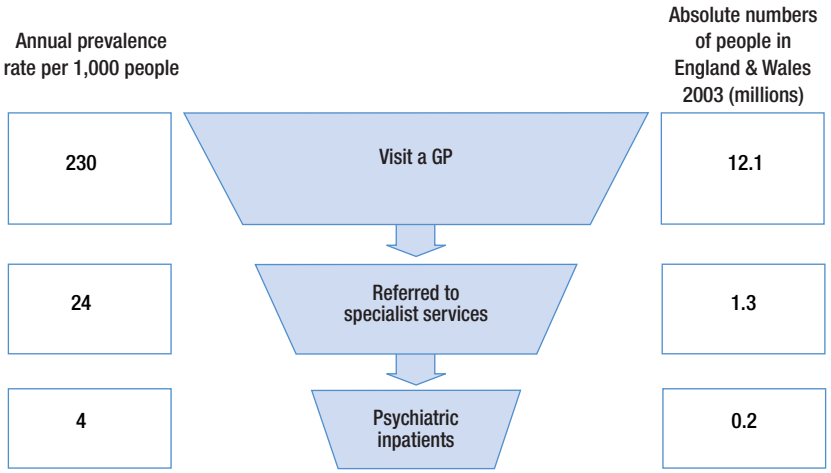



**Figure 7: People with mental health problems using services[2, 6, x]**




Roughly a third of GP consultations relate to mental health issues.[5]

**Box 6: The Care Programme Approach (CPA)[11]**

The main elements of the CPA are: an assessment of the health and social care needs; a written care plan; a care coordinator (who is responsible for making sure the care plan is carried out) and regular reviews of health and social care needs.

There are two types of CPA:

- The Standard CPA is for people who pose no danger to themselves or others and require the support of only one agency.
- The Enhanced CPA is for those people with more severe and complex mental health needs that need the input of both health and social services.

**Box 7: National Service Framework for Mental Health**

In 1997 the Government set out its top three priorities for the NHS – cancer, coronary heart disease and mental health. For mental health, this elevated status has meant additional funds and new services. The National Service Framework (NSF) for Mental Health was the centrepiece of the government's reform of mental health services. It was developed in 1999 and is a ten year programme of reform, modernisation and investment. The NSF straddles both health and social services and recognises that improvements in both areas will mutually reinforce the benefits. It is based around several key priority areas:

Standard 1: Mental health promotion

Standards 2 and 3: Primary care and access to services

Standards 4 and 5: Effective services for people with severe mental illness

Standard 6: Support for carers

Standard 7: Preventing suicide

The National Institute for Mental Health in England (NIMHE) was set up to oversee the implementation of the NSF for Mental Health. It has three strategic priorities: transformation of the overall system of mental health care, workforce development and implementation in practice.

Charities such as **Mental Health Foundation**, **Mind** and **Rethink** were proactively involved in developing the NSF priorities.[26]

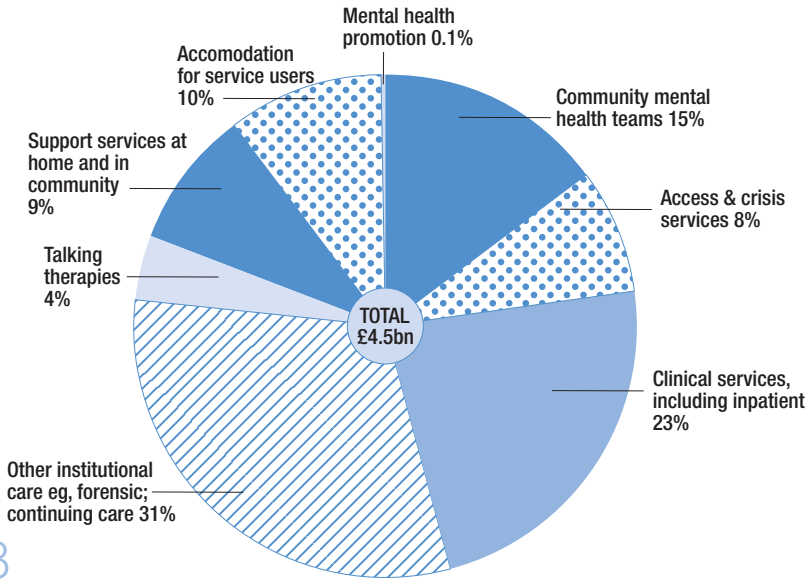
### Specialist community teams

The NHS Plan (2000) extended the agenda described by the National Service Framework for Mental Health (see Box 7) by detailing new models of working with people with mental health problems.[77] Among the new services highlighted were crisis resolution and assertive outreach teams. Both teams are multidisciplinary, with staff coming from health and social care backgrounds.

#### Crisis resolution teams

The main aim of crisis resolution is to help individuals manage and resolve their crisis through home assessment and treatment so as to avoid being admitted to hospital. This service should be available 24 hours a day, seven days a week. CMHTs are the main source of referral.

**Figure 8: Public expenditure on mental health services for adults in England 2004/2005[79]**




#### Assertive outreach teams

Assertive outreach teams work with adults with severe and lasting mental illness who cannot or will not engage with traditional services. Typically staff identify individuals who meet the following criteria: a history of non-engagement with mental health services, a history of non-compliance with medication, frequent unplanned psychiatric admissions, frequent involvement with the police, or complex multiple problems in addition to mental illness such as drug misuse.[78]

Assertive outreach teams work with individuals in their own environment, whether at home, in a cafe, in a park or in the street, wherever their support is most needed and most effective. This flexibility allows people who might otherwise not receive services to get help in an environment where they feel most comfortable. Workers may also visit or accompany individuals when they use other services.[78] Service users may access crisis resolution teams out of hours.

## Inpatient care

Some people with mental health problems are admitted to hospital for treatment. People can admit themselves to hospital if a psychiatrist agrees that this is necessary and if there is an available bed. Others are compulsorily placed in hospital care ('sectioned') under the Mental Health Act 1983. According to the Act, someone can only be compulsorily admitted to hospital if they are 'suffering from mental disorder' and detention is necessary: 'in the interests of their own health; in the interests of their own safety, or for the protection of other people'.[76]

## Government funding for services

The government has identified mental health services as a priority in health spending, alongside cancer and coronary heart disease. Box 7 outlines the National Service Framework for Mental Health, which was drawn up as a consequence of this newly elevated status. Figure 8 shows the public expenditure on adult mental health services by type of service. This dedicated mental health spending of £4.5bn excludes the cost of GPs and drug prescriptions, estimated at £0.9bn and £0.8bn in 2003 respectively (across all age groups).[71]

Figure 8 shows how substantial resources are devoted to the more acute areas of services, such as inpatient and institutional care and crisis services. A bed in a new inpatient unit costs £260 per night.[73] More specialist high-dependency units can cost up to £800 per night.[80]

Less funding is allocated to talking therapies and home support. Mental health promotion hardly features at all, receiving only £2m.

**Box 8: Commissioning mental health services**

At present, Primary Care Trusts (PCTs) receive 75% of the total NHS budget and commission mental health services to meet the needs of their population.[5] PCTs commission both health and social care services for people with mental health problems. PCTs are encouraged (under the General Medical Services contract) to commission high quality evidence-based care, and there is increased flexibility to commission services from new providers, such as charities that provide day care services for people with more severe mental health problems.

GPs now have opportunities for 'social prescribing' (arts activities on prescription and exercise referral schemes) to help keep people out of hospital. Again, charities frequently provide such services, particularly arts activities.

Thus the border between the NHS and social services is increasingly blurred, and charities often find themselves providing services required by both. The NHS has an incentive to fund social activities to keep people well and out of hospital. This is no bad thing, and NPC has been encouraged by the degree to which enlightened PCTs are paying for imaginative services commissioned from charities that have therapeutic benefits.

The commissioning of local services will vary depending on local structures and traditions. Activities funded by the PCT in one area will be the responsibility of the local authorities in another. Either funding stream is risky: PCTs and local authorities both experience budgetary pressure. In many areas, the two services work well together, but in other areas, particularly where cash is tight, services may be passed from one side to the other because of budgets. A charity providing services that are funded from the two sides will fight hard to maintain its funding and get the two sides to work together.

The challenge for charities when delivering government services is conflict of interest. Many of the charities are both the government's contracted service providers and its most vocal critics. This begs two questions: a) are charities sufficiently independent to criticise the hand that feeds them? b) do they have the capacity to be self-critical about the services that they increasingly provide themselves?

Some of this funding, together with the social services funding identified in Section 1, goes to charities providing services. The combined income of the members of the Mental Health Providers Forum (a group of charities that contract with the NHS and local authorities) was £320m in 2001/2002. [81] Almost 70% of this related to housing and residential care. Community services accounted for 23%, with the balance spent on a range of services including information, advocacy, research, support for carers and campaigning.

## Mental health services in Scotland

Whilst there are many similarities in the mental health services in Scotland compared with England and Wales, there are some important differences. The range of services and treatments available is similar, but there are differences in the legislative and policy frameworks. The new Mental Health (Care and Treatment) (Scotland) Act 2003 became effective in Scotland in October 2005. In addition to setting out the criteria and procedures to be followed before someone can be 'sectioned', the Act strengthens the rights of service users and carers, and also places new duties on health boards and local authorities to provide a range of services for people with a 'mental disorder' ie, mental illness, learning disability and personality disorder.[82]

## Treatments available

Various treatments are delivered by the services described previously, and ideally should be tailored to each individual and their condition. Treatment is reliant upon good service delivery to be effective. Treatments include:

### Medication

Medication is the most common form of treatment for mental health problems in the UK and is usually prescribed by doctors (psychiatrists or GPs). New legislation now allows nurses to prescribe under controlled conditions. Medication acts on the chemical balance in the brain so that thoughts, feelings and behaviour are stabilised. If used in conjunction with talking treatments (see below), medication can make a person's life much more bearable.

Medication is the most common form of treatment for mental health problems in the UK.

For people with common mental health problems, drugs can offer a short-term fix. For those with more enduring problems, medication is a long-term treatment that can allow them to manage their symptoms and lead a relatively normal life. The symptoms determine which category of drug one should take. Categories of drug include: anti-depressants, anti-psychotics, mood stabilisers, and anxiolytics (for anxiety).[83]

Unfortunately systematic monitoring of patients' symptoms before and after medication does not always take place. If monitoring was systematic, then the data could be used to measure the effectiveness of medication and learn about side-effects.

## Electro-convulsive therapy (ECT)

ECT involves sending an electric current through the brain to trigger a seizure, or fit, with the aim, in most cases, of relieving severe depression. The treatment is given under a general anaesthetic and using muscle relaxants, so that the muscles do not contract and the body does not convulse during the fit. Nobody seems to be able to explain clearly how ECT works, and this is a cause of controversy. On the one hand, its critics describe it as a crude treatment that causes brain damage; on the other hand, its supporters defend it as an effective and life-saving technique. ECT is used to treat people with severe depression who have not responded well to other forms of treatment, such as medication.[84]

## Talking treatments

Talking treatments (sometimes termed psychological therapies or psychotherapies) involve the client talking about their problem, usually to a trained listener.[85] There are many forms of talking treatments, including psychodynamic psychotherapy, counselling and cognitive behaviour therapy, each with their own advocates and practitioners. Some practitioners will deliver more than one type of talking treatment to their client. Talking treatments may be provided for adults or children, couples, families and groups.[83]

The following talking treatments are commonly administered:

**Cognitive behaviour therapy (CBT)** is focused on solutions and is particularly effective (see Box 9). CBT works by changing people's attitudes and their behaviour. During the sessions, the client and therapist work together to understand what the problems are and to develop a strategy for tackling them. CBT is usually provided by a psychologist, but doctors, nurses, counsellors and social workers may also use this type of therapy.[86] Online CBT is now used by a number GP practices and specialist mental health services. An important advantage of CBT is that it tends to be short, with 4–12 sessions the norm.

*Photograph supplied by Rethink*

**Box 9: Is CBT effective?**

Clinical trials show that CBT can substantially reduce the symptoms of a number of mental health problems, including depression, anxiety, schizophrenia, anorexia and phobias.

CBT is just as effective as drugs in treating mild to moderate depression and anxiety disorders. National Institute for Clinical Excellence (NICE) guidelines recommend that CBT is offered as a treatment option for people with mild to moderate depression, and that CBT be used in combination with anti-depressants for people with more severe depression.[19] In addition, CBT has been proven to be more effective than drugs in avoiding treatment failures and in preventing relapse after the end of treatment for people with severe mental illnesses, including schizophrenia and severe depression.[27]

**Psychodynamic psychotherapy** is intensive and long term. It is delivered by professional psychotherapists who will focus the discussion on a specific problem, for example, a certain time in the client's life, a relationship or a negative experience. This type of talking treatment is usually provided by the private sector.

**Counselling** provides a regular time and space for people to talk about their troubles and explore difficult feelings, in an environment that is dependable, free from intrusion and confidential. Despite the name, counsellors do not usually offer advice. Instead, they help the client to gain an insight into their feelings and behaviour. They do this by listening to what the client has to say and commenting on it from their particular professional perspective. Counselling is provided by a number of different agencies, including the NHS and charities.[87]

## Complementary therapies

Complementary therapies are those that differ from orthodox Western medicine, and may be used to complement, support or replace it. Complementary therapies include exercise, massage, yoga, aromatherapy, reflexology, nutritional therapy and homeopathy. In a survey carried out by the Mental Health Foundation, 85% of service users found different types of complementary therapies to be helpful and 97% reported finding them helpful at times.[88] Some NHS agencies offer complementary therapies. However, they are more readily available within the private and charitable sectors.[89]

### Exercise therapy

The mental health benefits of physical activity are well established. Exercise has been associated with reduced anxiety, decreased depression, enhanced mood, improved self-worth and body image and improved cognitive functioning.[90] It is also a sustainable recovery choice that promotes social inclusion.

*'When I left the gym that morning I felt as if someone had given me a million pounds – it was the sense of achievement, the fact that I'd been understood, the fact that I'd been able to do some work in a gym, and that I now had somewhere to go every Monday and Wednesday. I also had something to work towards – a goal – plus good support and a nice environment to go into.'*

Bea, 43[91]

GPs can 'prescribe' exercise for their patients, referring them to schemes where they will be helped to develop their own personal exercise programme, under supervision from a qualified trainer. There are now around 1,300 such schemes operating in the UK.[91]

## Addressing service delivery and treatment issues

Service delivery and treatment are interconnected: treatments can only work if delivered effectively; services need therapeutically beneficial treatments to achieve the best result for patients. Treatment and services rely on the availability of good resources, including funds and staff.

Mental health services have undergone huge changes in recent years. The movement away from institutional care, which began in the 1950s, resulted in a rapid decline in the number of people with mental health problems being treated in hospital and a move towards care in the community.[92] Despite these improvements, spending on services is still primarily focused on a relatively small number of people who are severely unwell. Funds have been concentrated on the most difficult patients, who are most likely to harm themselves or others, and those with more common mental health problems have been sidelined. In addition, some spending has been criticised because it lacks a sound evidence base and is not always linked to good outcomes for patients.[24]

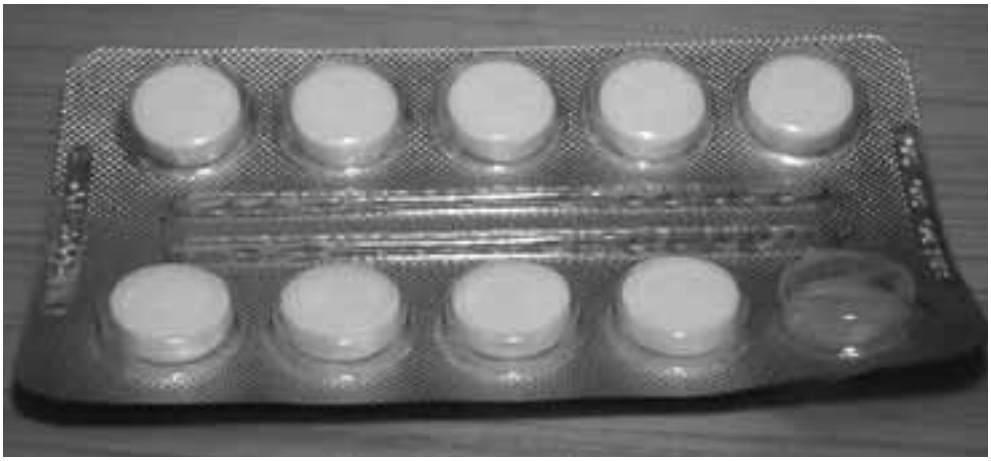
Prescriptions for antidepressant drugs have tripled in the last 12 years.

Patients need alternatives.

Charities can help to improve treatment and services by:

- providing activities that add value to medical services provided;
- offering alternatives to formal health service delivery, eg, crisis houses;
- holding a mirror to government on the state of statutory services;
- identifying areas of need that might be overlooked;
- developing and piloting solutions, sometimes jointly with government, to solve problems of service delivery; and
- lobbying the government to improve services at all levels.

In the past, charities have been successful in influencing government to address problems with service delivery. The National Service Framework (Box 7), which has been helpful in determining the government's strategic direction, had considerable input from some of the larger national mental health charities.



Photograph supplied by Istockphoto

Increasingly we are living in a world with 'a pill for every ill'

## Issues with medication

### Side effects

Many people with mental health problems take medication to mitigate their symptoms. However, a significant number of people on medication experience unpleasant and worrying side effects. Anti-psychotic drugs, for example, have a wide range of debilitating side effects, including hot sweats, spasms, shaking, heart damage, impotence, weight gain and diabetes.

*'It made me so sedated, I could only deal with minimal family commitments. I was sleeping during the day and I've got a seven-year-old child, so the two things don't mix very well.'*

Mental health service user[93]

It can be very difficult to stop taking some psychiatric drugs because of the adverse effects of withdrawal, such as mood swings, memory loss, hallucinations, paranoia, nausea, headaches and nightmares. Some of these effects are identical to the symptoms of distress, which can make coming off medication very difficult.[93]

Foundations such as the **Wellcome Trust** and **Big Lottery Fund,** together with charities such as **Rethink** and the **Mental Health Foundation**, are contributing to research to develop better medication.

### Over prescription

In recent years there have been concerns that doctors are over prescribing drugs, particularly in relation to more common mental health problems such as depression. Increasingly we are living in a world with 'a pill for every ill'.[94] Over the last 12 years, the number of prescriptions written for antidepressant drugs in England has almost tripled, from 9.9 million in 1992 to 27.7 million in 2003.[91] GPs know the problems associated with antidepressants; their clinical guidelines now say that medication should not be used as a first line treatment for mild depression and they are well versed in the merits of offering patients choice. However, many continue to prescribe their patients with medication without offering other options.

The **Mental Health Foundation** carried out some research to determine why this is the case. GPs appear to have limited access to alternatives. In the past three years, 78% of GPs have prescribed an antidepressant despite believing that an alternative approach might have been more appropriate. 66% of GPs have done so because a suitable alternative was not available and 62% because there was a waiting list for the suitable alternative.[91]

### Lack of choice and control

In relation to more severe mental health problems, concerns centre around lack of choice and control over medication.[24] NICE guidelines state that the choice of anti-psychotic medication should be made jointly by the individual and their clinician. Many patients receive cursory guidance on their medication, with limited information about the side effects and alternatives. Charities such as **Mind** and **Rethink** have detailed information on medication, side effects and alternative treatments on their websites. The **Mental Health Alliance** is lobbying the government on the Mental Health Bill, which, in draft form, proposed compulsory treatment in the community (see Box 10)

"It made me so sedated, I could only deal with minimal family commitments. I was sleeping during the day and I've got a seven-year-old child, so the two things don't mix very well."

Mental health service user

**Box 10: Mental Health Bill in England**

The current law governing mental health services in England is the Mental Health Act of 1983. The government plans to introduce a revised Mental Health Bill this parliamentary session, ie, before October 2006. In particular, the government wants to safeguard the public from the perceived risks posed by people with mental health problems. The Bill will adversely affect the treatment and care of thousands of people with more severe mental health problems.

The Bill is being opposed by many in the mental health sector, including professionals, charities and services users. One objection is the introduction of powers to enforce psychiatric treatment in the community, rather than only in hospital. There are concerns that people in need of treatment will not come forward for fear of being compulsorily treated or detained. Another concern is the complication of the discharge process. This would increase pressure on mental health services by blocking beds in inpatient units. Civil liberties are potentially compromised in a number of other clauses.

Sixty organisations have combined to form the **Mental Health Alliance**, which is marshalling the sector's views and proposals to amend the legislation. It has been working hard to help practitioners lobby against parts of the Bill that adversely affect people with mental health problems.

Meanwhile, the Department of Health has announced an extra £130m from 2006 to update acute psychiatric wards and to provide 'appropriate places of safety' when people are sectioned by the police.[29] It is hoped that this will reduce the number of psychiatric patients held in police cells.

It remains to be seen whether the Mental Health Alliance can influence the passage of the Bill through parliament. Even if unsuccessful with the Bill, a side benefit of the Mental Health Alliance is that it has brought together charities, practitioners, people with mental health problems and carers in a way that would not have been possible a decade ago. This could be the Bill's lasting legacy.

## Issues with primary care

### Waiting lists for talking therapies

CBT is effective and many patients want this treatment option.[95] However, there are frequently very long waiting lists for CBT and other talking treatments. The average is six to nine months, and waiting lists of two years have been reported.[24] The government has made moves to address this gap in provision. In recent years the number of psychiatrists and clinical psychologists in the NHS has increased. Between 1999 and 2004 the number of psychiatrists increased from around 2,500 to 3,200, while the number of clinical psychologists increased from 3,800 to 5,300.[24] The government is also expected to announce plans to act on recommendations by the economist, Richard Layard, who argues that an additional 10,000 therapists need to be trained in CBT if demand is to be met in the primary and secondary care setting.[3] If the government does act on Layard's recommendations, questions remain over the recruiting, training, managing and monitoring of these 10,000 new therapists.

Online CBT, such as *Beating the Blues*, is another way to reduce waiting lists of psychotherapies. This programme was designed to be used independently by patients in a GP surgery and does not require the presence of a trained therapist or counsellor. In August 2005 it was recommended by NICE as an option for all people with mild and moderate depression and represents a cost-effective and affordable method of delivering CBT.

Service users may access talking therapies such as counselling through a charity rather than their statutory provider for two different reasons. Firstly, there may be waiting lists for statutory counsellors, and secondly, charities will often have additional services to offer. The charity **Darlington Mind**, for example, provides counselling, as well as IT training, housing support, employment advice and self-help groups.

There are frequently very long waiting lists for talking therapies. The average is six to nine months, and waiting lists of two years have been reported.[24]

Charities provide helplines and crisis houses– plugging a gap in crisis provision that is not met by statutory services.

### GPs' limited understanding

In addition to funding issues, there are concerns around some GPs' limited understanding of mental illness, their failure to respond appropriately and their lack of interest in these problems.[24] GPs' underperformance in the detection and management of mental health problems is also a concern. It is estimated that half the patients presenting with depressive symptoms are missed on their first consultation.[75]

### Limited access to complementary therapies

There has been an increase in the use of complementary therapies within the NHS because of reforms that allow purchasers to commission alternative treatments on the basis of cost and effectiveness. For some complementary therapies, the lack of resources within the NHS and the lack of research on their efficacy has restricted their use.

The charitable sector is a key provider of complementary therapies. The charity **Saheliya** in Edinburgh is an example of a charity that delivers complementary therapies to people with poor mental health. It offers massage to women from black and minority ethnic groups who are facing mental health problems.

The **Mental Health Foundation** has recently launched their *Up and Running Campaign* to increase the use of exercise referral schemes to treat mild to moderate depression and raise awareness about the effectiveness of exercise as a way to treat depression. Only 5% of the 200 GPs surveyed by the Mental Health Foundation use exercise referral as one of their three most common treatment responses to mild or moderate depression.[91] The campaign is targeting GPs, patients and the general public.

## Issues with community care

### Sub-standard community mental health teams

Large numbers of people with severe mental health problems receive support from community mental health teams. These teams are under-funded and under-staffed. Since the creation of the crisis resolution and assertive outreach teams, many CMHTs have been subject to funding cuts and have lost experienced staff with local knowledge.[96] This diversion of resources away from CMHTs is most probably related to the sub-standard service that is frequently reported. Charities such as **Mind** have legal advice lines. Mind receives many calls from service users on CPA that either have not seen their care plan or have seen it but are unable to access the care services they were signposted to.[97]

The charity **Mental Health Matters Pathways** provides an independent advocacy service to help its clients to access the services they are entitled to. It also helps people to make complaints, understand their rights, and make informed choices about treatment and care. Many smaller charities, such as **Lambeth Mind**, provide its callers with local information on where to find advocacy services, as well as other mental health services, both statutory and non-statutory, in the community.

Service users at the **Peter Bedford Trust** 'audit' the services provided by their local mental health services. This has helped local practice to evolve.

### Poor crisis support

In some areas of the country, Mental Health Trusts[xi] have struggled to set up assertive outreach and crisis resolution teams.[97] For example, it is particularly difficult for assertive outreach teams to operate in rural areas. Unfortunately service users cannot rely on the statutory services, especially those that are out of hours.


*Photograph supplied by the Samaritans*

Telephone helplines, such as **Lincsline,** provide an alternative line of support for people in crisis. Participants in a survey carried out by **Rethink** (2005) identified the role of helplines as providing a valuable listening space and emotional support, particularly out of office hours. Participants also felt that helplines could play an active role in the prevention of self-harm and suicide. [98]

*'I suffer from agoraphobia so sometimes I just call if I've not spoken to someone for a while. I also suffer panic attacks and just want to talk to someone who understands the symptoms especially if I am feeling down and depressed.'*

Lincsline service user[98]

**Samaritans** provide a confidential 24-hour service staffed by trained volunteers, offering emotional support. It costs Samaritans £6 per call, in comparison with NHS Direct, which costs £25 per call. **Mental Health Matters Helpline**, **Focusline** and **Saneline** provide callers with a listening ear out-of-hours. Such helplines can offer a lifeline to people in crisis: 21% of Saneline callers are suicidal. In car parks in the New Forest, suicides (by exhaust fumes) dropped from ten to three a year when signs were put up advertising the Samaritans.[99] More prosaically, helplines also provide information on other local and national services specific to mental health. Unfortunately, however, the demand far outstrips supply.

Crisis houses provide out-of-hours or 24-hour support to people at risk of being admitted to hospital. Clients can be referred or they can refer themselves. **Highbury Grove** in North London and **The Nile Centre** in Hackney provide crisis beds for up to three weeks at a time. Providing a place at Highbury Grove costs £113 per person per day, which is cheaper than the cost of NHS inpatient care (estimates range from £144[100] to £260[xii] per person per day). There is evidence that crisis houses reduce hospital admissions. Some professionals believe that they bring about long-term improvements, helping to re-engage people and break cycles of dependency for those stuck in the 'revolving door' that sends them in and out of hospital.[100]

*'It is completely different compared to the hospital. I was in hospital for seven months, the staff sit and read newspapers and dish medication, you are not allowed out. It really does not compare, you get your own life back, people help to pick up pieces.'*

Highbury Grove service user

**Maytree** is a crisis house in North London that caters specifically for the suicidal and requires no referral. It can accommodate up to six people at any one time and the maximum length of stay is four days. It provides a supportive, non-medical environment for people to rest, reflect and recuperate. **Barnet Voice for Mental Health** is a user-led mental health charity. It wants to set up and run a crisis house in the London Borough of Barnet. It will offer accommodation for four people, from 1pm on Friday afternoon until 1pm on Monday afternoon. A support group will be held at the house mid-week to provide ongoing support for those people who have used the crisis house.

## Issues with inpatient care

In England and Wales, there are 38,000 inpatients on psychiatric wards.[2] In order for them to recover, these patients need to be provided with a safe, comfortable and therapeutic environment. There are some examples of good inpatient care, such as West Park Hospital in Darlington (Box 11). However, there are many examples of inpatient care that are sub-standard and even detrimental to people's prospects for recovery. In 2004, Mind carried out a national survey of people with experience of hospital services.[2] The results were shocking. Some 56% of patients felt that the ward was a non-therapeutic environment, 45% felt that ward conditions had a negative effect on their mental health, and 30% of patients found the atmosphere on the wards unsafe and frightening. A study by the Healthcare Commission finds mental health hospitals performed worst out of the 99 NHS and private hospitals inspected in 2005, accounting for all of the six hospitals in the lowest category and the majority of hospitals in the next lowest category.[101]

In England and Wales there are 38,000 inpatients on psychiatric wards.[2]

**Box 11: West Park Hospital**

**West Park Hospital, just outside Darlington, is an example of an excellent NHS facility. It is beautifully designed in a circle, with wards leading off an attractive circular courtyard planted with herbs and shrubs. The atmosphere is calm, welcoming and respectful. The 116 bed unit has been meticulously planned to allow maximum freedom and privacy for patients whilst safeguarding their safety. An objective of the clinical staff is to minimise the length of patients' stays to under a month.**

**Box 12: Jake's story**[1]

Jake was 16 when he developed psychosis induced by cannabis use. He was aggressive and confrontational one minute and would disappear into his own world the next. His parents found it very difficult to cope and struggled to get any professional help. Jake got to the stage where he would not eat, drink or sleep, believing that his food and drink would be contaminated and that he would be abducted if he slept. His GP assured his family it was the effect of street drugs and that he would come down in a couple of days. The community psychiatric nurse paid him a visit soon after, but it was too little too late.

After 15 days of inappropriate and delayed intervention, Jake's condition escalated. His parents called for an ambulance and they sent the police – 20 of them – who arrested him under the Mental Health Act, handcuffed him and put him in a caged van outside the house in front of a crowd. After a stint in a police cell, Jake was transferred to a decrepit secure adult unit (there was no adolescent bed) where he was physically subdued by six male nurse and injected with ultra sedatives. He was sexually assaulted by another patient and escaped.

During his re-arrest he was physically assaulted by two police officers who broke his arm when they handcuffed him. After a spell in hospital he was discharged and failed by the system again. The community psychiatric nurse visits were few and far between. Without the support he needed, he went into crisis again. At 18, Jake relapsed and was sectioned for a second time.

When Jake was discharged from hospital again, his psychiatrist recommended that his parents contact Rethink. The charity put them in touch with The Hollies, one of their community support services that offered advice and information. The attitude of Rethink staff at The Hollies was refreshing and enlightened. They seemed to genuinely understand Jake's problems and pointed Jake and his parents in the right direction to find the help they needed, such as Young Rethink, a support group for carers of 16–25 year olds, covering the crucial transition period between hospital and home. Thanks to Rethink, Jake now receives better support, and despite still being traumatised by his experiences, he is recovering rapidly and is about to embark on living independently.

**Mind** is lobbying the government on the poor state of inpatient wards for mental health patients. In September 2004 the charity launched the *Ward Watch* campaign, to improve conditions in hospital for mental health patients. Smaller local charities also work more directly with service users to deal with the problems highlighted below.

### Mixed sex wards

Despite targets for phasing out 'mixed sex' wards, which the Department of Health insists it has met, 23% of recent and current inpatient in England and Wales have been accommodated in mixed sex wards.[2]

*'I had to spend the first night on a fold up bed in the male wing because there were no beds on the female dormitory.'* [2]

### Safety concerns

A survey for the Healthcare Commission carried out by the Royal College of Psychiatrists (RCP) found that one in three inpatients in psychiatric wards in England and Wales experienced violent or threatening behaviour during a stay lasting, on average, about 40 days.[102] Nearly half of inpatients witnessed such violence.

*'Whilst I have been here on this ward I have been attacked and it was such a horrible thing to happen and I feel so unsafe.'* [102]

The RCP cites drug and alcohol misuse as the primary reason for violent or threatening behaviour. Three quarters of staff said problems were caused by patients getting drunk or taking illegal drugs. As one staff member put it:

*'There is a culture of using drugs and alcohol among the young men. It is almost accepted by staff and little is or can be done to stop it. There is even dealing witnessed on the ward or in the grounds of the hospital.'* [102]

The **Community Support Network (CSN)** in Lambeth is an example of a charity that provides independent mental health advocacy services for people on psychiatric wards. Advocates from CSN provide patients with information on their rights, they help them to get access to better services and encourage them to voice their concerns to staff. The cost per person, per annum is £265. In addition to their generic advocacy service, **Tower Hamlets Mind** has Bengali and African-Caribbean advocates to cater for the language and cultural needs of these BME populations on the wards.

### Non-therapeutic environment

A therapeutic environment is one that promotes recovery; one where there is a choice of treatment, meaningful activities, fresh air, a good standard of food and facilities that are in good repair. Unfortunately for many people like Jake (see Box 12), the hospital environment is quite poor.

*'The ward was dirty and unkempt. Carpets were badly stained and burnt. Furniture was damaged. My room smelt of urine. Doors were locked, although it was an open ward. The whole environment gave out a clear message that you were not worth caring for and did not deserve to be looked after.'* [2]

A report by the Sainsbury Centre for Mental Health on the state of inpatient services reports that only 20% of wards in England and Wales offer CBT, despite its strong evidence base.[103] In addition, many people report a lack of activities and staff engagement with them in inpatient facilities.[92]

*'There is nothing to do here at all except watch TV. The art room has lots of paint but no paint brushes. I find boredom gives me far too much time to think which doesn't help the depression.'*[102]


*Photograph supplied by Theatre Nemo*

> "I haven't thought about suicide since I started with Theatre Nemo."

Boredom not only hinders recovery[2] but it also causes frustration, which can lead to aggressive behaviour.[102]

**Theatre Nemo**, a charity based in Glasgow, delivers arts-based performance workshops in psychiatric hospitals. The workshops, occurring weekly on a drop-in basis, include circus skills (juggling, Diablo, uni-cycling), music and video animation. They relieve the boredom experienced by patients, giving them the chance to take part in activities that are therapeutic, as well as meaningful and fun. **Core Arts**, based in East London, takes its inpatient entertainment (provided by service users) a step further by using to help train staff in how to cope with mentally distressed inpatients.

## Issues with government spending

Although the government has increased resources for mental health problems, this is not necessarily achieving the results intended. The Institute for Public Policy Research (IPPR) has observed that, whilst mental ill health accounts for 13% of the NHS budget, it accounts for 20% of NHS users.[72] Increased expenditure aimed at early intervention, prevention and ways of reducing the high costs of acute and inpatient care is not being spent quickly enough. So the government will not benefit from the savings such activities may be generating (by reducing acute care usage) for some time.

The sums needed are substantial. Derek Wanless's 2002 report found that spending on mental health would need to double by 2010/2011 if the objectives of the National Services Framework were to be met (see Box 7).[104] Health costs (especially drugs) generally inflate more rapidly than inflation, so these pressures often outstrip increases in expenditure. Retaining staff is costly. Funds allocated for current mental health services are swallowed up by Primary Care Trust (PCT) and Strategic Health Authority (SHA) deficits (see Appendix 3). Although spending has increased overall in real terms by 19% between 2001/2 and estimated spending levels in 2004/5, the benefits are not apparent in all PCTs.[79]

Activities by charities can save government resources by preventing deterioration in the patient's condition. Meanwhile charities such as the **Sainsbury Centre for Mental Health** carry a watching brief on government spending to encourage investment in services that will result in subsequent savings.[46]

## Role of research in developing treatments and services

Research helps to determine why people develop mental health problems, how to prevent problems occurring and what to do about problems should they develop. Research into mental health is useful for the development of treatment and services on the following levels:

- Understanding the brain and mind (including genetics) and causal processes that lead to specific states, underpins inquiries into cause, effect, prevention, treatment and care.
- Improving assessment and diagnosis helps to determine which treatments or activities are suitable for which individuals; and
- Improving and evaluating therapies, treatments and social care activities improves outcomes for patients.

A Department of Health study in 2005 revealed that around £75m is spent on research into mental health problems each year.[105] The study unfortunately excludes spending by the Wellcome Trust, which was unable to supply the necessary data, but its spend is estimated at £25m per annum.

**Figure 9: Annual spend on mental health research and related neuroscience research**

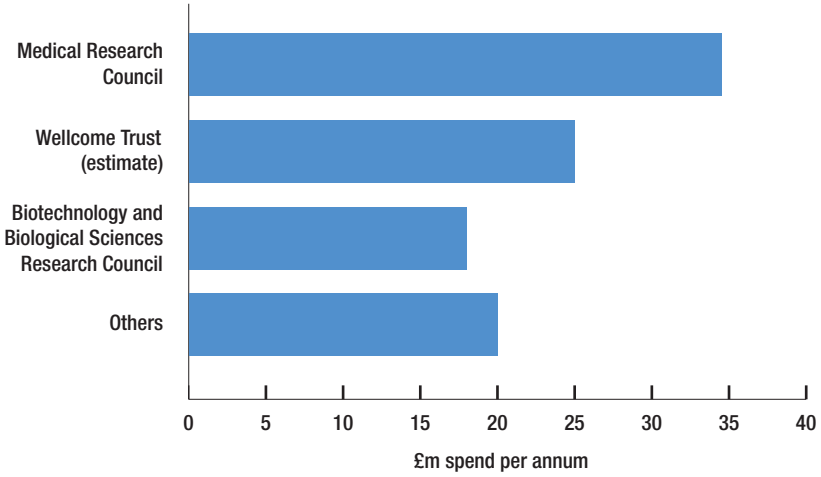



Figure 9 shows annual spend on mental health research and related neuroscience research by funder and includes spending on brain and developmental disorders such as autism, dementia and learning difficulties (which are not included in this report). If these disorders are excluded, spending drops to £56m. By comparison, the annual spends on cancer research in the UK is £1bn. Mental health research in the US is £1bn.

**Figure 10: Annual spend by research type (%) [105]**

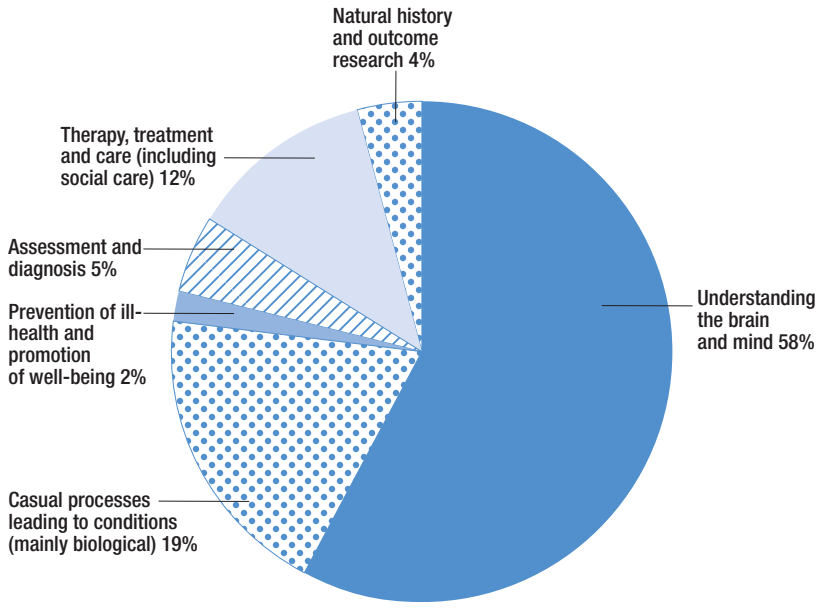



Figure 10 shows how the combined funds (excluding Wellcome Trust) are spent on different types of research.

Unlike cancer, there is no charity specifically dedicated to medical research into mental health in the UK. Although the Mental Health Research Funders Group has been convened to share information and to coordinate efforts, it is not an organisation in its own right. The absence of a charity with a particular focus on medical research is perceived as a disadvantage to the sector.

Some charities deliver services and conduct research. **Sane** has a dedicated research centre focusing on causes and treatments for schizophrenia and bipolar disorder. **Rethink**'s research agenda is in development, but it is keen to promote greater involvement of users and carers and to develop a research fund similar to that seen in the cancer sector, to support researchers around the country. The Department of Health is also keen that such a fund is developed in order to fill gaps in the evidence base for conducting research. All service deliverers could add to the evidence base by the systematic collection of data, and many charities, including **Mind** and the **Samaritans**, are starting to develop this process.

Funders are faced with a choice as to whether to support research centres housed in one physical place or institute, or to support a virtual collaboration of researchers in the field with no central physical point. The advantages of virtual collaborations are the low-cost base and the likely proximity of researchers to service users. However, a physical location has the advantage of bringing researchers together by the water cooler.

## Summary

Mental health services and treatments have been improving over recent decades. However, further improvements are still urgently needed. Greater investment in early and effective treatment and services should, in the long run, result in patients whose conditions are managed more effectively. This would result in less money being spent on inpatient and other acute services.

Although the government has, in theory, embraced this challenge, it needs the help of charities to achieve its objectives.

Charities can:

- provide services that contribute to recovery rates (eg, Theatre Nemo);
- remind government of its obligations and failings (eg, Mind's Ward Watch);
- help the government to develop more effective services (eg, Rethink's work on early intervention in psychosis; SCMH helping to implement the NSF);
- lobby for available solutions to be implemented (eg, Mental Health Foundation's work on exercise prescription by GPs); and
- provide a voice for people with mental health problems who deserve better legislation on mental health issues (eg, Mental Health Alliance's input into the Mental Health Bill).

Achieving these objectives will help to improve the lives of many people with mental health problems.

# How else is mental health improved?

3

**People's social circumstances can affect how they feel, how they cope with mental health problems and their chances of recovery. Stigma and discrimination, lack of work, debt, housing problems, social isolation and family pressures will have a negative impact on a person's mental health. Unfortunately, nearly a million people are out of work because of mental health problems and less than a quarter of people with long-term problems are in work. One in four tenants experiencing mental distress has serious rent arrears problems and risks losing their home; and 84% of people with mental health problems feel lonely and isolated. Preventing mental health problems by improving the fabric of society would obviate the need for so many resources to be devoted to people in mental ill health. Charities provide invaluable social support to people in mental distress and disadvantage. In doing so they are preventing crises, promoting recovery of the mentally ill and strengthening the mental health in vulnerable groups of people.**

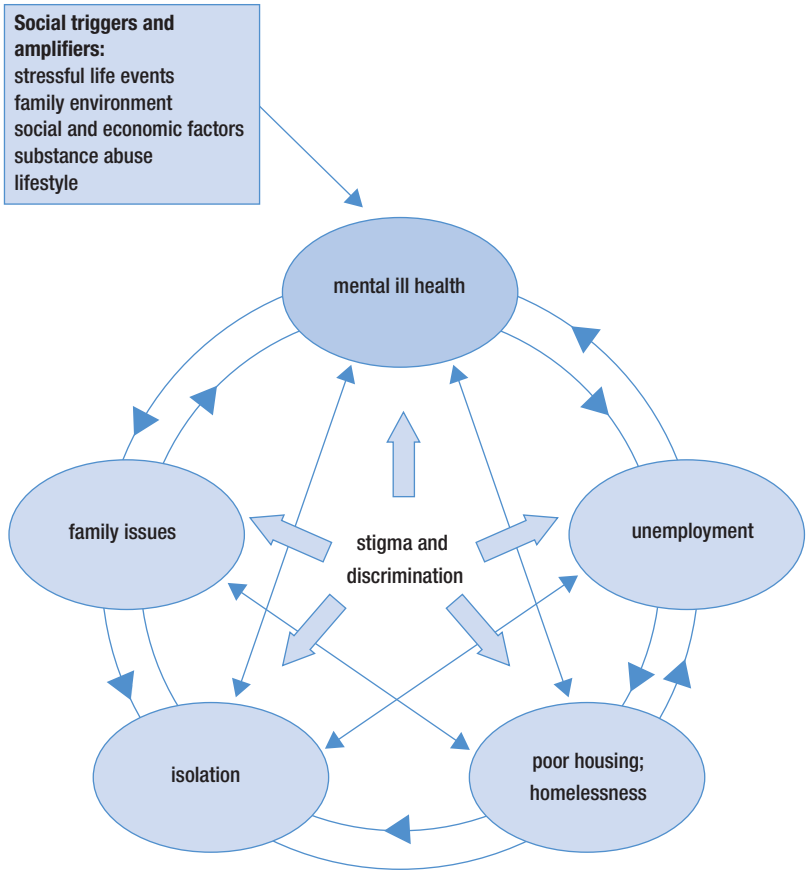
Treatment, care and services, covered in the previous section, are only half of the story where mental health is concerned. This section covers the social environment of people with mental health problems. Social factors such as unemployment, family pressures, homelessness, isolation and stigma are at the same time the cause and the consequence of mental ill health. If an individual's social situation improves, then so should their mental health.

This section examines how efforts to improve the social environment complement the efforts described in the previous section. It focuses on the circular action of cause and effect (see Figure 11) and breaks the issues down into the following areas:

- **Prevention**: tackling the social triggers and amplifiers of mental distress reduces the problem in the first instance.
- **Stigma and discrimination**: combating stigma reduces problems with employment, isolation and exclusion.
- **Employment**: gaining employment can improve recovery at the same time as helping to solve issues such as poverty, housing and isolation.
- **Housing**: living somewhere decent improves chances of recovery.
- **Isolation**: reducing isolation helps people to recover self-esteem and a sense of purpose, which also aids recovery.
- **Family**: supporting carers at home helps them to help the person they are caring for and also ensures that they maintain their own health.

> "O, let me not be mad, not mad, sweet heaven,
> Keep me in temper;
> I would not be mad."
>
> Shakespeare: *King Lear*
> Act 1, Scene 5

**Figure 11: The downward spiral of mental ill health**




Firstly each issue is explained, and then solutions to problems and the role of charities are described.

The section has a separate sub-section dealing with black and minority ethnic (BME) groups. The issues confronting these groups are particular as well as acute.

*Photograph supplied by Don McPhee/The Guardian*

## Prevention

Prevention is better than cure. Given that there are a number of causes of mental ill health, there are a number of different ways in which mental health problems can be prevented. Charities can help by:

- working to tackle the factors that cause or amplify mental health problems of adults, such as drugs misuse and child abuse; and
- promoting good mental health to the wider population.

## Tackling triggers and amplifiers

Tackling factors that trigger mental ill health is one way to prevent future problems. Section 1 grouped these interlinking issues as follows:

- stressful life events
- family environment
- social and economic circumstances
- substance abuse
- lifestyle

Avoiding or mitigating such issues will reduce the numbers of people suffering from mental health problems. Allocating effective resources to vulnerable groups may reduce the likelihood of problems developing in such populations. NPC's research programme covers many areas that impact on people's mental health. Some of the research is complete and other areas are not yet started. A list of completed and forthcoming research is at the back of the report.

### Stressful life events and family environment

Stressful life events range from divorce or job loss, to more serious experiences such as combat stress or rape. Some stressful life events overlap with the family environment, for instance domestic violence or the death of a parent.

Taking domestic violence as an example: between 175,000–350,000 women suffer mental health disorders resulting from domestic violence each year. So reducing the number of women experiencing violence by 10% would imply a 17,500–35,000 reduction in the number of women experiencing mental ill health. Therefore, supporting charities that tackle domestic violence is helpful in tackling mental health problems too. NPC's report *Charity begins at home* identifies domestic violence charities that are achieving excellent results.

General child and adolescent mental health and emotional well-being is likely to have a bearing on mental health in adulthood. Initiatives to improve childhood experiences, such as tackling child abuse and truancy and exclusion, will reap future benefits. This report talks about children and young people in more detail below.

### Social and economic circumstances

The report has already discussed how deprivation and mental ill health are mutually reinforcing. Arguably, improvements in the social and economic conditions of deprived populations would help to improve mental health.

### Substance abuse

Substance abuse (including alcohol abuse) may trigger mental health problems, or at the very least exacerbate existing problems. For example, the effects of cannabis use are increasingly well understood. Young cannabis users have a twofold increase in the risk of developing schizophrenia. Elimination of cannabis use would therefore reduce the incidence of schizophrenia by 8%.[68] A reduction of this scale would potentially reduce the number of mental health problems in 48,000 young people.[xiii]

### Lifestyle

The evidence that our lifestyle, including diet and exercise, affects our mental well-being is increasing. Addressing lifestyle issues is likely to improve our mental health. The **Mental Health Foundation** has recently published a report on the role of food in relation to mood and mental well-being. Together with the charity **Sustain**, the alliance for better farming and food, it has launched a campaign to increase awareness and understanding about the links between food and mental health and to press for shifts in policy and practice as a result.

### Vulnerable groups

There are many groups of people who are particularly disadvantaged and who therefore experience greater mental health problems. Refugees and asylum seekers, older people, and ex-servicemen are some examples. Other groups such as prisoners are particularly vulnerable.

## Improving the well-being of children and young people

One in ten children between five and 16 years old has a clinically diagnosed mental disorder.[106] Just under half of these diagnoses relate to anxiety or depression. The rest include behavioural or other disorders, such as autism. According to the charity **YoungMinds**, only 27% of the children who require help for mental health problems receive any assistance.[107]

Those who have mental health difficulties in childhood and adolescence are likely to carry problems into adulthood, unless they are dealt with quickly and effectively when the problems first emerge. It is also likely that a child's emotional well-being at school and at home may have a bearing on their future mental health, even if mental disorders are not obvious in childhood.

There are certain groups of children (discussed below) who are particularly vulnerable and are susceptible to mental ill health. Interventions that target such groups will reduce the likelihood of these children experiencing mental illnesses. To go one step further, efforts to prevent these children from becoming vulnerable in the first place will be a good social investment and will have positive outcomes for their mental health in the future.

### Truants and excluded children

NPC's research on truancy and exclusion, *School's out?* discussed mental health and behavioural problems of children at school. Common problems exhibited by children with mental health problems are disruptive, antisocial or aggressive behaviours. These problems then follow children into adulthood. Pupils who persistently truant or are excluded from school have very poor life chances. They leave school with no qualifications and excluded pupils are two-and-a-half times more likely to be out of work at the age of 19 than their peers. They leave school with low self-esteem, low confidence and few expectations. Excluded pupils are ten times more likely to use Class A drugs than non-excluded pupils and 65% of young offenders have been excluded or truanted regularly.

Together these factors result in higher levels of mental ill health:16–18 year olds not in education or employment are more likely to experience mental illness and depression at age 21; and truants are three times more likely to report depression in early adulthood. *School's out*? recommends a number of charities that are doing excellent work tackling the problems of truancy and exclusion.

### Looked after children

Children who are looked after by social services rather than parents are particularly vulnerable to mental ill health: 40% of looked after 10–15 year olds had significant disorders compared to 6% of children in private households.[108] Upon leaving care, 60–90% of looked after children have or will develop mental health difficulties.[109] Future NPC research will consider the reasons for this and potential actions in more detail.

### Abused children

Sexual abuse of children can result in sustained symptoms of psychological distress. In a 1998 study of abused children under 16, two years after initial contact, over 30% of children reported anxiety, depression, attention problems, sleep problems, difficulties at school and anger.[110] Eight per cent had attempted suicide, 10% were misusing substances and 17% had eating disorders. Problems with peers and sexual behaviour were also reported. These percentages were for individual difficulties, however. In aggregate, over 60% had problems of some sort, and in later follow-ups 37–41% indicated some sort of psychological or psychiatric disorder. Given that the prevalence of disorders in children is normally 10%,[106] in both absolute and comparative terms these numbers are high. NPC began research into child abuse in early 2006.

NPC has also briefly investigated bullying as part of its education overview, *On your marks*. At its most extreme, bullying can result in suicide.[111] More generally depressive and suicidal thoughts are more frequent among young people who have been bullied.[112]

### Cannabis users

Just over 14% of 16–24 year olds in this country have smoked cannabis in the last month and just over four in ten have tried it in their lifetime.[xiv,113] As drug use can trigger and exacerbate mental health problems, tackling

Around 5% of children have a mental health problem. Children who are abused or are in care are especially vulnerable.

Reducing the use of cannabis among young people would help to prevent future problems.

drug use (and also alcohol abuse) would go a long way to preventing future problems. NPC intends to carry out research on substance misuse in the near future.

Good diet and exercise helps to maintain good mental health. Promoting healthy lifestyles is important in combating the increasing incidence of depression.

## Promoting good mental health

It is important to recognise that everyone has mental health needs, whether or not they have a diagnosis of mental illness. Promoting the mental health and well-being of the general population, as well as that of vulnerable groups, is crucial if the mental health of the nation is to be improved.

Mental health promotion programmes work at the individual and the community level. At the individual level, they work to increase individuals' emotional resilience through interventions designed to promote self-esteem and life coping skills. Interventions that strengthen communities might focus on social inclusion and participation, improving neighbourhood environments, workplace health, community safety and self-help networks. Box 13 outlines an original experiment that was successful in promoting good mental health in Slough.

**Box 13: Making Slough Happy**

**In an unusual three month experiment, six experts from a variety of disciplines worked to improve the well-being and happiness of the people of Slough in Berkshire. The team of specialists tested techniques from the new 'science of happiness' on 50 Slough inhabitants. These measures included having a good laugh, saying 'hello' to one stranger a day, nurturing a plant, finding time to talk to loved ones, cutting TV viewing by half and exercising more. At the end of the experiment the volunteers' happiness levels were 33% higher than they were three months earlier.**

Making Slough Happy was broadcast on BBC2, Winter 2005

The National Institute for Mental Health in England (NIMHE) is implementing the 'mental health promotion' standard of the NSF for mental health. This involves increasing people's knowledge, skills and capacity to achieve positive mental health, through working with the media, families, schools, universities, employers and the voluntary and public sectors. One of its activities is the promotion of the 'five fruits and vegetables' of mental health (see Box 14).[9] However, there are question marks over the programme's ability to bring about change due to funding restrictions. The proportion of funding spent on promoting mental health (and preventing mental ill health) is only 0.1% of total mental health spending.

**Mentality** has advised NIMHE on how to implement the 'mental health promotion' standard of the NSF for mental health. As well as working with NIMHE and the public sector

**Box 14: NIMHE's 'five fruit and vegetables' equivalent for mental health:[9]**

**Keeping physically active • eating well • drinking in moderation • talking about your feelings • keeping in touch with friends and loved ones • learning new skills • doing something creative • caring for others • valuing yourself and others • getting involved and making a contribution • taking a break • asking for help**

to promote mental health, it works with the private sector, user and survivor groups and voluntary agencies to promote the mental health of individuals, families, organisations and communities. It has a number of activities, including consultation management, policy advice, training and research.

**Plymouth and District Mind** promotes mental health to students in 18 secondary schools in the local area. Its aim is to raise the awareness and understanding of mental health issues, to promote positive attitudes towards mental health, and to improve the coping abilities of young people in stressful situations. The programme focuses on subjects such as general mental health, stress management, eating disorders and bullying.

The **Mental Health Foundation (MHF)** promotes ways to improve the mental health of the general public. MHF's report *Feeding Minds*[70] highlights the links between diet and mental health and makes recommendation to government to improve the nation's diet. If by adding its weight to the national debate on diet more people eat better food, this will help reduce the occurrence of depression.[70]

Effectiveness of mental health promotion is difficult to measure, so when the MHF embarked on its mental health promotion programme in 2005, a central plank of the work included an evaluation of mental health promotion efforts. **Mentality** is also active promoting good mental health and has produced a helpful report on the available evidence of what works.[114]

## The role of research in prevention

Activities relating to the prevention of ill health and the promotion of well-being need evaluation. Better data gathering on the benefits of activities designed to improve people's social environment is also needed. More data is also required to develop the evidence base for promising social activities.

Not enough money is being spent on these areas. Figure 10 identified research spending patterns: only 2% is being spent on prevention and on the promotion of well-being. The sector is looking for support to develop a coherent strategy for gathering the data and evidence required to determine the best help for people with mental health problems and those at risk.

There are charities such as the **Sainsbury Centre for Mental Health, Mentality** and the **Mental Health Foundation** undertaking non-medical research. These efforts contribute to the understanding of the social environment and help to evaluate a range of approaches benefiting people with mental health problems.

## Stigma and discrimination

Stigma is at the root of many problems faced by people with mental health difficulties. Isolation, discrimination, barriers to employment, poor access to services; such problems arise because of the public's negative perceptions of mental ill health, perceptions that are based on myth rather than reality.

Charities and central government face the challenge of reversing public antipathy towards those who are mentally unwell. It requires effort on more than one level:

- improving media presentation of people who are mentally ill in order to reduce negative stereotypes; and
- challenging misconceptions through personal contact between the mentally well and the mentally ill.

### Public attitudes

In 2003, 1,737 adult members of the general public were asked by the Royal College of Psychiatrists about seven common mental health problems: severe depression, panic attacks, schizophrenia, dementia, eating disorders, alcoholism and drug addiction.[115] Most respondents (60–80%) regarded people with schizophrenia, alcoholism and drug addiction as unpredictable and dangerous (see Box 15). This survey was conducted after *Changing Minds*, a five-year campaign to reduce the stigma of mental illness. The respondents generally viewed people with mental health problems as being difficult to communicate with and empathise with. There was little sympathy for problems that were seen to be self-inflicted, such as addiction problems and eating disorders.[115] This sample demonstrates the stereotypical and inaccurate perceptions of mental distress held by the general public.

**Box 15 : Perceptions of people with mental health problems**

***'People with mental health problems are dangerous and violent and should be locked up.'***

**Although the number of homicides doubled between 1967 and 1997, and during this period the number of mental hospital beds halved, the number of people with a mental illness who committed murder remained almost unchanged. Since 1990, fewer than 90 homicides each year have been committed by someone with mental health problems.[23, 24] Less than a quarter of people committing homicide have ever had contact with psychiatric services, a number not dissimilar to the one in four lifetime prevalence in the wider population of mental health problems.**

**For comparison, twice as many women are killed each year in domestic violence incidents.[30] A person is more than 50 times more likely to be killed in a road accident than by a person as a result of mental health problems. Alcohol, drugs or fights are more frequent triggers of homicidal attacks.[32] However, it is important that people with mental disorders and schizophrenia are treated appropriately so that risks are minimised.**

### Effect of negative attitudes

People with mental health problems are at the receiving end of high levels of stigma and discrimination. In a survey of people with mental health problems in 2004, 83% of respondents identified stigma as an issue without any prompting.[5] Stigma affects people in the following ways:

- fear and discrimination lead to a loss of confidence and self-stigma, causing people to withdraw;
- prejudices fuel social isolation;
- discrimination is a barrier to accessing services and employment; and
- popular prejudices may also compromise the civil liberties of those affected.

In the same survey, 55% of respondents saw stigma as a barrier to employment and 52% mentioned negative attitudes towards mental health in the community.[5] In another survey, 75% of respondents felt that a lack of understanding by others leads to isolation.[116]

Stigma permeates a surprising range of situations. Even within health services people with mental health problems experience difficulties in getting their physical symptoms taken seriously. In 2000, 44% of people who had experienced mental distress had also experienced discrimination from their GP.[117] Anecdotally NPC heard that, in some inpatient units, even psychiatric staff exhibited poor attitudes towards those in their charge.

*'I have been told everything [by the GP] from "snap out of it" to "I can only help if you are suicidal'*

Service user[117]

*"I feel reluctant to admit I've got mental health problems; the stigma and rejection are too hard to face."*

Person with a mental health problem[10]

*"Those nutters up at West Park – some of them are free to come and go. They should be locked up for good."*

*Taxi driver expressing his opinion of the new inpatient unit in Darlington.*

47% of people with mental health problems experienced verbal or physical abuse in public.[5]

The fact that 47% of people with mental health problems experienced verbal or physical abuse in public is shocking, but not as disturbing as the 56% who reported discrimination from their own family, often as a consequence of negative media images. Children and young people are particularly intolerant of people with mental health problems.[5]

*'Acquaintances who have no experience of mental health take any knowledge from the media, and laugh and are disrespectful. I find my mental health problems are best kept secret because even close friends and family have been influenced by the media.'*

Service user[118]

The issue of employment, including discrimination in the workplace, will be discussed later in this section. People with mental health problems are also denied civic opportunities. Incredibly, current legislation disqualifies anyone from serving on a jury if they have been admitted to hospital or receive regular treatment for mental health problems.[119]

Stigma and discrimination also negatively affect government policy despite official government efforts to overcome stigma. At the time of writing, the drafting of the new Mental Health Bill (see Box 10) was being hotly debated. Mental health practitioners (in both government and the charitable sector) were viewing the Bill as a product of the Home Office in response to public perceptions of madness equalling violence, rather than in response to the health and social care needs of people with mental health problems and their families.

The effects of stigma and discrimination – self stigma, loss in confidence, isolation and fear – all combine to cause deepening mental distress.

## Tackling public attitudes

### Awareness raising

Changing public attitudes to mental distress and to people experiencing mental health problems is difficult. Negative attitudes occur on two levels: the person (will the mad person act weird all the time and never get better, in which case can we put them somewhere where they won't disturb us?) and the behaviour (if the person acts weird, what are we supposed to do?).

The public needs to understand that if someone is mentally ill, it does not mean that they are incapable. The public also has to understand that when a person is ill, they are still a person who needs to be treated as such.

Mass media campaigns, such as Scotland's *See Me* campaign involving posters and TV adverts, are thought to be effective in raising awareness, particularly if they play to local culture. However, the ability to change attitudes across a large nation through such campaigns is limited.

The presentation in the media of people with mental health problems affects public attitudes,[10] and so efforts to influence the media are important. **Mental Health Media, Mind, SANE, Rethink** and the **Samaritans** are all active in working with the media to improve presentation.

In 2004 the government launched an anti-stigma initiative in England called *Shift*, which targeted:

- young people via schools and the National Union of Students (NUS)
- public sector employees across most departments, prioritising NHS and social care
- private, voluntary and professional organisations
- media and the public.

There are a number of charities on *Shift's* advisory board, including Rethink, Mental Health Media, Mentality, Mind, SANE and the Mental Health Foundation. *Shift* recognises the need for efforts at both national and local levels and for those affected to be involved. However the budget (£1m for 2005/2006) is smaller than Scotland's *See Me* campaign (£4m per annum for three years).[109]

**Mental Health Media** has focused on the problem of discrimination for 40 years. As well as being involved with *Shift*, it holds an annual award ceremony for good media practice – the Mental Health Media Awards. Entries for this award doubled in the last year. Mental Health Media also trains people with mental health problems so that they have the tools to influence the media themselves in their local areas. For instance they might feel able to campaign about a derogatory reference to people with mental health problems in a local advertising campaign, or make their own materials for distribution to service providers, commissioners and people in education (see Box 16 on the Bleakest Ink). Such training gives people with mental health problems the tools to express themselves. By speaking about their experiences to local and national media, they are helping to combat stigma and discrimination. **ok2b** raises awareness of mental health issues by putting on high-profile events such as concerts, music festivals and comedy nights. It has only just become a registered charity so it is still young and unproven.

**Box 16: The Bleakest Ink**

The New Way Forward user group, which works with Mental Health Media, has made a video satirising The Weakest Link. It uses the quiz show format to explode myths around mental health at the same time as exposing poor media representation. The makers say:

*'We wanted to create a piece of work that would highlight how the media demonises us, and how that in turn affects the way the rest of society treats us … We have shown the film to a number of service users and professionals who were all profoundly affected by it. Some felt that it showed just how much knowledge around mental health and treatments we users have, and that it would show professionals how narrow their own fields are. … Some felt it gave … a sense of how mental illness can have a positive effect on your life, not just a negative one.'*

### Personal contact

Another way to break down public prejudice is for people to meet those who are affected by mental health problems. Personal contact changes attitudes more effectively than poster campaigns. Charities are well-placed to stimulate social contact between those experiencing mental health problems and the wider public. Given experiences of abuse amongst their users, many charities and projects are reluctant to 'mainstream' their activities. In many instances it is appropriate to give those affected a safe space in which to access services and meet people in similar positions. However, some projects are active in engaging with the general public so that people with problems form contacts with people who are well.

**South Tyneside Arts Studio,** a community arts centre in South Shields, is split 50:50 between service users and people not directly affected by mental distress. Charitable social firms employing people affected by mental health problems frequently provide public and commercial services. In this way the public comes into contact with people with mental ill health and gains a better understanding of what it means to be mentally ill. **Theatre Nemo** puts on performances in the community involving people with mental health problems. This helps to demystify mental ill health for the general public.

However, in these circumstances members of the public are generally meeting people with mental health problems on their 'good days' and they therefore seem 'normal'. A greater challenge is to change attitudes so that the public can cope if someone is having an episode of distress, which can be frightening for the uninitiated.

A **Mental Health First Aid** course has been successfully developed in Australia. The course trains people in basic mental health literacy and what to do if a person is agitated or distressed. Trials indicate that after training, people are better equipped to recognise mental health conditions, more confident in proposing appropriate action and feel less distanced from the distressed person.[120] **Mentality** is aiming to disseminate the course in the UK and would target people most likely to have to deal with people with mental distress: benefits agency workers, teachers, ambulance drivers and police.

This approach is not dissimilar to two intensive local projects undertaken with the police and school children by the Institute of Psychiatry.[121] Personal contact was particularly important in improving attitudes among school children.[122] Young people form stigmatising opinions early, which is why the government is addressing young people in its *Shift* programme. The **Mental Health Foundation**'s *A Place to Be* initiative in primary schools has influenced the guidelines for professionals in this area.

Local initiatives such as this will reinforce gradual improvements to messages within the media.

## Employment

Employment is good for mental health. Meaningful activity provides most people with a sense of purpose and achievement. Employment also improves income levels. However, too many people experiencing mental distress are not employed. Some of these people may be distressed because they are unemployed. Others may be unemployed because they have mental health problems. The data does not distinguish between categories. It is clear that unemployment and mental ill health result in a vicious circle with the added burden of worsening finances.

One third of people coming onto incapacity benefit cite mental health as their main disability.[5]


*Photograph supplied by Mental Health Media*

> I don't like it. Because I feel I do nothing and therefore don't deserve to eat or live.[15]

Charities are at the forefront of helping people to move towards employment after an episode of illness. The government is now adopting some of the techniques developed by charities. Charities can also help people to retain work once they have found it and even help to prevent people from losing their jobs in the first place.

## Links between mental health and work

### Many people who do not work have mental health problems

Statistics show how mental health and unemployment are closely linked. Around 35% of people coming onto incapacity benefit (benefits claimed by people who are unable to work due to mental or physical health problems) cite mental health as their main disability.[5] In the UK in 2004, there were more than 900,000 people claiming incapacity benefit due to mental health problems.[24] In addition, once people start to claim incapacity benefit, their chances of working again diminish. The average period of claim is eight years for someone who has been claiming incapacity benefit for one year.[123]

### Many people who have mental health problems do not work

A statistic from the Social Exclusion Unit report on mental health looks at the issue from a different angle. Only 24% of people with long-term mental health problems are in work, the lowest employment rate for any of the main groups of disabled people.[5] Those who are not employed are likely to have persistently low incomes as a result.

### Work is good for individuals

There is almost universal recognition that work is good for mental health. Studies show that having a job can lead to a reduction in symptoms,[124] fewer hospital admissions,[125] reduced service use[126] and improved social functioning.[127] This is because employment can give people a sense of purpose, an identity, financial benefits and opportunities to meet new people, all of which boost confidence and self-esteem. Conversely, unemployment can be harmful to our mental health.[128] As well as the loss of income, people can experience a loss of identity, loss of confidence and low self-esteem. Unemployed men face a two to three times' greater risk of suicide than the general population[53] and prolonged unemployment is linked to worsening mental health.[129]

Work is sometimes blamed for problems. For instance, 500,000 people believed work-related stress was making them ill in 2001–2002.[130] However this does not imply that work is bad in and of itself. It is more likely that employment practices, particularly jobs that are by nature stressful, are not minimising problems arising from stress.[131]

### Supporting people at work is good for employers

It is in the employer's best interest to deal with their employee's mental health problems early. Although there is no published cost–benefit analysis proving this, employment insurers know this to be the case.

*'We find that organisations that are proactive in managing their employees' mental health get better business results. This is not just about being nice to people, this is enlightened self-interest.'*

Occupational health insurance broker[132]

In view of this positive correlation between work and mental health, it is essential that measures are taken to help people with mental health problems either:

- to retain employment (if they are in work); or
- to acquire employment (if they are out of work).

## Tackling barriers to work

Many people with mental health problems want to work (see Box 17), but they face a number of barriers. These include stigma and discrimination, problems with the benefits system and a lack of support.

### Stigma and discrimination

Stigma and discrimination, both realised and perceived, are major barriers to gaining and retaining work. Fewer than four in ten employers would recruit someone with a mental health problem.[5] The problem is so acute that some people have reported that they would find it easier to find work after a prison sentence than a spell in a psychiatric unit.

**Box 17: Myth**

***'People with mental health problems can't work and don't want to work.'***

**Contrary to this myth, 35% of people with mental health problems are economically inactive but would like to work[5] Aspirations to work are widespread (around 50% would like to do so), even amongst those who have lost touch with the labour market over an extended period.[25]**

**Research shows that even those with severe and enduring conditions can gain and retain employment if they have the right kind of support (34% according to one piece of US research [31], 55-75% according to another.[25])**

*'On two occasions I lied when I applied for jobs. On both of 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 short-listed for the second. Whenever I have been truthful about my psychiatric past, I have never been accepted for a job.'*

30-year-old man, diagnosed with obsessive compulsive disorder[10]

Mind carried out a survey of the discrimination in the workplace. One third of respondents report having been dismissed or forced to resign from their job.[133]

Ironically it is sometimes those who work closest with people with mental health problems that unintentionally help to create barriers to employment.

*'Clinical and social care services often compound the very real problems of stigma and discrimination from employers and the general public by having as their basis the implicit assumption that they are there to support people out of work rather than in work.'*

Bob Grove, Sainsbury Centre for Mental Health[127]

There is also evidence of people having to leave work as a consequence of stigma and discrimination. Advisers at the Citizens Advice Bureau (CAB) came across a contract offered to one of their clients with a history of mental illness that contained the clause: '*The employer may end the employment … if you become of unsound mind or a patient under the Mental Health Act 1983.*' In a CAB survey on behalf of the Social Exclusion Unit, 60% of CAB advisers reported incidents where stigma, prejudice and discrimination in the workplace had caused people to give up work. One CAB client had her GP sickness certificate pinned to the staff notice board and photographed. Another client reported that his colleagues would say '*the men in white coats will be coming in a minute*' whenever he had difficulties. Attitudes like this discourage people from trying to get back into employment.

*'I tried to return but found it difficult "to fit in"; everyone knew, I felt quite stigmatised.'*[15]

The Disability Rights Commission has a number of cases on its books relating to dismissal for mental health problems, withdrawal of job offers upon learning of mental health history and outright rejection of applications where mental health histories are disclosed.[134] Many cases are ultimately settled out of court (see Box 18).

**Box 18: Employers' legal responsibilities**

**Under the Disability Discrimination Act (2005) employers have legal duties not to discriminate against disabled employees and job applicants, including people whose mental health problems result in them being disabled.**

**Employers must also make reasonable adjustments to the workplace and working conditions so that disabled people can work. However, not all employers or people with mental health problems will be aware of this. In addition, 'making reasonable adjustments' can be very hard to define and argue in court.**

Fewer than four in ten employers would recruit someone with a mental health problem.[5]

*Photograph supplied by Mosaic Clubhouse*

### Benefits system

The benefits system is a major barrier to people with mental health problems taking up employment. The rigidity of the rules, the complexity of the system, the anxiety and stress experienced in claiming benefits all prevent people with mental health problems from trying out work.[135]

*Inflexible rules*

A common concern for people with mental heath problems on benefits is what they perceive as a major leap from being unemployed and on benefits to full-time employment. The inflexible benefits rules prevent many people from going back to work for fear of losing benefits.

*'If you say you're well you lose benefits, but you don't know if you will cope with something until you have tried, so how do you know?'*

Benefits claimant[15]

The inflexible benefits rules prevent many people from going back to work for fear of losing benefits.

The Department for Work and Pensions (DWP) has addressed this by introducing more flexible rules. People who leave incapacity benefit to move into work or training (who can show that they had to give up work for health reasons) and reclaim the benefit within one year for the same health condition, will re-qualify for the same level of benefit (a linking rule). However, people with mental health problems are not confident that this will happen in practice and are fearful of what could happen if the relapse happened after one year.

The DWP has also introduced Permitted Work Rules (Box 19). Anecdotal evidence suggests that these rules are valued, but confusing and difficult to understand. The £20 weekly permitted earnings is seen as restrictive and too low.[135] In addition, the period of 52 weeks may be too short for some people to make the transition from permitted work to full-time employment. As such, it can put unnecessary pressure on people to move to full-time employment, inducing stress, which undermines progress into work and recovery.[24]

**Box 19 : Permitted Work Rules[5]**

**There is evidence that helping people with mental health problems to increase their hours gradually can improve their employment prospects. 'Permitted work' aims to bridge the gap between benefits and full-time work for people getting incapacity benefit.**

**Under the Permitted Work Rules, people can earn £20 a week for an unlimited period. Alternatively they can work for less than 16 hours a week (if a person works over 16 hours they cannot claim incapacity benefit), with earnings up to £81 a week after deductions, for a 26 week period. This can be extended for a further 26 weeks if the person is working with a specified job broker (eg, The Shaw Trust). After 52 weeks of permitted work, a further 52 weeks must elapse before permitted work can take place again.**

The charity **Mind** is currently campaigning on welfare benefits, specifically the reform of incapacity benefit. It has been in dialogue with the government to try and ensure that any changes in future do not penalise people with mental health problems who have to claim incapacity benefit.

*Lack of advice and complexities of the system*

People with mental health problems coming onto benefits for the first time find the system frustrating. On becoming ill, the lack of advice and the complexity of the system can be a major cause of financial hardship and stress. Many people experience problems and delays in registering for and receiving benefits.[135]

*'My payment was delayed for two months. I got into debt, became more stressed and anxious and my health just went downhill.'*[135]

Research by **Mind in Croydon** reveals that only one in three people with mental health problems get all the benefits they are entitled to. The remaining 66% are missing out on an average of £52 per week. Not knowing how to navigate the system is reported as one of the main reasons why these people were not receiving the correct level of benefits.[136] There are a number of charities that give people information and advice on benefits and their entitlements. **The Scottish Association for Mental Health** is one such charity. In the past two years one benefits officer has unlocked £700,000 in unclaimed benefits for 151 service users. This represents a 1,200% return on investment.

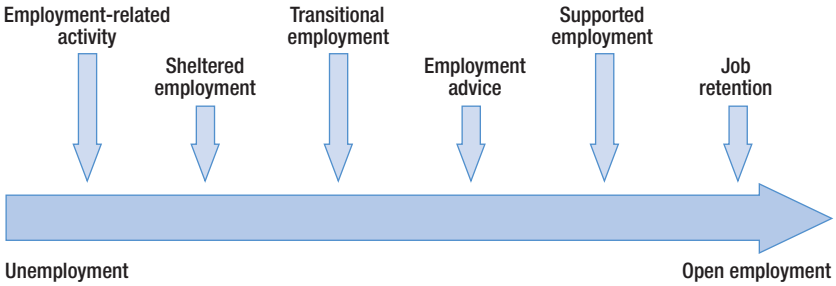
### Lack of support in the workplace

People with mental health problems can find it difficult retaining their existing job, or sustaining a new one. Around two thirds of people with mental health problems believe that heavy workloads, long hours and bad management causes or exacerbates their mental health problem.[5] A lack of flexibility in the workplace can also make it difficult for people to keep their job on becoming ill. People with mental health problems need flexible working hours and practices due to the fluctuating nature of their illness. The Royal College of Psychiatrists supports the need for flexibility and advocates that people should have access to a range of work, training and support that is relevant to their changing needs.[15]

## Moving people towards employment

If people with mental health problems are to keep and retain work, they must have a supportive and understanding work

**Figure 12: Employment spectrum**




environment. The levels of support and understanding will vary according to the needs of the individual, so it is important that there are a range of employment options on offer to them. For example, some people with more severe mental heath problems will not be able to work in the open labour market so they need alternative work opportunities, such as volunteering or vocational training. Others will want to move back into the workplace, but need more time, support, confidence and skills in order to do so. NPC visited a number of charities that offer employment services at different points along the employment spectrum (see Figure 12). The results were extremely encouraging. There are also a number of government programmes that lie along this spectrum. However, these are not tailored specifically towards people with mental health problems, and in that way do not always meet the specific and individual needs of clients with mental health problems.

### Employment-related activity

Many people with mental health problems have never had a job, or have been out of employment for a long time. Employment-related activities, such as voluntary work, training and education, help equip these individuals with some of the coping skills, confidence and qualifications needed to re-enter the labour market.

Charities are one of the main providers of employment-related activities. For example, the **Waddington Street Centre** in Durham, in partnership with the local college, provides IT training and a number of courses to build people's confidence and skills.

**Rethink Skills Training Chelmsford** provides a programme of activities based on a work-ordered day. The aim of the work-focused scheme is to give people a range of ways to meet their needs for confidence building, practical support, training and assistance to achieve their goals. The services include basic computer skills, office skills and catering skills.

**The Scottish Association for Mental Health** has a number of employment projects on offer to people in mental distress, for instance the Redhall Walled Garden in Edinburgh. This garden project offers training in both specific and general employment skills through the medium of horticulture for people recovering from mental health problems. Service users are unpaid and work at least three days for as long as they please. The working day is structured and is supervised by horticulture staff. Volunteers might be working on the vegetable patch, clearing hedges, weeding the pond or working on their own private patch. Those who attend gardening projects like Redhall derive the latent benefits normally associated with employment, such as structure, social contact, identity and self-esteem, without feeling the pressures sometimes felt in paid employment.

Employment-related activities, equip individuals with the coping skills, confidence and qualifications needed to re-enter the labour market.

*Photograph supplied by Redhall Walled Garden*

Charities provide a range of employment opportunities for people with mental health problems.

*'There's no pressure. If you've done a job you've done it for money – a normal job, and to earn your money you have to stick at it, do everything right, make no mistakes and that's to get your money and that is like the pressure of your job, you've got it do it right.'*

Peter, project client[137]

Some people view gardening projects as a stepping stone back into employment. Participants gain confidence and skills, and become familiar with a daily routine. Others, due to the fluctuating nature of their illness, will not want to go back to open employment and use the gardening for social and therapeutic purposes.

### Sheltered employment

Sheltered employment has a number of definitions. NPC uses the term loosely to describe employment that is exclusively for people with mental health problems, with high staffing levels and offering a limited range of low-skill activities. Most employees are unpaid or on permitted earnings.

**First Step Trust (FST)** is an example of a charity that provides sheltered employment. It runs 16 work projects, ranging from gardening to printing. **Abbevilles Restaurant,** described in Box 20, is one of the FST projects. FST's management style is firm but fair. Even if people are feeling unwell (hearing voices, for instance), they are strongly encouraged to keep working. The reasons for this are many: going home to 'rest' rarely improves symptoms and can make them worse; learning to manage the symptoms by continuing daily tasks and, for example, coping with the voices, is an important life skill; reaching the end of a bad day but still having achieved something (eg, preparing a dish, typing a letter) improves self-esteem and optimism so that people can manage and live with their condition.

**Box 20: Abbevilles Restaurant: a first hand experience**

**NPC's researchers went to lunch at Abbevilles Restaurant in South London, one of the projects run by First Step Trust (FST). A former chef from Langan's Brasserie runs the restaurant. The food was delicious (this researcher enjoyed the best Thai chicken curry in a long time) and the service was friendly and efficient. More importantly, the chef praises his workforce as one of the most reliable and effective he has ever worked with.**

**The restaurant's workforce consists entirely of people with severe and enduring mental health problems. The atmosphere was happy and industrious and the workers were enthusiastic about the improvements to their lives. Abbeville Restaurant offers proof that having a severe and enduring mental health condition need not exclude a person from contributing productively to a business.**

FST generates around 20–25%[xv] of its running costs from its projects and contracts. Only a few of its participants (there is little or no distinction between 'staff' and 'patient') are paid a full wage. Most participants are receiving benefits, so they only receive amounts allowable under the benefits system. The employment is heavily supported and the working environment is somewhat different to that of a normal employer. If a person is able to participate in supported employment with a mainstream employer, without risk of relapse and job loss, then the person should seek such employment. FST's experience is that, so long as participants are kept out of poverty through the benefit system and supported housing, the extra income from FST is sufficient for their needs.

### Transitional employment

*Employment placement schemes*

Clubhouse charities, such as **Mosaic Clubhouse,** run Transitional Employment Placements (TEP) for their members. Mosaic has close links with local employers who provide 14 work placements on a nine to 12 month basis. The placements are at the employer's place of business, are part-time, and offer members the opportunity to work for the prevailing wage on a job for which the clubhouse provides full training, absence cover and support. This is an excellent way for service users to move back into mainstream employment. The next step is supported employment where members are given help from the clubhouse to apply for a job of their own and then given ongoing support and encouragement once in the job.

*'TEP is least about earning the extra money but more about being back in the workplace and conquering those fears and uncertainties that make a 'proper' job hard to tackle. I have found the TEP to be a very real preparation for returning to permanent employment.'*

Mosaic member

*Social firms*

Social firms are charities that have both commercial and social objectives. They provide job opportunities for people with disabilities (in this case people with mental health problems) through running businesses. The key difference between social firms and private businesses are as follows:

- The use of profits: social firms would aim to use their profits to create more employment for disabled people rather than distribute to shareholders.

- The number of 'disabled' employees: social firms are deliberately aiming to employ disabled people and usually at levels of 25%–50% of staffing.
- The supportive working environment: social firms aim to make planned adjustments to employ disabled people, whereas mainstream businesses only make adjustments (if any) to comply with the Disability Discrimination Act.
- The stigma free environment: employees with mental health problems do not feel they have to cover up their problems for fear of being stigmatised.[138]

The charity **Forth Sector** runs five social firms, including Six Mary's Place (a Bed and Breakfast) and Rolls on Wheels (a catering company). **Social Firms Scotland** carried out a survey of employees in Scotland. The participants found many positive aspects of working for a social firm and the views expressed were related to the flexibility and the range of opportunities that social firms offered. Benefits included: being able to 'test the water' and try out work in a supportive environment; adjusting to a work routine and developing stamina; having an identity and a job title; the sense of having a real job with real pay; progressing to jobs within the social firm or into open employment if desired. Box 21 describes the positive experience of working for a social firm.

**Box 21: Forth Sector case study**

**Pamela is 34 years old. Until three years ago, she was a supervisor in a large insurance company. She suffered a breakdown and was diagnosed with anxiety and depression. Pamela was off sick from work for eight months before it was decided that she would be unable to return to her old position and was medically retired.**

**Unfortunately Pamela's experiences resulted in her losing her confidence and her mental health deteriorated. Pamela was offered counselling by her doctor who recommended that Pamela needed to get back into the workplace to try and rebuild her self-esteem.**

**Her counsellor referred Pamela to Forth Sector where she was offered a training placement within Six Mary's Place Guest House. After a few (sometimes difficult) months, Pamela is now starting to 'get back to her old self again' and is socialising and interacting in a way she thought she never would again. Pamela is now preparing to move on from Forth Sector and is due to start a college course in environmental studies later this year.**

**Box 22: Pathways to work programme**

**Key features of Pathways to work include:**

- **Six mandatory monthly work focused meetings for most new incapacity benefit claimants to discuss work options, explain benefit rules and medical tests and develop an action plan (there are sanctions for non-attendance).**
- **Voluntary rehabilitation programmes, focused on helping claimants to manage their health condition.**
- **Return to work credits of £40 a week to help people overcome the poverty traps.**

### Employment advice

The government has invested heavily in helping people with health conditions and disabilities, both physical and mental, to find work. Jobcentre Plus has introduced a number of initiatives to help disabled people to find work. In October, the DWP began piloting its flagship programme, *Pathways to Work* (see Box 22). It is designed to transform work opportunities for people making a claim for incapacity benefit and has been rolled out to a third of the UK. The pilots have been successful but have not yet been attempted on a large scale.

The *New Deal for Disabled People* is another such initiative. It is a voluntary programme that is aimed at getting unemployed disabled people back into work. It is delivered through a network of selected job brokers that specialise in working with disabled people. These job brokers should help the client discover what kind of work they want to do, give them advice about the local labour market, discuss the most appropriate route into employment and agree the next steps to be taken. However, charities receive many complaints about 'incompetent staff' who, for example, are ignorant of the basic issues around mental health, and who fail to match up their clients' expertise and desires with suitable employment.[139] Brokers also have a tendency to focus on 'easier' clients in order to meet their targets. People with more severe and enduring mental health problems can be sidelined.

Charities also provide employment advice. Their employment advisors specialise in getting people with mental health problems back to work. For example, **Darlington Mind** has a scheme called *Options,* which profiles participants in order to find an occupation (either voluntary or paid) that would suit them best. Since starting in 2003, *Options* has helped 82 people with severe needs. Eleven per cent have gone on to paid employment, 32% are volunteering and 20% have gone on to acquire further skills and education.

### Supported employment

This supported employment model has been most effective in helping people with mental health problems to get and keep employment.[127] Clubhouses, such as **CoreClub** in Dunfermline, offer supported employment to their members. One of their members works at the supermarket ASDA. Starting a job can be an extremely scary experience, especially for someone who has been out of work for a long time and who, due to their mental health problem, might be lacking in confidence. Coreclub helped overcome her fear by introducing her to ASDA staff on her first day. They also provide ongoing practical and emotional support.

Mainstream JobCentre Plus initiatives such as *Workstep* also provide ongoing support for people with disabilities once they are in work. Charities such as **The Shaw Trust** are contracted by the government to deliver this scheme. However, this JobCentre Plus programme has serious limitations. It requires people to work for 16 hours or more a week, which is not appropriate for many people, especially those with more serious mental health problems.

## Helping people to retain jobs

### Support for employees

As mentioned above, employers have a legal duty to make reasonable adjustments for their employees with mental health problems. They have a number of options for supporting people with common mental health problems in the workplace. Looking at the available evidence **The British Occupational Health Research Foundation (BOHRF)**, a charity promoting good health in the workplace, learnt that:

- The use of CBT and other cognitive approaches is effective, if used early. The charity **Mental Health Matters** is currently working with the NHS to develop a CBT employment-based project. CBT has also been found to double the rate at which unemployed people find work.[140]
- Support on multiple fronts is beneficial. People need individual management and support, including contact when employees are off sick.
- Supervisor behaviour may require improvements in some situations.

*Photograph supplied by Mosaic Clubhouse*

**BOHRF** conducted a review of the various employment support options in collaboration with **Mentality** and the **Sainsbury Centre for Mental Health**. This work was presented to a conference, which was attended by over 100 senior private and public sector delegates representing large UK employers such as British Airways, Royal Mail, the police, the NHS and insurers.

### Support for employers and managers

Employers of people with mental health problems also need support.

*'Many line managers are confused and fearful about engaging with a person who is experiencing mental distress. They worry that they will say the wrong thing or that they will open a can of worms that they have neither the time nor experience to handle.'* [5]

*Mindout for Mental Health* (the anti-stigma campaign run in England from 2001 to 2004) published a guide called *A line manager's resources: a practical guide to managing mental health in the work place.* This covers recruitment, early intervention, keeping in touch during sickness absence and managing return to work.

## Housing

The home environment of people with mental health problems is important to keep them well, or to help with recovery. Chaotic and unsuitable accommodation is not beneficial to people's mental health.

However, many people with difficulties lose their housing because of rent or mortgage arrears. They often need advocates to help. Discharge from hospital is extremely dangerous if there is nowhere appropriate for people to return to.

Charities and housing associations provide a great deal of the housing for the most vulnerable people in our society, with private landlords also offering accommodation. Most running costs are covered by the state via housing benefits. However, the state does not always cover the capital costs of expansion incurred by charities in order to meet shortages. There is a need to explore ways of funding this.

## Links between housing and mental health

Housing affects people's mental health, and people's mental health often affects their housing. Most people with mental illnesses live in mainstream housing, and problems with housing, such as rent arrears or poor accommodation, can exacerbate mental health problems. Home stability can be a real issue for people in mental distress:

- One in four tenants experiencing mental distress has a serious arrears problem and risks losing their home.[5]
- People with mental health problems are more likely to live in rented housing and twice as likely to express dissatisfaction with the state of their accommodation. Many say that their health has deteriorated because of housing problems.[5]

Four out of five people with severe and enduring conditions live in mainstream housing. The remaining one in five lives in supported housing or other specialist accommodation. These statistics exclude the homeless people who make up a startling number of vulnerable people with mental health problems. In 2003, there were 3,000 households in England registered as priority housing needs (ie, without appropriate accommodation but vulnerable through mental health problems, a euphemistic way of expressing homelessness).[5, xvi] These cases exist despite housing legislation prioritising people with mental health difficulties. In reality people are often placed in temporary situations that are unsatisfactory.

## Housing problems

### Losing homes

People with mental health problems may lose their homes because:

- they are in arrears on rent or mortgages due to losing their job or being hospitalised;
- their behaviour is perceived as antisocial by landlords or fellow tenants; or
- they are discriminated against by landlords, mortgage companies or insurance companies.

Charities are valuable in providing outreach support to people living independently and semi-independently so that such situations are avoided. The support can help tenants to: manage their finances so that they do not accumulate arrears; provide advocacy services that can help with negotiations to sort out financial problems; intervene and defuse difficult situations between landlords and neighbours arising from a person's behaviour; and provide emotional support to reduce isolation and help in periods of crisis. Box 23 provides a salutary reminder of the vulnerability of people with mental health problems to eviction.

### Discharge

There has been a very significant shift in healthcare provision from institutionalised asylums to 'care in the community' in the last 40 years. Supported housing is preferable to long-term hospitalisation (except in very acute circumstances) for the following reasons: therapeutic improvements are more likely; patients enjoy a better quality of life; and patients are better positioned to develop independence and life skills. It is also much cheaper for people to live in the community. A hostel that is highly-staffed 24-hours-a-day costs £60–78 per night per person; a low-staffed hostel costs £27–35 per night.[xvii, 141] This compares with inpatient costs for a low secure unit at around £260 per night.[xviii, 142]

**Box 23: Disability case study**

**A recent case (Manchester City Council v Romano & Samari, 2004) related to the eviction of two tenants with mental health problems for 'antisocial behaviour'. The Court of Appeal ultimately found in favour of the landlord because of the effect of such behaviour on the health of their neighbours. However, in handing down the judgement, the Court of Appeal expressed concern about the potential traumatic effect of eviction on tenants who are mentally impaired and urged that the health and social services become involved earlier so as to avoid circumstances leading to eviction. It also reminded landlords of the existence of the Disability Discrimination Act (DDA). It noted that the provisions of the DDA and the Housing Act 1996 (as amended by the Anti-Social Behaviour Act 2003) were contradictory, and urged a review of the legislation.[20]**

> "There were about six people out of the 20 on our rehabilitation ward that have been ready to move on… for some time. Having them still on the ward is a waste."[5]

Discharge into the community, however, is no straightforward matter. A person's needs upon discharge will vary widely depending on their condition and home circumstances. Different types of housing with different levels of support are required. One in four people have difficulty accessing transport to mental health services, which is an additional challenge.[5]

There is little evidence as to which models of supported housing work best in terms of staffing levels and group living versus single living. It is probable that there is no one-size-fits-all solution. However, quality of staff and management of supported housing units, especially the minimisation of criticism and negative encounters between staff and residents, is very important in achieving good outcomes.[141]

Some people will be discharged back to their own homes, in which case floating support (whether the person lives alone or with their families) will be important.

### Accommodation shortage

Unfortunately the right type of support is not always available upon discharge and people on psychiatric wards may stay on because there is no suitable accommodation lined up.

This problem exists at many steps in the chain: a person cannot be discharged because a hostel with 24-hour support is full or does not exist; another person cannot move on from the 24-hour supported hostel because there is no social housing available with regular part-time support; a further person using supported social housing who no longer needs the support cannot move on because there is no affordable independent housing (eg, in London).

**Box 24: Supporting people**

Launched in 2003, *Supporting People* is a government initiative to encourage independent living through housing-related support services for vulnerable people. It is delivered by local authorities in partnership with health services, probation services, service providers (including charities) and service users.

It links housing support with the Care Programme Approach and is designed to achieve three things:

- preventing escalation of mental health problems through early access to services;
- resolving housing-related crises before people become homeless; and
- resettlement and rehabilitation in stable housing following a period of homelessness or instability.

Charities are important providers of housing for people with mental health problems.

There are a wide range of bodies providing housing for people being discharged from hospital, so it is difficult to identify an obvious solution to the gaps in the housing chain. Housing providers include local housing authorities, housing associations, charities, health services and social landlords. There are often complex contractual arrangements between bodies' commissioning services (eg, PCTs and local authorities), the owners of houses (eg, housing associations, landlords and charities) and those providing support services (health teams or charities). Systems vary from area to area. Some have better service provision than others.

Charities in particular report inconsistent contracts with local authorities, despite the concerted effort of charities. The Audit Commission and some representative local authorities drafted some sensible guidelines in the *Supporting People* initiative (see Box 24).[143] Although *Supporting People* is well intentioned, many charities report that the initiative has generated significant extra administration.[144] *Supporting People* is only focused on accommodation and can dominate local authority funding. Employment schemes are finding that they may lose out in bidding for local authority funding.

NPC will be undertaking future research into homelessness and housing, which may shed further light on these issues. It appears that the current structural shortage of low-cost housing could be one of the factors affecting the ability of service providers to deliver enough housing offering a sufficient range of support. Obtaining funding for the operational costs of support to people with mental health problems did not appear to be difficult, not least because the benefits system pays the rent for those who are not employed.

### Charities providing housing support

Charities are important providers of housing for people with mental health problems and there are a number of charities that do this. **Together** was the first charity to provide housing in the community for people with mental ill health over 100 years ago. It now supports 2,500 people, through 100 different services across the country, many of them housing services. The **Richmond Fellowship** supports 1,500 people (see Box 25 ), and **Mental Health Matters** accommodates 250 people. **Rethink** has various projects around the country, such as accommodation in Eastleigh housing 40 tenants and providing 24-hour support. The **Peter Bedford Trust** provides a mixture of housing and support to over 300 service users.

Smaller organisations across the country will often run a hostel owned by the local housing association, for instance **Darlington Mind**. Other charities, such as **Together**, provide flats for semi-independent living with floating support to many people with mental health problems.

Many of these charities provide housing support as part of a wider range of services, such as employment, training and social activities. There are many advantages to providing integrated services to people, tackling more than one problem at once. Service users

**Box 25: Robert's story**

One day Robert started to hear voices. At first they were like friends and would just say 'Hi Rob' once in a while. However in 1994, when he was 22, he lost his job as a security guard and the voices became more menacing, telling him to harm people. Over the next few years, Robert's condition deteriorated. Robert did everything he could to help himself, including starting new jobs, even working abroad, but in the end he just couldn't cope. When he came back to England from working in Israel, he was diagnosed as a paranoid schizophrenic and was admitted to a psychiatric hospital. For the next two years, he was in the horrible revolving cycle of being admitted to hospital then sent home over and again.

When Robert left hospital the last time, he went to the **Richmond Fellowship's Hawthorns project** in Ipswich. Hawthorns is a nine-bedroom rehabilitation home that works with people with mental health problems to help them lead more independent lives. Whilst there, he made new friends amongst other residents and the staff and was encouraged to do new things and allowed to express himself. He really benefited from the way he was treated there, all the people were very helpful and at last he felt that people actually cared about him. Eventually he stopped hearing the voices altogether.

Now Robert lives independently and enjoys kick boxing and playing snooker. He has started a college course learning basic internet skills but hopes to become a care worker.

can find that the sum is greater than the parts, which is the experience of people using the **Peter Bedford Trust** services.[145]

Some research has been undertaken to determine what is important to service users. For instance, the goals of people using housing services need to be aligned with the goals of staff, particularly in respect of rehabilitation and moving on to more independent living. Unfortunately, goals often differ.[146] Anecdotally NPC heard of instances where supported housing staff could be restrictive and patronising.

Greater independence and choice in living is often associated with better outcomes, including decreased hospitalisation. Minimising 'restrictiveness' allows a less institutionalised feel to a place and puts residents in better control of their environment.[141]

One potential complication is that, as people get better and need less support, they may be required to move out of a home to which they have become attached, in a community where they feel safe. Accommodation where the tenancy is not 'tied' to a person's progress, and where support can be gradually phased out but the person can remain, is very desirable. It is equally important not to withdraw support too fast. **Peter Bedford Trust** is frustrated by the relapses they witness because a person appears to have got better, so the funding for support services is withdrawn, only for the person to relapse later.

The **Richmond Fellowship**, one of the largest housing charities specialising in mental health, reported that its contracts with local and health authorities to provide housing and housing support yielded sufficient income to cover costs. Richmond Fellowship needs to expand either its own housing stock or obtain access to housing stock owned elsewhere in order to meet demand for communal supported living. It is also expanding its services to support people in their own homes, thus reducing the need for bricks and mortar. However, this approach will not entirely obviate the need to find large amounts of capital to invest in appropriate housing. Futurebuilders may be a useful source of loan finance for such developments, as long as applicants meet the criteria for funding. Futurebuilders is the government backed £125 million investment fund to help the voluntary and community sector deliver better public services.[147] The fund provides a combination of grants and loans for organisations that deliver public services and earn revenue by forming contracts with public sector agencies. Statutory payments for future services must account for more than 50% of future income.

*Photograph supplied by South Tyneside Arts Studio*

## Isolation

People with mental health problems often feel lonely and isolated. They feel cut off from other people, they lose contact with friends and their family relationships break down. The isolation they experience exacerbates existing mental health problems and impedes recovery. Charities can help people to develop social networks and to recover confidence.

### The extent and causes of isolation

People with mental health problems are among the most isolated in society. A survey carried out by Mind[xix] found that 84% of people with mental health problems have felt isolated, compared to 29% of the general population.[116]

Mental ill health causes isolation, which in turn exacerbates mental ill health. A massive 80% of the survey respondents reported that isolation hinders their recovery from mental health problems. This self-reinforcing cycle of isolation and mental ill health condemns thousands of people to a life of segregation, cut off from friends, family and the rest of society.

84% of people with mental health problems have felt isolated, compared to 29% of the general population.[116]

Services offering activities help people to make friends and gain confidence.

It also keeps them out of hospital.

There are a number of reasons why people with mental health problems become isolated. Fear, withdrawal and other symptoms of mental distress contribute. Indeed, 79% of the Mind survey respondents felt that mental distress itself contributed to their isolation and 78% reported a lack of confidence due to mental ill health.[116]

Stigma and discrimination are major causes of social isolation for this group of people. In the same survey, 58% of respondents said that isolation was linked to discrimination relating to their mental health and 77% said that it was caused by a lack of understanding by others about mental health issues.[116]

*'I find I'm isolated because of people's reaction to me having a mental health problem. I get mocked, pushed and stared at, so feel isolated and I can't go out much or make friends, so I get more depressed as a result.'* [116]

Sixty-six per cent of respondents to a Mental Health Foundation survey said that the risk of discrimination and stigma would prevent them from telling some people about their mental distress.[117] This self-stigmatisation and fear of being discriminated against exacerbates isolation and mental ill health.

*'Feeling scared that I will be judged because of my mental health problems has resulted in me avoiding social contact. Social contact would make me feel more normal and in touch. I feel unable to seek out social contacts.'* [116]

Poverty and social exclusion have a pronounced impact on social isolation. Unemployment, homelessness, low income and lack of transport are all linked to isolation. Fifty-nine per cent of respondents with experience of mental distress said that a lack of money was an isolating factor.

*'Lack of work, money and transport intensify the very real aspect of social isolation and environmental or clinical depression.'*[116]

*Photograph supplied by Mosaic Clubhouse*

## Tackling isolation

One way to overcome isolation is to tackle the stigma around mental ill health. Another way is to help people form friendships and social networks. In Mind's survey, 47% of respondents said that support to make friends and contacts was helpful in overcoming isolation.[116] Support in going out, access to social and recreational activities and the provision of day services all scored highly as ways to reintegrate into society.

Having ready use of a telephone is another way of overcoming isolation. Fifty-five per cent of respondents said having access to a telephone was helpful, yet one in ten of these respondents did not have access to one. The picture was similar for internet use. One in five respondents without online access felt they would benefit from it.[116]

In providing services to combat isolation, the people who use the services benefit from being heavily involved. Indeed, some charities are user-led, such as **Lambeth Mind** and **SUN @ Bow** in London. Users can help to determine which services they receive to reflect their needs. Involving users also provides them with activities that benefit themselves and others, mutually reinforcing positive experiences.

### Day services

Modern day services provide people with mental health problems with a place to go, opportunities to meet other people, as well as something to do during the day. People can make friends in a supportive environment where they can be up front about their mental health problems without the fear of being judged or discriminated against. Day services usually operate on a drop-in basis, where people can access the service during the day as and when they like.

Traditionally day services have focused on people with more severe mental health problems. The **Waddington Street Centre** in Durham, for example, provides a drop-in facility for people with mental health problems who have been referred there by their care coordinator. The drop-in centre gives people a chance to meet other people with similar experiences in a friendly, supportive environment. They can have lunch in the café, meet friends for a chat, or participate in group activities ranging from computing to learning Spanish, arts and crafts to Tai Chi. **SUN @ Bow** in London is a day service that is run and managed by the people who use its services.

**Evergreen project (Scottish Association for Mental Health)** is a gardening project for people with mental health problems. Service users take part in structured gardening at least

three days a week. Friendships are formed through attendance and a shared enthusiasm for gardens, nature and outdoor activity.

*'They've got the friendship, companionship and also the interest. They don't feel that they're just sitting there doing nothing, just getting bored. They've actually got something to work towards.'*

Pete, gardening project organiser[137]

Increasingly, day centres provide more than a place to sit around, drink tea and smoke cigarettes (although there are some like this that still exist). Good day centres will offer constructive activities and also have links with mainstream services in the community, such as advice, leisure, arts and transport, because it is often the only opportunity such individuals will get to engage in the wider community. **Darlington Mind** provides service users with opportunities to develop the skills they need to reintegrate into wider society, such as IT courses and a careers advice service.

### Clubhouses

Clubhouses, such as **Core Clubhouse** in Dunfermline, and **Mosaic Clubhouse** in South London, are based on a model developed in 1948 in New York. They offer day services to people with mental health problems who join the club voluntarily and do so for life. Members can visit the clubhouse every day if they so wish. Work is an important part of clubhouse life and members are encouraged to assist with the club's running, by participating in work units that might include administration, food services and property maintenance of the coffee bar. Through participating in these activities, people make friends and gain the confidence to reintegrate into society. Another important facet of the clubhouse is outreach. Staff and members retain contact with colleagues who have not been attending for various reasons, thereby lessening the chance of members feeling alone and isolated within the community.

### Community arts

As well as having a therapeutic role, arts projects help people increase their self-esteem, confidence and social networks. In one survey, roughly half of participants reported feeling better or healthier since becoming involved in the arts.[5]

Community arts projects like **South Tyneside Arts Studio (STAS)** deliver a range of arts classes to members of the community (see Box 26). STAS was set up specifically to provide a service to people with mental health problems, but any member of the wider community can attend. STAS provides its members with a forum for making friends. Furthermore, the interaction between people with and without mental health problems helps to develop an understanding and to combat the stigma attached to mental illness. STAS's positive results have been recognised by the local health authority that part funds its activities because they believe that it reduces relapse and readmission into hospital.

**Box 26: A case study from South Tyneside Arts Studio**

***'When I was about 26, I was suffering from depression and anxiety. I went to see my doctor and she prescribed me the Arts on Prescription at South Tyneside Arts Studio. I went to the studio for five weeks and did drawing and painting. I was very interested so I thought "I'll give it a go". I am still here five years later and I absolutely love it.***

***Over the past few years the staff have given me so much support, that I have had exhibitions all over the country. The studio has also given me the confidence to study Open University, so I am currently doing a course in Art & Humanities of Art. South Tyneside Arts Studio has given me confidence, friendships and a new lease of life. Without the studio and all the staff and members, my life would not be the same.'***

**Theatre Nemo** in Glasgow runs performance arts workshops in the community. Many of its members have recently been discharged from hospital and are particularly at risk of relapse. The workshops provide these vulnerable people with a link into wider society, social support and contact and something to look forward to in their week.

**Core Arts** in Hackney includes music in its range of activities to help people with mental health problems. **Sound Minds** in South London helps service users to form bands, which sometimes play to people in inpatient units.

### Befriending services

The national charity **Rethink** runs a number of befriending services. Service users are matched up with volunteers who visit them once a week to offer social support on a range of activities. These may include having tea and a chat, going shopping or taking part in one of the social activities put on by the local Rethink group. **Depression Alliance** runs self-help groups, which provide a forum for people who are affected by depression to share their experiences and coping strategies. The groups provide mutual support and understanding in a non-judgemental, confidential environment.

### Telephone and internet

Access to the telephone and internet has great potential for maintaining links with social networks. These may be informal networks, such as friends or family, or more formal networks such as telephone or internet befriending services. Charities such as **Mind in Dacorum** offer its service users a weekly telephone befriending service and access to the group's internet befriending scheme. Here individuals can access the organisation's chat rooms and message boards and so have immediate access to social support.

Isolation hinders recovery from mental health problems.

Services offering activities help people to make friends and gain confidence.

"Carers are an integral part of the patient's support system. …The carer's voice… is ignored at everyone's peril and yet so often is."

Dr Mike Shooter, Royal College of Psychiatrists

## Families and carers

Up to 420,000 people in the UK care for someone with a mental health problem.[5] Families and carers can affect the well-being of people in mental distress. As far as charities are concerned, issues about caring fall into two main areas:

- The effect of caring for someone with a mental health problem on families and carers, and how families and carers can be helped to maintain their own well-being.[xx]
- The role that carers play in improving the well-being of the people they care for.

Charities not only support the emotional, social and practical needs of carers, they also help carers to care better. This improves the service users' chances of recovery and as a consequence reduces the likelihood of the carer becoming unwell.

### Effect of caring on families

Families are often integral to the care of people with mental health problems. Families provide emotional support, shelter and frequently financial assistance.

Caring for a loved one with a mental health problem is extremely demanding and can impact on the health and well-being of family members. A loved one's behaviour can be irrational and difficult to cope with.[33] Carers may have to cope with threats of suicide. Sleepless nights and depression are commonplace.

*'If our son was properly looked after we would have few needs. As it is we have the ever present worry about him which is debilitating and causes stress related conditions.'*

Carer[149]

*'Depression flies buzzing round my mum's head'.* Drawing by nine year old FWA Building Bridges service user.

Unfortunately the data on the effect of caring for people with mental health problems is limited, as it tends to be bound up with the data on people who care for disabled people. However, 28% of carers of people with mental health problems and disabilities have significant mental health problems of their own, compared with 14% if the problems of the person cared for are physical.[150] **Carers UK** is one of the main carers' charities, for all people who care. It is keen to undertake more detailed research into the well-being (or otherwise) of those caring for people in mental distress so that it can develop more resources for this group of carers.

### Caring for carers

#### Short breaks

Carers are twice as likely to suffer from mental ill health if they do not get a break from caring. There are a quarter of a million people providing substantial care to a loved one (over 50 hours a week) and over 90,000 of them (35–36%) are experiencing mental ill health themselves. Access to short breaks and social support reduces the risk of mental ill health to 15–17%.[xxi,148] This could affect 40,000 carers. Charities such as **Forresters** in the New Forest provide short holidays for carers and those they care for. Local authorities pay for the holidays, which cost £650 per week.

#### Support and information

Emotional support is essential for carers, especially those who are suffering from their own mental health problems. Carers networks are beneficial in this respect. Caring for someone can be quite isolating and having someone to talk to that has been through the same experiences can be comforting.

The **Princess Royal Trust for Carers** operates 118 carers' centres offering advice and information, emotional support and counselling, drop-in facilities and group activities. They can act as a voice for carers trying to influence local decisions and policy.

Caring for someone with a mental health problem is often extremely difficult. The relationship may be fraught because of the nature of the condition (which may include difficult behaviour) or because of an event that triggered the distress. Sometimes the family itself can be the cause of the problem. In order to care for someone effectively, information about the condition, and how to care for someone with that condition, is essential. **Together**, formerly the Mental After Care Association (Maca), has developed a handbook for carers, which provides people with information about conditions and how to help. Many of **Rethink**'s 135 voluntary support groups deliver their structured Carers' Education and Training Programme (CETP), offering help, information and advice over a ten-week period.

### Support for children

Between 20% and 50% of adults using mental health services are parents, and an estimated 28% of lone parents have mental health problems. Their children will suffer as a consequence. An estimated one third to two thirds of children whose parents have mental health problems will experience difficulties themselves, in part due to their genetic make-up and partly due to their environment.[151] Children are often confused and upset by their parent's behaviour, feel isolated and alone or have had to take on caring responsibilities well beyond their years. Of the 420,000 people caring for someone in mental distress, between 6,000 and 17,000 are young carers.[5]

The **Family Welfare Association's Building Bridges** service provides support to families where a parent has, or is at high risk of developing, a serious mental illness. The project bridges the gap that exists between childcare and mental health services. Staff help the parent carry out their parenting role and most importantly, support the healthy emotional development of the children. Work can include counselling for a mother or father, helping a child understand his or her parent's illness through play and pictures, or working with the whole family to put in place simple routines for breakfast in the morning, bath-time and bed-time at night.

*'It's better for me now that I know I can't catch my mummy's illness: it's inside her head and you catch things from throats and coughing usually.'*

Evie, 6 [152]

## Helping carers to care

Looking after carers will help them to care. However, it is also important that, where possible, they are involved in the planning of a person's care so that they care effectively. There are occasions when family relationships hinder rather than help a person's recovery, but in other cases family members could help.

### Improving carers' relationships with health professionals

Mental health professionals often ignore carers and family. This can cause frustration and upset. It can also have a negative impact on the level of care they are providing, causing unnecessary distress and prolongation of the mental health problem itself.

*'When my daughters were suffering from eating disorders, nobody would listen to me. My bulimic daughter looked fine, so they wouldn't believe me when I told them she was ill. Even when my (very manipulative) anorexic daughter lost two stone, the professionals wouldn't intervene. It was ages before either daughter was treated, but I was given no information about the conditions. Worse, nobody would talk to me about how to deal with my daughters at home. This had disastrous consequences therapeutically: I was unintentionally holding them back from recovery. Both daughters have admitted that they would have recovered quicker if I had stepped back instead of over-caring. But no-one had guided me on this. Once I was finally accepted as part of the care team, my daughters' recovery accelerated.'*

Parent of two girls[153]

The inclusion of family carers in the care team has positive benefits. Carers will know the behaviour and habits of those in their care and can therefore detect when something is wrong. They can also confirm to the professionals when a particular treatment or medication is yielding good results. With so many teams involved in the care of patients (one carer counted six), the carer is often a vital repository of information and case history.

*'Carers are an integral part of the patient's support system. … They are the ones with the day-to-day responsibility for the patient's welfare. The carer's voice in decision-making about admission and discharge is ignored at everyone's peril and yet so often is.'*

Psychiatrist[154]

One excuse for keeping carers out of the information loop is confidentiality. Of course, there are important legal considerations. However, it is frequently possible to obtain the consent of the patient to share information with the carer when they are well, so that when they are ill, the carer can be consulted. In the past, professionals have been sceptical that consent is achievable. In practice, it is often easy to obtain.

> "She is just so funny, you know, when she's well, she is just the best mum ever. … When she's not well … even though she's nasty to us, I haven't got the heart to be nasty back. Because I still love her, and it's not her fault."
>
> 15-year-old daughter.[16]

*Photograph supplied by Family Welfare Association*

The Royal College of Psychiatrists and the charity **Princess Royal Trust for Carers** have been running a joint campaign, *Partners in Care,* to improve working relationships between professionals, carers and patients. This campaign has been running since January 2004 and the evaluation was presented in September 2005.

The activities of the campaign have been:

- Producing a leaflet containing guidelines regarding confidentiality issues. It includes suggestions as to how to reach agreement between all parties on which information is confidential and what can be shared, including information relating to the carer (the issue cuts many ways). As this has the stamp of the Royal College of Psychiatrists, this will support carers in negotiations with professionals.
- Training of psychiatrists. From mid-2005 it is mandatory that all psychiatric training will use patients and carers in the training curriculum. However, there are fears that senior consultants may resist changes initiated by junior colleagues. So this initiative includes training schemes for continuing professional development that would target older professionals. Ultimately most of the 11,000 members of the Royal College of Psychiatrists will have been through some type of training on this issue.[155]
- Information for both carers and professionals. This covers conditions and how the carer is best able to help manage conditions.

As a result of the campaign one in seven psychiatrists say they will change their practices. There are 10,000–11,000 members of the Royal College of Psychiatrists, so up to 1,500 will change the way they treat carers. This could affect over 60,000 carers.[xxii]

*'If, as a psychiatrist, you are worried about your professional status, would you rather answer the General Medical Council for breaking confidentiality or to a coroner for the fact that you did not act and your patient killed himself? I know which I'd choose.'*

Psychiatrist[156]

## Influencing policy

**Carers UK** has successfully influenced government policy in the past. Its work helped develop the Carers Equal Opportunities Act 2004, which should improve carers' access to employment and leisure. It could, with resources, develop a more focused strategy for carers of people with mental health problems and also undertake research into their well-being. The charity **Rethink** campaigns specifically on behalf of carers of people with mental health problems. They managed to secure funding for 700 carers' support workers as part of the NHS Plan and the NSF for Mental Health.

African Caribbean people are three times more likely to be admitted to hospital and nearly twice as likely to be detained under the Mental Health Act, compared to the general population.[12]

## Black and minority ethnic groups

Mental health is an area of particular concern for people from black and minority ethnic (BME) communities. There is compelling research showing that there are large disparities between BME groups and the majority white population in the prevalence of mental health problems, service experience and service outcomes. This reflects a range of cultural, social and economic factors, including economic disadvantage and racism. Charities can provide services that encourage integration and advocate for more equitable treatment.

## Variations in experience and outcome

### African Caribbean people

The African Caribbean population is the most over represented minority ethnic group within mental health services. Their experience of these services, for instance how they are admitted and treated, also differs significantly from the experience of the majority white population. According to **the Sainsbury Centre for Mental Health** report *Breaking the Circles of Fear*, African Caribbean people are more likely to be subject to:[7, 12]

- compulsory hospital admission under the Mental Health Act;
- admission to medium and high secure facilities;
- excessive hospital admissions via the courts;
- involvement of police in hospital admission;
- readmission;
- over-diagnosis of schizophrenia and under-diagnosis of depression; and
- over use of medication and electro-convulsive therapy.

They are also less likely to receive psychotherapy, counselling or other complementary treatments.

### South Asian people

Evidence for prevalence rates of mental heath problems in Asian people is inconsistent. It has also been suggested that mental problems are often unrecognised or not diagnosed.[157] What is clear is that South Asian women are at particular risk of suicide and self-harm. In 2005, rates of suicide and self-harm were 60% higher for young Asian girls than the average for their white counterparts.[158]

## Explanations for the variance

### Racial inequalities

BME communities have long been subject to inequities and disadvantage as a result of racial discrimination. These negative experiences are reflected across all indices, including housing, employment and education. One study (1998) found that whereas 28% of white households had incomes below half the national average, the figure for African Caribbean families was 41%.[159] It also found a clear link between high levels of unemployment and areas of high ethnic minority concentrations. Black people also face disadvantages within the education system in terms of academic success and risk of being excluded from school.[7] The distress caused by these adverse socio-economic factors associated with discrimination can bring people into contact with mental health services.[160]

### Prejudice, fear and stereotyping

Prejudice and fear amongst health professionals can undermine the way in which mental health services assess and respond to the needs of the BME population, especially the African Caribbean population. Studies show that health professionals perceive African Caribbean patients as being more dangerous than white patients.[161] This racist and stereotypical view of black people with mental health problems appears to sometimes influence patient management. Indeed, black people are more likely than their white counterparts to be subjected to restrictive and punitive forms of treatment.[7]

White professionals often have a stereotyped view of what ethnic minorities believe and how they behave. Many mentally distressed Asian women, for example, are being misdiagnosed and are receiving inappropriate treatment because there is so little understanding of their particular backgrounds and individual needs.[162]

### Lack of engagement

Black people are fearful of using mental health services. They see the way services respond to them as a reflection of the discrimination against African Caribbean people in wider society, particularly in instances where individuals have experienced the more controlling and restricting aspects of treatment. Some service users have expressed fears about being admitted into hospital, some believing that it could eventually lead to their death.

*'I remember when I first went into hospital.... I feared that I was going to die'.*

Service user [7]

As a consequence, people with mental health problems become reluctant to ask for help or to comply with treatment, increasing the likelihood of a personal crisis, leading in some cases to self-harm or harm to others. In turn prejudices are reinforced and provoke even more coercive responses. This results in a vicious cycle where professionals see service users as potentially dangerous and service users perceive services as harmful.[7] The stigma associated with mental illness in some BME communities compounds the problem of service engagement.

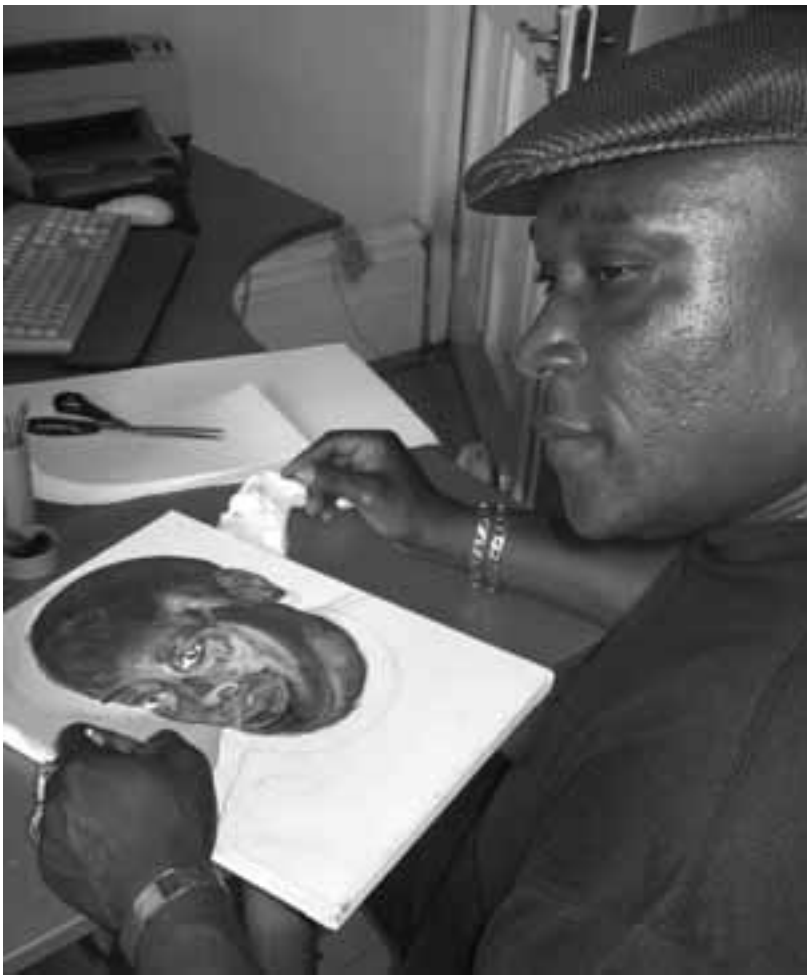
### Cultural pressures

South Asian women are more likely to experience mental health problems because of parental, family and community-related pressures they can often experience. Inequalities between men and women, domestic violence and containment and lack of communication by families were cited as reasons for emotional distress and self-harm in a study carried out by the **Newham Asian Women's Project**.[163]

> "I remember when I first went into hospital.... I feared that I was going to die."[7]

## Alleviating the problem

The government published *Delivering Race Equality in Mental Health Care (DRE)* in 2005,[164] an action plan for achieving equality and tackling discrimination in mental health services in England for BME groups. The recommendations themselves are sensible and, if implemented across the board, would improve the current situation. They are based on three building blocks: more appropriate and responsive services, community engagement and better information.



*Photograph supplied by Mosaic Clubhouse*

However, it is unlikely that these recommendations will be in place in mental health services across England and Wales in the next five years. There are no targets for leaders of NHS and social care organisations, and the processes necessary to bring about change are not adequately described. In addition, managers and leaders of NHS and social organisations are not being held to account. Given the failure of the state to tackle the inequalities in respect to the mental health of the BME population, there is a clear need for charitable action.

BME charities are uniquely placed to improve mental health experiences and outcomes for the BME population for two main reasons. Firstly, local people trust local community organisations. This means people have more confidence in the services that they offer and are open to participation and engagement. Secondly, BME organisations reflect the cultural traditions of the communities they serve. Unlike most statutory services, they have the ability to tap into and reflect personal experiences. Many deliver services in a variety of different languages.

BME-specific mental heath charities deliver a variety of activities in hospitals and the community. They aim to reduce the risk of a crisis and assist recovery by providing culturally-specific mental health services. They also strive to prevent mental health problems from developing or worsening by raising awareness of mental health and reducing the fear and stigma associated with mental illness.

The **African Caribbean Community Initiative (ACCI)** in Wolverhampton provides culturally sensitive services to its users, many of whom experience severe mental health problems. Its services include day care, outreach, supported housing and a wide range of activities to improve quality of life and enable individuals to interact socially. Volunteers are trained and supported to befriend members, visiting them at home or working with them at the day centre. The outreach team helps people to obtain appropriate housing, therefore reducing the risk of relapse and readmission.

**Awetu** provides practical and emotional support to BME people with mental health problems in Cardiff. It also runs an advocacy service, visiting people in hospital and assisting them with any issues they might have with their consultant or medication for example.

The **Afiya Trust** runs conferences that bring together experts in the BME mental health field to explore new approaches and share good practice. They also run the National Black and Minority Ethnic Mental Health Network (carers, users, professionals and charities), which aims to address the inequalities experienced and over representation of BME groups within the mental health system.

**Meridian** provides vocational, educational and social support to the BME population in Glasgow. It works to tackle isolation and exclusion and in doing so helps prevent mental health problems. English courses, computer literacy courses, counselling and social activities such as cooking and sewing are just some of the services it provides.

The **Asian Women's Advisory Service** provides an advice and information service for Asian women in the London Borough of Hackney. It operates the service in five different Asian languages, helping Asian women to understand their financial, legal and social rights. It also operates a culturally sensitive counselling service and a family support service, which helps Asian women to avoid crises and family breakdown.

BME mental health organisations are in great demand but are under-funded. **Rethink** is setting up a £3m fund for capacity-building in this area. It intends to give grants to local BME organisations working in mental health to extend their reach and impact. Rethink has also just opened a mosque-based outreach service in Birmingham, to build on a temple-based service in Kent.

## Summary

A person's environment and social activities are important in both avoiding mental health problems and also in recovering from episodes of distress. The cycle of ill health and disadvantage illustrates only too graphically how people can deteriorate. However, it also presents opportunities to break the cycle, either through prevention, early intervention or by working patiently with long-term cases.

Charities are ideally suited to the task of developing and providing appropriate social support. This explains why charities received £320m of government spending on non-clinical mental health services in 2001/2002.[81]

Charities have the patience and the appetite for innovation, to provide and develop social services that benefit people with mental distress.

# What to fund?

# 4

**There are plenty of opportunities for donors to help people experiencing mental distress. NPC has focused on the following priorities:**

- **Prevention of mental ill health is important and deserves more resources.**
- **Stigma and discrimination are major barriers to people's recovery and should be tackled.**
- **Employment is a route to better mental health for many people, and full employment reduces associated problems such as low income, debt, poor housing and isolation.**
- **Mental health services need further improvement.**

**In all these areas NPC has found charities working successfully to improve people's lives.**

## Finding good charities

There are many good charities working in mental health. When selecting charities to recommend, NPC examines: results of activities; capacity of the organisation; risks, and how the charity copes with them. NPC has recently published *Funding Success: NPC's approach to analysing charities*.

The evidence of results is discussed in more detail below. In order to deliver results, however, charities require capacity. They need management and governance that is effective, flexible and involves its users. NPC was impressed by the people with mental health problems who are working for charities, often in management roles. They sometimes live and work with difficult conditions requiring long-term medication and careful management. Many charities are following clear and well developed strategies for helping people. Some are focused on creating long-term change in the sector; others concentrate on helping smaller groups and sharing the learning from their activities.

A number of charities are exposed to risk. Funding streams are not always secure. They are sometimes experimenting with activities whose results are uncertain. When management and staff heavily involve people with mental health problems, occasionally key people become unwell and the organisation has to cope in their absence. Risk should not deter donors, for without risk there is no progress.

*Photograph supplied by Mosaic Clubhouse*

## Results and evidence

When visiting charities, NPC met many of the people that use their services. Through talking to them, and the charity staff, NPC gathered a large amount of anecdotal evidence on how charities had helped, and even saved the lives, of the people in mental distress using their services.

However, finding hard evidence of the benefits of these activities was more difficult. It has not always been possible to find hard evidence of the benefits of charities' activities. This is frustrating as the work of charities is very compelling. Evidence and data are important. They not only help to develop best practice, but they also help to inform decisions about resource allocation.

There is reluctance in many quarters to measure the effect of particular activities on people's well-being. This is partly because well-being is affected by many different factors, including the person's circumstances, his or her medication, and whether they attend local activities. Statutory authorities responsible for commissioning services seem generally untroubled by the absence of hard data and evidence. From witnessing the improvement in patients first hand, they view the benefits of the services as self-evident. There is also an understandable reluctance to conduct surveys among people when the baseline question is generally 'how miserable is your life?' In any case, funding for such research is scarce, even if charities were keen to carry it out.

That said, occasionally data does exist, but it is often out of date and too old to reflect advances in service provision. However, the existence of past data suggests that opportunities do exist to gather hard evidence, however flawed, that might throw up

Hard evidence of activities preventing ill health and promoting good health is limited.

However, potential returns are sufficiently high to outweigh the risks and uncertainty.

interesting findings. For instance, research carried out by social firms in Ireland in 1993 that compared the variation in hospitalisation and crisis patterns between patients who were offered supported employment or similar activities and those offered none, could have important implications for resource allocation.[165]

Evidence of people's experiences of medication and treatment could be collected to help with clinical developments. Formal randomised controlled trials, favoured by the medical establishment, are not the only valid means of collecting useful data on the effectiveness of activities. The collection of less formal evidence is also valid.

**Samaritans** is meeting the challenge of evaluating all its work. It will be expensive, costing an estimated £350,000, and it will take several years. Samaritans' largest corporate partner, UK Vodafone Foundation, is contributing to the cost. The results are likely to be valuable to many organisations operating in the mental health sector.

Other less comprehensive and less expensive evidence is also valid. For instance, evidence of people's experiences of medication and treatment could be collected to help with clinical developments. Formal randomised controlled trials, favoured by the medical establishment, are not the only valid means of collecting useful data on the effectiveness of activities.

To compensate for the absence of more formal data, there are fortunately many valuable and insightful anecdotes from people whose lives are improved by the work of charities. As we have seen in previous sections, some of their stories show how charities can make a valuable contribution to recovery and rehabilitation for people suffering from mental ill health.

## Preventing ill health and promoting good health

If the funding of charities can prevent people becoming distressed in the first place, then this is a rewarding place for donors to invest.

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If the funding of charities can prevent people becoming distressed in the first place, then this is a rewarding place for donors to invest. Although hard evidence of activities preventing ill health and promoting good health is limited, the potential returns are sufficiently high to outweigh the risks and uncertainty. This is also an area that is not well funded. Only 0.1% of government funding is allocated to mental health promotion and only 2% of research is spent on prevention and mental health promotion.

NPC has separately researched issues of social deprivation and disadvantage, such as domestic violence; refugees and asylum seekers; older people; prisoners; truanting and excluded school children, as well as victims of school bullying. Reports on child abuse and substance misuse are also in the pipeline. Mental health features prominently in many of these areas. If donors targeted their resources on activities that prevent stressful life events, this would go a long way towards improving the mental health of vulnerable groups.

NPC's research and reports into these subjects include examples of many charities working to improve the lives and mental well-being of groups of people who are at risk. If the lives of individuals, families and communities are improved, then it is likely to reduce or prevent mental ill health. A brief glance at these reports provides examples:

A donation to a domestic violence charity such as **Advance** may help women to escape a life of domestic violence by providing practical legal help, support and advocacy. Once safe, there is a chance that the mental health of these women will improve.

Bullied pupils are also likely to suffer mental health problems. The Home Office attributes between 10 and 14 youth suicides each year to bullying. If society was able to prevent bullying, the problem would be significantly reduced. **Kidscape** is a charity that runs anti-bullying self-help days for children. The course starts by talking about bullying and goes on to teach techniques for self-assertiveness that stops bullies in their tracks. Parents are also taught how to help their children cope with bullying. A follow-up survey of one of these courses revealed that 80% of the children taking part were no longer bullied one year later.

More directly, NPC found charities within the mental health sector working hard on the prevention of mental ill health and promotion of good health. Quantifying the benefit of a report on diet by the **Mental Health Foundation** is difficult.[70] However, if people eat better food and take more exercise, and this reduces the occurrence of depression, then this represents a clear benefit. Furthermore, if this benefit has arisen because the Mental Health Foundation's report influenced the media, GPs or other opinion formers to persuade people to change their lifestyle, then some of this benefit could be attributed to the Mental Health Foundation's work. Funding such activities is risky (in terms of achieving the desired outcome), but potentially achieves lasting change.

Table 2 illustrates activities in this area, including examples from NPC research into other sectors. As in the subsequent tables, this data gives an indication of the cost of such activities and potential results.

It is difficult to assess the mental health benefits of, for example, helping a woman to escape domestic violence. Whilst domestic violence charities may draw attention to the mental health problems experienced by their clients, which includes providing helpful statistics, they exist first and foremost to solve domestic violence, not to treat mental health. So they do not measure the mental health of past clients whose problems have been solved. Nevertheless, common sense would suggest that solving social problems such as domestic violence is likely to reduce the burden of mental ill health.

It is not always useful to compare charitable activities when the scope and depth of the activity varies. For instance, the practical activities of Advance and Kidscape are not comparable to the strategic lobbying of the Mental Health Foundation. However, showing the range of approaches to tackling prevention helps donors to make funding choices.

Table 2 provides illustrations of charities preventing mental health problems and promoting good mental health. The 'cost per unit' of activity is one indicator of successful intervention and can be calculated in many different ways, depending on the nature of the activity. Trying to improve the lives of all peoplewith mental health problems results in a very small cost per unit. The cost per success (ie, each instance where a change has occurred and can be attributed) is not possible to calculate in this instance. Cost per success can be calculated, however, in the example of Advance because it is easy for Advance to keep records of its successful cases. Kidscape also followed up on cases and can provide similar data.

## Tackling stigma and discrimination

Stigma and discrimination affect how people are treated everywhere they go: in the street, at home, in the hospitals where they receive treatment and in the workplace. Stigma denies people opportunities and isolates them, thus reinforcing their mental distress. If stigma and discrimination were removed, many of the problems surrounding employment, isolation and accessing good services would evaporate.

The government's budget for tackling discrimination, which is £1m per annum to target the attitudes of the entire population of England and Wales towards mental ill health, is not

Government funding to combat stigma and discrimination is inadequate.

It is therefore left up to charities to tackle stigma.

**Table 2: Examples of charities preventing ill health and promoting good health; how much they cost; and how they benefit people and society**

| Activity | Cost per unit | Cost | Results |
|---|---|---|---|
| Promoting good health eg, **Mental Health Foundation** providing better information for people wanting to improve their mental health, campaigns with government and service providers to promote better health through healthier living. | 33 pence per person with mental health problems.[xxiii] | £4m is the cost of running MHF overall for one year.<br><br>Approximately £100,000 paid for a report into role of diet and mental health. | National Services Framework lists promotion of good mental health as Standard 1.<br><br>Better information about diet may help service providers and people with mental health problems to improve their diet and their health. |
| Research into preventing mental ill health eg, **Mentality**. | n/a | £90,000 is estimated to cover the cost of a review of the evidence of what works.[xxiv] | Service commissioners, charities and government can refer to the report in determining priorities for action. |
| Supporting young people bullied at school eg, **Kidscape**. | £243 per family with successful results. | £35,000 pays for 180 children and their families to attend one course. | Children stand up for themselves and avoid bullying (80% from one course). If they avoid bullying, children are less likely to experience depression and suicidal thoughts brought on by being bullied. |
| Providing legal support to women experiencing domestic violence so they can escape abuse eg, **Advance**. | £600 per successful case. | £65,000 pa pays for an advocate covering 180 cases each year. | 80% of women referred to Advance now live safely. This is likely to result in improvements to their mental health. |

NPC recommends that employers examine how mental health issues are handled within their own organisations.

adequate. It is therefore left to charities to tackle stigma through their everyday work, or through specialist activities targeting the media.

**Mental Health Media** rewards broadcasters presenting mental ill health and people with mental distress in a responsible way at its annual awards ceremony. Gradually broadcasters are taking greater interest in the issue and are starting to improve the presentation of mental health issues. As the media is influential in determining public attitudes, by degrees these attitudes will change. Mental Health Media also trains people in mental distress so that they can campaign against discrimination locally. An external evaluation reported that participants felt more confident, inspired and determined to challenge discrimination after having been on a Mental Health Media course.

**South Tyneside Arts Studio** involves people with and without mental health problems in their social activities. Anecdotal evidence shows that the community arts centre gives people a forum to mix and an opportunity for people without mental health problems to appreciate the talents and abilities of people who may experience mental ill health.

**First Step Trust** employs people with long-term mental health problems whilst providing local councils, health trusts and the general public with goods and services. In this way they are exposing people with severe mental health problems to the public, who learn through interaction that people with mental ill health are capable, useful and friendly, contraryto popular perception. A visit to First Step Trust's restaurant changed the authors' perceptions of workers' reliability and stamina.

Measuring changes in public attitudes requires expensive surveys of the general public. It is also difficult to attribute positive changes to particular actions by charities or government. However, studies correlate public attitudes to media presentation. Common sense suggests that influencing media presentation is likely to be rewarding, even though the investment seems risky.

An alternative is to tackle stigma through local and personal action. People with mental distress view such efforts positively and report better experiences as a result. There are plenty of compelling anecdotes illustrating this.

Table 3 shows a variety of approaches.

## Employing people with mental health problems

In most cases, getting back to work is good for a person's mental health. It gives people a sense of purpose and improves self-esteem. It has the added advantage of increasing income. Yet many people with mental health problems do not work: only 24% of people with long-term problems are currently employed and almost a million people claim incapacity benefit because of mental health

**Table 3: Examples of charities tackling stigma and discrimination; how much they cost; and how they benefit people and society**

| Activity | Cost per unit | Cost | Results |
|---|---|---|---|
| Community arts workshops eg, **South Tyneside Arts Studio (STAS).** | £21 per member per visit (usually weekly). | £1m would pay for the cost of redeveloping and extending the premises to increase capacity to 75 people per day. | By encouraging social interaction between people with and without mental health problems, STAS is raising awareness and increasing understanding within the community of what it means to be 'mentally ill.' |
| Changing public perception through the media eg, **Mental Health Media**. | n/k | £65,000 to run annual media award. | Broadcasters are taking additional interest in the Mental Health Media Awards: entries rose from 70-85 in previous years to 117 in 2005.<br>Media presentation of mental health issues is likely to result in changes to public attitudes. |
| Helping people with mental health problems to overcome stigma in their own communities eg, **Mental Health Media.** | £233 per person.[xxv] | £31,000 pays for nine four-day anti-discrimination training courses and 15 people attend each course. | Training courses give people with mental health problems the confidence and the means to express themselves publicly. By speaking about their experiences to local and national media, they are helping to combat stigma and discrimination. |

**Table 4: Examples of charities helping people with employment, benefits and constructive activities; how much they cost; and how they benefit people and society**

| Activity | Cost per unit | Cost | Results |
|---|---|---|---|
| Benefits advice eg, **Scottish Association for Mental Health**. | 19.187 £400 per person pa | £60,000 pays for a benefits officer for two years. | Benefits advice helps people with mental health problems gain access to the benefits they are entitled to, thereby avoiding destitution. In the past two years one benefits officer unlocked £700,000 in unclaimed benefits for 151 clients. |
| Sheltered employment eg, **First Step Trust**, social firms. | £2,700 per person pa [xxvi] | £100,000 pays for 37 people to work in sheltered employment for one year | Employment helps people who have mental health problems and are out of work to gain confidence, self-esteem and a sense of purpose. They also acquire life skills and a working ethic and are less likely to be readmitted to hospital. |
| Gardening and horticulture eg, **Redhall Walled Garden**. | £1,400 per person pa [xxvii] | £50,000 could enable 35 people with mental health problems to work at the garden for one year. | Activities help people to make friends and build confidence and self-esteem. The gardening also has therapeutic benefits, as well as reducing the likelihood of relapse. |
| Working with employers to retain staff eg, **British Occupational Health Research Foundation (BOHRF)**. | n/k | £90,000 paid for a report on best practice in helping people in the workplace. | BOHRF's conference to share the results was attended by large-scale employers including British Airways, Royal Mail, the police, NHS and employee health insurers. Employers heeding the messages of the report are likely to be able to help employees more effectively, thereby reducing time off work and job losses. |

problems. Not everyone will be able to work in non-sheltered employment, but even those who are unable to work on an open employment basis often benefit from sheltered employment or other constructive activities, such as volunteering. These activities benefit the community as well as the person who suffers from mental health problems. There are many people who would have benefited from staying employed, with the right support, at the onset of their difficulties. A wide spectrum of services is required to suit the varying severity of mental health problems and the particular services that would benefit a wide range of people.

The government is keen to get people back to work, but it is often the activities of charities that provide specialist support and take on the more difficult cases. Charities also help the government to advise and train people, and to support them in the workplace.

**Mosaic Clubhouse** provides IT training, careers advice and support, as well as supported work placements in order to prepare people for full employment.

Social firms, such as **Forth Sector**, provide commercial services using employees with mental health problems. Health cost benefits are significant, with small-scale research indicating a 98% reduction in use of inpatient facilities, day centres and day hospitals and a 47% reduction in use of medication.[165] **First Step Trust** is another example of sheltered employment offering valued services to the community.

Table 4 shows the costs of working with people in different ways depending on their needs. By comparison the cost of an inpatient bed is £260 per night.[73] So if First Step Trust, for example, reduces a person's hospitalisation by nine days, the cost is worthwhile.

**Mind** lobbies the government to make improvements to the benefits system so that people are not put off finding employment. If Mind is to succeed in this lobbying and the system becomes sufficiently flexible that people can try employment without fear of losing their income lifeline, more people may experiment with employment and find they are able to take it up.

The **British Occupational Health Research Foundation (BOHRF)** is working with employers to help keep people with mental health problems in employment. Health insurers have found investment in early treatment is highly effective and minimises the prolonged costs associated with sick leave or staff replacement. Early intervention and job retention is also usually better for the distressed employee. The work of BOHRF in highlighting the advantages of good practice to employers, if heeded, is significant.

NPC not only recommends that donors fund employment initiatives, but also that employers examine how mental health issues are handled within their own organisations. Looking after employees quickly and well, is not only humane, it is also cost effective.

Charities accelerate the development of better service through testing and developing new ways of helping people. They also hold a mirror to government so that poor services are recognised and rectified.

## Improving mental health services

Although the government's National Service Framework for Mental Health has laudable objectives, there is some distance to go before all people receive the treatment, services and care they require. Further investment could, in the long run, not only improve people's welfare, but could also produce cost savings.

Charities augment the health services at a practical and personal level with their activities. Charities accelerate the development of better services through testing and developing new ways of helping people. They hold a mirror to government so that poor services are recognised and rectified. All these activities help government to deliver better services.

Below are some examples of how charities help people directly:

**Theatre Nemo** engages inpatients on otherwise gloomy hospital wards using fun activities such as juggling and acting. Given the numbers of patients on the wards in Glasgow, the cost per visit per patient is low: just £14. The improved recovery of patients is sufficiently exciting that the local PCT is likely to purchase Theatre Nemo's services in future. Another charity, **Core Arts**, not only entertains inpatients with music and comedy (provided by other service users), but also trains inpatient staff in how to treat people with mental health problems.

**Rethink** provides a wide range of advocacy services for service users. Medication problems are frequently reported. Patients are more likely to follow a medication regime if they have been able to agree its administration rather than having it imposed upon them. In addition, their often genuine concerns about side effects are heard and should be factored into the clinical knowledge base about such drugs.

**The Nile Centre** is a crisis house that provides an alternative to inpatient care for people in crisis. The important point about crisis centres is that they often provide a therapeutic environment, which accelerates patient recovery. The style and cost of centres vary: the Nile Centre operates with high occupancy levels and represents good value at around £110-120 per night. **Maytree** in Hackney is geared specifically towards people who are suicidal. It offers fewer beds and more intensive counselling. On a nightly basis it is more expensive than other services, at around £400 per night, but people stay for only two to four nights. This is usually sufficient to avert a crisis (if it is not, then the person is referred to specialist psychiatric help). So the cost of the averted crisis is low: £1,250 on average.

Charities augment the health services at a practical and personal level with their activities.

People who have used Maytree have said that it helped them to overcome their suicidal tendencies.

**Samaritans, SANE** and other charities provide telephone helplines to provide people in distress with a listening ear. They represent an alternative line of support for people in crisis. Depending on the structure of the service and how it is resourced, a phone call can cost between £5 and £25. Until Samaritans has undertaken a full evaluation of its services, it is unable to say specifically how many lives its helpline has saved. However a local study, where posters advertising Samaritans were placed in car parks used by the suicidal, showed that suicides in car parks with posters dropped by two-thirds. This illustrates how helplines can save lives at a modest cost.

Below are examples of charities that are helping the government to improve services:

**Rethink** is working with NIMHE to improve services for the 7,500 young people who develop psychosis each year in England. Rethink is developing a network through which early intervention teams can share best practice. It will also raise awareness of the initiative across health and social care services. If successful, these will reduce the cases of recurring psychosis.

The **Mental Health Foundation** has been working with GPs to prescribe exercise and better diet for depression and so avoid unnecessary medication, as well as keeping people out of specialist services.

**Mind** campaigns against the poor state of inpatient wards. It costs around £135,000 to produce a report like *Ward Watch*, which investigated the state of inpatient wards for mental health patients. However, if reports like this result in the government being shamed into improving inpatient facilities so that people get better more quickly, this will have been money well spent. The **Sainsbury Centre for Mental Health's** work in analysing (and publishing) the costs and effectiveness of services is well respected and could result in improvements in the allocation of resources.

It is extremely difficult to quantify the benefits of a campaign like *Ward Watch*. To what extent will Mind be able to take credit for future government actions that improve inpatient wards? There is also a risk that, if Mind and other charities do not keep up the pressure on the government to improve services, problems will simply not be resolved.

Table 5 illustrates the range of charitable activities that are helping to improve services or are offering alternatives to these services. It also indicates the costs and potential results of different approaches.

**Table 5: Examples of charities helping to improve services; how much they cost; and how they benefit people and society**

| Activity | Cost per unit | Cost | Results |
|---|---|---|---|
| Independent advocacy for people with mental health problems in hospitals and the community eg, **Community Support Network**. | £265 per person pa. | £30,000 pays for an advocate to work with 200 people for one year. | An advocate ensures people with mental health problems get the treatment and care they are entitled to. This is likely to improve their recovery. |
| Performance-based workshops in hospitals eg, **Theatre Nemo, Core Arts**. | £14 per person per visit. | £25,000 could pay for an administrator to help scale up activities. | The hospitals where these organisations work report that the activities are therapeutic for inpatients. |
| Crisis lines eg, **Samaritans** | £5 per call. (NHS direct is £25 a call [xxviii]). | £850 pays to train and support a Samaritans volunteer for a year.[xxix] | Helplines provide people in crisis with a listening ear. For those who are suicidal, this can be their lifeline. Samaritans signs erected in New Forest car parks reduced suicides in the area by two-thirds.[99] Each volunteer answers on average 136 calls each year.[xxx] |
| Crisis houses eg, **Highbury Grove, Maytree**. | £113 per person per day[xxxi] (assuming 100% occupancy) or £1,250 per crisis. | £330,000 could pay for a residential service for a year (8 people at any one time). £150,000 could pay for a smaller service that helps 120 desperate and suicidal people each year. | Crisis houses provide an alternative to inpatient care for people in crisis. The intensive staffing and holistic approach promotes recovery and reduces the likelihood of hospital readmission. For some, crisis houses save lives. |
| Developing services with government eg, **Rethink** partnership with NIMHE on early intervention in psychosis. | £32 per person pa.[xxxii] | £120,000 could pay for the *Early Intervention in Psychosis Network* for one year. | The network will raise awareness of the early intervention in psychosis initiative across health and social care services. It will also encourage the sharing of best practice between the 50 early intervention teams in England. If successful, these will reduce the cases of recurring psychosis. |
| Campaigning to give patients effective treatment options eg, **Mental Health Foundation's** *Up and Running campaign*, which calls for all patients with mild to moderate depression to be offered exercise therapy. | n/k Around 11 million[xxxiii] people in England and Wales rely on their GP for help with their condition. | £100,000 over two years pays for the running of the *Up and Running campaign*. This includes research, campaign material, dissemination and service development. | The campaign will make GPs more aware of the benefits of exercise therapy for people with mild to moderate depression and will encourage GPs to prescribe exercise therapy. Patients' conditions are likely to improve with this treatment. |
| Lobbying government to improve hospital conditions for mental health inpatients eg, **Mind's *Ward Watch***. | £1 per person using inpatient units.[xxxiv] | £135,000 pays for a campaign such as *Ward Watch*. This includes research, campaign materials, dissemination of report to local Mind associations, MPs, policy-makers and service providers, as well as workshop costs. | If Mind's *Ward Watch* shames the government into improving inpatient services, service users will recover more quickly, which is better for them and better for society. |

Direct comparison between activities is difficult when evidence is unclear. Finding a numerical measurement of success can be flawed when evidence of success is patchy and confined to anecdote. In any case, activities benefit people in different ways. Not all people will need crisis services, but instead may benefit from motivating activities in an inpatient unit. Furthermore, it is difficult in some instances to attribute benefit to a particular activity.

The returns of investing in crisis services and other areas of service improvement are exciting when they are achieved: lives may be saved and recovery rates improved. However, greater evidence would have allowed the authors to be more definite about results. Funding research or the collation of evidence of efficacy of an activity will help future donors and services commissioners to determine the best results for their investments.

NPC is recommending support for charities working in this area for the following reasons:

- anecdotal evidence points to benefits experienced by those using improved services; and
- improving services is important for people recovering from and living with, mental health problems.

Charities are, in many instances, pushing at an open door when partnering government at local or national levels because they are pioneering best practice. Therefore, the returns on a donor's investment are potentially increased many times over if the government adopts new developments as they become accepted examples of best practice.

## Other activities

There are also charities offering rewarding solutions to other mental health problems. For instance, there are some 420,000 people in the UK caring for someone with a mental health problem. Families are often integral to the care of people facing mental ill health. They need the right information and professional advice so that they can care effectively and promote the recovery of their loved one.

The **Princess Royal Trust for Carers** is successfully campaigning to improve the working relationships between professionals, carers and patients. The **Family Welfare Association's Building Bridges** project provides emotional and practical support to parents who have mental health problems, as well as supporting their children, who may be isolated and vulnerable.

As seen in Section 3, BME populations are severely affected by mental health issues. The African Caribbean population, for example, is over-represented in mental health services. The way they are treated and assessed differs greatly to that of the majority white population. The **Sainsbury Centre for Mental Health** exposed appalling inequalities in treatment in its report, *Breaking the Circles of Fear*.

Charities are working hard to address these inequalities. In fact, many of the charities identified in the previous four tables help people from BME communities. However, the problems in many communities are so acute that they would benefit from help directed specifically at them. Unfortunately, there are very few organisations on the ground and in these communities with enough capacity to tackle these problems.

NPC suggests the following approaches may help here:

- Supporting good local BME organisations generally will help to improve the social fabric of disadvantaged areas. This will reduce the number of mental health problems arising in these areas. Local organisations could also be encouraged to develop discreet mental health services as part of the other services they offer.
- If a good local BME organisation is found, long-term funding and other support would be beneficial. Such organisations often struggle to find financial stability because of capacity issues.

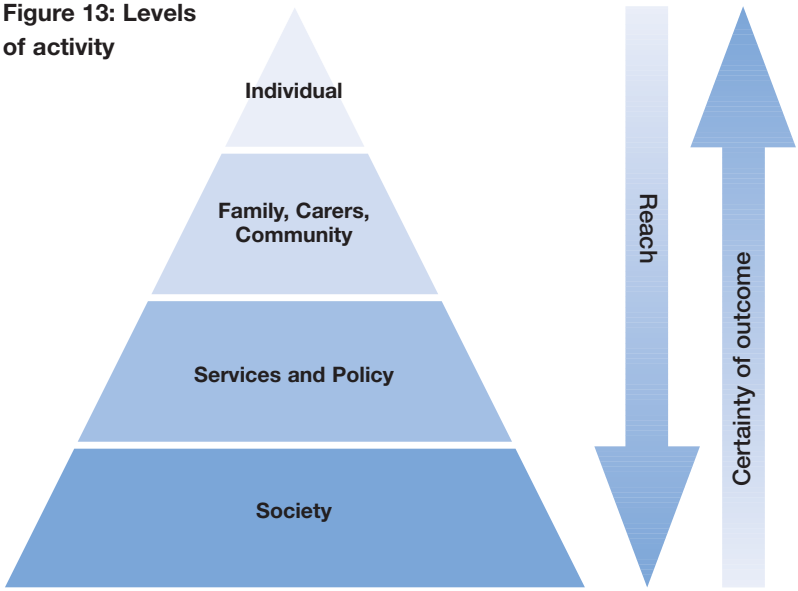
Using a large mental health charity such as **Rethink** to sponsor and support small BME organisations is an alternative approach.

## Forming a balanced portfolio

The charities working NPC's priority areas are active on different levels: individual, family, community, service delivery and society. This is best illustrated by Figure 13 which shows how there can be a trade-off between certainty of outcome (or result) and closeness of relationship to individuals. This triangle is a basic unit of NPC's analysis of charities and shows where different activities lie on the triangle.

A charity may focus on achieving results for individuals, or families and communities, with quite tangible effects. However, change for a section of the population on a particular issue may require activities such as government lobbying or challenging society's attitudes, the latter being particularly hard to measure.

**Figure 13: Levels of activity**




To achieve widespread and lasting change for the maximum number of people, aggregate resources need to be allocated across a balanced portfolio of activities (and results) at all levels.

To achieve widespread and lasting change for the maximum number of people, aggregate resources need to be allocated across a balanced portfolio of activities (and results) at all levels.

Figure 14 shows how charities' activities are placed on this triangle. Prevention and mental health promotion are present on all levels. Housing and projects mitigating isolation would appear at the individual level. Some charities are active on more than one level, using practical experience gained in serving individuals, families and communities to inform research, development of best practice and policy discussions with government.

In the mental health sector, there is a resource deficit at each level. However, some specific areas fare worse than others: prevention and mental health promotion receive very little funding. Returns in this area can be risky, particularly if targeted at the general population rather than specific groups. However, returns are potentially very rewarding.

A similar situation applies to efforts to tackle stigma (found at the society level). There is not enough money being allocated to this area despite stigma and discrimination compounding the problems faced by people with mental distress. Tackling stigma therefore offers donors plenty of risk, great difficulty in obtaining evidence, but potentially high rewards in an under-funded area.

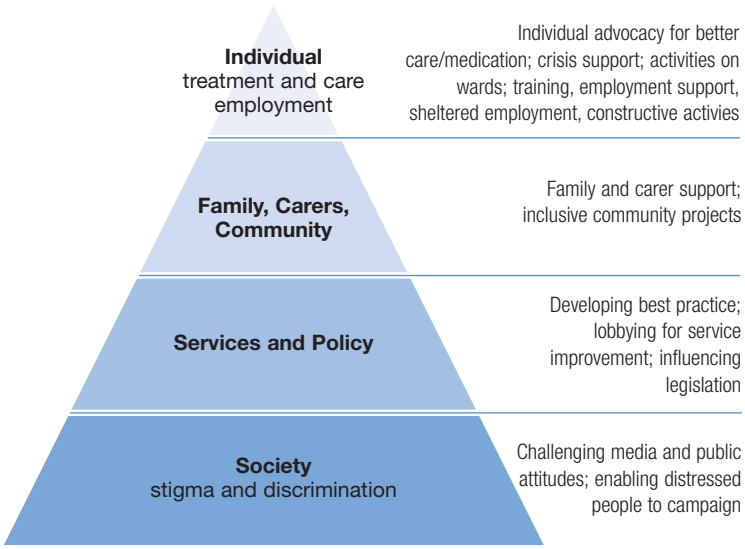
Employment initiatives receive partial contributions from statutory funders, but they rarely pay the full costs of such initiatives. Voluntary donations must cover the remainder. Relative to the funds allocated to conventional treatment and care, the sums are small. Fortunately, employment initiatives are popular with funders. This is with good reason, because the benefits are self-evident when visiting a charity with good employment activities. Investment in employment is attractive because it achieves benefits on several levels: it is therapeutically beneficial in itself and full employment also enables people to solve the problem of their poverty. However, there is still scope for more funding by private donors. Given the numbers of people affected, there is still an enormous gap between demand and supply.

The valuable services complementing the statutory health services have uncertain funding streams. Funding for helplines was cut recently and some crisis centres rely entirely on private donations to survive.

These services are directed at the people in distress themselves. Their families would also benefit from support.

The NHS spends significant sums on conventional treatment and care. However, extra resources directed at service

**Figure 14: Levels of activity in the mental health charitable field**



NPC recommends these priority areas because they represent exciting opportunities and high social returns.

development and policy to improve the efficacy of such spending is needed. There is limited statutory funding for this, and in any case charities lobbying government need private income streams in order to maintain their independence. Fortunately there is private funding available for organisations working with government to improve services. Some of the work is risky because it involves piloting new practices, but as these are usually evaluated, benefits would be reported to funders after the event. Additional support achieves good returns as it capitalises on other work and the impact of successful improvements will be felt widely.

NPC is recommending these priority areas because they represent exciting opportunities and high social returns. Though the hard evidence is often lacking, there is compelling anecdotal evidence supporting the case for charities. The lack of hard data makes all areas of mental healthy risky for donors seeking results, but the potential returns illustrated by the available evidence makes the risk worthwhile.

## Last word

Charities have a great deal to offer to people with mental health problems and vice versa. Many charities involve people with mental health problems in their management structure, on trustee boards and working as staff. NPC estimates that the combined income of charities working in the mental health sector is around £500m pa. Much of this income comes from non-statutory sources, most of which are voluntary donations, representing a valuable contribution.

The sector is tremendously dynamic. What it lacks in measurement of results, it makes up for in the enthusiasm of charities and those who use their services. It was impossible not to be convinced of the value of their work given the visible effect on beneficiaries.

To recap, NPC highly recommends that funders support charities in the following areas:

- charities working to prevent mental ill health and to promote good mental health;
- charities tackling stigma and discrimination;
- charities helping people to engage in employment and constructive activity; and
- charities improving service delivery, either complementing or working with health services.

Donors can change the lives of people like Vivian, whose story was told at the start of this report. Vivian and her family struggled to cope with her erratic behaviour for more than a decade before she finally got the help she needed. Once she found that help, her life was transformed. She and her parents were given the support they deserved and Vivian is now able to lead a happy life.

By supporting charities in the mental health sector, donors can make a real difference to the lives of many thousands of people like Vivian whose lives are made a misery by mental health problems. In some cases, early intervention can actually save lives.

By supporting charities in the mental health sector, donors can make a difference to the lives of thousands of people in the UK.

# Appendices

## Appendix 1: Mental health problems included in this report

A complete list of all mental and behavioural disorders is given in the International Classification of Diseases (ICD-10) classification of mental and behavioural disorders. This classification system was developed from Chapter V of the Tenth Revision of the International Classification of Diseases (ICD-10), published by the World Health Organization.[166]

| Category of mental or behavioural disorder | Examples | Included |
|---|---|---|
| **Schizophrenia, schizotypal and delusional disorder** | Schizophrenia | ✔ |
| **Mood (affective) disorders** | Depression<br>Bipolar disorder | ✔ |
| **Neurotic, stress-related and somatoform disorders** | Phobias<br>Anxiety disorder<br>Obsessive compulsive disorder | ✔ |
| **Behavioural syndromes associated with physiological and physical factors** | Anorexia nervosa<br>Bulimia<br>Post-natal depression | ✔ |
| **Disorders of adult personality and behaviour** | Personality disorders | ✔ |
| **Organic mental disorders** | Dementia | ✘ |
| **Disorders of psychological development** | Autism<br>Asperger's syndrome | ✘ |
| **Behavioural and emotional disorders with onset in childhood** | Attention deficit disorder | ✘ |
| **Mental retardation** | | ✘ |

Medical professionals sometimes group mental health problems into the following categories:

*Neurotic disorders*: various forms of mental health problem that can be regarded as severe forms of normal experiences. Examples of such disorders include depression and anxiety.

*Psychotic disorders*: involve the distortion of a person's perception of reality, often accompanied by delusions and/or hallucinations eg, bipolar disorder and schizophrenia.

Some diagnoses of mental health problems fall outside these groupings, which do not include personality disorders, substance misuse disorders, dementia and eating disorders.

## Appendix 2: Types of mental illness and disorder

| Mental health problem | Definition[167] |
|---|---|
| **Anorexia nervosa** | An illness involving an intense fear of being fat, distorted body image, under-eating and excessive weight loss. |
| **Anxiety** | A feeling of unease, apprehension or worry. It may be associated with physical symptoms such as rapid heart beat, feeling faint and trembling. It can be a normal reaction to stress, or worry or it can sometimes be part of a bigger problem. |
| **Bipolar disorder** | A condition in which people have mood swings that are far beyond what most people experience in the course of their lives. These mood swings may be low, as in depression, or high, as in periods when we might feel very elated. These high periods are known as 'manic' phases. Many sufferers have both high and low phases, but some will only experience either depression or mania. |
| **Bulimia nervosa** | An eating disorder characterised by binge-eating, vomiting and purging by making oneself sick, or abusing laxatives. |
| **Depression** | This is a common condition. The main symptoms are feeling low, sleep problems, loss of appetite, loss of concentration and low energy. |
| **Obsessive compulsive disorder** | This is a fairly common problem where people experience 'obsessions', recurring unwanted thoughts that are difficult to stop, and 'compulsions', rituals of checking behaviour or repetitive actions that are carried out in an attempt to relieve the thoughts. |
| **Personality disorder** | Personality disorder describes someone who has severe disturbances of their character and behaviour. Personality disorders usually appear in late childhood or adolescence and continue into adulthood. The thought patterns and behaviours cause distress to the person or to those around them. |
| **Phobia** | Phobia is an irrational and intense fear of a situation or object. A person with a phobia has intense symptoms of anxiety. However, these symptoms only arise from time to time in the particular situations that frighten them. |
| **Post-natal depression** | Post-natal depression is an illness that occurs within the weeks or months after childbirth. This depression comes on either gradually or all of a sudden and can range from being relatively mild to very hard-hitting. |
| **Schizophrenia** | This is a disorder that has a broader definition than is often imagined. Doctors may describe it as a psychosis. They mean that, in their view, a person cannot distinguish their own intense thoughts, ideas, perceptions and imaginings from reality. The main symptoms are hallucinations (hearing voices), delusions (a firm belief in something that is not true) and changes in outlook and personality. |

# Appendix 3: Role of government

## What does the government do?

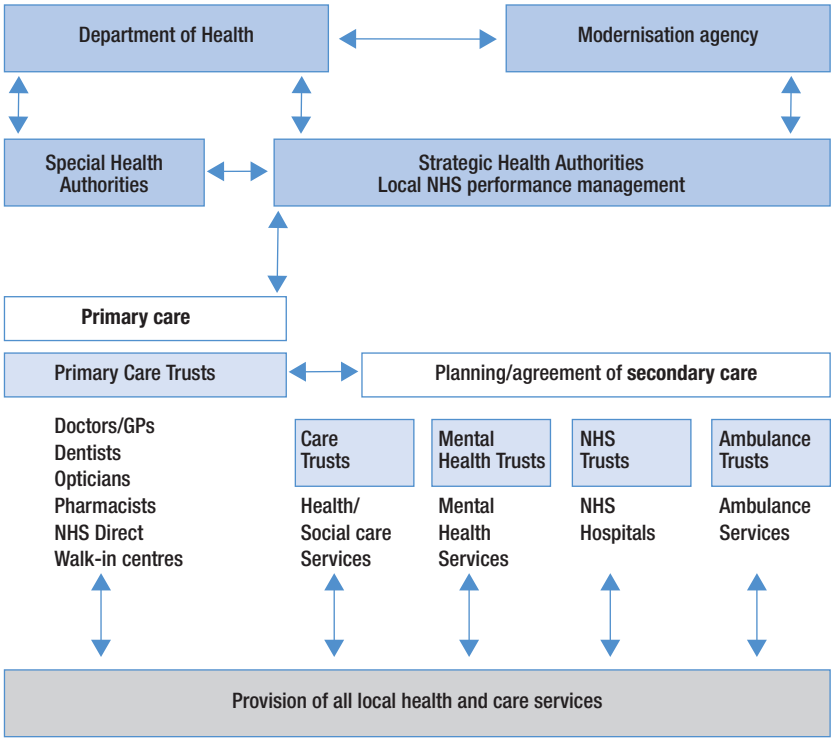
There are a number of areas of government responsibility affecting people with mental health problems:

- The Department of Health (DH), via the National Health Service (NHS) and Mental Health Trusts and Primary Care Trusts (PCTs), is responsible for providing appropriate care and treatment. It is also responsible for public health. Figure 15 details how these various bodies relate to each other. The DH drives many policy initiatives, for instance the National Service Framework (NSF). Figure 15 shows the structure of the NHS in England and Wales.
- Local authorities are more generally responsible for the well-being of its citizens and so they contract and pay for services to supplement those provided by the NHS.
- The Department of Work and Pensions (DWP) is responsible for looking after people who cannot work or who are out of work and relying on the benefits system.
- The Department for Education and Skills (DfES) may have young people within its schools and colleges who have mental health issues, and it may also offer training to adults with mental health problems.
- The Home Office is concerned with law and order. People with mental health problems frequently come into contact with the criminal justice system.
- Parliament legislates on issues relating to mental health.
- The Social Exclusion Unit (SEU), part of the Office of the Deputy Prime Minister (ODPM), tries to coordinate policy initiatives and to encourage 'joined up thinking'.

With so many departments involved in mental health care, inconsistencies between departments are bound to emerge. The situation is sometimes frustrating because potential strategies to address mental health issues are lost between competing objectives of departments. The bigger picture becomes obscured and local action is patchy.

Charities are sometimes at the nexus of these relationships and help to increase coherence. One challenge is for the government to incentivise departments to commission services that in aggregate make sense. Even if one department benefits by a second department's potentially beneficial activities, the second department is unlikely to develop such activities unless it is included within its direct targets. An example would be the benefit to the DWP of people staying in work despite being mentally distressed. An excellent way to keep people in work is to offer treatment early, such as cognitive behaviour therapy. However, this cost is incurred by the NHS. The NHS is only incentivised if providing therapy would save them money immediately. In the long term it would save money through reduced hospital admissions, but this would not be apparent in the current budget. However, the saving to the DWP (not having to pay incapacity benefit) would be more rapid. A charity could advocate for changes in NHS budgets to reflect this reality, or encourage action by the DWP.

**Figure 15: Structure of the NHS in England and Wales**



## Appendix 4: Summary of the activities of national charities

| Charity (income) | Activities and services |
|---|---|
| **First Step Trust** £1.8m | First Step Trust provides sheltered employment for 600 people with severe mental health problems each year. It runs 14 projects ranging from restaurants to print shops. www.fst.org.uk |
| **Manic Depression Fellowship** £0.7 | The Manic Depression Fellowship (MDF) is a voice for people with bipolar disorder (and other mental health problems). It provides information to service users, carers and also health professionals eg, GPs on the implications of a diagnosis. MDF also runs self-help groups and self-management programmes for people affected by mental health problems, and advises employers on mental health issues. www.mdf.org.uk |
| **Mental Health Foundation** £4.5m | The Mental Health Foundation (MHF) is a research and policy-into-practice agency that seeks to undertake a cycle of: a) research work to identify problems and solutions; b) service development to support implementation; c) policy development; d) information and campaigning to raise awareness and achieve change, and e) training and education to support change.<br><br>The MHF works on issues relating to public mental health awareness and people suffering from mental illness and works across England, Ireland, Scotland and Wales with a focus on both children and older people. It has one of the largest and most popular websites on these issues in the world at www.mentalhealth.org.uk. |
| **Mental Health Matters** £6.4m | Mental Health Matters (MHM), originating in the North East of England, provides a range of services (54) across England. MHM central office supports local projects to deliver services. Projects include residential care, social activities, independent advocacy and employment services. www.mentalhealthmatters.com |
| **Mental Health Media** £0.7m | Mental Health Media provides people with mental health problems with the means and confidence to express themselves. Mental Health Media's Open Up project runs four-day training programmes to help people express themselves publicly, at local and national levels. It also runs the Mental Health Media Awards, which celebrate examples of television and radio programmes that present mental distress accurately and help to change public perceptions. www.mhmedia.com |
| **Mind** £15m | Mind is a federal organisation with 209 affiliated charities across England and Wales. Local Mind affiliates offer services such as housing, day centres, employment support and advocacy. The central function of Mind helps local organisations with functions such as human resources, finance and contracts.<br><br>At its centre, Mind is a powerful lobbying organisation. Its policy work focuses on the interests of people with mental health problems rather than carers, as they are worried by conflicts of interest and are confident that carers' interests are protected by other organisations. Only 5% of Mind's income comes from statutory sources. Its independence allows it to freely and openly criticise government. www.mind.org.uk |
| **National Schizophrenia Fellowship (NSF) Scotland** £2.9m | The NSF Scotland separated from NSF (now Rethink) in 1984 and was originally set up to provide mutual help and support for carers in Scotland. It now supports both service users and families affected by schizophrenia and other mental health problems. It does this through 29 local projects that deliver various activities: campaigning, education and provision of practical help, support and advice. www.nsfscot.org.uk |
| **Rethink** (formerly National Schizophrenia Fellowship) £42m | Rethink activities cover people with severe mental illness, their carers, as well as professionals and volunteers working in the field. It offers 380 services in England and Northern Ireland, supporting 7,500 people including: 117 housing support services; community services eg, befriending and day centres; 53 carer support services providing help with information and advocacy; 37 employment and training services; 17 registered care services; 13 helplines for people with mental health problems and their carers; 26 advocacy services; and holidays. It is also developing ways for people with mental health problems to help themselves.<br><br>As well as delivering local services, Rethink campaigns for changes to policy and practice, raises awareness of mental health issues and challenges attitudes that create stigma. Rethink is currently developing a research programme to improve the evidence base of social and medical treatments. The programme involves users and carers to influence medical research to use their experience more actively. www.rethink.org |
| **Richmond Fellowship** £23m | The Richmond Fellowship provides housing and housing support to 1,500 service users and day services to a further 1,800 people. The Richmond Fellowship is fully funded by the state. In particular it is increasing its communal living properties so that people do not have to live alone.<br><br>The Richmond Fellowship has a subsidiary employment project called Richmond Fellowship Employment Trust. www.richmondfellowship.org.uk |

| Charity (income) | Activities and services |
|---|---|
| **Sainsbury Centre for Mental Health** £4.3m | The Sainsbury Centre for Mental Health (SCMH) carries out research and analysis on community and social issues relating to mental health problems. It tends to focus on acute areas of mental health.<br><br>It works alongside academics – not replicating their expertise but using it. Its research output ranges from the costs of mental health to society, to commentary on the current state of service delivery, and evaluating effectiveness of early intervention. SCMH produced a very important report on BME groups – *Breaking the Circles of Fear* – that highlighted the inequalities in mental health experienced by people from BME groups.<br><br>Mentality, another campaigning organisation, has recently come under SCMH's wing. It was set up in 2000 to promote good mental health. www.scmh.org.uk |
| **Samaritans** £16m including branches | Samaritans is a charity that operates the well-known national telephone helpline through a system of 18,000 trained volunteers, operating in 203 local branches. Some of these are open for people to drop in. It receives 2.7m substantive contacts each year (another 2m involve people hanging up) by phone and email from callers, both people in distress and their carers.<br><br>It is a listening rather than a counselling service, as its volunteers do not claim to be qualified mental health practitioners. However, sometimes this is sufficient for someone in crisis.<br><br>Samaritans is more generally involved in the promotion of good mental health. It uses its experience to train other service providers in contact with distressed people (eg, Inland Revenue). www.samaritans.org.uk |
| **SANE** £1.8m | SANE operates the well-known helpline, SANELINE, offering help to people in crisis. The training provided to volunteers is endorsed by the Royal College of Psychiatrists and SANELINE is often included in Care Programme Approaches (CPAs) (see Box 6, Section 2) – if a person cannot reach a member of their crisis team, then SANE can offer appropriate support. It also provides a website and chatroom at www.sane.org.uk. |
| **Scottish Association for Mental Health** £17.5m | The Scottish Association for Mental Health (SAMH), set up 80 years ago, is similar to Rethink in that it is a service provider and policy/campaigning organisation. It runs 84 different services across Scotland and works with 3,000 people each year. SAMH projects are primarily housing, employment and training projects. www.samh.org.uk |
| **Shaw Trust** £45.6m | The Shaw Trust is focused on employment (not only for people with mental health problems but for people with disabilities too). It supports 40,000 people each year through 200 local projects including: social enterprises; work placements; training and work experience prior to employment. The activities are tailored to individual needs. www.shaw-trust.org.uk |
| **Together** (formerly Mental After Care Association) £19.9m | Together supports 2,500 people through 100 different mental health services across England. It delivers mental health services by working in partnership with many other organisations, including housing associations, health trusts, local authorities, criminal justice agencies and private and other voluntary-sector bodies. 97% of Together's income comes from statutory sources. www.maca.org.uk |
| **Turning Point** £56.6m | Turning Point focuses on the dual problems of mental health and drug/alcohol abuse. It serves nearly 100,000 people each year. Its services include supported housing; advice, education and counselling on drugs and alcohol; outreach work; and support for carers and relatives; a helpline; education and employment; support for young people including young offenders; lobbying, and research. www.turning-point.co.uk |

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# Calculations and explanations

i This is an NPC estimate taken using Caritas data. The data is for the top 3,000 charities (over £110,000 in income). The submission of information by charities varies from 2001 to 2004, but is the latest information given to Caritas.

ii Prevalence rate taken from *Keys to Engagement* (3-15 per 1,000 adults). UK adult population is 44,776,000. Therefore, 15/1,000 x 44,776,000 = 671,640 adults.

iii The terminology for mental health problems varies considerably across professions and cultures, according to prevailing attitudes towards mental health. In this report 'mental health problem', 'mental distress' and 'mental ill health' will be used inter-changeably. The term 'mental illness' is usually used for more serious diagnoses.

iv Prevalence of mental health problems can be measured in several ways: by the incidence of problems or episodes during a single year (annual prevalence); by prevalence of a condition at any one time; or by lifetime prevalence, which measures who in the population will experience a condition during their lifetime. It is important to distinguish which measurement is being used. Data collated on mental health prevalence falls into all three different categories and so some statistics are only indirectly comparable.

v Obtaining consistent numbers of prevalence and definitions of what they described, in particular 'one in four' and 'one in six', was not possible. NPC has settled for the view of the Sainsbury Centre for Mental Health (SCMH).

vi In Figure 2, a mental health problem is any form of mental distress that ranges from a depressive illness or anxiety-related disorder to more severe illnesses such as schizophrenia and bi-polar affective disorder. SCMH defines 'severe mental illness' as 'a mental disorder (i.e. schizophrenia, bipolar disorder, severe depression, severe neurotic conditions and personality disorders) of such intensity that it disables people, preventing them from functioning adequately'; and a 'severe and enduring mental illness' as one 'that lasts for a period of at least 12 months'.

vii Due to differences in definitions, systems, and data collection it has not been possible to work out costs of mental illness in the UK. This section focuses on the costs of mental illness in England.

viii £21bn divided by 60m of population.

ix SCMH estimates that the proportion of total caring time by carers in England devoted to people with mental health issues is 16.5% (based on a Department of Health (DH) survey in 2000). Using Office of National Statistics (ONS) figures revised to take into account comments by reviewers, SCMH assumes that the aggregate cost of informal care in England in 2002/2003 is £23.4bn. 16.5% of £23.4bn is £3.86bn.

x Annual prevalence rate of psychiatric inpatients: unfinished episode in England and number of inpatients in England and Wales in 2003 (Ward Watch) x 6 (average length of stay is 2 months) = number of inpatients in one year. 37,986 x 6 = 227,916. Therefore, 227,916/52/52,794,000 = 0.004 or 4 in 1,000 people.

xi Mental Health Trusts provide health and social care services for people with mental health problems (see Appendix 3). Services are offered through primary and secondary care services.

xii West Park Budget Information 2005/2006: £10.9m for 116 beds.

xiii If one in 100 people suffers from schizophrenia in their lifetime (and this figure is likely to increase as drugs become more readily available to young people), 600,000 of us now living will experience, or have experienced, schizophrenia at some point in our lives. 8% of 600,000 = 48,000.

xiv Article uses data from British Crime Survey.

xv FST 2005/2006 budget: £400,000 from services sold out of a total income of £1.7m.

xvi NPC understands this may be an underestimate according to practitioners in the field.[60]

xvii Using 1997 figures (£51-66; 23-30 respectively) but adjusted using implied GDP deflator from national government statistics. (http://www.statistics.gov.uk/StatBase/expodata/files/10608237153.csv).

xviii West Park Budget Information 2005/2006: £10.9m for 116 beds.

xix 532 people with mental health problems took part in the survey. 984 members of the general public responded to the National Opinion Poll survey.

xx People caring for people with mental health problems are a subset of the six million people estimated to care for sick, disabled or otherwise dependent spouses, relatives and friends.

[xxi] The Carers UK data uses data from the 2001 census.

[xxii] 1,500 out of 10,000 psychiatrists = 15% of psychiatrists. 15% of 420,000 carers = 63,000 carers.

[xxiii] £4m (MHF's costs, although this includes other work involving people with learning disabilities and dementia) divided between the 12.1 million people in England and Wales visiting their GP each year.

[xxiv] NPC has used the same cost as BOHRF's literature review: both reports are similar in scope.

[xxv] Open up project: one four-day course costs £3,450. Therefore 9 courses cost £31,000. There are 15 people per course, so 135 in total will benefit.

[xxvi] Net income = £1.87m and there are around 700 users.

[xxvii] £228,000 per year. 160 people.

[xxviii] NHS direct: £80m to run 3.5m calls (2001/2002, NAO). £23 per call (£25 in 2004 prices). Samaritans: £10m head office + £5m branch costs. Total cost £15m. (2.7m substantive calls/contacts. Implies around £6 per call.) Samaritans costs also include some of their other work.

[xxix] Samaritans have 17,600 active volunteers. Divide £15m cost between them.

[xxx] 2.4 million calls answered; 17,600 volunteers = 136.

[xxxi] Taken from Being there in a crisis (MHF and SCMH) 2001. They state that the cost of inpatient care is £144 per person per day.

[xxxii] NPC estimates that the 50 teams reach 3,750 people. The network costs £120,000 a year to run. Cost per user per annum is £32.

[xxxiii] 12.1 million people visit a GP, but may get referred onwards. 90% of people are managed by primary care services. So this implies 11 million people depend on their GP for case management.

[xxxiv] £135,000 pa; 0.2 million pa using inpatient services.

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## Community

- **Inside and out:** People in prison and life after release (2005)
- **Ordinary lives:** Disabled children and their families (2005)
- **Grey matters:** Growing older in deprived areas (2004)
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- **Local action changing lives:** Community organisations tackling poverty and social exclusion (2004)
- **Charity begins at home:** Domestic violence (2003)

## Education

- **What next?:** Careers education and guidance for young people (2005)
- **School's out?:** Truancy and exclusion (2005)
- **Making sense of SEN:** Special educational needs (2004)

## Health

- **Valuing short lives:** Children with terminal conditions (2005)
- **Out of the shadows:** HIV/AIDS in Burundi, Democratic Republic of Congo and Rwanda (2005)
- **The hidden assassin:** Cancer in the UK (2004)
- **Caring about dying:** Palliative care and support for the terminally ill (2004)
- **Rhetoric to action:** HIV/AIDS in South Africa (2003)

## Other research

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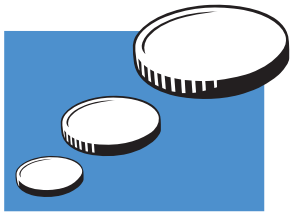

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